

Research Article

Communication Partner Engagement: A Relevant Factor for Functional Outcomes in Speech–Language Therapy for Aphasic Dementia

Emily Rogalski, PhD,^{1,2,*} Angela Roberts, PhD,³ Elizabeth Salley, MA,¹ Marie Saxon, MS, CCC-SLP,¹ Angela Fought, MA,^{1,4} Marissa Esparza, BA,¹ Erin Blaze, MS, CCC-SLP,¹ Christina Coventry, RN,¹ Marek-Marsel Mesulam, MD,¹ Sandra Weintraub, PhD,^{1,2} Aimee Mooney, MS, CCC-SLP,⁵ Becky Khayum, MS, CCC-SLP,¹ and Alfred Rademaker, PhD^{1,6}

¹Mesulam Center for Cognitive Neurology and Alzheimer's Disease, Northwestern University, Chicago, Illinois, USA. ²Department of Psychiatry and Behavioral Sciences, Northwestern University Feinberg School of Medicine, Chicago, Illinois, USA. ³Department of Communication Sciences and Disorders, Northwestern University, Evanston, Illinois, USA. ⁴Department of Biostatistics and Informatics, University of Colorado Denver Anschutz Medical Campus, Aurora, USA. ⁵Oregon Health & Science University, Portland, USA. ⁶Department of Preventive Medicine, Northwestern University Feinberg School of Medicine, Chicago, Illinois, USA.

*Address correspondence to: Emily Rogalski, PhD, Mesulam Center for Cognitive Neurology and Alzheimer's Disease, Northwestern University Feinberg School of Medicine, 300 E. Superior Street, Tarry 8-735, Chicago, IL 60611, USA. E-mail: erogalski@gmail.com

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Abstract

Objectives: Previous reports established the feasibility of a telehealth model for delivering speech–language therapy via Internet videoconferencing, which connects individuals with primary progressive aphasia (PPA) to an expert speech and language pathologist for treatment. This study reports feasibility of the same telehealth intervention in a larger set of progressive aphasia participants and explores factors potentially influencing functional intervention outcomes.

Methods: Participants with PPA or progressive aphasia in the context of a neurodegenerative dementia syndrome and their communication partners were enrolled into an 8-session intervention, with 3 evaluations (baseline, 2 months, and 6 months postenrollment). Half of the participants were randomized into a “check-in” group and received 3-monthly half-hour sessions postintervention. Mixed linear models with post hoc testing and percent change in area under the curve were used to examine communication confidence over time, as well as the influence of check-in sessions and the role of communication partner engagement on communication confidence.

Results: Communication confidence improved at the 2-month evaluation and showed no significant decline at the 6-month evaluation. Item-level analysis revealed gains in communication confidence across multiple communication contexts. Gains and maintenance of communication confidence were only present for the engaged communication partner group and were not bolstered by randomization to the check-in group.

Discussion: Internet-based, person-centered interventions demonstrate promise as a model for delivering speech–language therapy to individuals living with PPA. Maintenance is possible for at least 6 months postenrollment and is better for those with engaged communication partners, which supports the use of dyadic interventions.

Keywords: Alzheimer's disease, Frontotemporal dementia, Nonpharmacologic intervention, Primary progressive aphasia, Telehealth

Primary progressive aphasia (PPA) is a clinical neurodegenerative dementia syndrome characterized by deficits in spoken and written language (Mesulam, 2003; Mesulam et al., 2012, 2014). Criteria for three research subtypes (or variants) of PPA (semantic [PPA-S], logopenic [PPA-L], and agrammatic [PPA-G]) have been described based on the individual's language profile with consideration of their impairments and preserved abilities (Gorno-Tempini et al., 2011; Mesulam, 2003). Currently, there are no effective disease-modifying pharmacologic treatments to slow, halt, or reverse the proteinopathies associated with PPA or related aphasic dementia syndromes associated with neurodegenerative brain disease. However, there is mounting evidence for the potential utility of speech–language therapy (SLT) for optimizing communication abilities and quality of life for individuals living with PPA and related syndromes despite the fact that, unlike those with stroke-related aphasia, they are expected to decline and not improve with treatment (Farrajota et al., 2012; Henry et al., 2013, 2019; Rogalski et al., 2016; Taylor et al., 2009). Single case studies have been the predominant design, though additional interventions with robust study designs are emerging (e.g., randomized studies with control conditions; see [clinicaltrials.gov NCT03371706](https://clinicaltrials.gov/ct2/show/study/NCT03371706)). The majority of SLT interventions reported in PPA assessed treatment feasibility or efficacy within a particular PPA subtype. Restorative approaches (e.g., script training and word-retrieval training) are the most common, although functional communication approaches, which aim to support a person to engage in communication activities and participate in life situations, are becoming increasingly more prevalent (for reviews see Croot, 2018; Jokel et al., 2014; Volkmer et al., 2020).

Rogalski et al. (2016) previously established the feasibility of a telehealth model for delivering a multicomponent, person-centered, and tailored intervention, which connected individuals with PPA or related syndromes to an expert speech–language pathologist (SLP) for treatment and was supported by a custom web application. This telehealth approach allowed for improved access to care, which is important because PPA is relatively rare, and thus, locating local clinicians to support patients and families can be difficult. On average, participants, across all PPA variants, showed significant gains on the primary outcome, a patient-reported outcome (PRO) measure of communication confidence, posttherapy with no significant decline 6 months postenrollment. The first objective of the current study was to extend our previous findings by examining the same functional primary outcome, communication confidence, in a larger subset of participants with primary or other progressive aphasia.

