Title: Effects of functional communication interventions for people with primary progressive aphasia and their caregivers: A systematic review

Abstract

Objectives: Primary progressive aphasia (PPA) is a language led dementia characterised by progressive speech and language difficulties. Impairment focused PPA interventions that seek to remediate, alleviate or improve symptoms, dominate the research literature. Yet speech and language therapists (SLTs) report prioritising functional communication interventions (FCIs), which target engagement in an activity and participation in life situations. This systematic review investigates the research literature on FCIs for PPA to identify the key components of these interventions and their effectiveness.

Method: A systematic search of databases identified 19 studies published between 1998 and 2018. Data were extracted from the articles using the Intervention Taxonomy adaptation (ITAX, O'Rourke, Power, O'Halloran, & Rietdijk, 2018).

Results: Results show that the two most common components of FCIs are to build on communication strategies people currently use, and to practise these strategies with a communication partner. There are variations in the interventions, such as location and dosage. All 19 studies report improvements, of which eight report statistically significant results. Forty-two different measures are used across the 19 studies.

Conclusion: This study highlights that building on existing strategies and practising these with a CP, are key components of FCIs for people with PPA, yet there remains a lack of clarity around optimal dosage. Further rigorous research using a core set of outcome measures is a priority in this area.

PROSPERO Registration Number: CRD42018089126.

Keywords

Systematic review

Primary Progressive Aphasia

Intervention

Functional communication

Speech and language therapy

Introduction

Primary Progressive Aphasia (PPA) is a language-led dementia associated with Fronto-Temporal Dementia (FTD) and Alzheimer's disease (Marshall et al., 2018). Although relatively uncommon (estimated prevalence of three cases per 100,000 (Coyle-Gilchrist et al., 2016)), PPA is often diagnosed in people in late middle age who are still working and have busy family and social lives (Croot, 2009; Dua, Nichols & Setoya, 2012).

PPA describes a diverse group of disorders that cause atrophy of the frontal-temporal and temporal-parietal regions of the brain responsible for processing and producing language. People with PPA report a history of slowly worsening speech and language, on a background of little to no cognitive impairment in the initial stages of the disease (Bonner, Ash, & Grossman, 2010; Dickerson, 2011; Kertesz, Jesso, Harciarek, Blair, & McMonagle, 2010; Mesulam, 1982). There are currently three PPA syndromes recognized internationally, each presenting with a different pattern of language difficulties and associated underlying neuropathology (Gorno-Tempini et al., 2011; Marshall et al., 2018). Semantic variant PPA (svPPA/semantic dementia,

predominantly associated with an underlying TDP-43 (type C) pathology) presents as an impairment in understanding word meanings affecting both receptive and expressive language. Logopenic PPA (lvPPA, predominantly associated with an underlying Alzheimer's pathology) presents as a problem of word form retrieval; individuals demonstrate impairments in phonological assembly and sequencing. Non-fluent agrammatic variant PPA (navPPA, associated with multiple pathologies including Tau) presents with dysfluent (apraxic) speech and /or difficulties producing and understanding grammar.

Despite these significant impairments, there is limited research literature on the management of speech and language symptoms in PPA. Until recently, this area had been dominated by impairment focused interventions, specifically word retrieval therapies (Carthery-Goulart et al., 2013). Yet speech and language therapists (SLTs) in clinical practice report a preference for FCIs when working with this client group in the UK (Volkmer, Spector, Warren, & Beeke, 2018). The gap between the research literature and clinical practice emphasises the limited understanding of the unique management needs of people with PPA, which are different to those covered by a conventional stroke model of speech and language therapy (Rogalski & Khayum, 2018).

The International Classification of Functioning, Disability and Health (World Health Organization, 2001) classifies all non-pharmacological interventions into three domains; impairment, activity and participation. It describes impairment based interventions as those that seek to remediate, alleviate or improve symptoms. This includes interventions targeting the relearning of words and sentences, reading and

writing or restoration of oral movements. Activity and participation based interventions focus on functional communication; executing an activity and participating in life situations. This includes environmental modifications (e.g. working with families and caregivers), compensatory strategies or aids, and activities focused on engagement in an everyday task or situation. For the purposes of this study we describe interventions as either impairment focused or FCIs (the latter encompassing both activity and participation domains).

A systematic review of non-pharmacological treatments for people with PPA, including both impairment and functional communication interventions, found a total of 39 studies (Carthery-Goulart et al., 2013) of which 31 were impairment focused interventions and eight FCIs. The authors provide little guidance for clinical practice beyond a single recommendation that people with svPPA benefit from impairment focused word relearning interventions (aimed at lexical retrieval). This systematic review lacks detail on the key components of these interventions that would allow for replication by a researcher or clinician, instead focusing on study quality.

The Consolidated Standards of Reporting Trials (CONSORT) statement 2010 improved the standards of reporting healthcare trials. The Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) 2013 (Chan et al., 2013) built on this, highlighting the need for interventions in a trial to be named and described. The Template for Intervention Description and Replication (TIDieR, Hoffman et al, 2014) provides guidance on reporting on all intervention study designs, including trials. Despite this the TIDieR has been found to provide inadequate information

when examining complex speech and language interventions such as communication partner training (O'Rourke et al., 2018). O'Rourke and colleagues recommend the Intervention Taxonomy (ITAX, Schulz, Czaja, McKay, Ory, & Belle, 2012) as a superior tool as it encompasses both intervention characteristics, content and goals. O'Rourke et al adapted the ITAX and demonstrated its utility in providing a detailed analysis and comparison of complex speech and language therapy intervention components to inform future intervention development.

