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DISABILITY AND REHABILITATION: ASSISTIVE TECHNOLOGY
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ORIGINAL RESEARCH

A recent survey of augmentative and alternative communication use and service delivery experiences of people with amyotrophic lateral sclerosis in the United States

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ABSTRACT

Purpose: The objective of this study was to explore and describe current trends in the augmentative and alternative communication (AAC) use and service delivery experiences of people with amyotrophic lateral sclerosis (PALS) in the U.S.

Methods: Cross-sectional data were collected from 216 PALS *via* an anonymous online questionnaire in 2021.

Results: Over 70% of participants reported at least some detectable speech disturbance, and approximately half used aided communication during face-to-face interactions. Among respondents with severe speech impairment, over 90% reported using speech-generating devices, and just over half reported using low-tech AAC. Most participants had met with an SLP to discuss speech and communication, but varied in both timing of the initial intervention and frequency of ongoing intervention. Fewer than half reported that their family members or other important people had received education or support related to communication for PALS. Participants also shared their use of and experiences with telephone and video calls, access methods, mounting systems, word prediction and stored phrases, and message and voice banking.

Conclusions: Results highlight the importance of early referral for AAC intervention, ongoing re-evaluation and treatment, involvement of communication partners and support for multimodal communication and adaptation to changing needs.

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KEYWORDS
Amyotrophic lateral sclerosis; augmentative and alternative communication; dysarthria; speech-generating device; assistive technology

➤ IMPLICATIONS FOR REHABILITATION

- Most people with amyotrophic lateral sclerosis (PALS) in this sample reported experiencing dysarthria, with 71.3% indicating at least some detectable speech disturbance (Revised ALS Functional Rating Scale [ALSFRS-R] speech rating ≤ 3) and 56.5% reporting reduced intelligibility (ALSFRS-R speech rating ≤ 2).
- Respondents used a wide variety of communication methods. Among respondents who were unable to meet their communication needs with speech alone, 84.6% used unaided methods (including speech), 52.3% used low-tech augmentative and alternative communication (AAC) and 90.8% used a speech-generating device.
- Service delivery improvements are needed to ensure timely, ongoing and comprehensive AAC education and intervention for PALS and their families.
- Communication over video calls (including virtual healthcare visits) is common among PALS and may be an important target for AAC intervention as the COVID-19 pandemic continues to limit in-person gatherings and appointments.

Introduction

The motor neuron degeneration caused by amyotrophic lateral sclerosis (ALS) often affects the muscles of the face, lips, tongue, throat and respiratory system, and as a result up to 95% of people with ALS (PALS) experience dysarthria at some point in the disease process [1]. As with many ALS symptoms, the clinical presentation and progression of speech impairment can vary considerably from one individual to another. Some PALS demonstrate little or no change, while others see rapid or gradual reductions in intelligibility and may eventually progress to a state of anarthria. By the end of life (typically within two to five years after diagnosis), up to 75% of PALS lose the ability to speak [2].

Augmentative and alternative communication (AAC) approaches are considered part of the standard of care in ALS treatment, helping PALS to maintain the ability to communicate despite reduced speech intelligibility [1,3]. Options include unaided approaches such as gestures, blinks or eye movements; low-tech methods like writing or pointing to a word or letter

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board; and high-tech speech-generating devices (SGDs). Some SGDs are purpose-built for use as communication devices; they come pre-loaded with AAC software and text-to-speech capabilities, and often feature powerful speakers for speech output, durable cases to withstand heavy use and frequent transport, and many options for alternative access for users with limited upper extremity function. In recent years, mobile devices such as smartphones and tablets have become widely used around the world and are now commonly used as SGDs with the addition of AAC apps [4,5]. A combination of unaided, low-tech and high-tech methods, along with residual speech, may be used as part of a multimodal AAC approach, with a variety of tools and strategies suited for use in different contexts or with different communication partners [6,7].

PALS are a heterogeneous population, with a wide range of differences in symptom location and onset timing, rate of progression and degree of communication and physical impairment, as well as the manner and setting in which they receive healthcare services. Studies of AAC use by PALS reflect this variability. Some PALS readily accept AAC intervention, while others may delay or reject it despite increasing difficulties with communication [8]. PALS who use AAC may do so for only a short time or for many years [9,10]. One study included reports of PALS using AAC for anywhere from one month to 38 years [9]. They may use low-tech approaches, high-tech SGDs, residual speech or a combination of methods, and their AAC systems often change over time [11,12]. Frequency of AAC use among PALS also varies widely, again reflecting a range of communication needs and physical abilities [9].

Speech-language pathologists (SLPs) play an important role in addressing the communication challenges associated with ALS [13]. Before the onset of dysarthria, they may provide information and education to PALS and their loved ones about possible speech changes, provide reassurance that they will receive support to maintain communication should those changes occur and monitor for reductions in intelligibility or speaking rate. SLPs also provide AAC evaluations and treatment, recommending communication methods appropriate to a PALS's needs and abilities and providing training and support in learning and using those methods. Due to differences in initial symptom presentation, rate of disease progression and timeliness of ALS diagnosis, the point at which PALS first receive AAC intervention varies. One study found that PALS' speech intelligibility ranged from 0% to 98%, with speaking rates of one to 129 words per minute, at the time of their first AAC evaluation [10]. PALS may also receive different communication interventions based on where they live or where they receive their medical care. SLPs who specialize in AAC, particularly for adults with acquired communication disorders, are relatively rare and tend to be located in large cities. Although AAC is within the scope of practice of all SLPs, clinicians working with adults in healthcare settings in the U.S. report spending, on average, less than 3% of their time providing AAC services [14,15]. As a result, many have limited knowledge and experience in that area and limited time to devote to learning about AAC options, especially SGD hardware and software. PALS who do not attend multidisciplinary clinics, or who do not have access to a specialist SLP, may receive delayed, or less effective, AAC intervention [1].

There is limited current information available in the literature about many topics related to the AAC use and service delivery experiences of PALS. In the last several years, researchers have reported on device acquisition and alternative access methods for PALS in Scotland [16], changes in functional communication status and use of high- and low-tech AAC over time among PALS in Finland [11], the communication methods and challenges of PALS in Japan [17] and use of eye tracking SGDs by PALS in Germany [18]. There have been no recent large surveys of AAC tools and strategies used by PALS in the U.S., despite significant technological advances and changes in general consumer technology use. In 2012, Brownlee and Bruening reported on a survey of 625 surviving family members and caregivers of deceased PALS about the communication strategies used in the last six months of life. Most respondents reported that the PALS they knew had difficulty communicating near the end of life, and fewer than half indicated that the PALS had obtained an SGD [2]. Information about communication before the end of life and, crucially, the perspectives of PALS themselves are missing from these data, and SGD ownership and use among PALS may have changed along with the available technology in the subsequent decade. Other studies of AAC use and service delivery have had small sample sizes and involved PALS who received skilled, and timely, AAC intervention, or who were chosen because they already used AAC [8,10,12,18]. In 2018, McNaughton and colleagues described results of a survey of 21 PALS, all of whom used an SGD, about their experiences related to three recommended principles for AAC assessment and intervention [12]. Recruitment was conducted through internet-based ALS support groups and SLPs who provide AAC services to PALS. PALS who do not use high-tech AAC, or who are not connected to support groups or specialist SLPs, may have different experiences with AAC service delivery. Similarly, findings from Ball and colleagues indicating high rates of SGD acceptance [8], and of SGD use even near the end of life [10], among PALS who received expert AAC services at a specialty clinic may not reflect the experiences of PALS who do not receive such intervention, and appear to contradict the findings of Brownlee and Bruening's survey.

The aim of this study was to explore and summarize the recent AAC use and service delivery experiences of a large and heterogeneous sample of PALS from across the U.S. Participants completed an online questionnaire. Descriptive statistics and visualizations of the resulting data reveal current trends in the communication methods used by PALS in face-to-face, telephone and video call conversations; their ownership of and interaction with devices such as smartphones, tablets and computers; their use of alternative access, mounting systems and AAC software features; their awareness of and participation in message and voice banking; their experiences with SLP intervention and other sources of communication information and support; and barriers to accessing or using communication services or aids.

Methods

Study design

This was a cross-sectional study, with data collected *via* an anonymous online questionnaire from April to June of 2021.