As the field matures, there is an opportunity to strengthen the evidence for intervention efficacy but also to determine why (e.g., mechanisms), in what settings, and for whom

the intervention works best. This work is notoriously challenging in behavioral interventions where a multitude of factors can influence outcomes and remains relatively unexplored for those with PPA. Another objective of the current study was to utilize data from the Pilot Communication Bridge intervention to examine three of these factors: In what contexts do participants report increases in communication confidence posttreatment? Are check-in sessions (review sessions randomized to half of the participants and delivered between the 2- and 6-month evaluations, Figure 1) associated with better communication confidence outcomes? Does communication partner engagement influence communication confidence outcomes?

Method

Fifty-seven participants with a clinical diagnosis of dementia due to neurodegenerative disease and prominent aphasia symptoms were enrolled along with their communication partners into the dyadic Pilot Communication Bridge intervention. Participant medical records were provided and reviewed by the study team to support diagnoses. Participants were required to have a diagnosis of neurodegenerative dementia (i.e., a progressive decline from a prior level in one or more cognitive and/or behavioral domains, which compromised activities of daily living and was attributed to neurodegenerative disease) and a prominent aphasia (McKhann et al., 2011). The PPA designation was only made when the participant met root criteria for PPA (i.e., relatively isolated and progressive language impairment due to neurodegenerative disease; Mesulam, 2001). Subtype designations (PPA-G, PPA-L, and PPA-S) were assigned following research criteria (Gorno-Tempini et al., 2011; Mesulam, 2003; Mesulam et al., 2014). For all other participants, there was qualitative evidence for a prominent neurodegenerative aphasia, but within the context of more generalized cognitive impairment.

Participants were recruited from the Northwestern University PPA Research Program, clinicaltrials.gov, clinical referral, and the Mesulam Center for Cognitive Neurology and Alzheimer's Disease website (www.brain.northwestern.edu). The Northwestern University

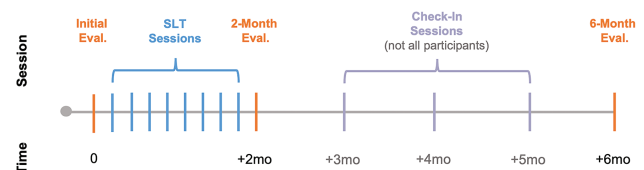


Figure 1. Study timeline: evaluation and intervention sessions. Participants received eight speech–language therapy (SLT) sessions and completed three evaluations (Evals). Half of the participants were randomized into the check-in group.

Institutional Review Board approved the study. Written informed consent was obtained from each participant.

The components of the intervention have been described previously (Rogalski et al., 2016), and an overview of the visit schedule is highlighted in Figure 1. Briefly, all participants received an initial evaluation, eight 1-h Internet video chat SLT intervention sessions with an SLP, followed by two evaluations (2 and 6 months postenrollment) to determine efficacy of the intervention over time. Evaluations included neuropsychological measures and questionnaires (to characterize functional capacity and cognitive strengths and challenges, especially in the domain of language) as well as an assessment by the clinician. Initial and 6-month evaluations occurred in-person at the Mesulam Center or via videoconference. The 2-month evaluation and eight treatment sessions occurred via videoconference. Half of the participants were randomized into a “check-in” group and received three-monthly half-hour check-in sessions (Figure 1). During check-in sessions, the SLP reviewed the recommended home exercises and communication strategies with participants and their communication partners. Participants provided feedback on use of the strategies in their daily activities and reported any barriers in implementing the recommendations. Check-in sessions also provided a time for participants to report new concerns from over the past month, and the SLP offered suggestions/modifications to the current strategies or introduced new strategies. One goal of this study was to determine whether randomization to the check-in group was associated with better communication confidence outcomes measured at the 6-month evaluation.

The focus of the SLT intervention sessions was informed by the individual living with PPA and their communication partner in collaboration with the treating SLP to address communication goals and functional challenges in daily life. The SLP used a multicomponent approach to care including impairment activities (e.g., script training), participation activities (e.g., communication strategies), as well as ongoing disease education and support. This model of individualized care draws in part from the Life Participation Approach for Aphasia (Kagan & Simmons-Mackie, 2007; Kagan et al., 2008) and the Care Pathway model (Morhardt et al., 2015) and recognizes that individual participant needs vary. The overall goal of the intervention was to maximize the participant’s quality of life by facilitating communication confidence and participation in everyday life situations and thus aligns most closely with participation-based frameworks of aphasia intervention (Haley et al., 2019; Kagan et al., 2008). The SLT sessions were supported by a custom-built web application, which served as a hub for the intervention, including individualized logins for each participant to connect to therapy sessions, practice personalized web-based exercises, and watch instructional videos assigned by their SLP to reinforce strategies provided during their intervention sessions.

