

Examining the perspectives of augmentative and alternative communication specialists on
conducting evaluations with people with Amyotrophic Lateral Sclerosis via telehealth

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Abstract

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Purpose: To examine the perspectives of speech language pathologists (SLPs), who are augmentative and alternative communication (AAC) specialists working with people with ALS (pALS), on conducting SGD evaluations via tele-AAC vs in-person.

Methods: Fifteen AAC specialists were assigned to watch videos of SGD assessments for eight pALS. The SLPs were provided with a checklist based on the AAC Clinical Assessment Project (AAC CAP) protocol that contained 17 different elements of an AAC assessment. The reviewers rated how comparable remote assessment was of each of the 17 elements to in-person evaluation and described any advantages or challenges with the tele-AAC assessment.

Results: Across all 17 elements, most reviewers rated tele-AAC assessment as “same/comparable” to in-person sessions. From qualitative comments, the most common

advantages that reviewers mentioned of tele-AAC assessment included that it was more functional, increased caregiver availability, and increased pALS' comfort at home. The most common challenges identified by reviewers were technical difficulties and a limited comprehensive assessment due to the remote modality. In a follow-up survey inquiring about possible changes in attitudes towards tele-AAC following the COVID-19 pandemic, most of the same reviewers indicated that they had transitioned to remote service provision during the pandemic and would likely continue with a mix of in-person and telehealth services depending largely on patient preference and the SLPs own comfort and preference in providing telehealth.

Conclusions: AAC specialists have found that conducting SGD assessments via tele-AAC is same or comparable to in-person evaluations with notable advantages and challenges. Tele-AAC should continue to be considered as a service modality for pAL

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Introduction/Literature Review

Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disease characterized by degeneration of both lower and upper motor neurons affecting respiration, speech, swallowing, and limb movement (Ball, Beukelman, & Pattee, 2004; Britton, Cleary, & Miller, 2013; Brown & Al-Chalabi, 2017). People with ALS (pALS) may experience dysarthria causing speech to be unintelligible. Approximately 75% - 95% of pALS will lose the ability to speak (Beukelman, Fager, & Nordness, 2011; Brownlee & Bruening, 2012). As ALS is a terminal disease, it is critical for pALS to have the ability to communicate in order to participate in end-of-life decisions, preserve a level of autonomy, and maintain connections to family and friends. Due to this, the majority of pALS turn to various forms of augmentative and alternative communication (AAC) across the course of their disease.

AAC with pALS

AAC is a broad term that encompasses strategies used to communicate when speech alone is not viable for effective communication. A combination of various AAC strategies may be used to allow multimodal ways for someone to communicate. Types of AAC include unaided (e.g. gestures, facial expressions), low tech (e.g. picture boards, ABC boards, Boogieboards (News, 2020), and high tech (e.g. speech generating devices (SGD)) (Brownlee & Bruening, 2012). SGDs are computer-based systems that can use advanced technology such as eye tracking control to allow for communication and environmental control. SGDs utilize a variety of text-to-speech synthesized voices available on the device. Another option for voice output is a process referred to as voice banking, in which users record series of phrases which contain a full complement of speech sounds prior to their speech being compromised by dysarthria. The speech sample is used to create a personalized synthetic voice for use on a future SGD (Mills, Bunnell,

& Patel, 2014). An additional option is referred to as message banking, in which the user makes digital recordings of their common or unique messages capturing their own personal delivery for use in their SGD (Oosthuizen, Dada, Bornman, & Koul, 2018). The use of an SGD has been shown to improve pALS' quality of life by increasing self-esteem, helping them maintain relationships and connections with their friends and family, and enabling them to be involved with their medical decisions (Hanson, Yorkston, & Britton, 2011; McCluskey, Brownlee, & Palovcak, 2007; Nordness, Ball, Fager, Beukelman, & Pattee, 2010).

While use of SGDs is considered standard care for pALS who have experienced functional speech loss, pALS' access to SGDs may be irregular and highly dependent on availability of a variety of resources. One critical factor is timely referral and adequate support from various healthcare providers (Londral, Pinto, Pinto, Azevedo, & De Carvalho, 2015). Late referral and lack of SGD training and customization, contribute to low AAC acceptance and device abandonment. Thus, early referral and evaluation for AAC use by speech language pathologists (SLPs) trained to deliver AAC services is critical for management of dysarthria in pALS (Hanson et al., 2011; Londral et al., 2015), particularly to ensure that AAC assessments and interventions are flexible and take into consideration pALS' current and future needs as the disease progresses (Doyle & Phillips, 2001).

SLPs play a vital role in helping pALS establish AAC use. SLPs are responsible for evaluating the pALS' current level of communication, identifying the types of unaided, low tech, or high tech SGD communication strategies that might be implemented, and closely monitoring and assisting with changing AAC needs as the disease progresses (Brownlee & Bruening, 2012; Hall, Gutmann, Juengling-Sudkamp, & Cohn, 2019). Unfortunately, some SLPs and other healthcare workers recruited to be on the AAC evaluation team, including physical therapists

(PT) and occupational therapists (OT), find the processes for assessing pALS for AAC, training pALS in AAC use, and navigating the funding process for an AAC device to be overwhelming and unclear (McCluskey et al., 2007). Although the majority of the AAC assessment responsibilities are within the scope of practice for SLPs, many feel ill-equipped with the skills or knowledge to perform these assessments (Hall et al., 2019). Many resort to referring patients to AAC specialists, but there is a shortage of these specialists (Hall et al., 2019).

Recommendations have been put forth for all SLPs to have more knowledge of AAC options and how pALS can benefit from AAC, and a way to increase access to AAC specialists (Brownlee & Bruening, 2012).

Another barrier in obtaining AAC services and receiving quality SGD evaluations for pALS are the logistics of how to get to ALS clinics. Approximately 45% of pALS in the U.S. live over 50 miles away from a multidisciplinary clinic specializing in ALS, and 25% live over 100 miles away from their closest clinic (Horton et al., 2018). Many pALS report that the distance to travel to their closest ALS clinic is a barrier to receiving services. Fatigue and weakness, as well as unique respiratory, positioning and comfort needs that pALS experience as the disease progresses make traveling to receive specialized care more difficult (Stephens, Young, Felgoise, & Simmons, 2016). The pALS who do travel report the in-person visits to be a burden and physically taxing (Van De Rijn et al., 2018).

Another limitation of in-person clinics is that they offer an artificial environment in which to assess use of AAC devices. Treatment or evaluation that takes place in a natural environment (e.g. pALS' homes) would allow for more involvement of family and for assessment to be more functional by addressing communication needs in their natural

environment (Curtis, 2014). Due to these reasons, a remote telehealth delivery of specialized care may be very beneficial for pALS.

Telehealth and use of Tele-AAC with pALS

Telehealth is a term that broadly describes healthcare services that are provided to patients through the use of technology and the internet. Other terms include ‘telemedicine’ or ‘eHealth.’ Although telehealth for neurology has been widely used since 1999 originating with telestroke, during which doctors would meet and treat stroke patients online, the use of telehealth with a broader range of patients with neurologic diagnoses has increased over the years (Howard & Kaufman, 2018; Savard, Borstad, Tkachuck, Lauderdale, & Conroy, 2003). Telehealth does come with some barriers including the cost and complexity to set up telehealth services, billing and reimbursement difficulty, state licensure of providers, and having a reliable and strong internet connection along with the needed hardware and software (Savard et al., 2003; Selkirk et al., 2017). However, SLPs and PTs who have delivered consultations via telehealth to patients with a range of acquired neurogenic disorders, have generally rated the sessions’ effectiveness as being good or excellent (Savard et al., 2003).

Specifically for pALS, benefits of telehealth include alleviating travel logistics including the time and cost of getting to an in-person clinic. For those living far away from ALS clinics and those who have mobility limitations, telehealth serves as a potential resolution to decrease the burden of travel while still allowing access to high quality care, including AAC specialists (Horton et al., 2018; Howard & Kaufman, 2018; Pinto, Quintarelli, & Silani, 2020). Selkirk et al (2017) compared the quality of overall medical care for pALS who received telehealth to in-person visits. Participants elected to be in either of two groups, 32 who received telehealth appointments, and 36 who received in-person visits. The outcomes measured were quality of

care, including communication device support referrals, any other health and compensatory intervention needs the patient required including PT, OT, and social work visits. They concluded that multidisciplinary health care services and evaluations delivered to pALS via telehealth were of equal quality when compared to in-person visits (Selkirk et al., 2017).

Focusing more specifically on providing AAC services via telehealth, tele-AAC is a term used to describe a cross-disciplinary service model in which AAC services are delivered to clients through telehealth (Anderson et al., 2012). Overall, tele-AAC allows for increased efficiency, removes the need for costly travel, and enables collaboration with the available AAC specialists and other team members (Hall et al., 2019). Past research has found a number of benefits of tele-AAC as well as some challenges. For example, thirteen SLPs based in Australia and families of children that had received previous tele-AAC evaluation and training were asked for their opinions on delivering and receiving therapy via tele-AAC, respectively (Anderson, Balandin, & Stancliffe, 2015). Although the SLPs reported that there were challenges in demonstrating set up of AAC equipment via tele-AAC and that they were concerned about slower rapport building, overall, they believed tele-AAC could be used as an effective supplement to in-person services. Similarly, the parents reported that tele-AAC would be helpful in the case that a family is unable to attend therapy sessions due to location, transportation difficulties, or long wait lists. Thus, there was positive feedback and opinions from both clinicians and consumers (Anderson et al., 2015).

A series of four case studies were reported using tele-AAC for training people who use AAC for various complex communication needs, including one pALS (Curtis, 2014). Although not specific to SGD evaluation, the researchers analyzed the use of tele-AAC in training new skills and increasing the patient's independence with their respective SGDs. Tele-AAC gave the

clinician the ability to see both the desktop that the pALS was looking at and their face simultaneously via webcam instead of having to look over their shoulder if it was in-person. A limitation was that the clinician was not able to assist with hands-on needs such as positioning for eye gaze. An unexpected benefit from using tele-AAC in the case study with the pALS was that a graduate student was able to join the remote session, allowing for an opportunity to increase collaboration and educate emerging professionals.

Although not specific to pALS, Styles (2008) used questionnaires to ask adult AAC users, caregivers, and SLPs their perspectives on whether AAC assessment and training sessions could be done via tele-AAC. In general, the feedback from both AAC users and SLPs were that videoconferencing is an acceptable way of delivering AAC assessment and training. The SLPs' critical feedback mostly included technical concerns such as sound and image quality. Other SLPs mentioned more difficulty assessing nonverbal communication via remote sessions (Styles, 2008).