Participants and recruitment

A convenience sample of PALS was recruited from across the U.S. through a variety of methods including the ALS Registry Research Notification Mechanism [19], study directories on the websites of the ALS Registry and the Northeast ALS Consortium, and flyers emailed to national and local staff of the ALS Association and other non-profit organizations serving PALS, to SLPs who work with PALS, and to PALS identified through the Oregon Health & Science University (OHSU) Cohort Discovery tool. Participants met the following inclusion criteria: (1) diagnosed with ALS, (2) 21 to

89 years old and (3) able to read and communicate in English. Respondents who did not complete any items relevant to the research questions were excluded from data analysis; there were no other exclusion criteria. On an information sheet presented at the beginning of the questionnaire, respondents were asked to confirm that they met the inclusion criteria and agreed to join the study. No direct compensation was provided, but the researchers donated $1 to the participant's choice of one of three non-profit organizations for each completed questionnaire. The study was approved by the OHSU Institutional Review Board (study #22543).

Questionnaire design

The questionnaire was designed and administered using Qualtrics online survey tools (Qualtrics, Provo, Utah). Responses were anonymized, and browser cookies were used to reduce the possibility of a respondent taking the questionnaire more than once. To accommodate difficulties with computer access, PALS were allowed to have another person enter their responses into the questionnaire if needed, but were instructed that all responses must be provided by the PALS. Respondents were allowed to skip any questions they did not wish to answer, aside from those required to ensure study eligibility. Branching logic was used to present relevant follow-up questions based on answers to earlier questions. Due to branching logic, and to some respondents not completing the entire questionnaire, some questions were answered by only a subset of participants. When appropriate, respondents were allowed to select more than one response to a multiple-choice question, for example, to indicate the use of several communication methods. A paper version of the questionnaire was available by request, as an alternative to the online platform.

The questionnaire comprised primarily multiple-choice questions in five topic areas: (1) physical and mental health; (2) communication methods; (3) communicative participation; (4) experiences with AAC service delivery and (5) demographics. The communication methods and service delivery sections are the primary focus of this article. The physical and mental health section included a self-administered version of the Revised ALS Functional Rating Scale (ALSFRS-R) [20,21], selected questions from the PROMIS Global Health scale [22] and additional questions regarding ALS onset type and duration as well as other health conditions. Questions in the communication methods and service delivery sections were written for the current study and were pretested with a sample of individuals with ALS ($n = 7$) or primary lateral sclerosis ($n = 3$; further details on questionnaire development and pretesting are available in [23] or upon request). Topics included communication methods used in face-to-face, telephone and video call interactions (including frequency of use for face-to-face methods); speech-generating device ownership and use; access methods; mounting; AAC software features; message and voice banking; SLP intervention and other information and support related to communication and barriers to accessing, obtaining or using communication intervention or aids. All questions written for the current study are presented in the supplemental online material for this article. Communicative participation was assessed using a modified version of the Communicative Participation Item Bank General Short Form [24]; these results are reported in [23] and in a separate manuscript for future publication.

Self-ratings of speech function were collected using the speech question of the ALSFRS-R, supporting visual analysis of responses from PALS at various stages of impairment. Ratings represented PALS experiencing no speech change (4), detectable speech disturbance without reduced intelligibility (3), speech intelligible with repeating (2), using a combination of speech and non-speech methods (1) and complete loss of speech function (0). Any computer-based device that could produce speech output was considered an SGD, including purpose-built SGDs as well as smartphones, tablets and computers with AAC software.

Data management and analysis

Tableau Prep Builder (Tableau Software, Seattle, Washington) was used for data cleaning (e.g., re-coding open-ended responses to existing response options or entering a null response for unanswered questions, when appropriate), preliminary data analysis (grouping response options into categories) and formatting and exporting data for further analysis. Tableau Desktop (Tableau Software, Seattle, Washington) was used to calculate descriptive statistics and visualize data. Additional figures were created in Google Drawings (Google, Mountain View, California). Relationships between SLP intervention and other variables related to AAC use and service delivery were examined with chi-square tests of independence in R [25].

Results

Participants

Of the 222 individuals who agreed to join the study, 216 were eligible to participate and provided information relevant to one or more research questions. All participants completed the online questionnaire, and there were no requests for the paper questionnaire format. Responses were received from 41 states, including a disproportionately large number from Oregon ($n = 21$, 9.7%) as a result of the additional recruitment efforts conducted there. Demographics and self-administered ALSFRS-R scores for the 216 PALS included in data analysis are summarized in Table 1.

Communication methods: face-to-face

Participants were asked to identify all communication methods they used in face-to-face interactions. A majority of respondents (59.3%) indicated use of more than one method; among PALS with reduced intelligibility or anarthria (ALSFRS-R speech ratings of 2, 1 or 0), the proportion rose to 73.8%. The distribution and mean of the total number of face-to-face communication methods for participants with different speech ratings is shown in Figure 1. The mean number of communication methods was highest for PALS with a speech rating of 1 (combining speech and non-speech methods) at 4.3 and dropped to 2.8 for those with a speech rating of 0 (unable to speak).

Unaided communication methods were most common among the 151 PALS with speech ratings of 4 (no speech change) through 2 (intelligible with repeating), with 70.2% of these respondents reporting no use of communication aids. By contrast, among the 65 PALS with speech ratings of 1 (combining speech and non-speech methods) or 0 (unable to speak) only 4.6% used unaided methods only. The proportions of respondents with speech ratings of 1 or 0 who used unaided, low-tech and high-tech methods (or a combination) are illustrated in Figure 2. Most PALS with speech ratings of 1 or 0 used two or more categories, with 44.6% using a combination of unaided, low-tech and SGD-based methods. More respondents in this group reported use of SGDs (90.8%) than low-tech AAC (52.3%).

Table 1. Participant demographics and self-administered ALSFRS-R scores ($n = 216$).

	n	%
Gender		
Female	77	35.6%
Male	130	60.2%
Unknown	9	4.2%
Race		
American Indian or Alaska Native	2	0.9%
Asian or Asian American	1	0.5%
Black or African American	4	1.9%
White	193	89.4%
More than one race	2	0.9%
Unknown	14	6.5%
Identifies as Hispanic or Latino		
Yes	6	2.8%
No	203	94.0%
Unknown	7	3.2%
Region		
Midwest	41	19.0%
Northeast	28	13.0%
South	77	35.6%
West	63	29.2%
Unknown	7	3.2%
Community type		
Urban	34	15.7%
Suburban	127	58.8%
Rural	48	22.2%
Unknown	7	3.2%
Highest level of education		
Elementary school or some high school	1	0.5%
High school diploma or equivalent	8	3.7%
Some college	29	13.4%
Associate degree	23	10.6%
Vocational/technical school	13	6.0%
Bachelor's degree	71	32.9%
Postgraduate degree	64	29.6%
Unknown	7	3.2%
Employment status		
Not working due to medical condition	92	42.6%
Retired (not due to medical condition)	86	39.8%
Employed full-time	23	10.6%
Employed part-time	6	2.8%
Self-employed	2	0.9%
Unknown	7	3.2%
Frequency of computer use prior to ALS dx		
Daily or almost daily	193	89.4%
A few times a week	6	2.8%
A few times a month or less	4	1.9%
Never or almost never	5	2.3%
Unknown	8	3.7%
Primary insurance provider		
Medicare	116	53.7%
Employer-based health insurance	56	25.9%
Veteran Affairs or TRICARE	27	12.5%
Medicaid or Medical Assistance	6	2.8%
Individual health insurance	2	0.9%
Uninsured	1	0.5%
Unknown	8	3.7%
Attends multidisciplinary ALS clinic		
Yes	185	85.6%
No	24	11.1%
Unknown	7	3.2%
Onset type		
Limb	144	66.7%
Bulbar	59	27.3%
Respiratory/trunk	4	1.9%
Mixed	9	4.2%
ALSFRS-R speech rating		
4 (No speech change)	62	28.7%
3 (Detectable speech disturbance)	32	14.8%
2 (Intelligible with repeating)	57	26.4%
1 (Combining speech & non-speech)	29	13.4%
0 (Unable to speak)	36	16.7%
	Mean (SD)	Range
Age (years)	64.4 (9.08)	34–84
Years since diagnosis	3.9 (5.10)	0—37
ALSFRS-R score		
Bulbar domain	7.6 (3.75)	0–12
Fine motor domain	6.5 (4.02)	0–12
Gross motor domain	5.7 (3.61)	0–12
Respiratory domain	8.4 (3.54)	0–12
Total	28.3 (10.92)	0–47

Notes: Seven participants did not answer all demographics questions. The ALSFRS-R has a possible score range of 0–12 for each domain and 0–48 for the total score, with lower scores indicating more severe impairment.