In summary, there has been no review to date examining the key components of FCIs for people with PPA and their caregivers. This systematic review seeks to answer the following research questions: 1. What are the current FCIs for people with PPA and their caregivers? 2. What is the effectiveness of these interventions? 3. What are the key intervention components?

Methods

The systematic review protocol was registered with PROSPERO on 1st March 2018 and updated on 13th February 2019 (registration number: CRD42018089126). The protocol follows the PRISMA-P and PRISMA E&E (Liberati et al., 2009) transparent reporting of systematic reviews recommendations (see PRISMA checklist in Appendix 1).

Data Sources

A systematic search was undertaken across the following databases: PubMed, MEDLINE, CINAHL, OVID-EMBASE, PsycINFO, Web of Science,

SPEECHBITE, LILACS and trial databases (Access Clinical Trials, Clinical trials.gov, ISRCTN Registry, Access EU Clinical Trials Register and Access the International Clinical Trials Registry Platform). A search of the grey literature was also undertaken using Google Scholar. Searches were implemented with controlled vocabulary, supplemented with free-text searching of keywords and titles. Database specific conventions such as mapping and use of multiple search fields and filters were customised for individual databases. English language filters were applied to all search results. Search terms included:

(primary progressive aphasia OR semantic dementia OR non-fluent progressive aphasia OR logopenic aphasia OR progressive language OR language variant FTD) AND (intervention OR therapy OR rehabilitation OR training OR treatment OR speech pathology OR support OR aids) OR (carer OR family OR caregiver OR conversation partner) AND (primary progressive aphasia OR semantic dementia OR non-fluent progressive aphasia OR logopenic aphasia OR progressive language OR language variant FTD) AND (education OR intervention OR therapy OR rehabilitation OR training OR treatment OR speech AND pathology OR support OR aids). The reference lists of all identified reports and articles were searched for additional studies. The search was conducted in September 2018.

Inclusion criteria

1) All study designs containing empirical data on interventions; randomised controlled trials (RCTs), controlled studies, case controlled studies, observational studies and qualitative studies using any recognisable qualitative methodology. 2) Adults who meet the international diagnostic criteria for PPA (Gorno-Tempini et al., 2011) or carers/family members of people with this diagnosis. 3) FCIs, defined as

interventions that meet the WHO ICF criteria (2001) for an activity / participation based intervention. 4) Indexed, published, peer reviewed literature written in English from 1998 to 2018.

Exclusion criteria

1) Participants presenting with a co-occurring history of stroke, brain lesions, major head trauma or a major psychiatric diagnosis. 2) Studies focused on impairment based interventions as defined by the ICF, WHO (2001). 3) Studies examining the effectiveness of pharmacological interventions.

Study selection

Reviewer one (AV) independently inspected citations from the searches against the study criteria and identified relevant abstracts. Given the topic did not require difficult judgments, in line with PRISMA-P, reviewer two (VM) re-inspected a random 10% sample of these abstracts to ensure reliability of selection. AV then obtained and inspected full reports of all the citations that met the inclusion criteria and VM re-inspected a random 10% sample of these to ensure reliability of selection. Disagreements between reviewers were resolved by contacting the study authors to provide clarification and through further discussion between reviewers to achieve consensus. Reasons for excluding studies from the review were recorded. Neither reviewer was blinded to the journal titles, study authors, or author institutions.

Data extraction

Reviewer one (AV) independently extracted and tabulated data from each included article; reviewer three (SB) independently extracted and tabulated data from a

random 20% (n=4) sample of these articles to ensure reliability of data extraction. Reviewers initially inspected each article to identify key components of the interventions using the 11 questions in O'Rourke et al. (2018)'s ITAX adaptation data sheet. As per the ITAX adaptation (O'Rourke et al, 2018), the theoretical underpinning for development of the intervention programmes was captured using the descriptive terms from Simmons-Mackie, Savage, & Worrall (2014), who encapsulate the philosophical, theoretical and practical roots for FCIs using the following terms: 1) conversation analysis (CA), a rigorous method of analysing naturally occurring talk that is used to inform interventions through focus on topic maintenance, repair and turn construction; 2) the social model, focused on participation in life situations and often described as a life participation approach; 3) functional-behavioural approaches, targeting practical or behavioural strategies that an SLT has knowledge and experience of using; 4) relationship orientated approaches, explicitly drawing on counselling literature. Finally, the ITAX adaptation domains of treatment content strategies (how the intervention is delivered) and mechanism of action (how it works) were extracted. Judgements on these two domains were achieved by reading the full text of each article and judging which ITAX-listed strategies and actions were most aligned with the described intervention.

Where reviewers were unsure of specific terminology the authors of the ITAX adaptation were contacted to provide clarification. The reviewers discussed and resolved any discrepancies for the four articles checked by SB. Data on study outcomes were extracted and tabulated by reviewer one (AV). The authors intended to subject the data to further scrutiny and statistical analysis, if appropriate. However, the heterogeneity of outcome measures, and the lack of appropriate and comparable statistical methods did not allow for this.