Specifically for pALS, Roman et al. (2021) analyzed the feasibility of tele-AAC for SGD evaluation and training from the pALS' and caregivers' perspectives (Roman, Baylor, Johnson, & Barton, 2021). Evaluations were delivered using the Zoom teleconferencing platform and consisted of up to six evaluation sessions in which the SLP was always present via Zoom, and SGD vendors were present in-person to help trial various equipment (all evaluation sessions were completed prior to the start of the COVID-19 pandemic). While the vendor representatives were in the pALS' homes to help with the physical set up of devices, the SLP via Zoom was able to take remote control of the SGDs to adjust settings or trial various communication applications. Each of the pALS was able to trial three different SGDs from various vendors, and the final session of evaluation consisted of discussion among the SLP, pALS, and caregivers regarding

choosing an SGD to use and processing funding. Receiving evaluations and training via tele-AAC were reported to be feasible, and the pALS and caregivers expressed many positive aspects to tele-AAC. Some of the major themes included reducing the burden of travel, and allowing real-life, at-home trials of the SGD, making the training more applicable and personable. Roman et al. (2021) concluded that tele-AAC should be considered for pALS due to the many benefits of having this alternative service model. While this study analyzed the feasibility of tele-AAC from the pALS and caregivers' perspective, there is still limited research available on the feasibility and quality of tele-AAC services for pALS from the perspectives of practicing SLPs or AAC specialists.

The Coronavirus pandemic which began in 2020, causing lockdowns worldwide, has led to increased challenges in providing care and conducting research for the ALS population (Andrews et al., 2020). Since the COVID-19 pandemic, there has been a sudden turn to and dependency on telehealth services due to the benefits of using technology to provide care for pALS. In addition, the structure and use of telehealth has improved and matured throughout the pandemic, making availability and efficiency of clinical care a possibility for pALS (Andrews et al., 2020). In regards to billing services, the Centers for Medicare and Medicaid Services (CMS) added speech and language and audiology codes to expand the coverage for telehealth services throughout the pandemic (ASHA, 2022; Warren, 2021).

More recently as the attention on tele-AAC has grown during COVID-19, over 300 SLPs who provided AAC services to children ages three to twenty-one via tele-AAC completed a survey on their opinions regarding tele-AAC (Biggs, Therrien, Douglas, & Snodgrass, 2022). The survey used a five-point scale that asked how the SLPs were delivering tele-AAC, how effective they felt tele-AAC was, and if they anticipated it being used after the end of the

pandemic. Results indicated that 66% of SLPs rated tele-AAC as either ‘moderately effective’ or ‘quite effective’. Challenges identified as reasons for reduced effectiveness of tele-AAC were access to quality internet, parent availability, and SLP’s limited experience and knowledge on providing tele-AAC, which presented a large learning curve (Biggs et al., 2022). Nearly 50% of the SLPs who provided consultation or coaching services to parents via tele-AAC indicated probably yes or yes to anticipating continuing remote services. Some of the reasons identified by the SLPs to continue tele-AAC were the benefits for the families they served, the convenience of the remote modality in reducing travel time, and increased service to medically fragile or homebound children (Biggs et al., 2022).

AAC Assessment Guidelines

Assessment protocol adherence is important in the field of speech pathology as a whole because assessment determines appropriate treatment (McKelvey, Weissling, Lund, Quach, & Dietz, 2021). The research into AAC assessment appears to be limited compared to the amount of research into treatment for adults with complex communication needs. It is unclear whether SLPs utilize research evidence when conducting AAC assessments for their clients, or if they rely heavily on their clinical judgement and previous experience (Schlosser & Raghavendra, 2004). The lack of attention to assessment protocols may pose risks in terms of SLPs being unprepared to select the most appropriate AAC devices or interventions (McKelvey et al., 2021). Although research in AAC assessment appears to be limited compared to the amount of research in treatment, some studies have explored this topic and are described in the following paragraphs.

Outside of peer-reviewed research literature, there are guidelines for general AAC assessment procedures. For example, both (Light & Beukelman, 2020) and Dodd (2017) provide

AAC assessment considerations for various populations and ages. Some studies have outlined principles for AAC assessment which include consistent re-evaluation of communication by SLPs, exploring what type of AAC (no-tech, low tech, or high tech) would be appropriate, systematic feature matching, and identifying the communication partners (Fried-Oken, Mooney, & Peters, 2015; Hall et al., 2019; McNaughton et al., 2018).

Dietz et al. (2012) conducted interviews with 25 SLPs with varying levels of AAC expertise asking how they approach the AAC assessment process (Dietz, Quach, Lund, & McKelvey, 2012). SLPs who were categorized as providing a wide variety of clinical services, but not specializing in AAC, came up with two main components of assessment, the language assessment and symbol assessment. They mostly chose to assess areas that were likely to be affected based on the client's impairment or diagnosis. On the other hand, the AAC specialists generated a six-step process: communication assessment using scenarios, need for alternative access, multimodal communication, instruction in use of AAC, symbol systems, and device trials. Their assessments looked more holistically at the client to be able to have functional and meaningful communication. Another large difference between the two groups was that AAC specialists tailored the assessment process based on how their client presented, whereas the generalist SLPs planned the assessment in a more linear approach. The various levels of SLP expertise and comfort in providing AAC services may have contributed to variability in how AAC assessments were conducted.

There is no single source that includes a comprehensive process for AAC assessment particular to pALS, and the specific tasks or techniques that should be included in an assessment are not clearly understood (McKelvey et al., 2021). To address this limitation in research for pALS, McKelvey et al. (2021) analyzed the AAC assessment process using a simulated case and

decisions from eight SLP AAC specialists. McKelvey et al. (2021) analyzed what domains AAC specialists included in their AAC assessment with pALS, as well as how they would evaluate those areas. The specialists reported they would evaluate speech intelligibility, communication needs, motor abilities, cognition, language, literacy, any confounding medical issues, hearing, and speech rate, as well as determining what device features would benefit the pALS. The AAC specialists collectively reported they would use informal assessment, formal assessment, and dynamic assessment. In general, the assessment plan considered the pALS' individual needs as well as the SLP's knowledge and experience with the progression of ALS. This information helped create a foundation of what should be included in assessments, but further research having AAC specialists conducting real life assessments with pALS, instead of simulated case studies, was recommended for more applicable results (McKelvey et al., 2021).

Based on their work, McKelvey et al., (2018) developed the Augmentative and Alternative Clinical Assessment Project (AAC CAP), a protocol for the assessment of pALS. First, the protocol describes essential information to collect in a pre-evaluation interview including the pALS' communication needs, current communication skills, medical considerations or where they are in the progression of the disease, motor access capabilities, pre-morbid sensory deficits, and the type of funding or insurance. Next, it provides guidelines for additional areas to assess including pALS's acceptance of using AAC, their cognition, language and literacy, sensory needs, and swallowing function. Finally, it provides elements to evaluate during AAC device trials including speech intelligibility, motor access, support system, and overall system feature analysis such as technology and vocabulary needs (McKelvey et al., 2018). The AAC CAP was developed for in-person AAC assessment and has not specifically been adapted for use with tele-AAC.

In general, there is limited research available on how SLPs conduct AAC evaluations for pALS in-person. Information regarding how SLPs conduct AAC evaluations for pALS via tele-AAC is even more sparse. Considering that tele-AAC services have likely grown during COVID and may continue to be a modality that is used to provide services, ensuring that tele-AAC assessments for pALS are comprehensive and commensurate in quality to those conducted in-person is valuable. Prior evidence from SLP perspectives using case studies, and from the perspective of pALS participating in tele-AAC are both promising. A gap in our understanding is the view of SLP experts in AAC regarding how well tele-AAC assessments for pALS adhere to recommended assessment principles and guidelines in actual delivery and how comparable they view it is to in-person services.

The purpose of this paper is to analyze SGD assessments conducted via tele-AAC for pALS through the lens of SLPs who are AAC specialists. This paper will examine whether the AAC specialists find that SGD evaluations completed via tele-AAC are comparable to what can be achieved with an in-person evaluation. This paper is an extension of the Roman et al (2021) study which evaluated the tele-AAC assessment and training process from the perspectives of pALS and their caregivers. This study will add to the limited research into assessment protocols in AAC, specifically regarding conducting SGD evaluations for pALS through tele-AAC.

Methods

This observational study consisted of obtaining qualitative and rating scale feedback from SLP AAC specialists who reviewed videos of SGD evaluations completed with pALS via tele-AAC. The protocol for the original study was approved by the IntegReview independent institutional review board of Austin, Texas, which provides reviews for research not affiliated

with a research institution. A follow up survey was determined exempt by the University of Washington Institutional Review Board.

The overall study has been described in Roman et al (2021). To summarize, eight pALS, each with a caregiver, were recruited to participate in SGD evaluation and training via tele-AAC. The pALS were selected for the study based on their difficulties accessing in-person AAC services. As part of the study, the pALS were provided with a range from four to six evaluation sessions depending on need. These evaluations were conducted by an AAC specialist and included trials of SGDs. Prior to the evaluation sessions, the pALS were asked to complete two questionnaires; a pre-evaluation questionnaire (Appendix A) which included questions regarding their sensory and physical abilities, any previous SLP services, and any mobility equipment they used and a technology needs questionnaire (Appendix B) to identify their top priority in technology needs such as internet or social media access. The caregivers were also asked to complete a pre-evaluation questionnaire (Appendix C) about any observation of behavioral changes in the pALS. The first session included an interview, vision exam, and assessment of positioning, physical abilities related to potential access options, language, cognition, speech rate, and intelligibility. During this session the AAC specialist trained the pALS and caregivers in a low tech communication method if the pALS was not using one that enabled novel message generation through spelling. The following assessment sessions consisted of device trials. In order to avoid over-taxing the pALS' often limited energy, each vendors' representative brought the SGDs and access equipment on a separate day. The final assessment session included reviewing the SGDs that were trialed, deciding on the best fit, determining a timeline for funding, and planning a training schedule once the AAC device arrived. The assessment sessions and device trials were directed by the SLP via remote access, but device vendor representatives

were present in-person with participants to provide the trial devices for their respective sessions. Both the SLP and the representative set up video cameras to enable the SLP to visualize both the SGD's display as well as a side profile of the pALS, and the room and environment they were in. After device selection and delivery, two training sessions were also conducted. All sessions were video recorded, with the recordings viewed by SLP AAC specialists. The reviews of the assessment (not treatment) sessions were the focus of this analysis.

Participants

The participants in this study, referred to as 'reviewers' in this manuscript, were SLPs with expertise in providing AAC services. The inclusion criteria were self-report that they (1) were American Speech Language Hearing Association (ASHA) certified and state licensed SLPs, (2) had provided SGD services to pALS for at least five years, and (3) had provided at least twenty-five SGD evaluations that resulted in funding for the SGD durable medical equipment they had recommended. Incentives to participate in this study were a stipend of \$200¹ after completion of the study activities. The reviewers were individually contacted by the principal investigator on the larger project (AR), being known to her based on their presence on listservs, being authors on relevant articles, attendance at SLP professional development conferences, or being referred to the principal investigator from other practicing SLPs who had worked with pALS. Sixteen reviewers accepted the invitation to participate in this study. Fifteen out of the sixteen reviewers completed and submitted their reviews.

¹ The \$200 stipend was determined considering the time commitment required to review the evaluation. Reviewers were asked to review 4-6 separate videos to cover the evaluation of a single pALS, and each video ranged, on average, from 55 to 99 minutes.

Data Collection Instrument

The AAC assessment used by the PI (AR) to evaluate the pALS followed the AAC CAP guidelines (McKelvey et al., 2018). The checklist used in this study (Appendix D) incorporated the AAC CAP elements, with additional elements added for this study by the PI. The checklist includes the following seventeen elements: identifying communication needs, current communication skills, perceptual measures of speech, medical status, motor and sensory abilities, vocabulary needs, funding information, type of equipment to trial, AAC acceptance, cognitive abilities, language and literacy, feature matching, patient caregiver preferences, the pALS' support system, computer and technology needs, and reviewing the next steps. The 17 elements along with their definitions and abbreviations used in this manuscript are in Table 1.