Communication partners were encouraged to be present during each treatment session. Communication partner engagement was rated by the treating SLP postintervention on a 5-point scale (1—Not present at sessions, 2—Occasionally present at sessions, 3—Present at all sessions, but does not actively participate/implement strategies, 4—Present at all sessions and participates/implements strategies at a moderate level, 5—Present at all sessions and participates/implements strategies at a maximum level). Communication partner engagement ratings were classified as a dichotomous variable for analysis as engaged (ratings 4 or 5) versus nonengaged (1, 2, or 3). This dichotomy resulted in two categories that accurately represent the engagement concept and result in categories with optimum sample sizes to identify whether having an engaged communication partner was associated with better intervention outcomes.

Four SLPs delivered the intervention over the course of the study. One SLP was assigned to each participant and stayed with their participant throughout the duration of the study. Trained research assistants administered neuropsychological tests and provided technical support.

To align with the functional focus of the intervention, the primary outcome was the Communication Confidence Rating Scale for Aphasia (CCRSA), a 10-item, psychometrically sound PRO measure for assessing communication confidence in different contexts (Babbitt et al., 2011; Cherney et al., 2011). The CCRSA was developed for persons with aphasia and is optimized for completion by persons with aphasia. Thus, the CCRSA is ideal because it is relatively brief, with easy to understand ratings, and requires a minimal explanation of the target questions (Babbitt et al., 2011). While its use in PPA is innovative (contributing to the impact of the current study), communication confidence, reported by the CCRSA, has been used as an endpoint/outcome measure in clinical trials in stroke aphasia (Marshall et al., 2016; Steele et al., 2014). The CCRSA uses a Likert scale, which asks persons to rate how confident they feel communicating in different situations both in the home (e.g., understanding a television program) and in the community (e.g., persuading others) where 0 = not confident and 100 = very confident, with 10-point increments. Participants complete the scale in paper format in a self-paced format, then meet with a research coordinator to review their responses to ensure that all items were understood, and that their responses reflect each item’s underlying construct. Item scores were entered into REDCap and verified by a second team member. The average CCRSA score across the 10 items was used in analyses. Self-reported CCRSA responses were obtained at baseline, 2 months, and 6 months postenrollment.

Statistical Analyses

The first analysis examined communication confidence, in a larger subset of participants with primary or

other progressive aphasia relative to our previous report (Rogalski et al., 2016). To maintain consistency with the previous report (Rogalski et al., 2016), mixed linear models were used to analyze the longitudinal course of the overall CCRSA over the three time point comparisons (2-month visit – Baseline, 6-month visit – Baseline, and 6-month visit – 2-month visit), with CCRSA as the dependent variable, time as a fixed effect, and participant as a random effect. An overall p value for differences across the three time points is reported. Post hoc t -tests were used for pairwise comparisons among the three time points. Analysis of variances were conducted to evaluate the effect of CCRSA responses at baseline and 2 months with sex and PPA subtype as covariates, with no significant findings of sex or subtype (all p s > .05). A Pearson correlation examined the relationship between differences in baseline and 2-month CCRSA responses by age and was also nonsignificant. Therefore, sex, subtype, and age were not included as covariates in subsequent analyses.

We extended the analysis from our previous report (Rogalski et al., 2016) to quantify average change from baseline over the entire 6-month observational period for each participant using the percent change in area under the CCRSA–time curve (Percent AUC). Percent AUC was calculated as the standardized area under the curve defined by Qian et al. (2000), where the calculation used percent change from baseline to each time point. Percent AUC is a measure of the average CCRSA percent change from baseline to all follow-up time points and was compared to zero using the Wilcoxon signed-rank test, consistent with an approach used in other clinical trials (Massin et al., 2016). A percent AUC over the intervention that is significantly greater than zero indicates gains in communication confidence, nonsignificant outcomes indicate no change in communication confidence, and values significantly less than zero reflect the loss of communication confidence.

In neurodegenerative disease, the expectation is that a decline in language (and eventually other cognitive and functional abilities) will happen with time. Thus, in contrast to stroke-based aphasia, lack of significant decline over time can be interpreted as a positive outcome, especially in SLT interventions where the intervention is not disease-modifying. Given the potential for a decline over a 6-month period as a result of the neurodegenerative process, in the current study, maintenance is described in two contexts, both of which assume gains at the 2-month postintervention block. First, assuming significant gains were present at 2 months relative to baseline, we asked whether there was a significant decline from 2 to 6 months. Second, assuming significant gains were present at 2 months relative to baseline, we further tested whether treatment gains persisted at 6 months (i.e., was the difference from baseline to 6 months significant). The strongest evidence for maintenance would occur when the change from 2 to 6 months is nonsignificant, with the persistence of significant gains at 6 months compared to baseline.

To understand the context in which communication confidence gains were occurring, exploratory longitudinal analyses of item-level CCRSA data were completed. A mixed linear model similar to the one used for the overall CCRSA was used for this analysis except only baseline and 2-month data were used (i.e., preintervention and postintervention). Bonferroni correction was defined as $p < .005$ (.05/10 items = .005). The 6-month data were not included in this analysis as the primary interest was in the mechanism of the intervention itself rather than its longitudinal maintenance.

Next, we examined whether check-in sessions were associated with better CCRSA outcomes. The time points of interest for this analysis are 2- and 6-month evaluations, where one group received check-in sessions between 2 and 6 months and the other did not (Figure 1). A mixed model analysis including only the 2- and 6-month assessments and a check-in by time fixed effect was used.

The last analyses examined whether those with engaged communication partners had better communication confidence outcomes. A mixed model analysis including all three time points (baseline, 2 months, and 6 months) with engagement and engagement by time interaction as fixed effects was used. The Percent AUC signed-rank analyses were used as described above for the engaged and nonengaged groups.