Risk of Bias

The risk of bias of each study was assessed by reviewer one (AV) using the tool developed by Dugmore, Orrell, & Spector (2015) to examine qualitative studies of psychosocial interventions for dementia. Twelve of the 19 studies in this review were qualitative and, given the need for a uniform procedure applied across studies, it seemed logical to use a tool tailored to these, enabling a smoother comparison. The scale comprises 12 criteria including relevance, and design of the study (see Table 2). Studies are assigned a score put of 12. Studies scoring below 8 are considered poor quality, with those scoring 9 or above considered good quality.

Results

Search results and characteristics

A PRISMA diagram of the search results is presented in Figure 1. Database searches identified 12,309 records, and searches of grey literature identified an additional 174. Following removal of duplicates, 10,201 records remained. As a result of screening (including an independent check of 10% of records with an initial inter-rate agreement rate of 97%, prior to discussion and final agreement), a further 10,097 records were excluded. After full text eligibility checking of the remaining 104 articles by reviewer one (AV), and independent examination of 10% of these by reviewer 2 (VM) (with an inter-rater agreement rate of 82% prior to discussion and final agreement), 85 further studies were excluded, leaving 19 studies for review. Table 1 presents an overview of the study design and participant characteristics for the 19 studies comprising 11 case studies, one case series, one pilot intervention trial, five intervention trials (no control) and one controlled intervention trial.

INSERT: Table 1. Study design and participant characteristics.
INSERT: Figure 1: PRISMA diagram providing a summary of the search results for the study

Risk of bias of included studies

Table 2 reveals study performance on the Dugmore et al (2015) risk of bias rating scale. All 19 studies provided a clear research question (item 2), yet none used 'member checking', i.e. using respondents to validate research findings (item 11). The lowest scoring study was also the oldest (Rogers & Alarcon, 1998) and the two scoring highest were the more recent (Jokel & Meltzer, 2017; Mooney, Bedrick, Noethe, Spaulding, & Fried-Oken, 2018b). Six of the 19 studies scored less than 8 and are thus considered of poor quality (Fried-oken, Rowland & Gibbons, 2010; Góral-Półrola et al., 2015; Rogers & Alarcon, 1998; Wong, Anand, Chapman, Rackley, & Zientz, 2009; Gibbons, Oken & Fried-Oken, 2012; Kindell, Wilkinson, Sage, & Keady, 2018). Six studies scored exactly 8 (Cress & King, 1999; Bier et al., 2015a; Morhardt et al., 2017; Murray, 1998; Pattee, Von Berg, & Ghezzi, 2006; Kim, Figeys, Hubbard, & Wilson, 2018,). Finally, seven studies scored 9 or above and can be considered good quality (Bier et al., 2011; Bier, Paquette & Macoir, 2015b; Cartwright & Elliott, 2009; Rogalski et al., 2016; Jokel & Meltzer, 2017; Mooney, Beale, & Fried-Oken, 2018a; Mooney et al., 2018b).

INSERT: Table 2. Risk of bias of included studies

Intervention Programmes

Delivery of Intervention Programmes

The delivery characteristics of the FCIs are summarised in table 3. Eighteen interventions were delivered face to face and one study was delivered via video conferencing. Fifteen interventions were delivered in either a dyadic or a group situation, involving communication partners (CPs). Of the 11 studies that reported on the interventionists' characteristics, 10 were delivered by an individual with disciplinary or professional expertise and the 11th provided specific training to the interventionist. Concerning sensitivity to participant characteristics, 17 studies reported using visual supplements or augmentative communication devices.

INSERT: Table 3. Delivery characteristics of FCIs for PPA using the ITAX adaptation (O'Rourke et al, 2018)

There was variability across interventions on the ITAX adaptation items including intervention materials, intervention delivery location, intervention schedule, provided scripts, and intervention adaptability. All 19 studies listed materials, and 11 reported using multiple types of materials. Most commonly reported intervention materials were: assistive devices (14 studies), additional items such as videotape (4), information sheets/checklists (4), manuals/workbooks (3), pamphlets (3), live demonstrations (3), CDs/DVDs (2), PowerPoint presentations (2), the internet (1), drawing materials (1), props of participants' choice (1) and materials for activities (1). Of the 15 studies that reported on intervention delivery location, seven were delivered in a research facility, five at participants' homes, and four at other locations including hospitals, nursing homes, in the local community, and at a "rustic location" (Kim et al., 2018, p. 272). Of the 13 studies that reported on intervention schedule, this ranged from a single session (length not specified) (Cress & King, 1999) to a

package of 41 hours of dyadic intervention, 10 hours of group intervention and 24 hours of individual intervention with a person with PPA (75 hours in total) (Murray, 1998). All 19 studies used a script to guide the interventionist, of these 11 studies described goals or tasks (a subset of these five provided goals or tasks for each individual session), four studies provided specific language with elaboration allowed, and four studies provided general guidelines. Of the 13 studies that reported on intervention adaptability, 12 reported adapting the content or target of the intervention, two reported also adapting the mode e.g. from individual to dyadic, and one reported adapting the number and schedule of sessions. Multiple reasons were cited for recommended adaptations, including participant preference, clinical judgment, spontaneous request, assessment, and participant progress at baseline, intake or at set intervals. Only one of the studies (Rogalski et al, 2016) reported on treatment implementation, asking participants to report on their adherence to the programme.

