


RESEARCH REPORT

‘Communication is difficult’: Speech, language and communication needs of people with young onset or rarer forms of non-language led dementia

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Abstract

Background: People with behavioural variant frontotemporal dementia, Lewy body dementia, posterior cortical atrophy and young onset Alzheimer’s disease may experience language and communication difficulties. However, the role of speech and language interventions for people with these non-language led dementias has received little attention.

Aims: This study aimed to explore the experiences and perspectives of people living with these conditions, and their families, regarding their language and communication difficulties and how speech and language therapy could address these needs.

Methods: This study employed a qualitative design to explore the experiences of people living with or caring for somebody with behavioural variant frontotemporal dementia, Lewy body dementia, posterior cortical atrophy or young onset Alzheimer’s disease, and to understand their opinions about speech and language therapy. Participants were recruited from a support service connected to a dementia clinic to attend one of five focus group meetings. Videorecorded focus groups and interviews were transcribed, and reflexive thematic analysis was used to analyse data from people affected by each type of dementia.

Results: A total of 25 participants were recruited to the study, with representation across the different forms of non-language led dementias. The four main themes identified were: (1) communication difficulties as a key difficulty, (2) loss and loneliness, (3) speech and language therapy, and (4) the role of the caregiver. Sixteen subthemes were also identified which highlighted individual issues across disease types.

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Discussion: Although all the forms of dementia studied here are not considered to be language-led, people with these conditions and/or their care partners identified speech, language and communication as common challenges. These communication difficulties were reported to have a negative impact on their social participation and mental health and participants felt speech and language interventions could help. There is a need for research exploring speech and language interventions developed for and with people with non-language led dementias and their care partners, to ensure they meet the needs of the people they are designed for.

KEYWORDS

Alzheimer's disease, communication difficulties, rare dementias, speech and language therapy, young onset dementia

What this paper adds

What is already known on the subject

- People with primary progressive aphasia present with speech, language and communication difficulties, and several speech and language interventions have been developed to meet the needs of this population. However, people with non-language led dementias may also experience speech, language and communication difficulties, and little is known about interventions that may address these difficulties.

What this paper adds to existing knowledge

- People living with or caring for somebody with behavioural variant frontotemporal dementia, Lewy body dementia, posterior cortical atrophy and young onset Alzheimer's disease report experiencing speech, language and communication difficulties that impact on the person with dementia's social participation and mood. Participants in this study also shared their opinions about how speech and language interventions could help, from the earliest stages of the disease.

What are the potential or actual clinical implications of this work?

- Speech and language therapists need to address the individual speech, language and communication needs of people with dementias, even those that are not thought to be language-led. Current speech and language therapy service provision does not meet the needs of people with non-language led dementias and further research is required to develop interventions and services to meet these needs.

INTRODUCTION

Dementia is a term that describes a group of progressive neurological diseases that result in a gradual deterioration

in cognitive skills. The most common type of dementia is Alzheimer's disease, accounting for around 650 000 of the 930 000 people living with dementia in the United Kingdom (Wittenberg et al., 2019). Typical Alzheimer's disease

presents as an amnesic condition, whereby people experience memory difficulties as the leading symptoms of the disease.

The primary progressive aphasia (PPA) are a rare group of dementias that are characterised by gradual and pervasive decline of speech, language and communication (Gorno-Tempini et al., 2011). PPA is often diagnosed when people are in the 60s or 70s and is estimated to affect at least 3000 people in the United Kingdom (Coyle-Gilchrist et al., 2016). There are three main variants of PPA, namely logopenic variant (lvPPA) which causes difficulties in word finding and verbal short-term memory, semantic variant (svPPA) which results in difficulties understanding word meanings and nonfluent/agrammatic variant (nfvPPA) which causes a difficulty in co-ordinating movement of speech muscles (apraxia) and/or an agrammatism (Rukse-naite et al., 2021). Speech and language therapists (SLTs) have made important contributions to understanding the wider impact of these communication difficulties on daily activities, relationships and quality of life in PPA (Ruggero et al., 2019). This has informed speech and language therapy literature and development of several key intervention approaches including lexical retrieval therapies, script therapy, communication partner training, communication aids and multimodal communication therapy (Wauters et al., 2023).

Other forms of dementia that are not thought to be language-led but are similar to PPA in terms of their rarity and/or being a young onset dementia include young onset Alzheimer's disease (YOAD), behavioural variant fronto-temporal dementia (bvFTD), posterior cortical atrophy (PCA) and Lewy body dementia (LBD). YOAD starts as a memory-led disease, but with onset several decades earlier than in typical Alzheimer's disease, and with more rapid progression (Mendez, 2017). bvFTD is characterised by changes in behaviour and personality (Convery et al., 2019). PCA is a visual-spatial led syndrome (Yong et al., 2023); and LBD comprises dementia with Lewy bodies and Parkinson's disease dementia and is associated with motor Parkinsonism, visual hallucinations and visuospatial deficits (McKeith et al., 2017).

Although language and communication deficits are not cardinal features in these dementias, emerging evidence suggests that people do experience these difficulties, either as the disease progresses, or as secondary symptoms. For example, people with PCA have been described as having difficulties in language and communication not dissimilar to people with lvPPA, including difficulties with word finding and verbal short-term memory (Crutch et al., 2013; Yong et al., 2023). Additional difficulties in reading, variously described as apperceptive or crowding dyslexia (difficulties recognising individual letters in a word), have also been observed in people with PCA (Yong et al., 2016).