Results

Participants

Of the 57 participants enrolled in the feasibility study, eight participants were excluded. Three of these participants discontinued study participation on their own accord. One participant was excluded due to noncompliance with the study protocol. Two participants were excluded due to severe comprehension deficits leading to an inability to collect valid responses on critical measures. To minimize threats from measurement bias within participants, we used triangulation methods (Carvalho & White, 1997) to compare the PRO responses with the debriefing interview responses from each participant to ensure that their responses on both measures were conceptually aligned. Misalignment was identified for three participants. For two of the three participants, CCRSA data conflicted directly with participants' qualitative descriptions of therapy benefit, and thus, data for these two participants were excluded from further analysis, while the third was retained. The final sample consisted of 49 individuals with mild to moderate progressive aphasia due to neurodegenerative disease (see Table 1 for demographics and clinical characteristics). About 76% of the sample met the criteria for the diagnosis of PPA and one of its subtypes (PPA-L: 18 [37%]; PPA-G: 15 [31%]; PPA-S: 4 [8%]). Nine participants (18%) met diagnostic criteria for PPA but did not clearly fit into one of the three research subtypes. This percentage is consistent with previous reports that suggest up to 40% of individuals

Table 1. Demographic, Clinical, and Neuropsychological Characteristics

Number of participants	49	
Age at onset, years		
Mean (SD)	62.8 (7.4)	Range: 46–80
Age at enrolment, years		
Mean (SD)	67.1 (7.3)	Range: 51–84
Sex	Male: 25	Female: 24
Handedness	Right: 45	Left: 4
Education, years	15.8 (2.5) [Range: 12–20]	
Symptom duration, years	3.9 (2.0) [Range: 1–10]	
	<i>Initial evaluation</i>	<i>6-month evaluation</i>
WAB-AQ (%)	83.7 (10.0)	79.4 (14.1)
BNT (out of 60)	38.4 (17.1)	34.7 (18.0)

Notes: WAB-AQ = Western Aphasia Battery—aphasia quotient; BNT = Boston Naming Test. Frequency, percent, or mean (SD) are reported. WAB-AQ and BNT were administered at the baseline and 6-month evaluations and are provided here as descriptive measures of aphasia severity and anomia, respectively.

with PPA do not fit uniquely within a particular PPA subtype (Mesulam et al., 2009, 2012; Mesulam & Weintraub, 2014; Sajjadi et al., 2012; Wicklund et al., 2014). Three additional participants (6%) had a neurodegenerative dementia diagnosis and prominent aphasia, but insufficient evidence that language was the first and most prominent symptom. Thus, participants in the final sample shared a prominent progressive aphasia of neurodegenerative origin and completed the intervention protocol.

Communication Confidence Ratings Over Time

CCRSA responses were analyzed over time across all participants (Figure 2). The mixed model analysis of CCRSA responses across all participants ($n = 49$) showed significant differences in mean CCRSA over time (average (SEM) CCRSA score at baseline: 70.4 (2.3); 2-month visit 76.3 (1.9); and 6-month visit 73.7 (2.2); $p = .0017$), with a significant increase in CCRSA from the baseline to 2-month visit ($p = .0006$; Figure 2). As a group CCRSA was not significantly higher at baseline compared to 6 months ($p = .093$) but decreased nonsignificantly from the 2-month to 6-month visit ($p = .082$), suggesting a modest maintenance of treatment gains over time (Figure 2). These data are consistent with previously reported findings (Rogalski et al., 2016). The median (interquartile range) of Percent AUC was 2.0 (−0.4 to 10.1), and the signed-rank analysis was significantly greater than zero ($p = .002$), confirming an overall positive effect of the Pilot Communication Bridge intervention on communication confidence when considering all time points.

Item-level responses were examined to better understand the contexts in which change in communication confidence occurred from baseline to the 2-month visit (Table 2). On average, the CCRSA increased for each of the 10 items from baseline to 2 months. The increase reached significance after Bonferroni correction for the following

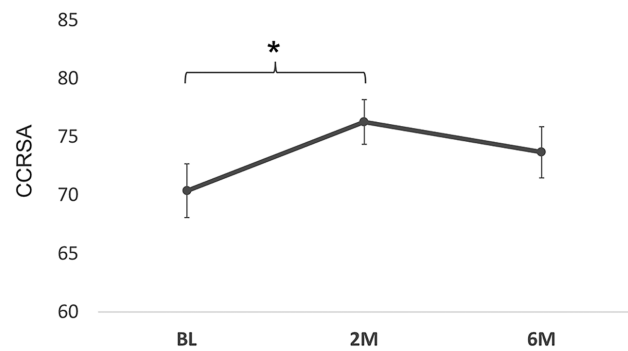


Figure 2. Communication confidence ratings increase from baseline to 2 months and show a nonsignificant decline from 2 to 6 months. CCRSA = Communication Confidence Rating Scale for Aphasia. *Denote significant changes.

three CCRSA questions: *How confident are you about your ability to follow news and sports on TV?*, *How confident are you that you can make your own decisions?*, and *How confident are you about your ability to speak for yourself?*

Communication Confidence Ratings by Check-in Randomization

Twenty-five participants (51%) were randomized into the check-in group. The time points of interest for this analysis are 2- and 6-month assessments, where one group received check-in sessions and the other did not. Results from the mixed model showed a nonsignificant decrease in CCRSA in each group from the 2-month visit to the 6-month visit, suggesting check-in status did not significantly influence the maintenance of communication confidence postintervention at the group level (check-in average CCRSA at 2 months: 74.3 (2.7), 6 months: 71.4 (2.9), $p = .071$; no-check-in average CCRSA at 2 months: 78.4 (2.6), 6 months: 76.0 (3.4), $p = .36$).