Content of Intervention Programmes

Of the 19 studies, 12 were identified as having one theoretical approach underpinning them, and seven were underpinned by more than one theory. Of the 12 studies underpinned by one approach, six used a functional-behavioural approach, five a social model approach and one a CA approach. Of the seven studies underpinned by more than one approach, three combined functional behavioural and social model theories, two combined CA and social model theories, and one combined relationship orientated and social model theories. Finally, one study combined functional behavioural and social model theories in stage 1 and then CA

and social model theories in stage 2. All interventions had different goals related to functional communication.

In terms of treatment content strategy, all 19 studies used skill building techniques (i.e. building on areas of current strength) and provision of instruction. Of these, 15 also used problem solving techniques. An assessment strategy was used the least, in only 7 interventions. The most common mechanism of action was behavioural skills (i.e. practical actions undertaken with participants to learn and practise the skills and content being taught, such as practising having a conversation), noted in 18 studies, with evaluation the least common mechanism of action, in four studies.

Outcome measures and intervention effects

In total, the 19 studies listed 42 different outcome measures (see table 4 for details, and the reported significance of results). Only two studies deployed the same outcome measure, the smartphone function measure developed by Bier et al. (2015a) and used also by Bier et al. (2015b). A wide variety of outcome measures were used including: formal language tests such as the Boston Naming Test (BNT; Kaplan et al., 1983); measurements of discrete behaviours such as use of a communication aid; social validity judgements such as transactional communication success judged by a naïve listener; qualitative methods such as semi structured interviews and questionnaires; CA; rating scales such as the Communication Confidence Rating Scale in Aphasia (CCRSA; Babbitt, Heinemann, Semik, & Cherney, 2011). Of the 42 measures, significance data is reported for 19 measures from across eight different studies. Of these 19 measures, 17 revealed a statistically significant improvement

across eight different studies. Two measures across two of these same eight studies also reported a statistically significant deterioration.

INSERT: Table 4. Outcome measures and reported significance

Discussion

This systematic review was designed to identify the key components of functional communication focused interventions, and the effectiveness of these, for people with PPA and their caregivers. Nineteen studies, published between 1998 and 2018, met the inclusion criteria for this review. This represents a significant increase in the number of published articles over the 5 years since Carthery-Goulart et al's (2013) review, which identified only eight FCI studies. The 19 studies identified were of better quality than those in Carthery-Goulart et al (2013), which reported on five case studies, one case series, one intervention trial (no control) and one intervention trial with a control group. This review included five intervention trials (no control) and one controlled intervention trial, as well as one pilot intervention trial. Five studies in this review can be classified as class II level evidence and meet the criteria leading to recommendations on practice guidelines (Cicerone et al., 2000).

Key Components of the Interventions

Fifteen of the 19 studies include CPs in the intervention, either delivering dyadic or group interventions. This has parallels with the clinical practice of SLTs across the UK, who report prioritising CP training for PPA (Volkmer et al., 2018). Of relevance is Medical Research Council guidance that states it is common for new complex interventions to be "informed by … factors such as past experience or common

sense" (Moore et al., 2015, p.1). One of the most common theoretical underpinnings for intervention development in these studies was identified as a functional-behavioural approach, which draws on the knowledge and experience of the interventionist to provide practical strategies to modify communication behaviour. In addition, Rogalski et al. (2016) and Kim et al. (2018) explicitly state they used research evidence from post stroke aphasia to guide the development of their interventions. CP training is an established intervention for post stroke aphasia (Simmons-Mackie, Raymer, & Cherney, 2016; Cruice Blom Johansson, Isaksen, & Horton., 2018) and it appears that its carry-over into PPA interventions is motivated by opportunities for the person with PPA and the CP to practise strategies in a relevant context, i.e. together.

All but one study was underpinned by the interventionist using skill building techniques (i.e. building on areas of current strength) to change communication behaviours, indicating that this is a key component for FCIs for PPA. This result can be interpreted in the light of knowledge from the post stroke aphasia literature, where researchers have found that building on existing communication skills rather than introducing new strategies may be a more effective method of compensating for communication difficulties (Simmons-Mackie & Damico, 1997). These authors emphasise that the goal of therapy must be to develop automatic, efficient communication strategy use that does not place a cognitive burden on an individual. Skill-building techniques are hypothesised to minimise cognitive burden for people with post stroke aphasia, who can struggle to change behaviour in response to a communication breakdown because of impaired cognitive flexibility (Chiou &

Kennedy, 2009). Thus, it seems logical that people with PPA may similarly benefit from a skill building approach.

There were variations in key components of the interventions such as location, duration and intensity, making it difficult to draw any conclusions on optimal location and dosage for functional communication focused interventions for PPA. A potential explanation for the large variation in dosage and location can be found in a consideration of how PPA variant may affect response to intervention. Cadório, Lousada, Martins, & Figueiredo (2017) in a review of generalisation of treatment gains for impairment focused interventions (predominantly single word relearning), reported people with svPPA have more difficulties maintaining and generalising personally relevant words learnt in therapy. This group require large amounts of practice delivered in as natural an environment as possible. In contrast, Cadório et al report that individuals with navPPA and lvPPA are better able to generalise as they do not have item specific impairments, and thus require fewer sessions which can be delivered in any setting. Of the 91 participants included in the studies in this review, 62% were not diagnosed with a specific PPA variant. This may be attributed to a lack of reporting, but adds to the difficultly of drawing conclusions on optimal location and dosage for FCIs for PPA.