Table 1:

Assessment elements, their abbreviation, and definition

Element	Abbreviation	Definition
1. Communication needs identified	Comm Needs	Person's level of participation, roles they play, situations they communicate in. (e.g. biographical information, languages spoken, favorite topics, who are their communication partners)
2. Current communication skills identified	Comm Skills	Any changes in person's speech, intelligibility, communication modalities/strategies, how do they repair communication breakdowns
3. Speech assessed	Speech	Intelligibility of speech with familiar communication partners, unfamiliar communication partners, and in various environments
4. Medical status assessed	Medical	Current medications, date of diagnosis, progression of symptoms, difficulty breathing

Element	Abbreviation	Definition
5. Motor abilities and alternative access assessed	Motor	Weakness in hands/arms, sit unsupported, use of any mobility aids, any falls, any adapted technology to use keyboard/mouse, fine motor skills
6. Sensory abilities assessed	Sensory	Hard of hearing, wearing hearing aids, any communication partners who have hearing loss, vision, use of glasses, visual deficits
7. Vocabulary needs explored	Vocab	The type of vocabulary needed on device, what are the most common words, phrases, etc. that is used in day-to-day life (e.g., diet, swallowing, strategies, hobbies, interests, communication partners)
8. Funding information gathered	Funding	Type of insurance, coverage of a SGD device, copayment requirement, backup funding, hospice
9. Information gathered to determine equipment for clinical trials*	SGD	From interviews and screenings, ability to determine what equipment, software, and strategies should be trialed with pALS.
10. Exploration of AAC acceptance	AAC	PALS' and caregiver's willingness to explore alternate modes of communication, discussing voice and message banking, willingness to try and use AAC strategies
11. Cognitive abilities	Cog	Screening cognition, determine any changes in cognition
12. Language and literacy abilities	Lang	Can the person read and spell messages word finding difficulties, general grammatical ability, auditory comprehension, length and complexity of utterances
13. Determination of features that match needs	Feat	Voice available, font size, storing messages, voice and message banking, access selection, portability, word prediction
14. Patient and caregiver preferences elicited and explored	Pt Pref	Understanding Patients idea of what they want in their AAC system by showing them a variety of features and devices (e.g., features, size, styling, perception of ease of use, ease of message storage, etc.)

Element	Abbreviation	Definition
15. Support system	Support	What supports the PALS has in place (e.g., who, level of comfort with technology, availability, etc.)
16. Patient's computer and technology needs explored*	Tech	What pALS' computer needs and preferences were. What technology would they be interested in using? (e.g., email, eBooks, environmental controls, entertainment, web browsing, applications/programs)
17. Review next steps*	Future	Ability to go over the next steps after the clinical trials (e.g., funding process, wait time, loan options, training plan)

* Elements added by PI, not directly following AAC CAP assessment guidelines

The reviewers were asked to consider each of the 17 sections of the checklist. For each section they were asked to qualitatively describe any challenges they noticed about evaluating that element over tele-AAC rather than if it was in-person. They were asked to note if the challenge was overcome, how was it done, and if it was not overcome to provide insight as to how the SLP could have overcome it or why there is no resolution. The reviewers were also asked to describe any advantages to evaluating the element using tele-AAC rather than in-person. The reviewers were also asked to complete a rating comparing tele-AAC to in-person evaluations for each element on a 5-point rating scale indicating if tele-AAC was 'Much superior,' 'Somewhat superior,' 'Same/comparable,' 'Somewhat inferior,' or 'Much Inferior.'

Finally, the reviewers were given open ended, free text questions. These additional questions asked about the inclusion of the SGD vendor representatives, any feedback on the pre-evaluation questionnaires for the pALS and caregivers, and finally, any additional thoughts or suggestions they may have had for conducting the evaluation. See Appendix D for a copy of the data collection instrument.

Data collection methods

Each reviewer was randomly assigned to watch the assessment videos (4-6 videos covering all evaluation sessions) for one pALS. There were two reviewers assigned to each pALS, with a different pair of reviewers assigned to each of the eight pALS. The reviewers were emailed the checklist (Appendix D), the ALS caregiver behavioral portion of the ALS Cognitive Behavioral Screen (Woolley et al., 2010) (Appendix C), the pALS' pre-evaluation questionnaire (Appendix A), the Patient's Rating of Technology Needs portion of the Communication Needs Questionnaire (Bardach, 2017) (Appendix B), and the McKelvey et al. (2018) AAC CAP Protocol through encrypted emails. The reviewers were emailed a link to a HIPAA compliant Zoom cloud where they were able to access their assigned pALS' evaluation videos, but were not able to download them. They could watch the videos multiple times if they wished while completing the task. They were asked to watch them independently and at their own pace, but to complete their ratings within ten days after getting access to the videos. The reviewers completed the checklists on a Microsoft Word document and returned them to the researchers via email.

Data analysis

The completed checklists were analyzed through the use of both descriptive quantitative and qualitative analyses. All analyses were completed using Excel spreadsheets for data storage and organization. For each of the 17 checklist elements, the qualitative data analysis began by considering each of the 17 elements individually, and advantages and challenges were initially summarized separately for each element. Similar reviewer comments were grouped within each element by content, regardless of minor wording variations. For example, if multiple reviewers commented for Element 1 (communication needs identified) that an advantage of doing tele-AAC was increased patient comfort due to the pALS being able to stay in their home, all of these

related comments would be grouped together. A summary phrase that captured the main idea of the group of comments was generated, such as, ‘comfort in home.’ This process was completed until all the reviewers’ comments were organized under a summary phrase for either an advantages or challenge, and the number of the reviewers’ contributing comments to each topic area was tabulated.

After completing a summary of comments for each of the 17 elements, an additional level of qualitative analysis was completed to identify common themes in reviewer feedback that spanned across the elements and were reported most frequently. These most common and salient advantages and challenges were further described and illustrated using direct quotes from the reviewers. These analyses were conducted by the first author (MB) with a second researcher re-analyzing at least 20% of responses to assess reliability.

The Likert-scale ratings comparing tele-AAC to in-person assessment were analyzed by tallying the frequency of responses for each response option for each checklist element.

Addressing the impact of the COVID pandemic

The data for this study were collected just prior to the COVID pandemic. There was the potential that the reviewers’ perspectives regarding tele-AAC could have changed due to likely changes in their own clinical practice during COVID. While prior to the pandemic, tele-AAC was utilized less often and not typically covered by insurance, it became essential in many situations during the pandemic. Considering how the pandemic may have impacted the perspectives of the reviewers, the question may be asked how they felt after the pandemic about providing AAC assessments via tele-AAC. To address this question, the research team recontacted the reviewers and asked them to complete a brief questionnaire (Appendix E).

The questionnaire asked the reviewers to provide demographic information (which was not collected in the original study), and to comment on how the pandemic had changed their perceptions of providing SGD evaluations via tele-AAC, if at all. The questions were programmed into an online survey tool available through the University of Washington, and completion of the survey was anticipated to take no more than 10 minutes, depending on the length of comments participants provided. The first questions of the survey asked the reviewers about the frequency with which they provided SGD assessment and training via tele-AAC before COVID and during the peak lockdown period of COVID using the following response options: Never (0%), Very Rarely (1-5%), Occasionally (20-30%), About half (40-60%), Almost always (75-90%), and Always (100%). These data were analyzed by tallying responses in each category. Reviewers were asked to indicate whether they anticipated using tele-AAC after the pandemic by choosing among the response options of “Plan on returning to ALL in-person,” “Plan on providing most or all assessment/training via tele-AAC,” and “Plan on a mix of both in-person and tele-AAC.” The second part of this question asked reviewers to select the reasons that drove their decision as to whether they anticipated providing AAC services via tele-AAC or in-person post COVID. They were able to select all that applied or add their own reason to the following choices that were provided: Patient preference, Insurance/payment requirements and regulations, Rules and regulations of my facility, My own preference/comfort for providing services, and Other (please describe). These reasons were analyzed by tallying the number of reviewers who selected each reason. The final question in the survey was open-ended and asked reviewers for any additional comments on their perspectives of providing tele-AAC since COVID. These comments were analyzed to determine if any new topics were raised that were not included in their original data, or that illustrated evolving perspectives.

Results

Participants

A total of 16 reviewers were recruited, and 15 of the 16 returned completed checklists. Thirteen of the 15 reviewers provided demographic information in the follow-up survey; 1 did not respond, and 1 responded to report having retired, but did not provide further information. Demographic information is in Table 2.

Table 2

Demographic Information for Reviewers (n = 13 unless otherwise specified ^a)

Age (years; n= 10)	Frequency		
41-50	5	Mean	51.5
51-60	3	Minimum	41
61-70	2	Maximum	67
# of years of clinical experience	Frequency		
10-20	4	Mean	25.77
21-30	6	Minimum	14
31-40	1	Maximum	45
41-50	2		
# of years doing SGD ^b evaluations	Frequency		
10-20	7	Mean	21.08
21-30	4	Minimum	10
31-40	1	Maximum	45
41-50	1		
# of years of experience with pALS	Frequency		
5-10	3	Mean	16.77
11-20	6	Minimum	6
21-30	3	Maximum	34
31-40	1		

^a Fifteen reviewers were asked to participate in follow up survey, 2 did not report their demographic information. 1 of the 2 reported retiring.

^b Speech generating device

Qualitative Data

The summaries of both advantages and challenges for each element, along with the number of reviewers providing data related to that topic, are in Table 3.

Table 3

The Advantages and Challenges of Tele-AAC according to Reviewers (numbers in parentheses indicate number of reviewers commenting on this topic)

Element	Advantages of evaluating element via tele-AAC	Challenges of evaluating element via tele-AAC
1. Communication needs identified	<ol style="list-style-type: none"> 1. Functional assessment, seeing pALS' main communication environment (6) 2. Caregivers able participate and help in sessions more (4) 3. Added comfort being in the home, pALS appeared relaxed (3) 4. Access to personal items at home (1) 5. Increased access for those who live far away (1) 	<ol style="list-style-type: none"> 1. Assessing multimodal communication, having pALS demonstrate low tech AAC use (2) 2. Technical difficulties and camera positioning (1) 3. Understanding speech and rapport building (1)
2. Current communication skills Identified	<ol style="list-style-type: none"> 1. Able to see pALS' natural environment in their home and identify more functional needs (6) 2. Easily review low tech AAC and assess nonverbal communication strategies (2) 3. Increase need for pALS to actively participate and self-advocate (2) 4. Increased ability for caregiver participation (1) 5. Access to personal items at home (1) 	<ol style="list-style-type: none"> 1. Technical difficulties and camera positioning (2) 2. Assessing multimodal communication, having pALS demonstrate low tech AAC use (2)
3: Speech Assessed	<ol style="list-style-type: none"> 1. More functional assessment of speech in more challenging situations (e.g. via video, phone) (4) 2. Easy to collect intelligibility rating (2) 	<ol style="list-style-type: none"> 1. Limited analysis of motor speech and speech quality (4) 2. Inaccurate intelligibility assessment due to remote connection/audio quality (4)