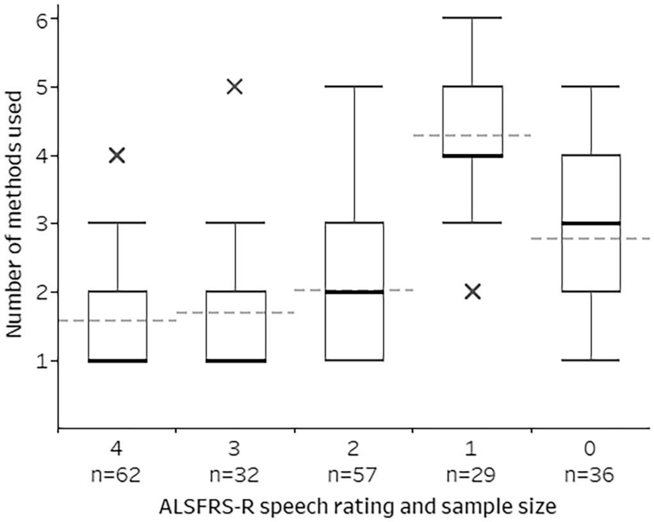


Figure 1. Distribution of number of communication methods per respondent ($n = 216$), by ALSFRS-R speech rating (range 0–4 with 4 indicating no change in speech). Dashed lines indicate mean number of methods for each speech rating. Bold lines represent median number of methods for each speech rating, which corresponds with the 25th percentile for participants with ratings 4, 3, and 1.

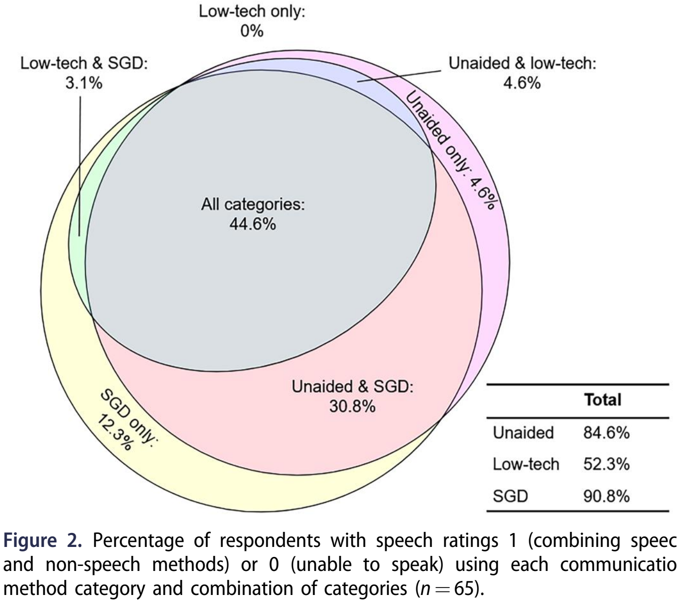
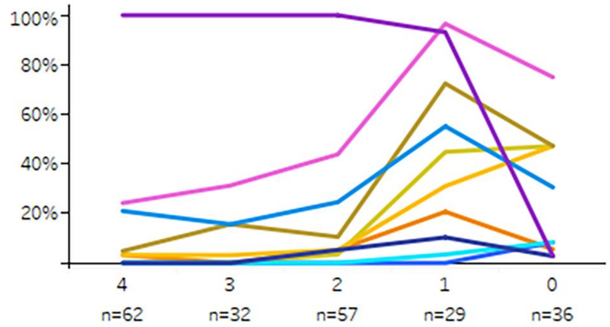
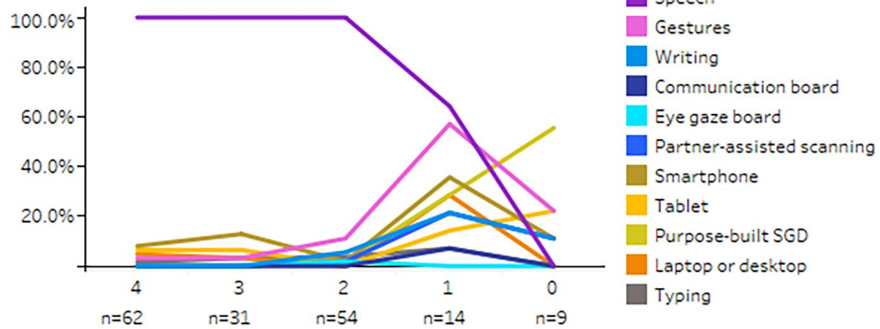


Figure 2. Percentage of respondents with speech ratings 1 (combining speech and non-speech methods) or 0 (unable to speak) using each communication method category and combination of categories ($n = 65$).


(a) Face-to-face (n=216)


(b) Telephone calls (n=170)

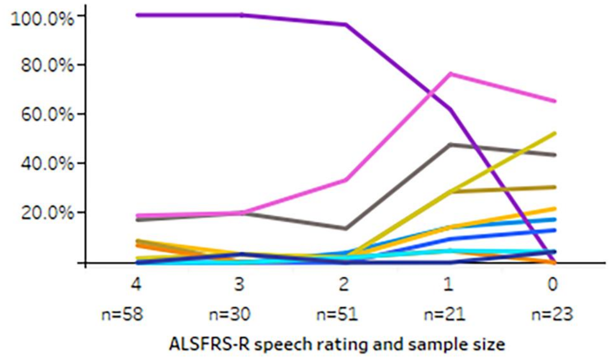

(c) Video calls (n=183)

Figure 3. Percentage of respondents using individual communication methods for face-to-face communication (a), telephone calls (b), and video calls (c), by ALSFRS-R speech rating (range 0–4, with 4 indicating no change in speech).

Figure 3(a) shows the percentage of respondents who reported using specific communication methods in face-to-face interactions at each stage of speech impairment. The most commonly used non-speech methods for the 151 participants with speech ratings of 4 (no speech change) through 2 (intelligible with repeating) were gestures and writing. At speech rating 1 (combining speech and non-speech methods, $n = 29$), more respondents reported using gestures than speech, and smartphones were the most commonly used SGDs, followed by purpose-built SGDs, tablets and laptop or desktop computers. A small number of PALS at this stage of speech impairment reported use of communication boards or eye gaze boards. Gestures remained the most-used method for PALS with speech score 0 (unable to speak, $n = 36$), and smartphones, tablets and purpose-built SGDs were used at equal rates. Participants in this group used gestures, writing, smartphones, laptop or desktop computers, and communication boards at lower rates than those with speech score 1, possibly as a result of reduced upper extremity function at more advanced stages of ALS. Overall, 49.5% of respondents ($n = 107$) reported using some form of aided communication in face-to-face interactions.

The frequency with which participants at each level of speech impairment used each method for face-to-face communication is shown in Figure 4. All 151 respondents with speech ratings of 4 (no speech change) through 2 (intelligible with repeating) reported using their speech either "almost always" or "more than half the time," and few reported frequent use of any other method. For PALS with a speech rating of 1 (combining speech and non-speech methods, $n = 29$), there was more variation in the reported frequency of speech use as use of other methods increased. More PALS at this level of speech impairment indicated they used gestures "almost always" than any other method. At speech rating 0 (unable to speak, $n = 36$), the percentage of participants who reported using an SGD "almost always" increased for all four SGD types, while frequent use of gestures and writing declined.

