Research Note

Use and Perceived Effectiveness of Communication Modes Reported by Persons With Primary Progressive Aphasia

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ABSTRACT

Purpose: Primary progressive aphasia (PPA) is a clinical neurodegenerative dementia syndrome characterized by early, selective, and progressive language impairment. PPA onset is gradual, providing time to potentially identify additional or alternative expressive communication modes; however, reports of communication mode use and effectiveness by persons with PPA have not been described. This study characterized the use, frequency, and perceived effectiveness of communication modes reported by individuals with PPA.
Method: Forty-one participants with mild-to-moderate PPA completed a structured interview detailing the type, frequency, and perceived effectiveness of 12 potential communication modes, categorized by technology required (no-tech, low-tech, and high-tech). The ratio of modes used was compared across technology categories with a repeated-measures generalized linear model assuming a binomial distribution with an overall Wald chi-square statistic, followed by pairwise post hoc t-test comparisons.
Results: Of the 12 communication modes assessed, participants reported using a median of eight (range: 5–10). All participants affirmed using speech, facial expressions, and talking on the phone. Frequency and perceived effectiveness ratings for these three modes were endorsed at the "some/most of the time" level for more than 80% of the participants. No-tech mode use was significantly higher than reported high-tech and low-tech modes ($p = .004$ and $p < .0001$, respectively). Even so, while some high-tech modes (apps) and some low-tech modes (nonelectronic augmentative and alternative communication) had fewer users, effectiveness ratings were moderate to high for all but one user.
Conclusions: Persons with mild-to-moderate language impairment due to PPA report using a range of communication modes with moderate-to-high frequency and perceived effectiveness. These outcomes provide practical information when considering mode refinement or expansion during intervention to maximize communication participation. Barriers to modality use may include low awareness or access, which could be queried by future studies and supported by speech and language interventions.
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Primary progressive aphasia (PPA) is a neurodegenerative syndrome characterized by initial and insidious deterioration of language production and processing caused by neuropathological diseases, including Alzheimer's disease or frontotemporal lobar degeneration (Mesulam,

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2001). Language impairment is the initial and predominant cause of functional limitations in activities of daily living (Moeller et al., 2021; Utianski et al., 2019; Wicklund et al., 2007). The three most common PPA variants are agrammatic (PPA-G), semantic (PPA-S), and logopenic (PPA-L), which are associated with prominent deficits in grammar production and/or comprehension, single-word comprehension, and word retrieval, respectively (Gorno-Tempini et al., 2011; Mesulam, 1982, 2003; Mesulam et al., 2014). Inevitable worsening of language skills over time and the potential emergence of cognitive and/or motor changes throughout disease progression may limit access to expressive communication modes, which in turn may negatively impact quality of life. Our speech-language intervention studies (Roberts et al., 2022; Rogalski et al., 2016, 2021) and a recent review (Volkmer, Spector, Meitanis, et al., 2020) acknowledge that speech-language therapy may provide opportunities to build on existing communication strategies and/or to develop use of additional functional communication modes to improve quality of life for individuals with PPA. However, reports of communication mode use and effectiveness by persons with PPA have not been described.

Multimodal Communication in Language Impairment

Aphasia rehabilitation and augmentative and alternative communication (AAC) highlight the importance of multimodal communication for managing language impairment (Fried-Oken et al., 2015; McLaughlin et al., 2021). In AAC intervention for stroke-induced aphasia, individuals are trained in flexible use of multiple communication modes to enhance the user's ability to efficiently combine modes to meet the demands of the environment, the listener, and their intended message (Dietz et al., 2020). Likewise, multimodal communication has been shown to facilitate accurate transmission of messages and to aid in the management of conversational interaction for those with stroke-induced aphasia (Simmons-Mackie et al., 2013). Similarly, AAC intervention for language impairment in neurodegenerative and nonneurodegenerative dementia syndromes suggests that layering additional communication modes to speech not only strengthens the message but also supports the needs of individuals as their abilities vary and change over time (Bourgeois et al., 2010; Lanzi et al., 2017). A recent review and case reports of AAC interventions for people with neurodegenerative dementia syndromes including PPA reported that multimodal strategies, when scaffolded by communication partners, may support both receptive and expressive language, increase social participation, and improve decision making (Cress & King, 1999; May et al., 2019; Rebstock & Wallace, 2020).