Clinical Implications

This review indicates that the speech and language therapy profession should consider routinely offering CP training in order to increase opportunities for strategy generalisation for the person with PPA. Additionally interventions should be planned

around current strategies the person with PPA is already using, and work toward strengthening these through a skill building approach. Further recommendations for clinical practice, such as location, duration and intensity of interventions, are more difficult to make at present and should be informed by the individual's current needs.

Limitations

Due to heterogeneity of interventions and outcomes, meta-analysis was not possible. Complex interventions can result in a range of possible outcomes (Craig et al., 2008) which is reflected in the use of 42 different measures, across the 19 studies included in this review, measuring constructs that ranged from language to functional performance and confidence in communicating.

The study may also be limited by the inclusion of research articles describing participants diagnosed with all three PPA variants, resulting in a heterogeneous participant group who have different communication strengths and areas of difficulty, and thus different therapeutic needs. In fact, many of the studies included pre-date the publication of an article where the classification of PPA and its variants was internationally recognised and agreed upon (Gorno-Tempini et al., 2011). This may have affected the nomenclature used in earlier studies but excluding them would significantly reduce the number of available articles. Even the studies published after 2011 did not select participants based on PPA variant.

Studies with both high and low risk of bias scores were included in the analysis. The individual study scores are included to allow the reader to judge this issue.

Future Directions

The FCIs described in this review represent an emerging PPA research literature. Future studies have an obligation to use rigorous research methods, and, ideally, a core set of outcome measures. While using multiple measures can more consistently capture unanticipated gains if samples are adequate (Craig et al., 2008), the choice of at least some core measures, such as those focused on confidence and quality of life, to allow for cross-study comparison, is a priority.

It is also vital that future studies consistently report key intervention components. When compared to tools such as the TIDieR, the ITAX adaptation is superior, enabling comparison of both key intervention components, such as dosage, in addition to the content, mechanism of action, and goals of intervention (O'Rourke et al., 2018). Tools such as the ITAX adaptation will permit the investigation of links between core intervention components and outcomes in the longer term. Examining treatment response to FCIs across PPA variants may highlight different outcomes.

PPA is a rare disorder, thus there is a real need to cooperate across centres and internationally, with agreed uniform terminology and collaboration for intervention trials. This will be particularly important if speech and language therapy is to take its place as an adjunct to disease modifying therapies in due course.

Conclusion

This study highlights that, just as in post stroke aphasia, building on existing strategies and practising these with a CP, are key strategies and delivery components across 19 studies of FCIs for people with PPA. Yet there remains a lack of clarity

around optimal dosage, which requires further investigation. Research needs to use robust designs and common outcome measures, identify PPA variant, and more comprehensively report interventions with guidance from tools such as O'Rourke et al's ITAX (2018), so the effectiveness of functional communication interventions for PPA can be fully appraised. This will in turn strengthen the evidence base for clinical practice.

Disclosure Statement:

The authors report no conflict of interest

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Appenidx 1: PRISMA checklist

Table 1. Study design and participant characteristics.

	Participant diagnosis	**Participant age/gender**	**Study design**
Murray, 1998	navPPA	F 64 years at start of study	Case study - Class III
Rogers & Alarcon, 1998	navPPA	M 69 years at start of study	Case study - Class III
Cress &King, 1999	navPPA PPA (variant not reported)	F 59 years at start of study M 60 years at start of study	Case series; 2 participants - Class III
Pattee et al., 2006	PPA with Apraxia of speech	F 57 years	Case study - Class III
Cartwright & Elliott, 2009	PPA- variant not reported	Four participants 3F:1M aged 59,62,65,66 years	Intervention trial; 4 participants – Class II
Wong et al., 2009	svPPA	M 61 years old	Case study – Class III
Fried-Oken et al, 2010	navPPA	3M:4F aged 71-78 years	Intervention trial; 7 participants – Class II
Bier et al., 2011	svPPA	F 68 years old	Case study – Class III
Gibbons et al., 2012	Aphasia & word deafness with bvFTD	M 57 years of age	Case study – Class III
Bier et al., 2015b	svPPA	M 56 years of age	Case study – Class III
Bier et al., 2015a	svPPA	M 55 years of age	Case study – Class III
Góral-Półrola et al., 2015	navPPA	F 73 years of age	Case study – Class III
Rogalski et al., 2016	PPA, Variant not reported	13M:18F aged 56-83 years	Pilot intervention trial; 34 participants – Class III
Morhardt et al., 2017	PPA, Variant not reported	Pilot phase: 4M:2F, aged 53-80 years Full trial: People with PPA 5M:4F aged 55-82 years CPs 2M:6:F	Pilot intervention trial; six participants) followed by intervention trial; 17 participants (9 people with PPA and 8 CPs) – Class III
Jokel & Meltzer, 2017	Treatment group: 3 navPPA & 2 lvPPA Control group: 3 navPPA & 2 lvPPA	Treatment group: 3M:2F aged 71- 80 years (spouses aged 58-85). Control group: 4M:1F aged 64-73 (CPs aged 59-75)	Unrandomised controlled trial; five people with PPA and their CPs in each group – Class II
Kindell et al., 2018	svPPA	F 64 years of age	Case study – Class III
Mooney et al., 2018a	PPA, Variant not reported	Treatment group: 3M:2F aged 63-73 years (6 CPs aged 49-76)	Intervention trial; five people with PPA and their CPs – Class II
Mooney et al., 2018b	3- navPPA 2 svPPA 1 lvPPA	3M:3F aged 62-80 years	Crossover study; 6 participants. (alternating interventions experimental trial) – Class II
Kim et al., 2018	lvPPA	F 62 years of age (spouse = 68 years of age)	Case study; dyad – Class III
Total:	navPPA: 20 lvPPA: 6 svPPA: 7 unspecified PPA: 56 Other: 2	Male: 46 Female: 47 Age range from 53 years to 83 years (unable to report average data due to incomplete reporting in original studies)	Case studies: 11 Case series design: 1 Pilot intervention trial: 1 Intervention trials: 5 Controlled intervention trials: 1
Total no. of participants across all studies:	91		