Participation in telephone and video calls

Overall, 78.7% of respondents reported communicating over the telephone, and 84.7% reported participating in video calls. Figure

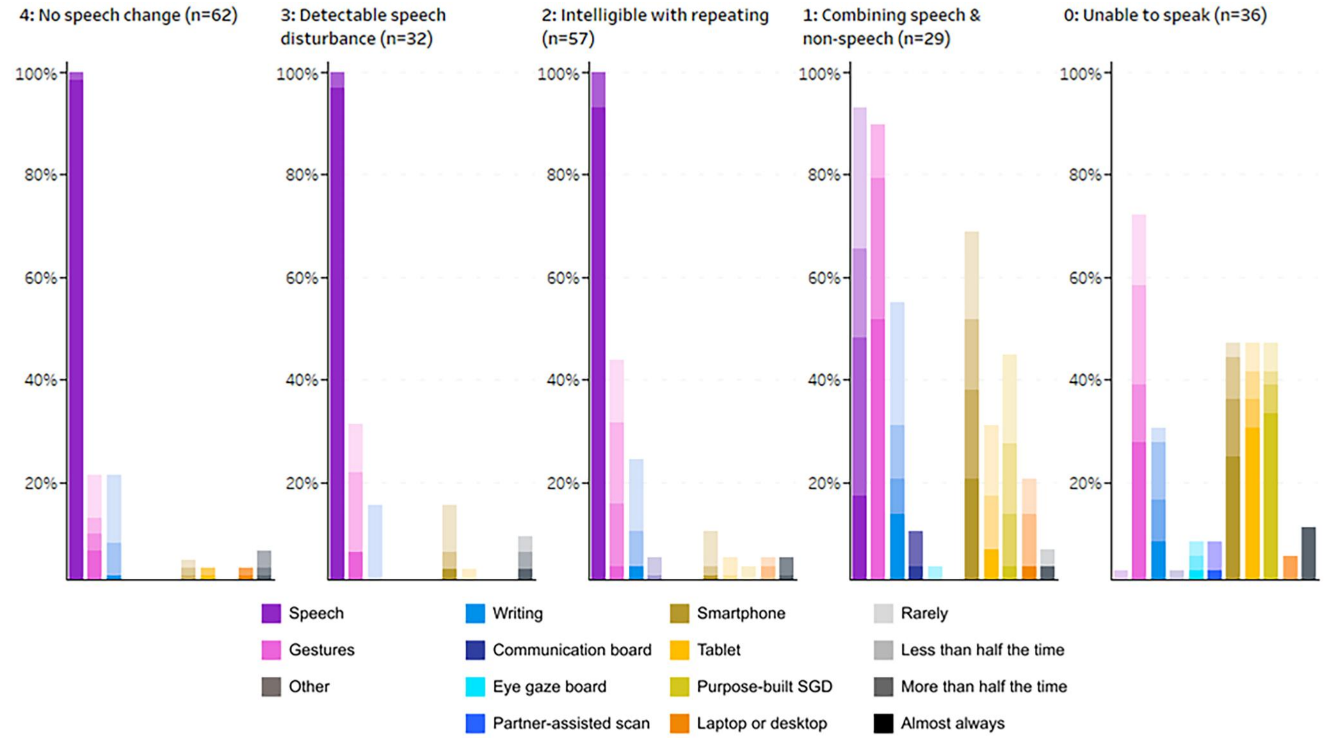


Figure 4. Frequency of use of each communication method in face-to-face interactions ($n = 216$), by ALSFRS-R speech rating (range 0–4, with 4 indicating no change in speech). Each colour represents a different method, with bar height indicating the total percentage of respondents with a given speech rating who reported use of that method. The shading within each bar indicates the frequency with which participants used the method, with deeper shades representing more frequent use.

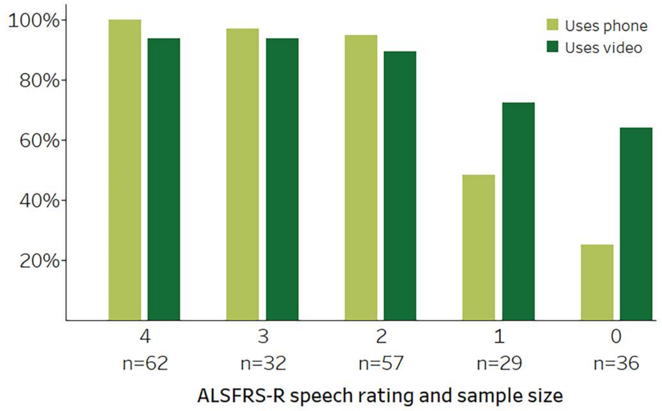


Figure 5. Percentage of respondents who reported participating in telephone or video calls ($n = 216$), by ALSFRS-R speech rating (range 0–4 with 4 indicating no change in speech).

5 illustrates usage rates for these modalities by PALS with different ALSFRS-R speech ratings. Among the 151 participants with speech ratings of 4 (no speech change) through 2 (intelligible with repeating), rates of telephone and video call participation were high and were similar across modalities and speech ratings, with telephone use being slightly more common. For PALS with speech ratings of 1 (combining speech and non-speech methods, $n = 29$) and 0 (unable to speak, $n = 36$), usage rates dropped to 72.4% and 63.9% for video calls and to 48.3% and 25.0% for telephone calls.

Communication methods: telephone

Usage of various communication methods during telephone calls at each level of speech impairment for respondents who reported using the telephone ($n = 170$) is illustrated in Figure 3(b). Response options were the same as those available for face-to-face methods, with the addition of typing/TTY. Low-tech and gesture methods for telephone use involved a communication partner who would relay the PALS's message into the phone. All 147 telephone users with speech ratings of 4 (no speech change) through 2 (intelligible with repeating) reported using speech over the phone, with limited use of other methods. At speech rating 1 (combining speech and non-speech methods, $n = 14$), speech use dropped and use of other methods, particularly gestures and SGDs, increased. Purpose-built SGDs emerged as the most common method for telephone users at speech rating 0 (unable to speak, $n = 9$). Some respondents used SGDs during telephone calls but not for face-to-face communication.

Communication methods: video calls

Figure 3(c) shows the methods used by PALS who participated in video calls ($n = 183$) at each ALSFRS-R speech rating. As with telephone calls, all video call users with speech ratings of 4 or 3 (no speech change or detectable speech disturbance, $n = 88$), and most of those with a speech rating of 2 (intelligible with repeating, $n = 51$), used speech when communicating over video calls. Gestures and typing were the next most commonly used methods among these groups. For video call users with a speech rating of 1 (combining speech and non-speech methods, $n = 21$), gestures were the most-used method, followed by speech and typing. Smartphones and purpose-built SGDs were used more than other SGD types. At speech rating 0 (unable to speak, $n = 23$), the most-used methods were gestures, purpose-built SGDs and typing. Again, some PALS who indicated they did not use SGDs for face-to-face communication did use them when participating in video calls.

Device ownership and use

All but four participants reported owning at least one device that could be used as an SGD: 202 (93.5%) of respondents owned a smartphone, at least 162 (75.0%) a tablet, 186 (86.1%) a laptop or desktop computer, and at least 44 (20.4%) a purpose-built SGD. (Due to an oversight in the branching logic, respondents who reported using a smartphone, tablet or laptop or desktop computer for communication, but not a purpose-built SGD, were not asked whether they also owned a purpose-built SGD, so this was unknown for 77 (35.6%) respondents.) Not all participants who owned one or more devices were using those devices for communication or other purposes; see Table 2 for details. Among the 65 participants with speech ratings of 1 (combining speech and non-speech methods) or 0 (unable to speak), 49.2% reported that they owned and used a purpose-built SGD.

When asked about their communication methods earlier in the questionnaire, 91 respondents indicated that they used at least one type of SGD for face-to-face, telephone or video call interactions. The remaining 125 respondents were asked whether they owned an SGD, including purpose-built SGDs or consumer devices with communication apps. Ninety-five said that they did not, while 27 said they had a device but were not using it for communication (three either answered “I don’t know” or did not answer the question). Overall, 118 respondents (54.6%) owned an SGD, including nearly all of the 65 respondents with speech ratings of 1 or 0 (combining speech and non-speech methods or unable to speak; 96.6% and 94.4%, respectively). Among respondents with a speech rating of 2 (intelligible with repeating), only 43.9% reported owning an SGD. The percentage of participants in each speech rating group who reported owning an SGD is displayed in Supplementary Figure 1.

Barriers to obtaining or using an SGD

Of the 95 participants who reported that they did not have a device that could be used as an SGD, 34 (35.8%) indicated that a recommendation had been made for them to obtain one. When asked why they did not have an SGD despite the recommendation, a majority of these 34 respondents (52.9%) answered that they did not need it at that time, while 35.3% reported that they had begun the process of obtaining an SGD but had not yet received it. Other selected reasons included a preference for other communication methods (8.9%), concerns about getting support for learning and using the device (5.9%), finding the device hard to use (2.9%), the device not working well (2.9%) and high cost due to insurance co-payments (2.9%). Of the 27 participants who reported that they had an SGD but were not using it for face-to-face, telephone or video call communication, the majority (96.3%) indicated that they did not need the device for communication at that time, but might use it in the future. Other reasons for not using an SGD included a preference for other communication methods (11.1%), not knowing how to use the device (7.4%), not liking to use the device (7.4%) and difficulties with device positioning (3.7%). Respondents could choose more than one reason for both of these questions.

Table 2. Ownership and use (for any purpose) of smartphones, tablets, laptop or desktop computers, and purpose-built SGDs ($n = 216$).