Exploring the Association of Communication Partner Engagement With Participant Communication Confidence Ratings

Next, we examined the influence of communication partner engagement on communication confidence outcomes. The level of engagement was not equally distributed across participants, as 37 communication partners (76%) were rated as “engaged,” while 12 (24%) were rated as “nonengaged.” The mixed model analysis of CCRSA over time by communication partner engagement showed that only the “engaged” group showed strong evidence for gains and maintenance with a significant increase in mean CCRSA from baseline (mean (SEM): 69.5 (2.8)) to the 2-month visit (mean (SEM): 76.2 (2.3), $p = .0008$, engaged; Figure 3); no significant decrease in CCRSA from the 2-month visit to the 6-month visit (mean (SEM): 74.5 (2.7); i.e., maintenance, $p = .32$, engaged; Figure 3); and a significant increase in CCRSA from baseline compared to 6 months ($p = .035$; Figure 3). The

Table 2. Item-Level CCRSA Responses From Baseline to 2 Months

CCRSA question	Baseline	2 months	<i>p</i>
1. How confident do you feel about your ability to talk with people?	62.7 (3.3)	69.2 (3.2)	.0076
2. How confident do you feel about your ability to stay in touch with family and friends?	79.6 (2.7)	83.7 (2.2)	.09
3. How confident do you feel about your ability to follow news and sports on TV?	77.6 (3.3)	83.1 (2.3)	.035
4. How confident do you feel about your ability to follow movies on TV or in a theater?	73.2 (3.4)	83.9 (2.1)	.0005*
5. How confident do you feel about your ability to speak on the telephone?	56.1 (3.6)	62.0 (3.5)	.034
6. How confident do you feel that people understand you when you talk?	61.8 (3.2)	68.0 (3.0)	.033
7. How confident do you feel that people include you in conversations?	69.2 (3.4)	74.3 (3.3)	.08
8. How confident do you feel about your ability to speak for yourself?	65.3 (3.5)	73.9 (2.9)	.004*
9. How confident do you feel that you can make your own decisions?	83.3 (2.2)	88.4 (1.6)	.003*
10. How confident do you feel that you can participate in discussions about your finances?	73.5 (3.8)	76.7 (3.4)	.17

Notes: CCRSA = Communication Confidence Rating Scale for Aphasia. Data are reported as means and (standard error of the mean).

*Indicates significance with Bonferroni correction ($p < .005$).

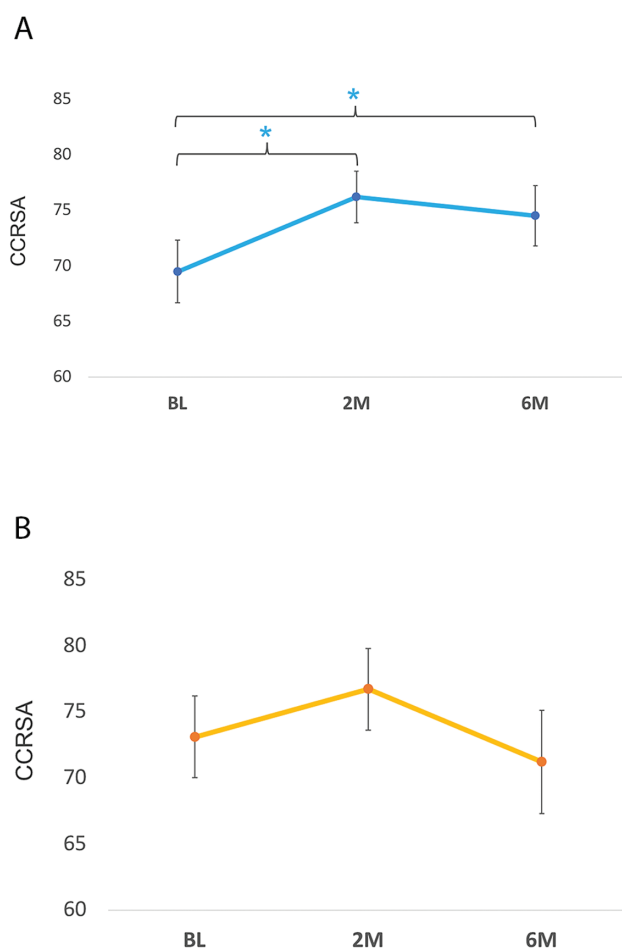


Figure 3. Participants with “engaged” communication partners showed significant postintervention communication confidence gains and maintenance at 6 months. (A) Average Communication Confidence Rating Scale for Aphasia (CCRSA) responses for the engaged communication group over time (baseline visit [BL]: 69.5 (2.8), 2-month evaluation [2M]: 76.2 (2.3), 6-month evaluation [6M]: 74.5 (2.7)). (B) Average CCRSA responses for the nonengaged communication partner group (BL: 73.1 (3.1), 2M: 76.7 (3.1), 6M: 71.2 (3.9)). *Denote significant changes.

nonengaged groups failed to show significant gains from baseline to 2 months ($p = .20$; baseline mean 73.1 (3.1); 2-month mean 76.7 (3.1)), and therefore, maintenance of

gains from 2 to 6 months was not relevant (6-month mean 71.2 (3.9); Figure 3). The Percent AUC signed-rank analysis extended the results of the mixed model analysis by showing a significant overall positive effect on communication confidence for the engaged group when considering all time points (median [IQR] of Percent AUC was 3.1% [−0.2% to 12.2%]; $p = .001$) but not the nonengaged group (median: 0.4% [−4.0% to 5.5%], $p = .70$).