While the literature underscores the importance of considering multimodal communication for individuals with language impairment, there are no qualitative or quantitative description of communication mode use from persons with PPA. The onset in PPA often includes a prolonged journey (i.e., years) to obtain an accurate diagnosis (Khayum et al., 2012; Taylor et al., 2009; Volkmer, Spector, Warren, & Beeke, 2020). During this time, persons with PPA may either reduce use of certain communication modes or explore alternative modes for communication; these modes have yet to be documented.

Purpose

Given the limited characterization of communication modes reported by individuals with PPA, this study aimed to characterize the type, frequency, and perceived effectiveness of communication modes reported by people with PPA.

Method

Data were collected during structured communication modes interviews as part of the study, "Communication Bridge-2 (CB2): A Person-Centered Internet-Based Intervention for Individuals With PPA," an NIH Stage 2 (Onken et al., 2014), single-blind, randomized, parallel group, active-control, behavioral clinical trial delivered virtually within a telehealth service delivery model (CB2; NCT03371706; PI: E. Rogalski; Roberts et al., 2022). Data from the first 41 consecutively enrolled CB2 participants were included in the analysis. Participants were recruited from multiple sources including the clinical cores of the National Institute on Aging–funded Alzheimer's Disease Research Centers at Northwestern University and Oregon Health & Science University, ClinicalTrials.gov, the Alzheimer's Association TrialMatch website, The Association for Frontotemporal Degeneration, and other clinician referrals. The institutional review board at Northwestern University approved study procedures, and all participants provided written informed consent.

Participants

Participants included 41 individuals with diagnoses of mild-to-moderate PPA. Detailed inclusion criteria are described in the CB2 trial protocol manuscript (Roberts et al., 2022). Briefly, the diagnosis of PPA was made by a neurologist and supported through medical record review based on current PPA criteria (Gorno-Tempini et al., 2011; Mesulam et al., 2014). As such, a diagnosis of primary progressive apraxia of speech was exclusionary. Although not the focus of this study, PPA subtype designations were assigned based on prominent language profile features according to previously established research

criteria (Gorno-Tempini et al., 2011; Mesulam, 2003; Mesulam et al., 2014). All participants were English speakers who self-reported as having sufficient hearing for understanding conversation in a quiet environment and sufficient vision for reading the newspaper (corrected or uncorrected for both hearing and vision). Prior to enrollment, participants were required to demonstrate proficiency in using a video chat platform for completing a structured interview. Each participant was required to have an eligible communication partner who was willing to co-enroll into the trial. The CB2 trial defined a *communication partner* as a person who had known the participant for greater than 12 months; had close and regular contact with the participant; and provided emotional, communication, and/or activities of daily living support to the participant. Communication partners were 18 years of age or older, were primary English speakers, and had adequate hearing (aided or unaided) for communicating with others in a crowded room (by self-report).

Measures

The Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners (SNI; Blackstone & Hunt Berg, 2004) is an assessment and intervention planning tool designed to help clinicians determine appropriate communication supports for individuals with complex communication needs in order to guide therapeutic interventions that enhance perceived quality of life and participation in daily activities. The measure was developed under a framework that acknowledges the multimodal nature of communication and recognizes that interaction patterns vary across social situations and partners. The

SNI is based on theoretical backgrounds including the participation model (Beukelman & Mirenda, 1998), the multimodal nature of communication, and the World Health Organization's International Classification of Functioning, Disability and Health framework (World Health Organization, 2001). The SNI facilitates an understanding of an individual's circle of communication partners and participation environments, the modes of expression used with partners and in environments within that circle, and about the perceived effectiveness of each mode. The authors created a structured communication modes interview including commonly recognized methods of expression (Blackstone & Hunt Berg, 2004, p. 25).

For this study, the communication modes interview queried type, frequency, and perceived effectiveness of 12 communication modes: facial expression, gestures, speech, writing/drawing, nonelectronic AAC, apps on a smartphone/smart tablet, speech-generating device (SGD), talking on the phone, texting, video chat, e-mail, and other (see Table 1). The questionnaire can be accessed through our Communication Bridge Trial Handbook.