Device	Owns and uses	Owns but doesn’t use	Does not own	Unknown
Smartphone	185 (85.6%)	17 (7.9%)	14 (6.5%)	–
Laptop or desktop	162 (75.0%)	24 (11.1%)	30 (13.9%)	–
Tablet	137 (63.4%)	25 (11.6%)	53 (24.5%)	1 (0.5%)
Purpose-built SGD	40 (18.5%)	4 (1.9%)	95 (44.0%)	77 (35.6%)

Other purposes of device use

The 212 PALS who used one or more devices reported a variety of purposes of use in addition to face-to-face, telephone or video call interactions, as shown in Figure 6. Overall, email was the most popular purpose of use, followed by browsing the internet, text messaging, online shopping and accessing healthcare (e.g., patient portal websites or virtual visits with providers). The most common use of specific device types varied; text messaging was the most common use for smartphones, while face-to-face, telephone or video call interactions were most common for purpose-built SGDs.

Access methods

Participants reported using a variety of access methods to control their smartphones, tablets, laptop or desktop computers, and purpose-built SGDs, as shown in Figure 7. Of the 212 respondents who used one or more of these devices, 181 (85.4%) reported using standard access (i.e., touching a screen, mouse or keyboard with their fingers or a stylus), and 98 (46.2%) reported using one or more alternative access methods (some respondents used both standard and alternative access). Alternative access methods included cursor control with a mouse, trackball or joystick only (without activating the touch screen or a physical keyboard), used by 22.2% of device users; eye tracking (17.9%); switch scanning (3.8%); head movement (1.9%) and touching the device with a foot (1.4%) or nose (0.5%). Voice control or speech recognition technology was reported as an access method (primarily for smartphones) by 15.6% of device users, including 16.5% of those with reduced intelligibility (ALSFRS-R speech ratings of 2 or 1). Three device users (1.4%) indicated that another person operated the device for them; two of these had no independent device access, and the third reported use of voice control. Finally, nine device users (4.2%) said they controlled a smartphone, tablet or computer remotely with an app on another device.

While alternative access was used with all device categories, it was more common for control of purpose-built SGDs than for smartphones, tablets or laptop or desktop computers. Among the 40 PALS who reported using a purpose-built SGD, 90.0% used one or more alternative access methods. The most common access method for purpose-built SGDs was eye tracking, used by 72.5% of respondents in this group. In addition, 45.0% used standard access with a purpose-built SGD; 25.0% a mouse, trackball or joystick; 5.0% switch scanning; 5.0% voice control and 2.5% head movement.

Eye tracking is available as an access method (sometimes with additional hardware) for many purpose-built SGDs, and for some consumer tablets, computers and smartphones. Respondents who used one or more devices but were not using eye control for access were asked whether they had a device that was, or could be, set up for eye control. Of these 174 participants, 12.1% indicated that their device already had eye control capability, and 11.5% said that eye control was possible with their device but not yet set up. However, 27.6% reported that their device could not be set up for eye control, and another 48.9% did not know. Most respondents who either were not using eye control when it was available, or did not yet have a device set up for eye control, indicated that they did not need it for access; this was the case for 73.2% of the 41 PALS in these two categories. Another four

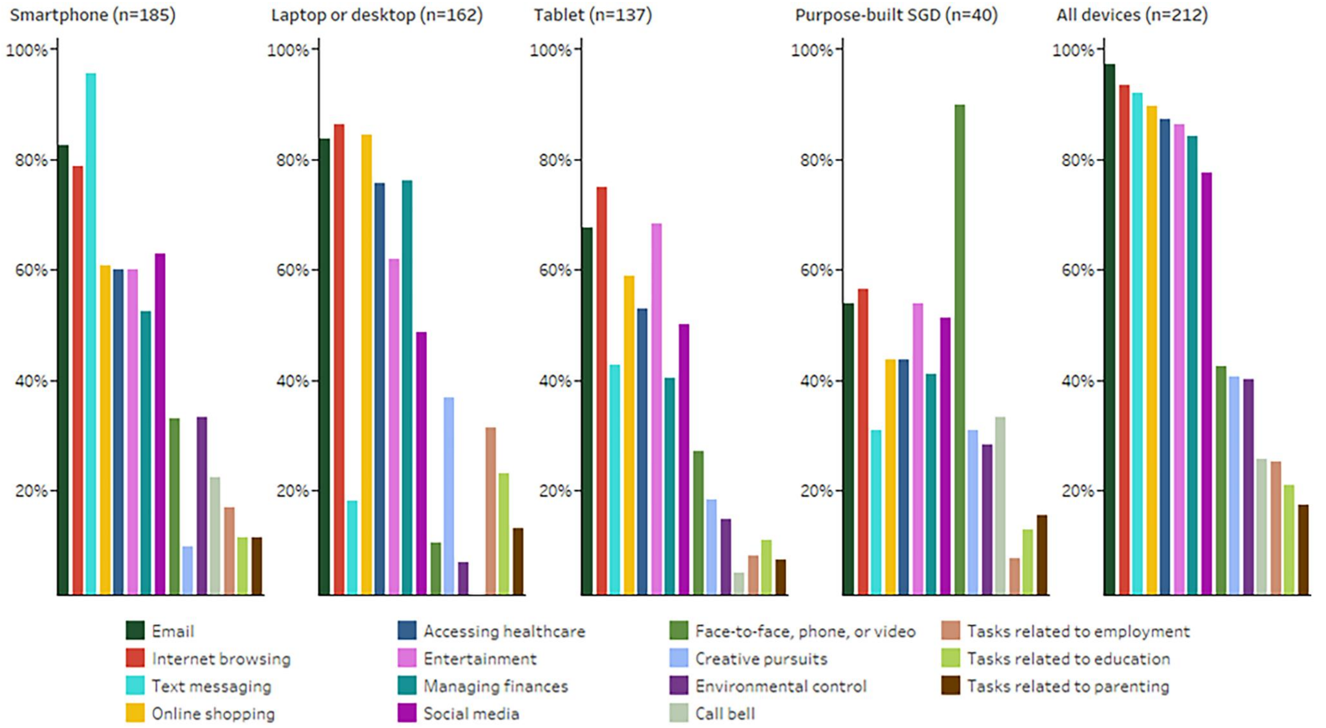


Figure 6. Percentage of device owners reporting specific purposes of use ($n = 212$), by device. Respondents could select multiple purposes of use for each device.

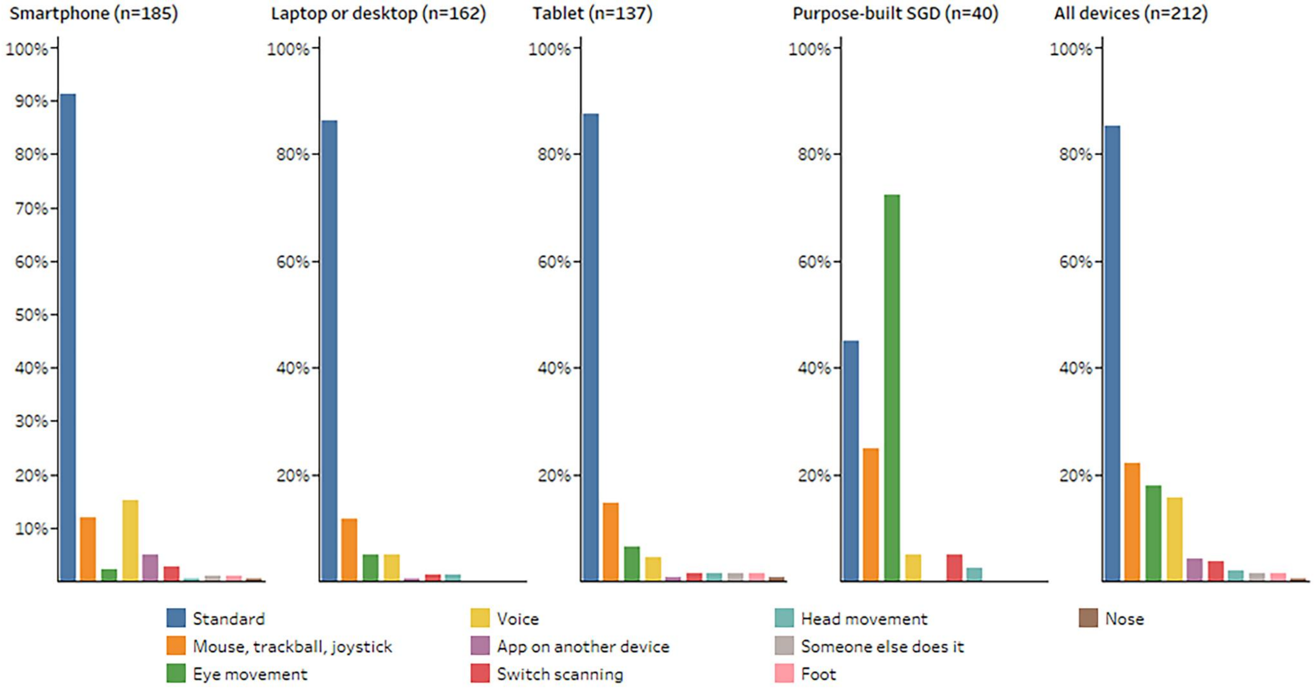


Figure 7. Percentage of device owners reporting use of specific access methods ($n = 212$), by device. Respondents could select multiple access methods for each device.