Discussion

This pilot study reinforces the feasibility of providing SLT intervention over the Internet via videoconference (telehealth) for individuals living with PPA or a related neurodegenerative dementia syndrome with prominent aphasia. These results also extend our previous findings regarding the effects of the Communication Bridge intervention on communication confidence to a larger sample of persons with progressive aphasia (Rogalski et al., 2016) and expand previous analyses with the objective of uncovering factors influencing communication confidence outcomes. As a group, participants showed gains in communication confidence postintervention across a variety of communication contexts, including confidence in understanding content on TV, in making decisions, and speaking for oneself. Communication partner engagement appears to be a relevant factor in determining who will experience gains and maintenance as the group with an engaged communication partner showed significant communication confidence gains and maintenance, while the group with an unengaged communication partner did not. The percent change in AUC analysis provided a useful summary measure of CCRSA ratings over the entire follow-up period, which may be helpful for future interventions with multiple evaluation points over time.

The results of this intervention are consistent with previous research (Jokel et al., 2017; Moon & Adams, 2013; Nykanen et al., 2013; Simmons-Mackie et al., 2016), documenting the value of dyadic intervention approaches, and highlight communication partner engagement as a potentially relevant factor. Conversation by nature requires

at least two participants (a sender and at least one recipient). PPA can disrupt communication whether the person with a diagnosis is the sender or the recipient. To achieve successful communication, new strategies are required not only for the individual with a diagnosis but also for their communication partner. This need provided part of the rationale for the dyadic approach utilized in this pilot study. The SLP provided strategies to meet the changing communication needs for both the individual living with dementia and their communication partner and in other communication settings. Our results suggest that level of engagement is a relevant factor for gains and maintenance of SLT intervention for individuals living with PPA. The lack of significant response suggests that the intervention is not effective for those without engaged communication partners; however, the nonengaged group had a smaller subset of participants ($n = 12$, 24%), which may have affected our ability to detect smaller effects. Future studies may benefit from including intentional assessments of engagement prior to enrollment and over the course of the intervention from both the individual living with a diagnosis and their communication partner. Such assessments may aid in determining readiness for an intervention as well as opportunities to increase engagement through disease education, counseling, and other approaches, which may, in turn, enhance participant outcomes. Likewise, the study protocol would have been strengthened by having a second rater for caregiver engagement to establish agreement.

Both the check-in and no-check-in groups showed similar trajectories in communication confidence over the intervention, suggesting these booster sessions were not the primary driver in maintenance of communication gains. In this study, check-in sessions did not provide active intervention, but instead, a touchpoint between the clinician and the participant to remind them of their recommended care plan. The optimal timing of sessions, number of sessions, and their duration as well as the utility of check-in sessions at different intervals deserve additional empirical investigation.

Our tailored intervention approach, which focused on communication confidence outcomes, allowed for the enrollment of those with a prominent neurodegenerative aphasia and included all PPA subtypes, which is a strength. The study was not designed for equal enrollment by PPA subtype, which limited analysis possibilities for examining response differences by PPA variant.

Conclusions

This pilot study provides clues for refining future interventions, though additional studies focused on the efficacy of SLT interventions are required along with investigations examining why interventions work, which strategies are optimal, and for whom. The CCRSA is a PRO measure that appears to capture intervention gains in the context of everyday life activities, which may be useful for future clinical trials and in clinical settings for those with progressive

communication challenges. This intervention did not explicitly examine whether an increase in communication confidence was accompanied by an increase in communication participation or participation in daily life activities, which may be an important future functional outcome. Internet delivery of SLT offers an opportunity to lessen geographic challenges associated with access to care. The development of and access to evidence-based interventions may allow for prolonged independence for individuals living with rare dementias like PPA and decreased burden for those caring for them.

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Declaration of Conflicting Interests

B. Khayum is the President of MemoryCare Corporation. The authors have no additional disclosures to report.

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Author Contributions

E. Rogalski planned the study, supervised the data analysis and its interpretation, and wrote the manuscript. A. Roberts contributed to data analysis interpretation and manuscript revision. E. Salley contributed to data collection, data pulls, and manuscript revision. M. Saxon contributed to data collection and manuscript revision. A. Fought assisted with statistical analyses. M. Esparza contributed to data collection and organization of the data. E. Blaze contributed to data analysis and rating of certain data. C. Coventry contributed to study design and manuscript revision. M.-M. Mesulam contributed to identifying appropriate participants for the study and manuscript revision. S. Weintraub

contributed to study design, data evaluation and interpretation, and manuscript revision. A. Mooney contributed to intervention delivery and manuscript revision. B. Khayum contributed to intervention delivery, data collection, and manuscript revision. A. Rademaker assisted with statistical analyses, study design, and contributed to manuscript writing and revision.