Procedure

A research speech-language pathologist (SLP) conducted a structured interview with each participant and their communication partner as part of the baseline evaluation for the CB2 trial. Interviews occurred over the Internet via videoconference with a secure web application. All interviews were recorded for later response verification. SLPs instructed the participant and their communication partner to provide a response to each question following a collaborative discussion. To support comprehension and

Table 1. Communication modes of based on Blackstone & Hunt Berg (2004) classified by the amount of technology required.

No-tech	
Facial expression	Natural, often unintentional, mode of expression that others may (or may not) interpret as meaningful
Gesture	Body movements that establish reference and convey meaning, e.g., pointing, headshakes, and idiosyncratic gestures such as looking at door to indicate "let me out of here"
Speech	Intelligible spoken words or phrases; includes word approximations understood by familiar partners
Low-tech	
Writing/drawing	Text produced using pen/pencil and paper, or drawings
Nonelectronic AAC	Any low-tech display developed for language comprehension or expression, using any variety of symbols including letters, words, photos, icons, pictures, or other
High-tech	
Apps on smartphone/smart tablet	Any apps that are used for reading, processing, or expressing language (Administration clarification states: "These are not apps simply being used but apps that are used "to communicate with another person."")
Speech-generating device	Electronic AAC device that provides digitized or synthesized speech output to generate spelling and language
Phone	Use of telephone to communicate verbally across distances
Text	Use of texting app to communicate across distances
Video chat	Use of video chat (e.g., Zoom or Skype) to communicate across distances
E-mail	Use of e-mail to communicate across distances
Other	
Other	Any other communication modes not previously discussed (e.g., manual sign language); recorded as an open-ended response

Note.   AAC = augmentative and alternative communication.

expression, SLPs presented questions using augmented input and written choice communication strategies (Garrett & Beukelman, 1995; Garrett & Lasker, 2007). The original version of the "modes of expression" portion of the SNI includes multiple questions about each mode, such as efficiency, intelligibility, and size of the vocabulary for that mode. Our adapted version posed three questions for each communication mode: (a) Do you use X (mode) to communicate? (b) How often do you use X (mode) to communicate? (c) When you use X (mode), how often is this an effective communication mode? Participants were shown (digitally, via screen share) a visual aid that listed the response options. The response options provided for *use* were "yes/no." The response options provided for *frequency* and *effectiveness* were "most of the time," "some of the time," "rarely," or "never."

Data Analysis

Each mode was statistically summarized by determining its use (yes vs. no), its frequency of use (most/some of the time vs. rarely/never), and its effectiveness when used (most/some of the time vs. rarely/never). For frequency and effectiveness analyses, the 4-point response scale was collapsed into dichotomous responses by combining "rarely" with "never" and "most of the time" with "some of the time." For each question category (use, frequency, and effectiveness), percentages were calculated (percent yes responses for *use,* percent most/some responses for *frequency* and *effectiveness*). Percentages for use are out of a denominator of 41. Percentages for frequency of usage and for effectiveness are out of a denominator of the number of users.

SLPs who specialize in AAC have categorized communication modes by their reliance on technology: those that require no technology (speaking, facial expressions, or gestures), low technology (writing, nonelectronic communication aids such as boards/books, wallet cards, or real objects), or high technology (video chat or apps on a device or complex communication devices; Blackstone & Hunt Berg, 2004; Loncke et al., 2006). Consistent with this model, each mode queried for this study was classified into one of three categories based on the amount of technology required: (a) no-tech modes (facial expressions, gestures, speech, and other), (b) low-tech modes (writing/drawing and nonelectronic), and (c) high-tech modes (apps, talking on the phone, texting, video chat, e-mail, and SGDs). Use for each technology level (high-tech, low-tech, and no-tech) was calculated by dividing the number of modes each person used in each technology category by the total number of modes in that category. This ratio used was compared across technology categories with a repeated-measures generalized linear model assuming a binomial distribution with an overall Wald chi-square statistic, followed by pairwise post hoc t-test comparisons. Results are reported as the mean percentage of modes used in each technology-level category, calculated with the Tukey–Kramer correction for multiple significance testing. Statistical significance was noted if adjusted $p < .05$.

Results

Responses from 41 individuals with PPA were included in this analysis (PPA-G = 13, 32%; PPA-S = 8, 19%; PPA-L = 20, 49%). Participants were 20 men (49%) and 21 women (51%), aged 55–81 years ($M = 66.8$, $SD = 6.8$). Over 68% had postsecondary or higher education ($M = 16$, $SD = 2.5$). Forty participants (97.6%) identified their race as White; one participant (2.4%) identified as Asian. Demographics and characterization of language performance of the participants are provided in Table 2.