(9.8%) had begun the process of getting a device set up for eye control, and one (2.4%) indicated that it was not covered by insurance. Among the seven respondents who had a device with eye tracking but were not using it, and did not report that they “didn’t need it right now”, barriers to use included insufficient training ($n = 5$), the device not working well for them ($n = 3$) or being difficult to use ($n = 3$), hardware or software problems ($n = 1$), and the time or energy required to learn something new ($n = 1$). For the five participants who either didn’t have or didn’t use eye control because it was difficult or didn’t work well for them, problems included poor tracking accuracy, reduced ocular motility, incorrect selections, eye strain or fatigue and ptosis. Respondents could choose more than one response to all questions about reasons for not having or using eye control.

Mounting

Some people who use SGDs or other mobile devices use a mounting system to position the device for optimal access. Mounting systems may be attached to a wheelchair, bed frame, or other piece of furniture, or may be free-standing and adjustable to meet various positioning needs. PALS who reported use of one or more devices were asked whether they had a mounting system. Of the 212 respondents who use one or more devices, 50.9% reported that they did not need a mount as they were able to hold or position the device independently. Another 26.4% had one or more mounting systems, and 16.5% indicated that they would benefit from a mounting system but did not have one (6.1% answered "I don't know" or skipped the question).

Of the 56 PALS who had one or more mounting systems, 46.4% indicated that it worked well in most or all situations when they wanted to use an SGD or other mobile device. None felt that their mounting system did not work for them at all, but 48.2% reported that it worked well in some situations but not others (5.4% answered "I don't know" or skipped the question). For the 27 PALS who had a mounting system that did not work well in all situations, challenges included: not having an appropriate mount for a specific settings or applications, such as having a floor mount but not a wheelchair mount, or not having an option that worked while riding in a car (66.7%); difficulty with setup or positioning (33.3%); difficulty using the mount at home, for example due to narrow doorways (11.1%); and not having the mount properly assembled or installed (7.4%; respondents could choose more than one option).

AAC software features

Word prediction and stored messages or phrase pages are common features of AAC software that can support faster message generation or retrieval. Of the 91 respondents who reported using an SGD for communication during face-to-face, telephone or video call interactions, 71.4% said they used word prediction, 7.7% said their SGD had this feature but they did not use it and 2.2% said their SGD did not have this feature (18.7% answered "I don't know" or skipped the question). Stored messages or phrase pages were used less frequently, with 57.1% reporting that they used this feature, 16.5% indicating their SGD had this feature but they did not use it and 9.9% indicating their SGD did not have this feature (16.5% answered "I don't know" or skipped the question). The questionnaire did not address language representation methods, so it is unknown whether any participants used icons in addition to or instead of text on their SGDs.

Message and voice banking

Message and voice banking are often recommended to PALS who wish to use their own recorded speech, or a custom synthesized voice based on their own voice, with an SGD [26]. Two hundred thirteen respondents answered questions about their awareness of message and voice banking, and a strong majority (83.6%) had heard of both. Another 3.8% had heard of one but not the other, and 12.7% had heard of neither.

Of 182 respondents who had heard of message banking, 62 (34.1%) had recorded at least some messages, and 45 of them were currently using an SGD for face-to-face, telephone, or video call communication. Of those 45, 24.4% were using their recorded messages to communicate with others, 33.3% had the messages added to their communication software but were not using them, and 40.0% had not added the messages to their SGD (one respondent skipped the question).

Of 182 participants who had heard of voice banking, 37 (20.3%) had completed the process, 32 (17.6%) had started the process but not completed it, and 113 (62.1%) had done no voice banking. Thirty respondents had completed the voice banking process and were currently using an SGD for face-to-face, telephone or video call communication. Of those 30, 23.3% were using their custom synthesized voice to communicate with others, 43.3% had installed the voice on their SGD but were not using it, and 30.0% had not installed the voice (one respondent did not know whether the voice had been installed).

Education and support for PALS and communication partners

The service delivery section of the questionnaire was completed by 209 PALS. Participants were asked where or from whom they received information and support related to speech, communication, or AAC. Respondents who were using AAC, and those who had changed their AAC or access methods due to changes in physical function, were asked where they received support and training with their AAC systems, or assistance with adapting to changes in function. They consulted a variety of sources, as shown in Figure 8, and many consulted more than one. SLPs were the most common source of information about speech changes and communication options (Figure 8(a)); support with SGD setup, training, and troubleshooting (Figure 8(b)) and help with modifying communication methods to adapt to changes in function (Figure 8(c)). However, only 46.0% of the 113 respondents who used communication aids reported that they had received SLP support with setup or training, and 62.2% of the 45 who reported having to adapt to changes in function indicated that an SLP had helped with those adaptations. Device or app company representatives were the next most popular source of help with setup and training, consulted by 25.7% of respondents to this question. Participants who needed to adapt to changes in function often did so with the support of family members or friends (48.9%) or information on the internet (35.6%). Other important sources of support, particularly for general information about communication, included ALS-focused non-profit organizations and other healthcare providers.

Participants were also asked whether anyone had provided education or support to their family members or other important people about the potential communication changes associated with ALS, how to support their communication, or how to respond to communication changes. Overall, 42.6% ($n = 89$) of the 209 respondents to this question indicated that such education or support had been provided. The percentage was highest for PALS with more impaired speech, ranging from 30.0% of respondents with a speech rating of 4 (no change, $n = 60$) to 60.6% of those with a speech rating of 0 (unable to speak, $n = 33$). Supplementary Figure 2 summarizes the responses of participants at each level of speech impairment.

SLP intervention

Among the 209 participants who completed the service delivery section of the questionnaire, 74.2% ($n = 155$) of participants had met with an SLP to discuss speech changes or communication options; 23.0% ($n = 48$) had not met with an SLP and 2.9% ($n = 6$) answered "I don't know" or did not answer the question. The percentage of respondents who had met with an SLP was higher for those with greater speech impairment, ranging from 53.3% at

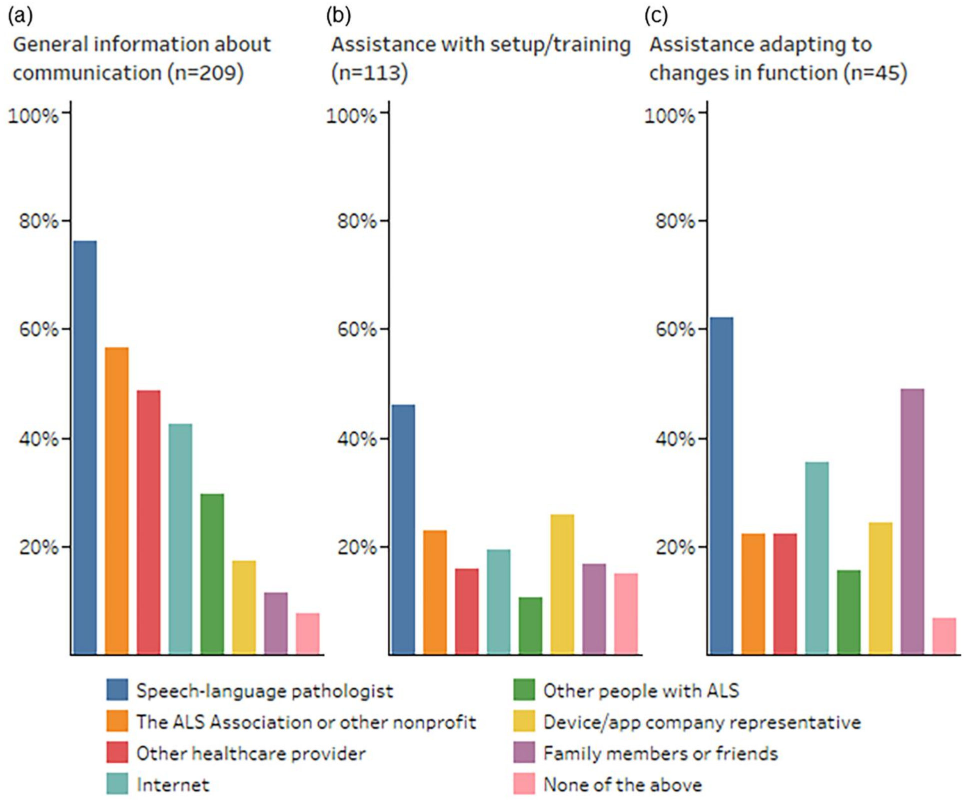


Figure 8. Percentage of respondents who accessed specific sources of general information about speech and communication (a), assistance with AAC setup or training (b), and assistance with adaptation of AAC methods in response to changes in function (c).