NB: navPPA=nonfluent aggrammtic variant primary progressive aphasia; lvPPA= logopenic variant primary progressive aphasia; svPPA= semantic variant primary progressive aphasia; bvFTD= behavioural variant frontotemporal dementia; CP= communication partner; M= make; F= female. Cicerone et al. (2000), p.1598 define class II level evidence as “prospective, nonrandomized cohort studies; retrospective, nonrandomized case-control studies; or clinical series with well-designed controls that permitted between- subject comparisons of treatment conditions, such as multiple baseline across subjects” and class III level evidence as "Clinical series without concurrent controls, or studies with results from 1 or more single cases that used appropriate single-subject methods”.

Table 2. Risk of bias of included studies

Adapted from Mays and Pope (2000)	(1) Worth or relevance	(2) Clarity of research question	(3) Appropriateness of the design to the question	(4) Context	(5) Sampling	(6) Data collection and analysis systematic	(7) 'Audit trail'	(8) Disconfirming cases	(9) Analytical criteria	(10) Findings triangulated	(11) Member checking	(12) Reflexivity of the account	**Total score out of 12:**
Murray, 1998	Y	Y	Y	Y	Y	Y	Y	N	N	Y	N	N	8
Rogers and Alarcon, 1998	Y	Y	N	N	Y	N	N	N	N	N	N	N	3
Cress and King, 1999	Y	Y	N	Y	Y	Y	Y	N	N	Y	N	Y	8
Pattee et al., 2006	Y	Y	Y	Y	N	Y	Y	N	Y	Y	N	N	8
Wong et al., 2009	Y	Y	Y	Y	Y	N	N	N	N	N	N	N	5
Cartwright and Elliott, 2009	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	10
Fried-oken and Gibbons, 2010	Y	Y	Y	Y	N	Y	Y	N	N	N	N	N	6
Bier et al., 2011	Y	Y	Y	Y	N	Y	Y	Y	N	Y	N	N	9
Gibbons et al., 2012	N	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	7
Bier et al., 2015b	Y	Y	Y	Y	N	Y	Y	Y	N	Y	N	N	9
Bier et al., 2015a	Y	Y	Y	Y	Y	Y	Y	N	N	Y	N	N	8
Góral-Półrola et al., 2015	Y	Y	Y	N	Y	N	Y	N	N	N	N	N	5
Rogalski et al., 2016	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	10
Jokel et al., 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	12
Morhardt et al., 2017	Y	Y	Y	Y	Y	Y	Y	N	Y	N	N	N	8
Kindell et al., 2018	Y	Y	Y	N	N	Y	N	N	Y	Y	N	N	6
Kim et al., 2018	Y	Y	Y	N	Y	Y	Y	Y	Y	N	N	N	8
Mooney et al., 2018a	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N	N	10
Mooney et al., 2018b	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	11
No. or articles that fulfil this criteria of total 19 articles	18	19	17	15	14	16	16	8	9	12	0	3	

Quality Rating Scale adapted from (Mays and Pope, 2000) by (Dugmore et al., 2015). NB: < 8/12: poor quality, > 8/12: good quality

Table 3. Characteristics of FCIs using the adapted ITAX (O'Rourke et al, 2018)