Type of Communication Mode Use

The median number of communication modes reported was eight per participant (range: 5–10; see Figure 1a and Table 3). All participants with PPA reported using three modes: facial expressions, speech, and talking on the phone. Over 70% of participants reported using an additional five modes: text (93%), gestures (90%), e-mail (90%), writing/drawing (76%), and video chat (71%; see Figure 1a and Table 3).

The generalized linear model showed significant differences in the reported use of modes according to the level of technology ($p < .0001$, $\chi^2 = 42.3$; see Figure 1b). Post hoc testing showed that high-tech (66%) and no-tech (73%) modes were each reported as being used more frequently than low-tech modes (46%; $p < .0001$ comparing high-tech with low-tech and $p < .0001$ comparing no-tech with low-tech), whereas reported no-tech mode use was significantly greater than high-tech mode use ($p = .004$; see Figure 1b).

Table 2. Participant demographics and characterization of language performance.

Variable	*M (SD)*	Range	*N*
Age (years)	66.8 (6.8)	55–81	41
Years of education	16.0 (2.5)	12–21	41
Duration of symptoms (years)	3.8 (1.9)	1.3–8.6	41
WAB-R AQ (/100)	80.5 (9.0)	54.9–95.4	41
BNT (/60)	35.7 (19.5)	1–60	41
PPVT-4 (/36)	29.8 (6.6)	11–36	41

Note. WAB-R AQ = Western Aphasia Battery–Revised Aphasia Quotient (Kertesz, 2007); BNT = Boston Naming Test (Kaplan et al., 2001); PPVT-4 = Peabody Picture Vocabulary Test–Fourth Edition (Dunn & Dunn, 2007).

Figure 1. (a) Communication modes reported by percent and characterized by technology required. All participants with primary progressive aphasia (PPA) validated use of facial expressions, speech, and talking on the phone; 70% reported using additional five modes. The median number of communication modes reported was eight per participant (range: 5–10). (b) Reported communication mode use according to the technology level. Each technology level has a different number of communication modes ("no" has four modes, "low" has two modes, and "high" has six modes). The average number of modes used cannot be compared because of the different number of modes in each technology level. An alternate statistical model is used (a repeated-measures generalized linear model with a binomial/log link) to calculate, for each person and for each of the three levels, the ratio (expressed as percent) of the number of modes used in that level divided by the total number of modes in that level. The model then averages these person-specific percentages for each level, resulting in the mean percentages in Panel b. AAC = augmentative and alternative communication.