speech rating 4 (no change, $n = 60$) to 93.9% at speech rating 0 (unable to speak, $n = 33$), as shown in Supplementary Figure 3. Of the 48 respondents who said they had not met with an SLP about speech or communication, 26 (54.2%) indicated that they didn't "need that kind of information or support now", and 10 (20.8%) that SLP intervention had not been offered to them. Other barriers included not being "ready to talk about it" ($n = 6$), the difficulty or inconvenience of travelling to an appointment ($n = 5$), delays in getting an appointment ($n = 3$) and lack of awareness about SLPs and what they do ($n = 2$).

Among respondents who had met with an SLP about speech or communication, the timing of the initial visit varied. Of 155 respondents to this question, 21 (13.5%; primarily with bulbar onset) had their first meeting or appointment before their ALS diagnosis, 38.7% after diagnosis but before their speech began to change, 38.1% after their speech began to change but before others had trouble understanding them and 9.7% only after their speech became difficult for others to understand. Most of the 155 participants who had met with an SLP about speech or communication did so several times a year, either every one to three months (37.4%) or every four to six months (25.8%); see Supplementary Figure 4 for additional details. Respondents reported several settings and modalities for SLP interactions related to communication (respondents could choose more than one option for this question). A brief visit or check-in during an ALS clinic appointment was the most common setting, checked by 78.7% of respondents to this question. The next most frequent settings were appointments at an SLP's office (45.2%) and video calls or virtual visits (26.5%); see Supplementary Figure 5. Write-in "other" responses mentioned working with an SLP as a research participant ($n = 2$), during an inpatient stay ($n = 1$), and during a swallowing assessment ($n = 1$).

Chi-square tests of independence were used to examine relationships between SLP intervention and several other variables, with results presented in Table 3. Participants who had met with an SLP to discuss communication were significantly more likely to own an SGD, be aware of message and voice banking, and have their loved ones or other important people receive education or support related to their communication needs. No significant relationship was found between SLP intervention and use of alternative access.

Discussion

In this study, a sample of 216 PALS from across the U.S., at all levels of speech and physical function, completed an online questionnaire about their experiences with communication, AAC use, and AAC service delivery. Most reported experiencing dysarthria, with 71.3% of respondents indicating at least some detectable speech disturbance (ALSFRS-R speech rating $\leq$ 3), and 56.5% reduced intelligibility (ALSFRS-R speech rating $\leq$ 2). Overall, approximately half of respondents reported using aided communication during face-to-face interactions. The number of communication methods per participant ranged from one to six, with means of 4.3 methods for PALS who were combining speech and non-speech methods and 2.8 methods for those who were unable to speak. This is consistent with earlier research showing that PALS with dysarthria often use more than one AAC method at a time [11,12]. The use of fewer methods by participants who were unable to speak may reflect more severe physical impairments, and resulting AAC access challenges, in the later stages of disease progression, as well as the loss of speech.

Nearly all respondents reported owning at least one device that could be used as an SGD. Ownership of smartphones, tablets, and laptop or desktop computers (see Table 2) was higher among

Table 3. Chi-square tests of independence examining the relationship between SLP intervention and SGD ownership, use of alternative access, awareness of message and voice banking, and education and support provided to family members or other communication partners.

		Has met with SLP	Has not met with SLP	χ^2 (1)	*p*
Owns SGD (n = 203)	Yes	55	3	15.35	<.001
	No	100	45		
Uses alternative access (n = 203)	Yes	75	19	1.14	.143
	No	80	29		
Has heard of message banking (n = 203)	Yes	147	28	41.08	<.001
	No	8	20		
Has heard of voice banking (n = 203)	Yes	147	27	44.57	<.001
	No	8	21		
Support for communication partners (n = 195)	Yes	80	7	17.93	<.001
	No	72	36		

Note: The sample for each question excludes participants who did not answer the relevant questions or responded "I don't know."

participants than in the general U.S. adult population [27]. Not all of these devices were currently set up to function as SGDs, however. Fewer than half of respondents with speech ratings of 4 (no change) through 2 (intelligible with repeating) reported owning an SGD (either a purpose-built SGD or a consumer device with AAC software). Among participants with speech ratings of 1 (combining speech and non-speech methods) or 0 (unable to speak), the vast majority owned at least one type of SGD, with approximately half indicating that they owned and used a purpose-built SGD. Respondents who had met with an SLP were significantly more likely to own an SGD. SGD ownership rates for participants in this U.S.-based study were higher than those recently reported for PALS in Japan [17] and Scotland (though AAC acquisition data in that study, extracted from the Scottish National MND Register, were incomplete) [16], and were considerably higher than those reported by surviving family members and caregivers of U.S. PALS who passed away between 2006 and 2010 [2]. Possible reasons for this apparent increase include the availability of more SGD hardware and software options to meet PALS' varying communication and access needs, or improved awareness of SGDs and their potential benefits among PALS, family members, and funding agencies. Selection bias may also be a factor (see limitations and future directions below).

Among respondents who identified as either combining speech and non-speech methods or unable to speak, 90.8% reported using one or more SGDs for face-to-face communication. Smartphones were the most-used SGD type overall for PALS in these two stages of speech function, though for individuals with anarthria, smartphone use declined and tablets and purpose-built SGDs became equally as common. Again, this may be related to an increased need at this stage for alternative access options that are unavailable on a smartphone. Purpose-built SGDs were the most-used SGD type for telephone and video calls among this subset of respondents, perhaps because of their high-quality sound output for synthesized or digitized speech or software features such as telephone-specific phrase pages, or because of the difficulty of using a smartphone to both place a call and compose messages for use in that call. Only 52.3% of participants who combined speech and non-speech methods, or were unable to speak, reported using low-tech AAC during face-to-face interactions. Writing was the most common low-tech method, and use of other methods such as communication boards and partner-assisted scanning was limited. Most respondents in these categories used unaided methods, including gestures and residual speech, in addition to their low-tech or high-tech methods. Overall use of low-tech and unaided AAC by PALS with impaired speech was similar to that reported in a smaller survey sample from 2018 [12]. All participants in the 2018 study reported use of an SGD (required for study eligibility), though only one participant in that study used a smartphone, which was the most common SGD type in the current study. This difference may reflect a rise in overall rates of smartphone ownership in the U.S. since 2018, particularly among older adults [28], as well as improvements in AAC app options for PALS and greater awareness of those options among PALS, SLPs, and other stakeholders.

Although many respondents were not using their devices for face-to-face, telephone, or video call interactions, most reported using them for written communication, including email and text messaging. Other popular purposes of device use included browsing the internet, online shopping, accessing healthcare, entertainment, managing finances, and social media. Such activities have been found to contribute to independence, participation, and quality of life for PALS and other individuals with disabilities [29–31]. Participants were least likely to use their devices for tasks related to employment, education, and parenting, perhaps due to the demographic characteristics of this sample (and of PALS in general), as participants were mostly retired and aged 55 or older. Communication during face-to-face, telephone, or video call interactions was by far the most common use of purpose-built SGDs, reported by 90.0% of respondents who use such devices, but they were also used for many of the same purposes as consumer devices.