	Mode	**Method of contact**	**Materials**	**Location**	**Duration**	**Scripting**	**Interventionist**
Murray, 1998	individual, dyadic and group treatment	face to face	Videotapes, drawing materials and assistive devices	Research facility	Period 1. 24 sessions (1 hr 2 x p/wk for 12 weeks). Period 2. 41 hours dyad, 10 hours group therapy over 12 months).	Goals and exercises/tasks of each session are specified.	Required disciplinary/professional expertise for interventionists
Rogers & Alarcon, 1998	individual and dyadic	face to face	Videotapes, Assistive devices	Research facility (University Clinic)	Not reported	General guidelines provided	Required disciplinary/professional expertise for interventionists
Cress &King, 1999	individually and dyadic and group	face to face	Manuals/workbooks, Assistive devices	Research facility (plus in the community)	Two case studies- MC: One off session CE: 4 years advice, 1 month intervention (3-4 hour individual sessions p/week, 4-6 hours of training with/for family)	General guidelines provided	Not reported
Pattee et al., 2006	individually	face to face	Assistive devices, Information sheets/checklists	Not reported	8 sessions over 9 weeks	Goals and exercises/tasks of each session are specified.	Required disciplinary/professional expertise for interventionists
Cartwright &Elliott, 2009	group treatment with 4 individual participants (partially delivered with CP)	face to face	Pamphlets, Videotapes, Assistive devices	Hospital	8sessions, 90 minutes each, over 8 weeks (1 x weekly)	Specific language is provided, with room for elaboration	Required disciplinary/professional expertise for interventionists
Wong et al., 2009	individual and group treatment (unclear if also dyadic but CP included in therapy)	face to face	CDs/DVDs, Assistive Devices, Workbooks and props of participants choosing	Research facility (University Clinic)	Not reported	Goals/tasks specified but no further scripting	Not reported
Fried-oken et al, 2010	dyadic	face to face	Assistive devices	Research facility (University Clinic)	6 sessions	Goals/tasks specified but no further scripting	Required disciplinary/professional expertise for interventionists
Bier et al., 2011	individually	face to face	Assistive devices, Manuals/workbooks.	Participants home	11 sessions, fortnightly where possible re participants schedule, over 5-month period	Specific language is provided, with room for elaboration	Not reported
Gibbons et al., 2012	Individually, and dyadic	face to face	Assistive devices	Not reported	Not reported	Goals/tasks specified but no further scripting.	Not reported
Bier et al., 2015b	individually	face to face	Assistive devices (smartphone)	Participants home	7 sessions, 1.5 hours, 1 x weekly.	Specific language provided with elaboration allowed / not allowed	Not reported

Bier et al., 2015a	individually	face to face	Assistive devices (smartphone)	Research facility	5 intervention sessions	Specific language provided with elaboration allowed / not allowed	Not reported
Góral-Półrola et al., 2015	individually and group	face to face	Assistive devices	Nursing home	20 sessions	General guidelines provided	Not reported
Rogalski et al., 2016	internet and video instruction, individually and dyadic	telephone contact with computer (Video conferencing)	Internet, videotapes	Participants home	8 sessions, 1-hour	Goals/tasks specified but no further scripting	Required disciplinary/professional expertise for interventionists
Morhardt et al., 2017	group	face to face	PowerPoint presentations, materials for activities	Not reported	Pilot: 5 x 90-minute bimonthly sessions Formal Intervention: 10 sessions, twice p/month over 5 months	Goals of each exercises/tasks of each session are specified but no further scripting	Required disciplinary/professional expertise for interventionists
Jokel & Meltzer., 2017	lectures, group treatment	face to face	Information sheets, pamphlets, live demonstration, presentation materials	Not reported	10 sessions, 2 hours each, once weekly	Goals/tasks specified but no further scripting	Required disciplinary/professional expertise for interventionists
Kindell et al., 2018	individual and group treatment	face to face and group	CDs/DVDs	Participants home	2 intervention sessions, 40 minutes	General guidelines provided	Not reported
Mooney et al., 2018a	group lectures	face to face	Information sheets/checklists, Pamphlets, Assistive devices, Live demonstrations	Research facility (University Clinic)	12 sessions, 1 hour per sessions, held twice weekly for 6 weeks	Goals and exercises/tasks of each session are specified but no further scripting	Required disciplinary/professional expertise for interventionists
Mooney et al., 2018b	individually and dyadic	face to face	Assistive devices	Participants home	6-7 sessions, 3 months	Goals/tasks specified but no further scripting	Type and quantity of training provided
Kim et al., 2018	group	face to face and group	Live demonstrations	"Rustic location"	One weekend annually in September	Goals/tasks specified but no further scripting	Required disciplinary/professional expertise for interventionists

CP: Communication Partner

Table 4. Outcome measures and reported significance

	Category		Outcome measure	Significance (for experimental group)
Murray, 1998	formal language tests	x	Daily Mishaps Test (Helm-Estabrooks & Albert, 1991) Communication Activities in Daily Living (CADL, Holland, 1980)	+ NR
	measurements of discrete behaviours			
	social validity judgements	x	American speech-language Hearing Association Functional Assessment of Communication Skills for Adults (AHSA FACS, (Frattali et al., 1995)	NR
	interviews and questionnaires			
	conversation analysis	x	Qualitative analysis of pre and post intervention conversation samples	NR
	rating scales	x	The four-point communicative rating scale developed by (Davis and Wilcox, 1981) Communication Effectiveness Index (CETI, Lomas et al., 1989)	NR NR
	Other			
Rogers & Alarcon, 1998	formal language tests	x	Boston Naming Test (BNT; Kaplan, 1983) Reading Commands subtest Western aphasia battery (WAB, Kertesz, 2006) Written subtest of the Minnesota test for differential diagnosis of Aphasia (MTDDA, (Schuell and Sefer, 1977) Controlled Oral Word Association Test (COWAT, Benton, 1967)	NR NR NR NR
	measurements of discrete behaviours			
	social validity judgements	x	Content Unit Identification using the Cookie theft picture from the Boston Diagnostic Aphasia Examination (BDAE; Goodglass et al., 2000)	NR
	interviews and questionnaires			
	conversation analysis			
	rating scales			
	Other			
Cress & King, 1999	formal language tests			
	measurements of discrete behaviours	x	Specific functional communication tasks	NR
	social validity judgements	x	Family observations	NR
	interviews and questionnaires			
	conversation analysis			
	rating scales			
	Other			
Pattee et al., 2006	formal language tests			
	measurements of discrete behaviours			
	social validity judgements	x	Discourse analysis using Correct Information Units (CIUs) protocol	NR