Element	Advantages of evaluating element via tele-AAC	Challenges of evaluating element via tele-AAC
	<ol style="list-style-type: none"> 3. Increased ability for caregiver participation (1) 4. Reducing fatigue from traveling to in-person sessions (1) 	<ol style="list-style-type: none"> 3. Challenging to complete oral motor/cranial nerve examination (3)
4: Medical Status Assessed	<ol style="list-style-type: none"> 1. Seeing pALS function in main home setting (3) 2. Increased input from caregivers (2) 	<ol style="list-style-type: none"> 1. Assessing specific medical issues (e.g. fasciculations, vision) (2)
5: Motor Abilities & Alternative Access Assessed	<ol style="list-style-type: none"> 1. Assessing access in functional setting with actual home lighting and positioning (5) 2. Able to break up sessions to be manageable (2) 3. Increase need for pALS and caregiver to demonstrate skills, troubleshoot, and use of SGD (1) 4. Increased ability for caregiver participation (1) 	<ol style="list-style-type: none"> 1. Limited assessment of complete motor skills due to limited view of both upper and lower extremities (7) 2. Requires strong coordination between vendor representative and the clinician SLP, requires more time to assess (3) 3. Requires caregiver participation and assistance (2) 4. Positioning for eye-tracking difficult to troubleshoot (1)
6: Sensory Abilities Assessed	<ol style="list-style-type: none"> 1. Access to personal items at home that could be forgotten in-person (e.g. glasses) (4) 2. Functional assessment in daily environment (4) 	<ol style="list-style-type: none"> 1. Assessing visual preferences of device (e.g. color preference) (1) 2. Requires quality audio and video for complete assessment (1)
7: Vocabulary Needs Explored	<ol style="list-style-type: none"> 1. Increased caregiver input and availability (2) 2. Identifying functional vocabulary used in main communication environment (2) 3. Increase need for pALS to learn how to program device (1) 	<ol style="list-style-type: none"> 1. None reported
8: Funding Information Gathered	<ol style="list-style-type: none"> 1. Access to personal documentation in home (2) 	<ol style="list-style-type: none"> 1. None reported
9: Information Gathered to Determine Equipment for Clinical Trials	<ol style="list-style-type: none"> 1. Functional assessment in home environment, easier to identify positioning needs (3) 2. More time for caregiver to respond (1) 	<ol style="list-style-type: none"> 1. Requires reliable internet connection (1) 2. Faster to rule out devices and provide demos in-person (1) 3. Requires experience with technology and equipment (1)
10: Exploration of AAC acceptance	<ol style="list-style-type: none"> 1. Added comfort being in the home, pALS able to feel relaxed and less pressured (5) 	<ol style="list-style-type: none"> 1. Technological difficulties between vendor rep and SLP (1)

Element	Advantages of evaluating element via tele-AAC	Challenges of evaluating element via tele-AAC
11: Cognitive Abilities	<ol style="list-style-type: none"> 2. Functional assessment in home in main communication environment and problem solve real issues (3) 1. Less stress and fatigue in home setting (3) 2. Easier to score assessments and make notes (1) 	<ol style="list-style-type: none"> 2. If pALS require use of low tech AAC, easier in-person (1) 3. Limited perspective of pALS' reservations, unable to "read the room" (1) 1. Possibility of caregiver assisting during testing, leading to inaccurate scores (2) 2. Getting materials for assessment to pALS and access to additional screening measures (2) 3. Some screeners are not approved or adapted for telehealth use (1)
12: Language and Literacy Abilities	<ol style="list-style-type: none"> 1. Increased comfort and less fatigue being in home (2) 2. Assessment in main communication environment (1) 	<ol style="list-style-type: none"> 1. Requires reliable internet connection to visualize facial expressions, assess full picture (1) 2. Some screeners are not approved or adapted for telehealth use (1) 3. Getting access to additional screening measures (1) 4. Presenting visual stimuli requires quality video (1)
13: Determination of features that match needs	<ol style="list-style-type: none"> 1. Functional assessment seeing daily environment (2) 2. Allows increased time for interview (1) 3. Increased comfort in home setting (1) 	<ol style="list-style-type: none"> 1. Troubleshooting remotely is more difficult, highly dependent on caregiver and vendor rep support (2)
14: Patient and Caregiver Preferences Elicited and Explored	<ol style="list-style-type: none"> 1. Seeing device use in real functional setting, able to identify needs easier (2) 2. Increased comfort in home setting (1) 	<ol style="list-style-type: none"> 1. Technology limitations due to camera view, internet connection (3) 2. Requires coordination between vendor rep and clinician (1) 3. If pALS require use of low tech AAC, easier in-person (1)
15: Support system identified	<ol style="list-style-type: none"> 1. Demonstrate pALS and caregivers' skills and their ability to troubleshoot and problem solve in real time (5) 2. Able to see who is in home environment (2) 3. Allow for caregiver training and availability (2) 	<ol style="list-style-type: none"> 1. Technical support difficulties (1) 2. Requires caregiver to be at all sessions (1) 3. Increased difficulty to train caregiver (1)

Element	Advantages of evaluating element via tele-AAC	Challenges of evaluating element via tele-AAC
16: Patients computer and technology needs identified	<ol style="list-style-type: none"> 1. Able to see home environment and available technology (3) 2. Demonstrate pALS and caregivers' skills and their ability to troubleshoot and problem solve in real time (1) 3. Increase time and availability of caregivers (2) 	<ol style="list-style-type: none"> 1. Limited camera view via video (2) 2. Technology difficulties including audio and screen access (2) 3. If pALS require use of low tech AAC, easier in-person (1)
17: Review next steps	<ol style="list-style-type: none"> 1. Increased caregiver involvement (1) 2. Comfortability in home (1) 	<ol style="list-style-type: none"> 1. If using loaner device, may be easier to access in-person (1) 2. If pALS require use of low tech AAC, easier in-person (1)

Most Common Advantages of Tele-AAC

The following are the most common advantages raised by reviewers across all 17 elements.

Functional Assessment.

The word “functional” was used by many of the reviewers across the majority of the elements as an advantage of doing SGD evaluations remotely. They commented how being able to see the pALS’ home, which was also their main communication environment, enabled the SLP to make recommendations that may be more appropriate for the pALS’ home and lifestyle:

The ability to see the patient in their home environment is very helpful for identifying communication needs and other logistics of implementing a SGD successfully. Visiting the patient’s home in telehealth, while not the same as begin there in person, nevertheless improved the ability to identify communication needs as well as other logistics (i.e., lighting, positioning, etc.) of assessing/implementing the SGD. (Reviewer G, Element 1)

When the evaluation takes place in the home, the SLP and vendor could see the pALS’ environment. Another commented that, “Environmental concerns for eye gaze (e.g., lighting) are

exactly what they will be,” (Reviewer D, Element 6). Furthermore, other environmental factors such as the space that the pALS have at home may influence what equipment may be appropriate. For example, another reviewer mentioned that having:

[SGD] trials virtually as opposed to in person, allowed the evaluator to use clinical judgment and experience to observe behaviors/interactions in the home environment that the patient or caregiver might not verbalize or realize as a preference. One example of this is that the SLP may have recommended a rolling floor mount if the patient was seen in clinic based on experience/other patients’ preference but after seeing home environment and patient/family preference, a table mount was recommended. (Reviewer M, Element 14)

In addition to visualization of the home environment allowing for a more functional assessment, the pALS also had access to equipment, documents, or information that they needed for the appointment but may have forgotten if going to an in-person clinic. One reviewer commented that this, “Patient had access to her glasses! Lots of times things like these are forgotten in the outpatient setting and we have to carry on the assessment without them,” (Reviewer C, Element 6). When pALS have easier access to their personal items, it may be helpful in gathering a more accurate evaluation of their needs and skills.

Another issue is that the equipment or positioning the pALS may be using in a clinic setting is not the same as they may be using in their homes. For example, they may spend most of their time needing to communicate in bed or on their couch. A reviewer expressed that with tele-AAC, “The clinician was able to observe the PALS using her current communication methods...in a frequently-used chair in her home, and was able to see the positioning challenges she experiences,” (Reviewer W, Element 2).

Caregiver Availability.

A second reoccurring topic the majority of the reviewers commented on was that doing the evaluations via tele-AAC allowed for an increase in caregiver availability and support during sessions. This comment was not limited to only the primary caregiver. Holding the session at home allowed for more people/family in general to be involved in the process. One reviewer commented that, “It may be easier for family/caregivers who plan to provide AAC support to be there so they can ask questions and bring up specific concerns,” (Reviewer D, Element 15). In addition to the increased ability for the caregivers to be present for a session, the remote evaluation provided an opportunity to provide caregiver training. One reviewer commented:

Interestingly, I think this [tele-AAC] is a terrific method for getting caregivers engaged in the process immediately. In face-to-face encounters, the clinician often does the positioning and adjusting and later trains caregivers. But this had to be supported immediately by the caregiver with the remote instruction. Wonder if overall support and engagement might even be stronger if we required this level of hands-on involvement this early on regularly. You really get to see immediately who is and is not competent at helping support from a technical perspective. (Reviewer O, Element 15)

The remote format may also give the caregiver flexibility to multitask. For example, one reviewer commented that they, “Believe the interaction via tele practice allowed the caregiver to take care of the patient’s needs and still answer questions,” (Reviewer A, Element 1). In general, many of the reviewers addressed that an advantage of doing tele-AAC in pALS’ homes is that it allowed for more caregiver involvement and availability, as well as flexibility throughout the evaluation process.

Comfort at Home.

A third main advantage reported across the elements was increased patient comfort for remote evaluations compared to in-person evaluations. Having the evaluations at home relieved the need for pALS to travel possibly long distances to get to a clinic. One reviewer commented that the SLPs can, “Assess status without stress and fatigue of travel,” (Reviewer K, Element 3). This relief of stress and fatigue that can come with travelling can allow for more energy allocated to the session itself. Another comment about a pALS was that, “The patient was resting comfortably and so I anticipate her endurance for participation was likely increased as opposed to participating in the outpatient setting,” (Reviewer C, Element 1). The same reviewer expressed that it was, “Great to be able to break the evaluation into multiple, shorter sessions to minimize fatigue,” (Reviewer C, Element 5). As another reviewer wrote, “MAJOR ADVANTAGE (capitalized by reviewer): Patient is in his own bed with positioning that will be daily standard when he actually uses the system. Not fatigued from coming into clinic. Actually positioned for real-world use. MUCH better than clinic visit,” (Reviewer J, Element 9). In general, when the pALS is able to have the evaluation done at home, the reviewers commented on the sense that they appeared more comfortable. For example, one expressed that the, “Advantage to being in home, pALS is more relaxed and comfortable,” (Reviewer B, Element 1).

Most Common Challenges of Tele-AAC

The following are the most common challenges reported by reviewers across all 17 elements.

Technical difficulties.

The first challenge of doing tele-AAC compared to in-person evaluations that reviewers commented on across the 17 elements were technical difficulties. Overall, an anticipated challenge may be the availability of internet for all pALS. One reviewer commented:

Some patients that I work with are in such rural areas their internet is not reliable. Many of my patients do not have smart phones either. So, I would need to make sure their internet was reliable and that they had a device. (Reviewer A, Element 9)

A possible solution brought up by Reviewer A for lack of hardware was that the SLP could, “Also send them a tablet or a laptop for the evaluation.” Multiple reviewers mentioned the concerns about unstable internet, the video lagging, or broken audio that added additional time or was otherwise an obstacle to doing the tele-AAC evaluation. For example, one noted that there was, “Freezing of the second screen,” (Reviewer N, Element 16). Another stated that the, “Brief lag with remote access also makes problem-solving more difficult,” (Reviewer H, Element 5).