a — Communication Modalities Used by People With PPA

b — Technology Type Used by People With PPA
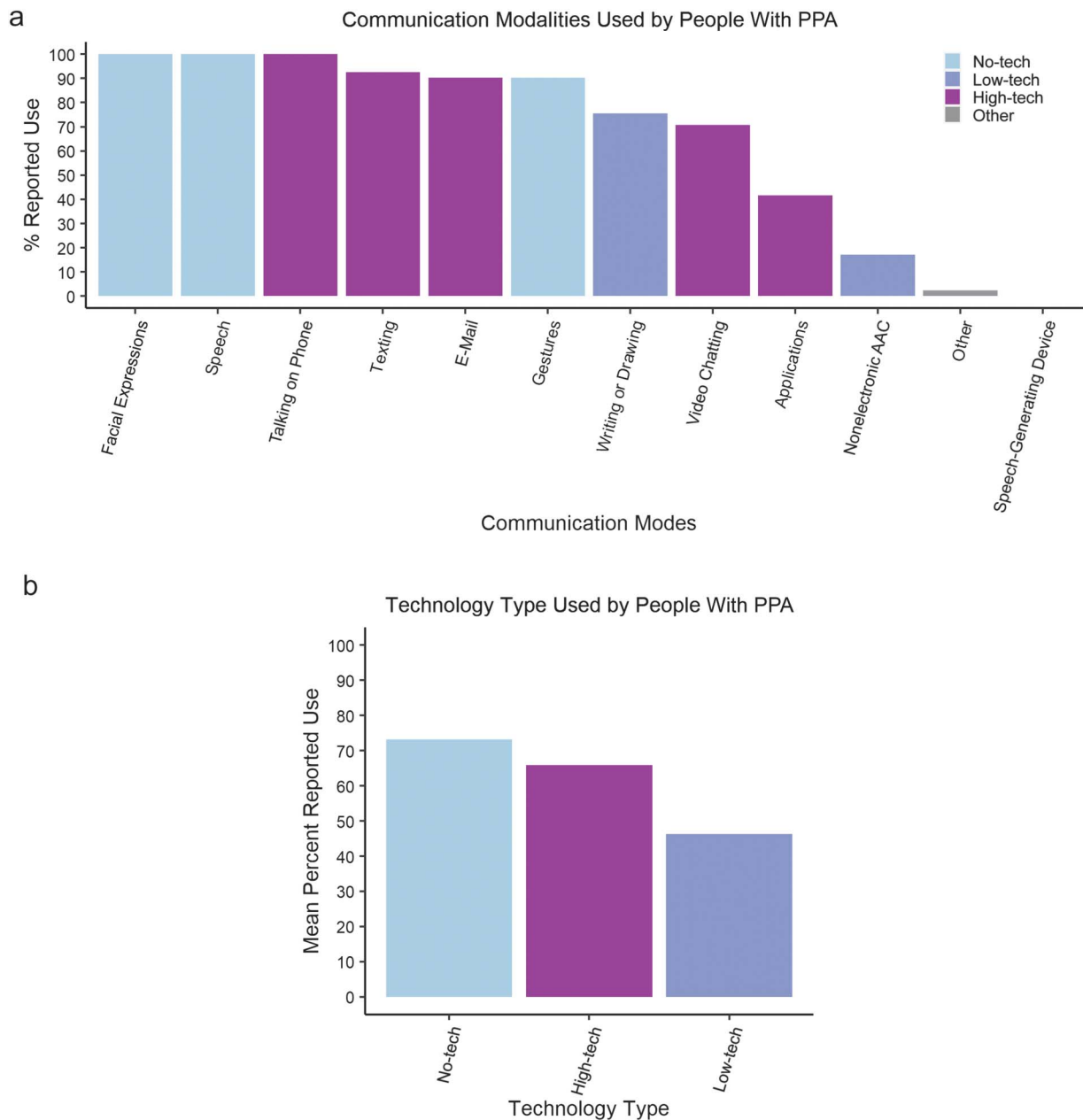
Frequency of Communication Mode Use

The reported frequency of use by mode is provided in Table 3. All participants with PPA reported using speech "most/some of the time." Mode use ratings of "most/some of the time" remained above 55% (see Table 3), except for the "other" category, which was only endorsed by one participant and with a reported frequency of rarely used, and SGDs, which were not reported as being used.

Table 3. Reported frequency and perceived effectiveness of communication modes used by persons with primary progressive aphasia.

Communication mode	No. of users	*n* Used some/most	% Used some/most[a]	*n* Effective some/most	% Effective some/most[a]
Speech	41	41	100	40	98
Facial	41	34	83	40	98
Phone	41	34	83	39	95
Text	38	32	84	38	100
Gestures	37	31	84	35	95
E-mail	37	32	86	36	97
Write/draw	31	22	71	31	100
Video chat	29	16	55	28	97
Apps on smartphone/ smart tablet	17	13	76	16	94
Nonelectronic	7	5	71	7	100
Other	1	0	0	1	100
SGD	0	0	0	0	0

Note. SGD = speech-generating device.

[a]Percentage was calculated by dividing the number used some/most of the time or the number effective some/most of the time by the number of users.

Perceived Effectiveness of Communication Mode Use

The percentage of participants with PPA who perceived each mode as effective most/some of the time is presented in Table 3. Effectiveness ratings of "most/some of the time" were consistently given (i.e., ≥ 95 of participants) across 10 of the 11 domains that were used, even for modes where few participants endorsed using the domain. Descriptive statistics on mode frequency of use and effectiveness by clinical variant are provided in Supplemental Material S1.