	interviews and questionnaires			
	conversation analysis			
	rating scales			
	Other	x	Participant preference	NR
Cartwright & Elliott, 2009	formal language tests			
	measurements of discrete behaviours	x	Discourse comprehension Concrete Opinion Inferential	 + + -
	social validity judgements	x	Production of story information units	+
	interviews and questionnaires			
	conversation analysis			
	rating scales			
	Other	x	Transactional success	NR
Wong et al., 2009	formal language tests			
	measurements of discrete behaviours			
	social validity judgements	x	Communication Effectiveness- rated by the therapist	NR
	interviews and questionnaires			
	conversation analysis			
	rating scales			
	Other			
Fried-oken et al, 2010	formal language tests			
	measurements of discrete behaviours			
	social validity judgements	x	Weighted conversation scores	+
	interviews and questionnaires			
	conversation analysis			
	rating scales			
	Other			
Bier et al., 2011	formal language tests			
	measurements of discrete behaviours	x	Instrumental Activities of Daily Living Profile (IADL, Bottari et al., 2010) Reported frequency of functional task	+ +
	social validity judgements			
	interviews and questionnaires			
	conversation analysis			
	rating scales			
	Other	x	Generation of semantic attributes	+
Gibbons et al., 2012	formal language tests			
	measurements of discrete behaviours	x	Communication board use Functional communication test	NR NR
	social validity judgements			
	interviews and questionnaires			
	conversation analysis			

	rating scales			
	Other			
Bier et al., 2015b	formal language tests			
	measurements of discrete behaviours	x	Smartphone function measures Daily integration of functions	+ +
	social validity judgements			
	interviews and questionnaires			
	conversation analysis			
	rating scales			
	Other	x	Semantic knowledge about Functions	+
Bier et al., 2015a	formal language tests			
	measurements of discrete behaviours	x	Smartphone function measures	+
	social validity judgements			
	interviews and questionnaires			
	conversation analysis			
	rating scales			
	Other	x	Personalised semantic measure	-
Góral-Półrola et al., 2015	formal language tests			
	measurements of discrete behaviours	x	Use of communication aid Participation in functional tasks	NR NR
	social validity judgements			
	interviews and questionnaires			
	conversation analysis			
	rating scales			
	Other			
Rogalski et al., 2016	formal language tests			
	measurements of discrete behaviours			
	social validity judgements	x	Clinician rated participants on ongoing compliance	NR
	interviews and questionnaires	x	Semi structured interviews	
	conversation analysis			
	rating scales	x	Communication Confidence Rating Scale for Aphasia (CCRSA; Babbitt et al., 2011). American Speech–Language–Hearing Association functional communication measures (ASHA-FCM; American Speech Hearing Association, 2009)	+ NR
	Other			
Morhardt et al., 2017	formal language tests			
	measurements of discrete behaviours			
	social validity judgements			
	interviews and questionnaires	x	Post group evaluation	NR
	conversation analysis			
	rating scales			
	Other	x	Observational field notes	NR

			Transcription of group sessions	NR
Jokel & Meltzer, 2017	formal language tests			
	measurements of discrete behaviours	x	Use of communication strategies as rated from video recorded interactions with CP	NR
	social validity judgements			
	interviews and questionnaires	x	Spousal Questionnaire	+
	conversation analysis			
	rating scales	x	Quality of Communication Life Scale (QCLS, Paul et al., 2004)	+
	Other			
Kindell et al., 2018	formal language tests			
	measurements of discrete behaviours			
	social validity judgements			
	interviews and questionnaires			
	conversation analysis	x	Qualitative Analysis using conversation analysis	NR
	rating scales			
	Other			
Mooney et al., 2018a	formal language tests			
	measurements of discrete behaviours			
	social validity judgements			
	interviews and questionnaires	x	Mode of communication survey CP evaluation of mode of communication	NR NR
	conversation analysis			
	rating scales			
	Other			
Mooney et al., 2018b	formal language tests			
	measurements of discrete behaviours	x	Mastery of tablet operations Story retell using no technology, photo and only and GoChat app	NR NR
	social validity judgements			
	interviews and questionnaires	x	User feedback	NR
	conversation analysis			
	rating scales			
	Other			
Kim et al., 2018	formal language tests			
	measurements of discrete behaviours			
	social validity judgements			
	interviews and questionnaires	x	Semi-structured interviews using the Living with Aphasia: Framework for Outcome Measurement (A-FROM; Kagan et al, 2008)	NR
	conversation analysis			
	rating scales			
	Other			

+, positive effect for experimental group; −, negative effect for experimental group; NR, not reported;

Figure 1: PRISMA diagram