Another barrier that fell under technical difficulties was that tele-AAC requires an adequate level of competency using technology. One reviewer explained that, “For use of telepractice, really need an ‘e-helper’ or someone who is identified and knowledgeable [regarding] set-up and tech support. Otherwise, this fast becomes a disadvantage of telepractice and makes this type of [access] less feasible,” (Reviewer R, Element 9).

During the assessment, one technical challenge cited was the limited camera view. One reviewer reported that, “It’s difficult to problem-solve access issues when you can only see the patient from one view,” They included that this challenge could be, “Overcome by use of multiple cameras in addition to software allowing evaluator to see/access the screen of the SGD being used,” (Reviewer H, Element 5). Similarly, another reviewer commented that an SLP would, “Need additional cameras set-up so that audience can view what client is seeing and doing,” (Reviewer R, Element 9). A second camera was always in use during the evaluations, but due to Zoom recording settings for some of the evaluations the reviewers were rating, they were

not always able to see the side view of the second camera used which captured the pALS from the waist up.

Limitations to comprehensive assessment.

A second theme across the challenges reported was that the use of tele-AAC, for various reasons, limited the ability to gather a complete perspective or understanding of the element being assessed. When assessing the pALS' speech, reviewers commented on a few barriers. For example, one stated that the SLP, "May underestimate in-person intelligibility due to remote connection," (Reviewer N, Element 3) Another added that, "It would be more difficult to conduct a full cranial nerve (oral mechanism) assessment in telehealth," (Reviewer G, Element 3). Another example was with assessing element 11, cognitive abilities, in that it was difficult to ensure that the pALS were not receiving any assistance from caregivers when formally evaluating their cognition.

Other examples that mentioned a limitation to comprehensive assessment was determining access method for the SGD or medical status and needs. One reviewer commented that it was, "Difficult to see/visualize all physical access options... if needed to assess for various switch sites (e.g., for selection method) this would have been less-than-optimal," (Reviewer O, Element 5). A reviewer expressed that tele-AAC would be, "Same/comparable," to in-person evaluation, "As long as audio/video is responding appropriately, and cameras are placed to provide visual feedback," They added that, "One issue that could be more challenging is if the patient has nystagmus or both eyes don't work together. It might be difficult to adequately observe this in telepractice session," (Reviewer I, Element 6). Similarly, this reviewer commented on possible medical presentations that may be difficult to diagnose or determine via tele-AAC, "It is difficult to observe signs such as fasciculations in this setting." They added that,

“...The SGD eval is not diagnostic so those signs are not factors that necessarily influence the evaluation,” (Reviewer F, Element 4). Another example of a general limitation was that clinicians, “...May not get the full picture during tele-eval (there’s something to be said for “reading the room”),” (Reviewer D, Element 10). In general, reviewers commented that doing the evaluation remotely had various challenges in retrieving all the information a clinician may want or need in an SGD evaluation.

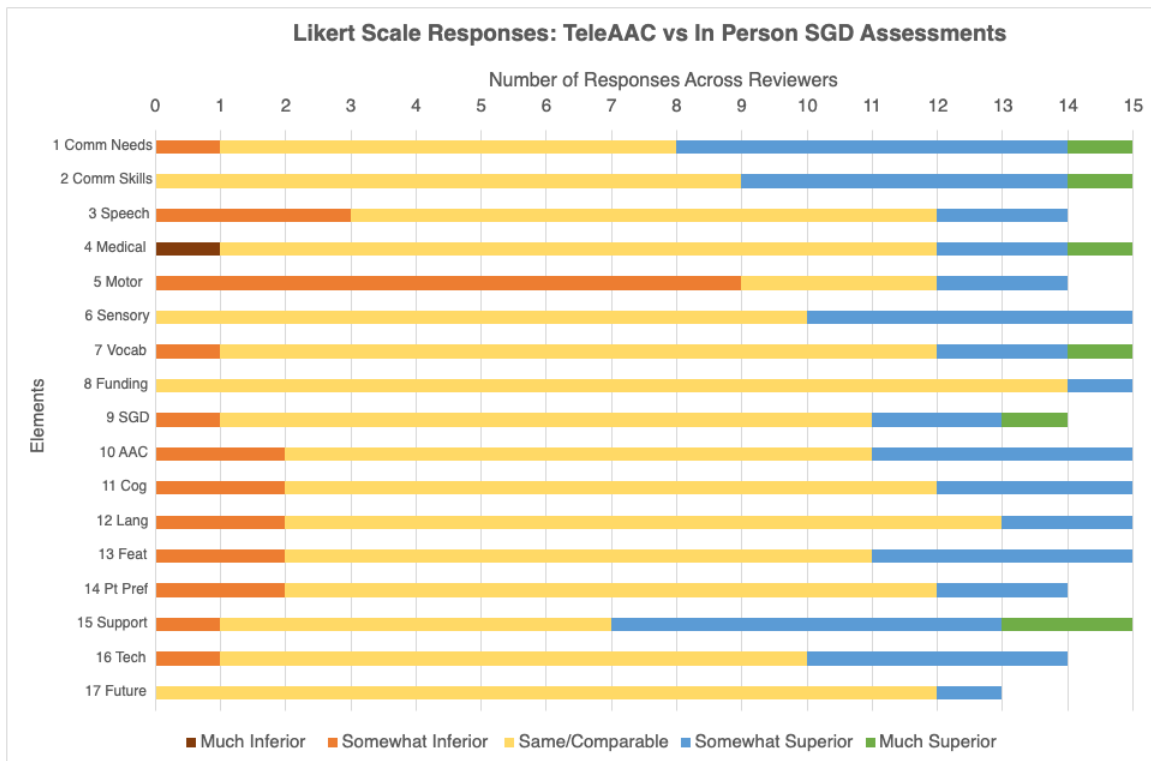
Rating Scale Data

The reviewers were asked to complete a rating that compared each assessment element via tele-AAC vs in-person using a 5-point rating scale of tele-AAC being ‘Much superior,’ ‘Somewhat superior,’ ‘Same/comparable,’ ‘Somewhat inferior,’ or ‘Much Inferior.’ These data are presented in Figure 1. On 6 different elements, there are data from 14 reviewers, and on one element there are data from 13 reviewers. The missing data are due to reviewers leaving items blank or choosing two options in which case the data were uninterpretable. The labels used for each element on the Y-axis (e.g. Comm Needs) in Figure 1 are defined in Table 1.

The most common rating across all 17 elements was that tele-AAC was the “same/comparable” to in-person evaluations. The 3 elements on which the pattern differed from this trend were with assessing motor abilities, assessing the pALS’ support system, and identifying the pALS’ communication needs. For assessing motor abilities, the majority of reviewers rated tele-AAC as “somewhat inferior” to in-person assessment. For assessing their support system, over half of the reviewers rated tele-AAC as either “much superior” or “somewhat superior to in-person.” For identifying communication needs, half of the reviewers rated tele-AAC as being “much superior” or “somewhat superior” and the other half rated it as

being “same/comparable.” Out of all 17 elements, only one reviewer rated one element, assessing medical status, as being “much inferior via tele-AAC.”

Figure 1:

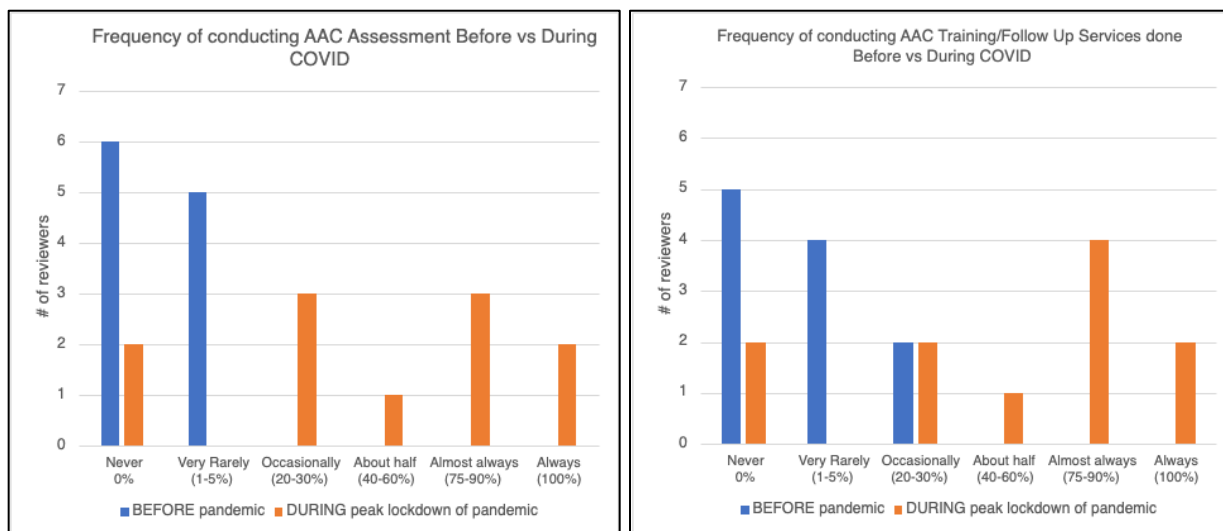


COVID-19 Follow Up Survey

The results from the follow-up survey regarding perspectives on tele-AAC after onset of COVID are reported in this section.

Frequency of AAC services conducted via tele-AAC prior vs during COVID

Figure 2 provides a summary of how often reviewers conducted tele-AAC assessment and training (assessments on the left, trainings on the right) in their own clinical practice before and after onset of COVID.

Figure 2:

Prior to the start of the pandemic, reviewers generally reported conducting assessment and training via tele-AAC “never” or “very rarely”. A similar pattern was seen for AAC training, with 2 reviewers occasionally providing tele-AAC for training prior to COVID. During the peak lockdown of the pandemic, reviewers’ responses covered the range of frequencies of conducting tele-AAC sessions. Two reviewers did not move to tele-AAC at all, with the others ranging from “occasionally” to “always”. Reasons given by the two reviewers who did not transition to AAC included:

I stopped evaluating and treating patients during the pandemic. My remote technology skills were not adequate to provide the level of service that I expect in my practice, and my patients were too complex. Often my patients did not have adequate Internet access of computers to work remotely, and I had no way to provide the systems or pay for internet for them. When AAC telehealth was initially not reimbursed by Medicare and insurance,

my outpatient clinic restricted provision of services. That put me over the top and I passed on my clinical responsibilities to another SLP. (Reviewer 18)²

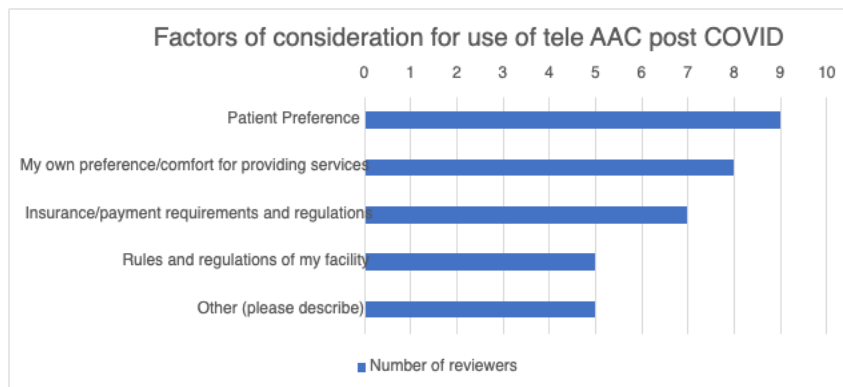
The second reviewer who never switched to tele-health commented that they, “Still prefer in-person assessment(s) as there are too many moving parts in an AAC eval to be entirely telehealth for me. Some aspects of the evaluation lend themselves more readily to telehealth than others,” (Reviewer 16).