Data Availability

Data may be requested through our online collaborative request process (<https://www.brain.northwestern.edu/scientists-students/collaborative-request.html>).

References

- Babbitt, E. M., Heinemann, A. W., Semik, P., & Cherney, L. R. (2011). Psychometric properties of the Communication Confidence Rating Scale for Aphasia (CCRSA): Phase 2. *Aphasiology*, *25*(6–7), 727–735. doi:10.1080/02687038.2010.537347
- Carvalho, S., & White, H. (1997). *Combining the quantitative and qualitative approaches to poverty measurement and analysis*. The World Bank. doi:10.1596/0-8213-3955-9
- Cherney, L. R., Babbitt, E. M., Semik, P., & Heinemann, A. W. (2011). Psychometric properties of the communication Confidence Rating Scale for Aphasia (CCRSA): Phase 1 [Clinical Trial, Phase I Research Support, U.S. Gov't, Non-P.H.S.]. *Topics in Stroke Rehabilitation*, *18*(4), 352–360. doi:10.1310/tsr1804-352
- Croot, K. (2018). Treatment for lexical retrieval impairments in primary progressive aphasia: A research update with implications for clinical practice. *Seminars in Speech and Language*, *39*(3), 242–256. doi:10.1055/s-0038-1660783
- Farrajota, L., Maruta, C., Maroco, J., Martins, I. P., Guerreiro, M., & de Mendonça, A. (2012). Speech therapy in primary progressive aphasia: A pilot study. *Dementia and Geriatric Cognitive Disorders Extra*, *2*(1), 321–331. doi:10.1159/000341602
- Gorno-Tempini, M. L., Hillis, A. E., Weintraub, S., Kertesz, A., Mendez, M., Cappa, S. F., Ogar, J. M., Rohrer, J. D., Black, S., Boeve, B. F., Manes, F., Dronkers, N. F., Vandenbergh, R., Rascovsky, K., Patterson, K., Miller, B. L., Knopman, D. S., Hodges, J. R., Mesulam, M. M., ... Grossman, M. (2011). Classification of primary progressive aphasia and its variants. *Neurology*, *76*(11), 1006–1014. doi:10.1212/WNL.0b013e31821103e6
- Haley, K. L., Cunningham, K. T., Barry, J., & de Riesthal, M. (2019). Collaborative goals for communicative life participation in aphasia: The FOURC Model. *American Journal of Speech-Language Pathology*, *28*(1), 1–13. doi:10.1044/2018_AJSLP-18-0163
- Henry, M. L., Hubbard, H. I., Grasso, S. M., Dial, H. R., Beeson, P. M., Miller, B. L., & Gorno-Tempini, M. L. (2019). Treatment for word retrieval in semantic and logopenic variants of primary progressive aphasia: Immediate and long-term outcomes. *Journal of Speech, Language, and Hearing Research*, *62*(8), 2723–2749. doi:10.1044/2018_JSLHR-L-18-0144
- Henry, M. L., Meese, M. V., Truong, S., Babiak, M. C., Miller, B. L., & Gorno-Tempini, M. L. (2013). Treatment for apraxia of speech in nonfluent variant primary progressive aphasia. *Behavioural Neurology*, *26*(1–2), 77–88. doi:10.3233/BEN-2012-120260
- Jokel, R., Graham, N. L., Rochon, E., & Leonard, C. (2014). Word retrieval therapies in primary progressive aphasia. *Aphasiology*, *28*(8–9), 1038–1068. doi:10.1080/02687038.2014.899306
- Jokel, R., Meltzer, J., D R, J., D M, L., J C, J., A N, E., & D T, C. (2017). Group intervention for individuals with primary progressive aphasia and their spouses: Who comes first? *Journal of Communication Disorders*, *66*, 51–64. doi:10.1016/j.jcomdis.2017.04.002. <https://pubmed.ncbi.nlm.nih.gov/28412599/>
- Kagan, A., & Simmons-Mackie, N. (2007). Beginning with the end. *Topics in Language Disorders*, *27*(4), 309–317. doi:10.1097/01.TLD.0000299885.39488.bf
- Kagan, A., Simmons-Mackie, N., Rowland, A., Huijbregts, M., Shumway, E., McEwen, S., Threats, T., & Sharp, S. (2008). Counting what counts: A framework for capturing real-life outcomes of aphasia intervention. *Aphasiology*, *22*(3), 258–280. doi:10.1080/02687030701282595
- Marshall, J., Booth, T., Devane, N., Galliers, J., Greenwood, H., Hilari, K., Talbot, R., Wilson, S., & Woolf, C. (2016). Evaluating the benefits of aphasia intervention delivered in virtual reality: Results of a quasi-randomised study. *PLoS One*, *11*(8), e0160381. doi:10.1371/journal.pone.0160381
- Massin, P., Erginay, A., Dupas, B., Couturier, A., & Tadayoni, R. (2016). Efficacy and safety of sustained-delivery fluocinolone acetonide intravitreal implant in patients with chronic diabetic macular edema insufficiently responsive to available therapies: A real-life study. *Clinical Ophthalmology (Auckland, N.Z.)*, *10*, 1257–1264. doi:10.2147/OPHTH.S105385
- McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack, C. R. Jr, Kawas, C. H., Klunk, W. E., Koroshetz, W. J., Manly, J. J., Mayeux, R., Mohs, R. C., Morris, J. C., Rossor, M. N., Scheltens, P., Carrillo, M. C., Thies, B., Weintraub, S., & Phelps, C. H. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging–Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, *7*(3), 263–269. doi:10.1016/j.jalz.2011.03.005
- Mesulam, M. M. (2001). Primary progressive aphasia. *Annals of Neurology*, *49*(4), 425–432. doi:10.1002/ana.91
- Mesulam, M. M. (2003). Primary progressive aphasia—A language-based dementia. *The New England Journal of Medicine*, *349*(16), 1535–1542. doi:10.1056/NEJMra022435
- Mesulam, M. M., Rogalski, E. J., Wieneke, C., Hurley, R. S., Geula, C., Bigio, E. H., Thompson, C. K., & Weintraub, S. (2014). Primary progressive aphasia and the evolving neurology of the language network. *Nature Reviews. Neurology*, *10*(10), 554–569. doi:10.1038/nrneurol.2014.159
- Mesulam, M. M., & Weintraub, S. (2014). Is it time to revisit the classification guidelines for primary progressive aphasia? *Neurology*, *82*(13), 1108–1109. doi:10.1212/WNL.0000000000000272
- Mesulam, M., Wieneke, C., Rogalski, E., Cobia, D., Thompson, C., & Weintraub, S. (2009). Quantitative template for subtyping primary progressive aphasia. *Archives of Neurology*, *66*(12), 1545–1551. doi:10.1001/archneurol.2009.288
- Mesulam, M. M., Wieneke, C., Thompson, C., Rogalski, E., & Weintraub, S. (2012). Quantitative classification of primary progressive aphasia at early and mild impairment stages. *Brain*, *135*(Pt 5), 1537–1553. doi:10.1093/brain/aws080