Discussion

The majority of participants with mild-to-moderate language impairment in PPA report using at least eight modes for communication, with moderate-to-high frequency and effectiveness for functional communication and a preference for no-tech and high-tech modes over low-tech modes. A key strength of this work is the systematic assessment of modality use, frequency, and effectiveness across PPA variants for individuals with mild-to-moderate impairment. Despite their expressive language impairment, all participants with PPA reported using speech most/some of the time. While some high-tech modes (apps) and some low-tech modes (nonelectronic AAC) had fewer users (17 and seven participants, respectively), effectiveness ratings were moderate to high for all but one user (see Table 3).

Persons with PPA reported the highest use of no-tech communication modes, followed by high-tech modes and then low-tech modes. No-tech modes included facial expressions, speech, and gestures. These modes may be considered habitual or routine patterns of communication that individuals have come to expect to be effective during conversation. With respect to high-tech modes, over 90% of all participants endorsed using talking and texting on the phone and also e-mail. Use of these communication modes is consistent with the general public use of mobile technologies. Recent research indicated that 97% of Americans now own a cell phone; 83% of adults ages 50–64 years own a smartphone, and 61% of adults over 65 years of age own a smartphone (Statista, 2021). The use of SGDs was queried as a high-tech mode, and no participants reported using them. There could be multiple explanations, including that in the relatively mild stages of language impairment in PPA, individuals retain access to spoken language, thus limiting motivation or perceived need to use SGDs. Other reasons may include simply not being aware of SGDs, not having access to speech-language treatment where the concept of SGDs may be introduced, or financial barriers. The low-tech modes queried included writing/drawing and nonelectronic (communication boards and books). It is unclear whether modality use in these areas is limited because of inadequate knowledge of the utility of multimodal communication for individuals with language impairment, of reduced resources/support, or it is simply a reflection of the mild-to-moderate severity of the participants. However, the high effectiveness ratings for those who did endorse these modes provide a promising opportunity for clinicians and future studies to explore.

A key finding of this study was that participants in the mild-to-moderate stages of PPA report using multiple modes of communication with high effectiveness. This information may be practically useful for the SLP clinician at initial assessment and in treatment planning over time. Taking personal preference and participation goals

into consideration, SLPs may create a treatment plan to optimize or expand the initially reported modality repertoire to maximize participation in language-based activities. To optimize communication participation throughout disease progression, SLPs may intermittently reassess communication modes to gauge successes, identify barriers, and add or expand communication mode use. Incorporation of recurrent assessment and expansion of communication strategies into clinical practice would be consistent with our previous intervention models and findings of a recent review of functional communication interventions for people with PPA, which reported that a key treatment component of speech-language treatment is to build on an individual's current communication strategies (Roberts et al., 2022; Rogalski et al., 2016; Volkmer, Rogalski, et al., 2020). Furthermore, a recent scoping review of the lived experience of people with PPA reported that the number one concern for these individuals was the need to develop adaptations for overcoming language difficulties (Davies & Howe, 2020). Effective use of multiple communication modes may provide an opportunity for maximizing quality of life and communication participation for those with PPA.

Our current study was potentially limited by the communication modes, tools, and strategies queried. Although the 12 modes probed are inclusive of many forms of communication, there were no specific questions about the use of scripts, visual aids, or remnants as communication modes. Furthermore, the response format for questions regarding modality use did not specify language expression versus language comprehension. Thus, interpretation regarding which modes support these distinct language functions is limited. Similarly, the response format of "never" to "most of the time" may lack specificity of frequency, limiting explanation of the data. Finally, although this interview was conducted at baseline enrollment into the CB intervention, analysis of the impact of previous enrollment in speech-language treatment (with potential exposure to multimodal communication) on mode use was not conducted.

The purpose of this study was to characterize the use, frequency, and perceived effectiveness of communication modes reported by individuals with PPA. Participants with mild-to-moderate language impairment report using a range of communication modes effectively for functional communication some or most of the time. They prefer no-tech and high-tech modes over low-tech modes. None report use of SGDs.

Given the neurodegenerative nature of PPA, communication modes may shift as PPA progresses. Information from a recent scoping review of the lived experience of people with PPA reveals that their number one concern was the need to develop adaptations for overcoming language difficulties (Davies & Howe, 2020). In other words, they want to be ready to manage this shift. Future studies may include longitudinal assessment of communication

mode use and effectiveness, characterization of mode use for individuals with more severe impairment, or evalution of the efficacy of interventions aimed at increasing mode use.

Data Availability Statement

The data sets analyzed during this study are available from author Rogalski upon reasonable request.

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