Prediction of use of tele-AAC post COVID

The reviewers were also asked how often they anticipated conducting assessment and training via tele-AAC after the pandemic ends. For assessments, 8 of 11 reviewers responding to this question indicated that they anticipated providing a mix of both in-person and tele-AAC; 2 responded that they plan to return to all in-person; and 1 responded that they anticipate conducting most or all assessment via tele-AAC. For training/follow up services, 9 out of 11 reviewers responded that they plan to continue with a mix of both in-person and tele-AAC services; 1 responded with returning to all in-person, and 1 responded with providing most or all via tele-AAC.

Figure 3 provides a summary of the reasons that would drive reviewers’ decisions regarding whether to deliver AAC services via tele-AAC or in-person. For the 5 reviewers who selected ‘other’, 4 commented on travel or the pALS’ distance from a clinic as being a reason for continuing to provide tele-AAC. For the reviewer who responded with expecting to do all in-person assessments, the reasons they provided were the, “Availability/need for caregivers to assist during remote sessions,” as well as the client’s internet (Reviewer 12).

² Due to an error in file linking, we were not able to connect the reviewer identifiers from COVID follow up survey to the original reviewer IDs so we are using a different identification system between the two sets of data.

Figure 3:

In the option to provide additional comments on tele-AAC, some reviewers commented on their own clinical growth of providing tele-AAC since COVID. One expressed, “My skill in providing AAC services via telehealth has improved exponentially,” (Reviewer 13). While another mentioned that they, “Feel that [they] now have a structure for virtual training and implementation,” (Reviewer 12). Other reviewers commented on the advantage of tele-AAC and having sessions held at home for pALS. One reviewer expressed that:

Many years ago, when I worked in another setting, I had the opportunity to do home visits with my ALS patients that allowed me to customize their AAC systems to their needs in the home environment. This type of service is not practical for most SLPs. I found telehealth to be the "next best thing" to being physically in the patient's home when conducting AAC evaluations and follow up sessions. (Reviewer 3)

Another reviewer commented that, “Many [pALS] report satisfaction with not needing to leave the home/be exposed to COVID-19 to access SLP services,” (Reviewer 5). Multiple reviewers commented on the increased ability to provide services to pALS that could not be reached prior to tele-AAC. One stated that, “People who were previously not served or underserved due to geographic location will now be served for the most part,” (Reviewer 4). Another commented

that they, “Like the ability to reach so many more people with telehealth,” (Reviewer 5). In general, a majority of reviewers commented on benefits of having tele-AAC be an option for pALS. For example, one concluded with stating, “I hope I can always offer remote/telehealth services!,” (Reviewer 6). Another stated that, “Telehealth platforms are a good way to conduct SGD evals for ALS patients,” (Reviewer 4).

While many reviewers commented on the advantages of tele-AAC in the follow-up survey, others also reinforced the challenges with tele-AAC. Some expressed that the success of remote sessions were contingent upon various factors. For example, one commented that “remote evaluations are optimized when the patient and her support partners are technologically sophisticated and have the resources to focus their attention and participation in both evaluation and subsequent training on device use,” (Reviewer 11). In addition, another reviewer expressed that they “felt that the sessions were longer and it required increased preparation to ensure an appropriate and functional evaluation,” (Reviewer 12).

Discussion

The purpose of this study was to examine the perspectives of SLPs, who specialize in AAC and have clinical experience with pALS, on conducting SGD evaluations via tele-AAC services rather than in-person. The SLPs reviewed and critiqued videos of tele-AAC evaluations conducted with pALS, commenting on any advantages and challenges of telehealth sessions. In addition, this study analyzed how the perspectives of the SLPs may have changed after the COVID-19 pandemic that compelled many SLPs to convert their practices to tele-health.

Overall, when considering all elements of an SGD assessment, reviewers reported that doing the assessment remotely was comparable or of similar quality to in-person. In general, the reviewers’ perspectives were positive with a consensus that tele-AAC may be beneficial in many

areas, but comes with some challenges and limitations. The advantages appeared to outweigh the challenges in terms of how functional the assessment could be when the SLP was able to visualize the pALS' home and main communication environment, the reduced pALS' fatigue due to traveling to a clinic, and the ability to include caregivers in the discussion from a very early stage. In addition, remote sessions allow for increased flexibility with the ability to break up the assessment into more manageable sessions, rather than being pressured to fit all of an assessment into one session to avoid the pALS having to make the trip back to an in-person clinic again. The main challenges were typical to what may be expected with a remote session in terms of technical difficulties. Having unreliable internet, unstable audio or video quality, and a possibly limited camera view due to size or placement of the pALS' laptop/device may be obstacles that SLPs have to overcome when providing an assessment remotely.

The results from this study support existing literature on benefits of telehealth services with pALS. Previous literature including Van De Rijn et al. (2018) report that traveling long distances to their closest ALS clinic is physically fatiguing for pALS. The advantage of tele-AAC reported by reviewers in this study included increased comfort for patients, and that this modality allows SLPs to be able to reach more pALS regardless of their geographic location. This also aligns well with advantages of telehealth decreasing the need for travel seen by Horten et al. (2018), Howard & Kaufman (2018), Hall et al. (2019) and Pinto et al. (2020). Although not specific to pALS, parents participating in tele-AAC sessions for their children also reported that remote sessions would assist with transportation difficulties or long wait lists (Anderson et al., 2015). The SLPs conducting the sessions also believed that tele-AAC could be used as a supplement for in-person sessions (Anderson et al., 2015).

While not directly related to SGD evaluations, Selkirk et al. (2019) compared general medical care for pALS provided via telehealth to in-person and found, similar to what this study's reviewers reported, that the remote evaluations were of commensurate quality to in-person sessions. In addition, Curtis (2014) found that when an assessment or treatment is able to take place in natural environments, family can be more involved and assessment is more functional. Similar findings emerged from this study with the main advantage of tele-AAC reported by reviewers including increased caregiver involvement and functionality of assessment.

Andrews et al. (2020) found that the use of telehealth has grown for pALS since COVID, which was also seen in this study's survey results. Most reviewers increased the frequency of AAC assessment and training they were providing remotely in their own clinical practices (independent of their involvement in this study) since COVID. Although the majority of reviewers reported feeling more competent with conducting remote assessments and training, and being able to reach more pALS regardless of geographic location, a few did not make the transition to tele-AAC and stopped practicing clinically. Biggs et al. (2022) discussed challenges that SLPs identified about conducting tele-AAC, not specific to pALS, including the SLPs knowledge and experience being a hinderance to providing services. This is comparable to results from the post COVID survey in our study in which reviewers cited "their own preference and comfort providing services" as the second most common reason driving their decision to continue with tele-AAC or in-person services.

Challenges identified in this study of conducting tele-AAC including camera positioning, audio quality, and requirement for reliable internet connection were comparable to conclusions found with other diagnoses not specific to ALS in Styles et al. (2008) and Savard et al. (2003).

Styles et al. (2008) and Anderson et al. (2015) additionally addressed SLPs concerns with rapport building via tele-AAC which closely related to one comment made of difficulty “reading the room” by a reviewer in this study. Another limitation addressed by both Anderson et al. (2015) and Curtis (2014) were of difficulty with helping with positioning and demonstrating setting up AAC equipment via telehealth. Difficulty with coordinating between the in-person vendor and the SLP via online and requiring additional time for the remote assessment was also identified as a challenge by a few of the reviewers in this study.

Clinical Implications

Practicing clinicians may want to consider conducting tele-AAC evaluation with pALS due to the advantages that have been raised in this study and in prior research, with the caveat of being mindful of licensing and billing requirements for providing telehealth services. Tele-AAC offers another modality that may increase pALS’ access to equitable care other than in-person services. SLPs who do provide tele-AAC services should consider the various elements outlined in the checklist, which was used in this study, during an SGD evaluation with pALS to remind them of the important components of an assessment. Clinicians may be mindful of the challenges that were raised in this study and prepare for them in advance to minimize their intrusion into the clinical session. The results from this study are encouraging to clinicians who may have been deterred from providing tele-AAC with pALS, that there are advantages to this modality of service that warrant pursuing this option. SLPs who do not feel qualified to provide AAC services, but who identify clients who could benefit from such services, may help advocate for referral to AAC specialists who could reach these clients via tele-AAC.

Limitations/Future Directions

A small sample size of reviewers with reduced diversity of ages and years of clinical experience was a limitation of the study. While it is valuable to understand the perspectives of SLPs who have had extensive experience with pALS and providing AAC services; all reviewers had a large number of years of clinical experience working as SLPs. This may have contributed to a smaller scope of SLP perspectives on tele-AAC. Further research should consider a more diverse age range of reviewers and perspectives from emerging clinicians.

A second limitation was the small sample size of pALS who participated in being evaluated for an SGD, leading to a small number of assessments that the reviewers were critiquing. The 8 pALS all self-reported with having relatively high comfort using technology and no history of cognitive or language impairments (full inclusion and exclusion criteria of pALS as well as their demographic information can found in (Roman et al., 2021)). These factors may have led to a limited reporting of challenges or benefits in tele-AAC that may have been raised if there were a larger number of SGD assessments being done with a larger number of pALS. Further research may focus on including a wider variety of pALS' communication characteristics, progression of disease, and various low tech or high tech AAC needs.

Third, this study utilized checklists that reviewers completed on their own. While highly feasible, this method of data collection did not allow for gathering more detail or clarifying comments. Other methods of collecting data such as in-depth interviews where the researcher may have asked clarifying or follow up questions could have helped with gathering more comprehensive qualitative data.

Conclusion

In conclusion, SLPs who are AAC specialists have found that providing SGD assessments via tele-AAC is comparable to in-person assessments with pALS. Advantages of tele-AAC include assessments being more functional, increased caregiver availability/training, and reduced fatigue felt by pALS. Challenges of tele-AAC included technical difficulties and possibly a less comprehensive assessment due to obstacles from using technology. While the success of the assessment may be contingent on internet access, technological competency, and video and audio quality, this modality of assessment should continue to be a possibility for pALS as appropriate, and may grow in popularity after COVID-19. Overall, this study highlights that providing SGD assessments via tele-AAC for pALS is possible, relatively comparable to doing the assessment in-person, and even has some advantages. As Reviewer A reflected, “Effective and efficient AAC evaluations can be conducted online!”

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Appendix A: pALS' Pre-evaluation Questionnaire

Name: _____

Date of Birth: _____



Hi,

I am a speech pathologist who specializes in augmentative communication for people with ALS.