Participants who reported using smartphones, tablets, laptops, desktops, or purpose-built SGDs did so with a variety of access methods. Most respondents used standard access (touching a screen, mouse, or keyboard with their fingers or a stylus), and that was the most common means of access for smartphones, tablets, and laptop or desktop computers. Most participants who reported use of a purpose-built SGD also reported that they used alternative access. This may indicate that PALS prefer to use mainstream consumer devices while they have the necessary physical function to do so, then switch to purpose-built SGDs (which are typically easier to configure for alternative access methods, particularly eye tracking) when standard access is no longer effective. Overall, 32.5% of participants reported using one or more alternative access methods in combination with standard access, and 13.7% only used alternative access. Two participants denied use of any access method and relied on another person to operate the device for them. The most common alternative access method was cursor control with a mouse, trackball, or joystick only (without activating the touch screen or a physical keyboard), followed by eye tracking. Eye tracking was the most common access method for purpose-built SGDs.

Among participants who used one or more devices, 26.4% used a mounting system for positioning. About half reported that their mounting system worked well in most or all situations when they wanted to use their device, but others faced challenges with mount use in some situations, including not having an appropriate mount for specific applications, difficulty with setup or positioning, physical barriers in the environment, and not having the mount properly assembled or installed.

Most respondents had heard of both message banking and voice banking, with significantly higher rates among those who had met with an SLP. However, relatively few had actually participated in these activities or used the resulting messages or voice for communication. Of those who had heard of message banking, 34.1% had recorded at least some messages, and of those who had heard of voice banking, 20.3% had completed the process. Only about one quarter of participants who had completed these processes, and used SGDs for communication, actually used their recorded messages or custom synthesized voice with their SGDs. The potential reasons for this low adoption were not addressed in the current study, but previous research suggests that barriers to message and voice banking include concerns about the time or effort it would require, limited awareness of how banked messages or a custom voice would be used with an SGD, and a lack of support and training [32,33].

Most participants reported that they had met with an SLP to discuss speech changes or communication options, though this was less common for those with no speech change or only minor speech disturbance. Among participants who had met with an SLP, only 38.7% had their first meeting before their speech began to change. Once they began seeing an SLP, most reported that they did so several times a year, likely during ALS clinic appointments, as this was the most common setting in which participants met with their SLPs. Fewer than half of participants who used AAC indicated that an SLP had provided assistance with setup and training. Respondents got information and support related to AAC from a range of sources in addition to SLPs, including other providers, other PALS, family members or friends, company representatives, and the internet. Fewer than half of participants reported that their family members or other important people had received education or support related to communication for PALS, though this was significantly more likely for participants who had met with an SLP.

Clinical implications

Results point to several opportunities for improving AAC service delivery for PALS. Both expert clinicians and PALS themselves have recommended that AAC intervention in this population should begin early, include ongoing re-evaluation, provide information and education to communication partners to encourage AAC acceptance and use, and support the use of multiple communication methods and adaptation to changing needs and abilities [1,7,12,13]. Participants in the current study reported a range of experiences related to these recommendations. Many of them first met with an SLP only after their speech began to change, or had not yet had any discussions with an SLP about potential speech changes or AAC options. More than half of those who had not yet met with an SLP said it was because they didn't need help with communication, or weren't ready to talk about it. PALS should receive early referrals for SLP services, and, crucially, education about the importance of such services even for individuals whose speech has not yet changed. Specific targets for early intervention could include message and voice banking, as well as information about available AAC approaches and how consumer devices can be used as SGDs. Though most participants had heard of message and voice banking, relatively few had taken advantage of these options. The clinical framework described by Costello and Smith suggests guidelines for introducing and supporting these processes [26]. Respondents who did not use AAC also demonstrated signs of limited preparation for possible future speech changes. Many had not set up their existing consumer devices as SGDs, and were unaware of whether or not their devices could support eye control. Providing early education about SGD options may help PALS make informed decisions about purchasing technology that can adapt to their changing needs. Additional intervention may be needed for PALS after AAC acquisition, as well. Although most participants who had seen an SLP reported interactions occurring at least once a year, the proportion of AAC users who received SLP support with setup and training, or with adapting to changes in function, was relatively low, potentially creating barriers to AAC adoption and use.

Family, friends, and caregivers are vital to the success of AAC intervention, both as communication partners and to facilitate access to SGDs and other aids, but relatively few respondents indicated that their communication partners had received education or support in these areas. Even among participants who had met with an SLP, nearly 50% indicated that this type of support had not been provided. Additional intervention for loved ones could be provided through many of the sources participants were already consulting for information about communication, including healthcare providers, ALS-focused non-profit organizations and AAC-related websites, as well as during SLP appointments and ALS clinic visits.

Finally, survey responses indicated room for improvement in support for multimodal AAC. Although many participants with dysarthria reported use of multiple communication methods, use of low-tech AAC was relatively rare and mostly involved writing. Other low-tech approaches such as communication boards, eye gaze boards, and partner-assisted scanning, which may be especially helpful for PALS who cannot write, were used by only a small number of participants, and approximately 15% of this group denied use of unaided methods such as speech or gestures (including blinks or eye movements). Some participants reported that they used only high-tech AAC, potentially leaving them without a means of communication if their SGD were unavailable or became difficult to access. Additional education and training in low-tech and unaided AAC, either as primary methods or as backup methods to an SGD, may be necessary to give PALS more tools to support effective communication.

Results also shed light on PALS' use of video call technology during the COVID-19 pandemic. This survey was conducted in 2021, over a year into the pandemic, during which video calls became a ubiquitous part of many people's social and professional lives. This trend appears to extend to PALS, as 84.7% of respondents reported participating in video calls (compared to 78.7% who reported communicating over the telephone). Video calls also offer a safe and convenient means of seeing doctors and other healthcare professionals [34,35], and 87.4% of respondents indicated that they used their SGDs or mobile devices for accessing healthcare (though this includes web-based patient portals and other healthcare tools in addition to virtual visits). The visual component of video calls gives them a clear advantage over phone calls for people who use AAC. As shown in Figure 3, more participants with severe speech impairment used gestures during video calls than during phone calls, and typing (i.e., with the chat function available in many video call platforms) emerged as an important communication support. Communicative participation ratings collected in this same survey, and reported in [23] and in a planned future publication, indicated that 63.5% of the participants included in that sample who used aided communication to participate in video calls ($n = 63$) found it no more than "a little" difficult to do so. The popularity of, and relative ease of participation in, video calls among PALS who use AAC indicates that they may be an appropriate target for treatment goals. PALS may benefit from support in obtaining the internet access, hardware, and software required for video calling, as well as training in how to use the video call platform and incorporate various AAC methods during calls. Recent research also indicates that virtual visits are a feasible and highly satisfactory option for conducting SGD evaluations and treatment [36].

Limitations and future directions

The recruitment methods for this study, and the use of convenience sampling, may have introduced selection bias. PALS from racial or ethnic minority groups may be underrepresented, in part due to the use of the National ALS Registry Research Notification Mechanism as a primary recruitment method. The racial and ethnic makeup of this sample is comparable to that observed in the Registry [19,37], but the Registry has been found to be less likely to identify and enrol non-white and Hispanic PALS [38]. In addition, participants in this study were all PALS with internet access and an email address (or the assistance of a family member or other support person with those resources), and most reported frequent computer use prior to their ALS diagnosis. Individuals with less access to or familiarity with technology may have been less likely to participate. As such, results such as the high percentage of respondents with dysarthria who reported use of SGDs should be interpreted with caution. PALS with more severe physical impairments may also be underrepresented due to difficulties with computer control or fatigue. Although some participants in the current study had very low scores on the self-administered ALSFRS-R, indicating substantial reductions in physical function, these scores provide little information about a person's ability to use assistive technologies designed for individuals with minimal movement. Two PALS may each have an ALSFRS-R score of 0, but one may have excellent control of an SGD or other devices using eye tracking or switch scanning, while the other struggles to use these access methods due to reduced ocular motility or the lack of a reliable movement for switch activation. Finally, the fact that these data were collected in 2021, during the COVID-19 pandemic, may have affected some results, such as the reported frequency of SLP intervention *via* video calls or virtual visits. Considering these characteristics of the survey sample, generalizability of the results may be limited.

Future research might explore current trends in AAC use and service delivery experiences with a random sample of PALS, or with the same group of participants over time to observe changes with disease progression. Interviews with PALS and communication partners could provide guidance on patient-centred approaches to promoting timely AAC intervention, inclusion of and support for communication partners, and increased adoption of multimodal AAC strategies and video call technology.

Conclusion

Results of this survey emphasized the heterogeneity of PALS' experiences with communication, AAC use, and AAC intervention, and revealed areas where many PALS may benefit from additional training and support. To improve their experiences and outcomes, clinicians should work to implement the expert- and PALS-recommended principles of early referral and ongoing treatment, education and support for communication partners, and intervention that addresses the varied and changing communication needs of individual PALS.

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