- Moon, H., & Adams, K. B. (2013). The effectiveness of dyadic interventions for people with dementia and their caregivers. *Dementia (London, England)*, 12(6), 821–839. doi:10.1177/1471301212447026
- Morhardt, D., Weintraub, S., Khayum, B., Robinson, J., Medina, J., O'Hara, M., Mesulam, M., & Rogalski, E. J. (2015). The CARE pathway model for dementia: Psychosocial and rehabilitative strategies for care in young-onset dementias. *The Psychiatric Clinics of North America*, 38(2), 333–352. doi:10.1016/j.psc.2015.01.005
- Nykanen, A., Nyrkko, H., Nykanen, M., Brunou, R., & Rautakoski, P. (2013). Communication therapy for people with aphasia and their partners (APPUTE). *Aphasiology*, 27(10), 1159–1179. doi:10.1080/02687038.2013.802284
- Qian, W., Parmar, M. K., Sambrook, R. J., Fayers, P. M., Girling, D. J., & Stephens, R. J. (2000). Analysis of messy longitudinal data from a randomized clinical trial. MRC Lung Cancer Working Party. *Statistics in Medicine*, 19(19), 2657–2674. doi:10.1002/1097-0258(20001015)19:19<2657::aid-sim557>3.0.co;2-3
- Rogalski, E. J., Saxon, M., McKenna, H., Wieneke, C., Rademaker, A., Corden, M. E., Borio, K., Mesulam, M. M., & Khayum, B. (2016). Communication Bridge: A pilot feasibility study of Internet-based speech–language therapy for individuals with progressive aphasia. *Alzheimer's & Dementia*, 2(4), 213–221. doi:10.1016/j.trci.2016.08.005
- Sajjadi, S. A., Patterson, K., Arnold, R. J., Watson, P. C., & Nestor, P. J. (2012). Primary progressive aphasia: A tale of two syndromes and the rest. *Neurology*, 78(21), 1670–1677. doi:10.1212/WNL.0b013e3182574f79
- Simmons-Mackie, N., Raymer, A., & Cherney, L. R. (2016). Communication partner training in aphasia: An updated systematic review. *Archives of Physical Medicine and Rehabilitation*, 97(12), 2202–2221.e8. doi:10.1016/j.apmr.2016.03.023
- Steele, R. D., Baird, A., McCall, D., & Haynes, L. (2014). Combining teletherapy and on-line language exercises in the treatment of chronic aphasia: An outcome study. *International Journal of Telerehabilitation*, 6(2), 3–20. doi:10.5195/ijt.2014.6157
- Taylor, C., Kingma, R. M., Croot, K., & Nickels, L. (2009). Speech pathology services for primary progressive aphasia: Exploring an emerging area of practice. *Aphasiology*, 23(2), 161–174. doi:10.1080/02687030801943039
- Volkmer, A., Spector, A., Meitanis, V., Warren, J. D., & Beeke, S. (2020). Effects of functional communication interventions for people with primary progressive aphasia and their caregivers: A systematic review. *Aging & Mental Health*, 24(9), 1381–1393. doi:10.1080/13607863.2019.1617246
- Wicklund, M. R., Duffy, J. R., Strand, E. A., Machulda, M. M., Whitwell, J. L., & Josephs, K. A. (2014). Quantitative application of the primary progressive aphasia consensus criteria. *Neurology*, 82(13), 1119–1126. doi:10.1212/WNL.0000000000000261