I'm excited to help you find some communication solutions. Please answer the following questions so I can plan for the tools and strategies we will explore together.

Many of the responses are check-boxes to save you time and energy (click on a box to mark it) but free to add any additional information you think would be helpful. If you are uncertain of a response, **highlight** or mark it and we can discuss it during our first meeting.

1. Do you or any of your communication partners have a hearing loss?

Multiple boxes can be selected.

- Yes, I have a hearing loss.
 Yes, one or more of my communication partner's has a hearing loss.
 No

2. Do you wear glasses or contacts when using a computer?

Multiple boxes can be selected.

- Yes, single prescription.
 Yes, bifocals.
 Yes, progressives.
 Yes, contacts
 No

3. Do you have any of the following eye conditions?

Multiple boxes can be selected.

- Astigmatism
 Double vision
 Dry eyes
 Difficulty opening or closing eyes completely
 Droopy eye lids

- Irregular eye movements or lack of ability to move eyes
 Other: _____

4. What was your date of diagnosis with ALS?
5. What was the approximate month and year of your first symptom of ALS?
6. What was your first symptom?
7. What was the approximate month and year that you first experienced, or others noticed, a change in your speech?
8. What was the approximate month and year you began to experience hand or arm weakness?
9. Are you using any equipment to help you to move around and where do you use it? **Multiple boxes can be selected.**

- | | | |
|-------------------|--------------------------------------|---------------------------------------|
| Cane | <input type="checkbox"/> Inside home | <input type="checkbox"/> Outside home |
| Walker | <input type="checkbox"/> Inside home | <input type="checkbox"/> Outside home |
| Manual wheelchair | <input type="checkbox"/> Inside home | <input type="checkbox"/> Outside home |
| Power wheelchair | <input type="checkbox"/> Inside home | <input type="checkbox"/> Outside home |

10. How often do you go out into the community? **Select only ONE box.**

- Daily
 A few times per week
 A few times per month
 A few times per year
 Never

11. If you currently use a wheelchair/s what is/are the make and model? (e.g. Permobil M300, Quantum Edge, Invacare TDX, Pride Jazzy, etc.)

12. Describe any difficulty you experience with writing? **Select only ONE box.**

- I can write clearly and without fatigue.
 I experience some fatigue, slowness, or loss of legibility with writing.
 Writing is very fatiguing or my writing can be hard to read.
 I am only able to write a word or two.

I am unable to write.

13. Describe any problems you have with keyboarding/typing? **Multiple boxes can be selected.**

- I can keyboard normally and without fatigue.
- I experience some fatigue, slowness, or inaccuracy with keyboarding.
- Keyboarding is very fatiguing, slow, or I make frequent errors.
- I can only use one hand for keyboarding.
- I only use a single finger for keyboarding.
- I am unable to use a keyboard with my hands.
- _____

14. Describe any problems you have moving a mouse? **Multiple boxes can be selected.**

- I have no problem moving a mouse.
- I experience some fatigue, slowness, or inaccuracy with mousing.
- Mousing is very fatiguing or slow.
- I have to use my non-dominant hand for mousing.
- I use a mouse alternative with my hand (touchpad, ergonomic, or adapted, etc.).
- I am unable to use my hands to operate a mouse or mouse alternative.

15. Describe any problems you have clicking on a mouse? **Multiple boxes can be selected.**

- I have no problem with right, left or double clicking.
- I experience some fatigue, slowness or inaccuracy with mouse clicks.
- I can move a mouse but can't do any clicking.
- I am unable to use a mouse with my hands.
- I use an alternative method for mouse clicks (dwell, switch, etc.):
- _____

Questions 13 – 17 ask you about weakness in various parts of your body. For these questions, use the following key for choosing the answer that best fits your abilities.

***Key**

Mild: Movements in this part of my body may be slower or may lack previous accuracy. Activities with this part of my body are possible with independence but may be fatiguing.

Moderate: Activities with this part of my body require at least occasional assistance or modifications due to weakness, fatigue or slowness.

Severe: The movement in this part of my body may be very slow, minimal, highly fatiguing or not possible. Activities utilizing this part of my body require assistance.

16. Are you experiencing any finger weakness? (use key above)

- No weakness
- Mild
- Moderate
- Severe

17. Are you experiencing any wrist weakness?

- No weakness
- Mild
- Moderate
- Severe

18. Are you experiencing any biceps/triceps weakness (i.e. bending or straitening elbow)?

- No weakness
- Mild
- Moderate
- Severe

19. Are you experiencing any shoulder weakness?

- No weakness
- Mild
- Moderate
- Severe

20. Are you experiencing any neck weakness?

- No weakness
- Mild
- Moderate
- Severe

21. If you have neck weakness do use any of the following supports?

Multiple boxes can be selected.

- Neck collar
- Wheelchair headrest
- Other: _____

22. Are you experiencing any neck or shoulder pain?

Yes

No

If yes, are there certain positions or activities that aggravate the pain?

23. How often do people ask you to repeat yourself? **Select only ONE box.**

On occasion (approximately once a day)

Regularly (many times a day)

Most of the time

I rarely or no longer use speech for communication

24. If speech is not adequate to communicate at all times, which other methods you use to communicate. **Multiple boxes can be selected.**

Writing

Communication board (non-electronic)

Communication board with only eye movement

Responding to yes/no questions. How do you indicate yes _____
no _____

Signs or gestures

Other:

25. Do you currently have a way to communicate with people not in your immediate environment? **Multiple boxes can be selected.**

- I can use my phone for text messaging.
- I can use my phone for emailing.
- I can use my phone to dial and speak.
 - I can use a speaker phone if someone else dials.
 - I can use my tablet for emailing.
 - I can use a computer for emailing

- I don't have a way to communicate with those not in my immediate environment.
26. Do you have an emergency alerting system or caregiver call chime in your home/facility? **Multiple boxes can be selected.**
- I have a reliable caregiver call chime I can use within my home/facility.
- I do not have a caregiver call chime that reliably works for me.
- I am able to use an emergency call chime to reach people outside of my home.
- I am not able to reach people outside of my home in an emergency.
27. Do you spend more than a just few minutes alone in a room at times?
- Yes
- No
28. Do you spend time alone in your home each day?
- Yes
- No
29. Have you worked with a speech therapist (aka: SLP, speech language pathologist) since your diagnosis with ALS? **Multiple boxes can be selected.**
- | | | |
|---|--------------------------------------|--------------------------|
| <input type="checkbox"/> Yes-from a home health agency
Currently | <input type="checkbox"/> In the past | <input type="checkbox"/> |
| <input type="checkbox"/> Yes-at an outpatient clinic
Currently | <input type="checkbox"/> In the past | <input type="checkbox"/> |
| <input type="checkbox"/> Yes-at the facility or hospital where I reside
Currently | <input type="checkbox"/> In the past | <input type="checkbox"/> |
| <input type="checkbox"/> No- I have not worked with a speech therapist since I was given a diagnosis of ALS | | |
30. If you answered YES to question 26
Please provide the name and contact information for the speech therapist if you have it:
- Speech therapist name: _____
- Speech therapist Email: _____
- Speech therapist phone: _____

- Did the speech therapist work with you on eating and drinking strategies?

- Yes
- No

- Did the speech therapist work with you on ways to improve communication?

- Yes
- No

- If the speech therapist did work with you on improving communication, briefly describe some of the strategies, recommendation or tools she/he offered.

- Did the speech therapist do any of the following: **Multiple boxes can be selected.**

- Provide information & hands-on training on message banking
- Provide information on message banking
- Provide information & hands-on training on voice banking
- Provide information on voice banking

31. Have you done of the following? **Multiple boxes can be selected.**

- I have banked messages (recorded messages in my own voice).
- I have voice banked and created my own synthesized voice. Program used: _____
- I started voice banking but didn't complete it. Program used: _____
- I have extensive recordings of my own voice.

32. Select your seating for various activities. **Multiple boxes can be selected.** If you are currently unable to do an activity but hope to in the future with

technology, mark “Currently unable” and also where you would likely be seated to do this activity.

Activity	Power wheelchai r	Manual wheelchai r	Be d	Eas y chair	Sof a	Standar d chair	Currentl y unable
Computer work & Email	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Phone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Watching TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reading	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerts, events, services, sports, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speaking to groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Socializing at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Socializing away from home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hobby - _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Riding in auto, van, bus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

33. What technology do you already own? **Multiple boxes can be selected.**

Model or Operating System

Tablet: Windows 10 iPad Android Other

Desktop: Windows 10 Mac Other

Laptop: Windows 10 Mac Other

Smartphone: iPhone Android Other

34. Describe the internet connection in your home/facility?

- I have reliable internet.
 The internet can be unreliable.
 I don't have any internet in my home/facility.

Questions 32 and 33 ask about your and your primary communication partners' comfort with technology. To answer these questions, please use the following key:

****Key**

- High:** I use a lot of technology, am very comfortable with setting it up and doing my own problem solving etc.
- Average:** I use much of the same technology that most people do (smart phone, computer). I am comfortable doing most basic things and can do some problem solving, but I occasionally need help from other people.
- Low** While I do use some technology, I use it at a very basic level – just a few functions. I often need help problem solving or setting it up because of my limited knowledge.
- Not comfortable** I either prefer not to use a lot of technology; or when I do I rely heavily on the knowledge of other people to help me.

35. What is your level of comfort with technology? ** (use key above)

- High
 Average
 Low
 Not comfortable

36. Please list your primary communication partners (please include paid caregivers too):

Name	Relationship	How often are they with you?	Partner's comfort level with technology?	Will they join us for the evaluation or trainings?
		<input type="checkbox"/> Daily <input type="checkbox"/> A few times per week <input type="checkbox"/> A few times per month <input type="checkbox"/> A few times per year	<input type="checkbox"/> High <input type="checkbox"/> Average <input type="checkbox"/> Low <input type="checkbox"/> Not Comfortable	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Some of it <input type="checkbox"/> Maybe
		<input type="checkbox"/> Daily <input type="checkbox"/> A few times per week <input type="checkbox"/> A few times per month <input type="checkbox"/> A few times per year	<input type="checkbox"/> High <input type="checkbox"/> Average <input type="checkbox"/> Low <input type="checkbox"/> Not Comfortable	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Some of it <input type="checkbox"/> Maybe
		<input type="checkbox"/> Daily <input type="checkbox"/> A few times per week <input type="checkbox"/> A few times per month <input type="checkbox"/> A few times per year	<input type="checkbox"/> High <input type="checkbox"/> Average <input type="checkbox"/> Low <input type="checkbox"/> Not Comfortable	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Some of it <input type="checkbox"/> Maybe
		<input type="checkbox"/> Daily <input type="checkbox"/> A few times per week <input type="checkbox"/> A few times per month <input type="checkbox"/> A few times per year	<input type="checkbox"/> High <input type="checkbox"/> Average <input type="checkbox"/> Low <input type="checkbox"/> Not Comfortable	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Some of it <input type="checkbox"/> Maybe

37. Will you have an opportunity to see a doctor face-to-face in the next few months?

- Yes
 No

Please provide the name and contact information for the doctor (important for obtaining equipment)

Doctor's name: _____
 Doctor's Email: _____

Doctor's phone: _____

38. What insurance/s do you have? _____ (please send copy of front and back of card with this form)

39. What assistance did you, the person with ALS, receive in filling out these questions? **Select only ONE box.**

- None.
- I provided all of the content and someone else just marked the boxes or wrote down what I communicated.
- I provided most of the content but someone else helped me decide how to answer some questions and wrote down my answers.
- I provided some of the content but someone else took the lead in answering the items.
- Someone else provided most of the content and filled out this form; the person with the communication difficulty participated minimally or not at all.

If you received assistance filling out these questions, who assisted you?

_____ Date of Completion:

Thank you for the time and thought you put into responding to these questions and I look forward to developing solutions with you. Please save this form and send it back to us as a "reply" to the encrypted email by which it was sent to you. Call me with any questions at (415) 518-0592.

Communication Partner Information (The individual who will be participating in study with you.)

Name: _____

Date of Birth: _____

Relationship to pALS: _____

I am this person's primary communication partner (person with whom they communicate with most often).

I am not this person's primary communication partner.

If you are not the primary communication partner to the person with ALS, please describe why you rather than the primary communication partner will be participating in the study.

Thank you,
Amy Roman, M.S., CCC-SLP
Augmentative Alternative Communication Specialist

Appendix B: Technology Needs Questionnaire



Name: _____

Date: _____

Assisted filling out form provided by: _____

Technology Needs Questionnaire Page 2

On a scale of 1-10 (10=most, 1=least), how important is the following:

Communication	1	2	3	4	5	6	7	8	9	10
Email	1	2	3	4	5	6	7	8	9	10
Internet Access	1	2	3	4	5	6	7	8	9	10
Text Message	1	2	3	4	5	6	7	8	9	10
Environmental Ctrl	1	2	3	4	5	6	7	8	9	10
Facebook/Social media	1	2	3	4	5	6	7	8	9	10
Music	1	2	3	4	5	6	7	8	9	10
Photos	1	2	3	4	5	6	7	8	9	10
E-media	1	2	3	4	5	6	7	8	9	10
Games	1	2	3	4	5	6	7	8	9	10
Skype/FaceTime	1	2	3	4	5	6	7	8	9	10
Make/receive phone calls	1	2	3	4	5	6	7	8	9	10
Other computer Functions	1	2	3	4	5	6	7	8	9	10
Computer specs	1	2	3	4	5	6	7	8	9	10
Overall mouse ctrl	1	2	3	4	5	6	7	8	9	10

Notes:

Appendix C: ALS Caregiver Behavioral Questionnaire

ALS CBST™ ALS Cognitive Behavioral Screen



Susan C. Woolley, Ph.D.

ALS Caregiver Behavioral Questionnaire

These questions pertain to possible changes that you have noticed since the onset of ALS symptoms. As best you can, consider changes that are unrelated to physical weakness. For example, question #1 asks about interest in activities. If the person can no longer play tennis but still seems interested in it (i.e. talks about it, watches it on television), then you would circle 3 for no change in level of interest.

If the person has always had the trait in question, please respond No Change, since there has been no change over time.

Compared to before ALS, does he/she:

	No Change	Small Change	Medium Change	Large Change
1. Have less interest in topics/events that used to be important to them?	3	2	1	0
2. Show little emotion, or seem less responsive emotionally?	3	2	1	0
3. Seem more agreeable or pleasant than in the past with fewer worries?	3	2	1	0
4. Fail to think things through before acting?	3	2	1	0
5. Seem more withdrawn from others but not sad?	3	2	1	0
6. Get confused or distracted more easily?	3	2	1	0
7. Have less ability to deal with frustration or stress?	3	2	1	0
8. Seem less concerned about the feelings or concerns of others than before?	3	2	1	0
9. Get angry or irritable more easily than before?	3	2	1	0
10. Seem more sarcastic or childlike than before?	3	2	1	0
11. Eat more or have a new preference for particular foods (i.e. sweets)?	3	2	1	0
12. Have more trouble changing opinions or adapting to new situations?	3	2	1	0
13. Show less judgment or more problems making good decisions (i.e. regarding safety, finances, etc)?	3	2	1	0
14. Have less awareness of obvious problems or changes, or deny them?	3	2	1	0
15. Have new problems with language, such as saying the wrong word more often, making up new words, or declines in spelling ability?	3	2	1	0

TOTAL SCORE: ____/45

The following questions relate to current symptoms, not changes over time:

Do you think your loved one:

	YES	NO
• Seems depressed on most days?	[]	[]
• Seems anxious on most days?	[]	[]
• Seems extremely fatigued on most days?	[]	[]
• Suffers from unexpected crying or laughing spells?	[]	[]

Appendix D:

AAC CAP Protocol for ALS Evaluation Checklist

Instructions: After you have watched the videos and reviewed the documents the pALS and caregiver submitted (Pre-Evaluation Questionnaire, Technology Needs Questionnaire, and Behavioral Screen) please fill in this checklist. Please write a response of any length in order to fully express your thoughts in columns 2 and 3. In column 4, click on one box for each element. You can refer to the CAP Protocol (provided) if you would like clarification or an explanation of any of the 17 elements. Please remember to reflect on information gathered via Questionnaires and Screens too as part of the complete telepractice evaluation process.

<p style="text-align: center;">Elements of Evaluation</p>	<p>Describe any challenges you observed to addressing this element of the evaluation via telepractice in the patient's place of residence rather than in a face to face evaluation in a clinical setting.</p> <p>If challenge was overcome, provide means by which potential barrier was addressed.</p> <p>If challenge was not overcome, please provide suggestions to overcome it or reasons why it can't be overcome.</p>	<p>Describe any advantages you observed to addressing this element of the evaluation via telepractice in the patient's place of residence rather than in a face to face evaluation in a clinical setting.</p>	<p>Was this element of the evaluation addressed via telepractice in the patient's place of residence in a way that was comparable, superior, or inferior to what can be achieved in a face to face evaluation in a clinical setting?</p>
<p>1. Communication Needs Identified</p>			<p><input type="checkbox"/> Much Superior</p> <p><input type="checkbox"/> Somewhat Superior</p> <p><input type="checkbox"/> Same/Comparable</p> <p><input type="checkbox"/> Somewhat Inferior</p> <p><input type="checkbox"/> Much Inferior</p>

2. Current Communication Skills Identified			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
3. Speech Assessed			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
4. Medical Status Assessed			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
5. Motor Abilities & Alternative Access Assessed			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
6. Sensory Abilities Assessed			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
7. Vocabulary Needs Explored (e.g., diet, swallowing strategies, hobbies, interests, communication partners)			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
8. Funding Information Gathered			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior

			<input type="checkbox"/> Much Inferior
9. Information Gathered to Determine Equipment for Clinical Trials.			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
10. Exploration of AAC Acceptance			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
11. Cognitive Abilities			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
12. Language & Literacy Abilities			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
13. Determination of Features that Match Needs			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
14. Patient and Caregiver Preferences Elicited and Explored (e.g., features, size, styling, perception of ease of use, ease of message storage, etc.)			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
15. Support System (e.g., who, level of comfort with			<input type="checkbox"/> Much Superior

technology, availability, etc.)			<input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
16. Patient's computer and technology needs explored (e.g., email, eBooks, environmental controls, entertainment, web browsing, applications/ programs)			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior
17. Review Next Steps (e.g., funding process, wait time, loan options, training plan)			<input type="checkbox"/> Much Superior <input type="checkbox"/> Somewhat Superior <input type="checkbox"/> Same/Comparable <input type="checkbox"/> Somewhat Inferior <input type="checkbox"/> Much Inferior

Additional Questions

- Did you think the utilization of the vendor representative was
 appropriate inappropriate
Please explain your selection of appropriate or inappropriate:
- Please provide feedback on the Pre-Evaluation Questionnaire and Technology Needs Questionnaire. Would you find these helpful if providing a telepractice evaluation and would you add, modify or eliminate any components of these questionnaires?
- Please provide any additional feedback, thoughts, or suggestions you have.

Appendix E: Email and questionnaire

Hello!

My name is Mayaka Barton and I am one of the research assistants who worked with Amy Roman on her study about telepractice with patients with ALS in 2019. You kindly participated in her study at the time. As a part of that study, you watched 3-5 videos of Amy conducting SGD evaluations via Zoom. You then completed a rating scale on various elements of an AAC assessment and provided comments on how comparable telehealth was to in person evaluation. Amy has kindly allowed me to use some of these data for my master's thesis and we are currently in the process of analyzing these data on those ratings.

I am contacting you again in hopes to get an updated perspective on your thoughts on telehealth and conducting remote SGD evaluations with patients with ALS, now that telehealth has become commonplace during the COVID-19 pandemic. We would also like to collect some demographic information. I do know that it has been quite some time since you originally participated in the study, but if you're able, it would be tremendously helpful if you could fill out this survey with your thoughts. This survey should take approximately 5 minutes of your time and we would appreciate your response in the next 10 days.

Here is the survey link: <https://catalyst.uw.edu/webq/survey/mayakab/419410>

Here is your ID number (please use this ID number as your answer to the first question on the survey):

Survey Questions:

Age (not required):

years of clinical experience

years doing SGD evaluations:

years of experience with pALS:

1. Approximately what percentage of AAC ASSESSMENTS did you do via **telehealth** BEFORE the pandemic?
 - a. Never (0%)
 - b. Very rarely (1-5%)
 - c. Occasionally (20-30%)
 - d. About half (40-60%)
 - e. Almost always (75-90%)
 - f. Always (100%)

2. Approximately what percentage of AAC TRAINING/FOLLOW UP SERVICES did you do via **telehealth** BEFORE the pandemic?
 - a. Never (0%)
 - b. Very rarely (1-5%)
 - c. Occasionally (20-30%)
 - d. About half (40-60%)
 - e. Almost always (75-90%)
 - f. Always (100%)

3. Approximately what percentage of AAC ASSESSMENTS did you do via **telehealth** DURING the pandemic?
 - a. Very rarely (1-5%)
 - b. Occasionally (20-30%)
 - c. About half (40-60%)

- d. Almost always (75-90%)
 - e. Always (100%)
4. Approximately what percentage AAC TRAINING/FOLLOW UP SERVICES did you do via **telehealth** DURING the pandemic?
- a. Very rarely (1-5%)
 - b. Occasionally (20-30%)
 - c. About half (40-60%)
 - d. Almost always (75-90%)
 - e. Always (100%)
5. How often do you anticipate conducting AAC ASSESSMENTS via telehealth AFTER the pandemic ends?
- a. Plan on returning to ALL in person assessment
 - b. Plan on providing most or all assessments via telehealth
 - c. Plan on a mix of both in-person and telehealth
6. How often do you anticipate conducting AAC TRAINING/FOLLOW UP SERVICES via telehealth AFTER the pandemic ends?
- a. Plan on returning to ALL in person training
 - b. Plan on providing most or all training via telehealth
 - c. Plan on a mix of both in-person and telehealth
7. What reasons will drive your decisions as to whether you anticipate providing AAC services via telehealth or in person after COVID subsides and no longer drives service provision modes? (select all that may apply)
- a. Patient preference

- b. Insurance/payment requirements and regulations
 - c. Rules and regulations of my facility
 - d. My own preference/comfort for providing services
 - e. Other (please describe)
8. Please provide any comments you would like regarding your opinions about providing AAC services via telehealth, and how they may have changed due to COVID.