People with Alzheimer's disease also describe difficulties in communication during activities of daily living (Volkmer et al., 2023a). In fact, aphasia is not an unusual secondary symptom in bvFTD, PCA and Alzheimer's disease (American Psychiatric Association, 2022; Hardy et al., 2016). Primary language difficulties (language as the leading symptom) are reported in 5% of people with LBD (Doubleday et al., 2002), and lvPPA can precede the onset of a frank LBD in rare cases (Kakinuma et al., 2020). Though other reports suggest language difficulties are likely to be more common later in the disease process in LBD (Macoir, 2022). Despite these observations, an important recent review identified relatively little research investigating or evidencing these language and communication difficulties (Suárez-González et al., 2021), and virtually no literature describing the experiences of people living with these difficulties.

Gaining an understanding of people's experiences of living with dementia can highlight how symptoms impact on daily living. Within the broader dementia research, there has been little focus on the experiences of communication difficulties amongst people living with dementia. A 2017 review exploring what constitutes good communication for people living with dementia highlighted that of 15 articles found, 14 focused only on the views of healthcare workers and care partners (CPs), rather than people with the condition themselves (Alsawy et al., 2017). There have been some studies since then exploring views of people with dementia (Alsawy et al., 2020) PPA (Loizidou et al., 2022) and Alzheimer's disease (Volkmer et al., 2023a). The latter study demonstrated that people with dementia and their families view many of their cognitive difficulties through the lens of interaction. They are aware of their difficulties, and specifically their communication difficulties, and often share the views of those around them in wanting to reduce the impact of these difficulties in interactions. People with dementia and the people around them adopt strategies to try to alleviate these difficulties. Above all else people are often searching for guidance on how to improve their communication difficulties (Loizidou et al., 2022).

There has been little research exploring language interventions for people with for people with rarer or young onset dementias. One exception to this is reading interventions for PCA, including the reading aid, ReadClear (Suárez-González et al., 2019) and other adaptive reading strategies (Yong et al., 2015). A single case study describing a speech and language intervention for a person with PCA has also been published (Volkmer et al., 2022). However, a recent review of nonpharmacological interventions for LBD did not identify any speech and language therapy interventions at all (Connors et al., 2018). However, to meet the needs of people living with bvFTD, LBD, PCA and YOAD, it is important to understand their and their



families' lived experiences. Development of appropriate interventions cannot be undertaken without an adequate understanding of the language difficulties of people with bvFTD, LBD, PCA and YOAD, and their impact in daily life. This study therefore aims to address this gap by exploring the experiences and perspective of people with bvFTD, LBD, PCA and YOAD and their families regarding their language and communication difficulties and how speech and language therapy could address these needs.

METHODS

Design

This study employed a qualitative design, using online focus groups to explore the experiences of people living with bvFTD, LBD, PCA and YOAD, and their families or care partners, and to understand their opinions about speech and language therapy. Qualitative methods allow a rich, in-depth understanding of people's experiences and opinions (Braithwaite et al., 2022). Focus groups enable participants to reflect on their experiences, give in depth opinions and listen to others in a safe environment. They also allow group discussion and consequent synthesis of novel ideas (Steward & Shamdasani, 2014). This study followed the same methodology used for a previous focus group study led by authors A.V. and C.J.D.H. with people with PPA and their caregivers (Loizidou et al., 2022). The current study was conducted in compliance with the Consolidated Criteria for Reporting Qualitative Research Checklist (Tong et al., 2007) and was given ethical approval as part of the wider Rare Dementia Support (RDS) Impact Study (Brotherhood et al., 2020), which received approval from the University College London (UCL) Research Ethics Committee (8545/004: Rare Dementia Support Impact Study).

Recruitment

Participants were recruited via RDS (www.raredementiasupport.org), a third-sector organisation that provides support for people with seven types of rare dementia including bvFTD, LBD, PCA and YOAD. RDS is a UK-based support service within the Dementia Research Centre at UCL delivering support and a community for those with rare dementias. Student SLTs created written and videorecorded advertisements about the study, circulated in the support group newsletters and via email to support group members. The advertisement invited potential participants to complete an online survey indicating their availability and submitting basic demographic infor-

mation (gender, relationship and whether full time/part time/bereaved care partner, if not a person living with dementia, diagnosis, time since symptom onset, time since diagnosis, any prior SLT input and contact details). We did not pre-specify an anticipated sample size per individual disease, but rather sought to recruit representatives across the dementia subtypes we were interested in.

The lead and senior author and designated student SLTs (C.J. for bvFTD; L.C. for LBD; C.S. for PCA and L.H. for YOAD) met to review the list of potential participants to ensure they met the inclusion criteria and availability for group meetings. Inclusion criteria comprised diagnosis of bvFTD/LBD/PCA/YOAD or current/bereaved care partner for someone with one of these diagnoses, access to internet and relevant device. Potential participants were excluded if they were under 18 or unable to participate in an online meeting.

Potential participants were invited to attend an individual consent session, held and recorded digitally on the video conferencing platform GoToMeeting, in line with RDS Impact Study protocol (Brotherhood et al., 2020). Participants were then allocated to attend a focus group meeting, also held on a video conference platform due to constraints imposed by COVID-19.

Participants

A total of 25 participants were recruited to the study. Nine participants were recruited to the bvFTD focus groups comprising five male and four female care partners. Seven participants were recruited to the LBD focus groups comprising four male and three female care partners. Seven participants were recruited to PCA focus groups comprising one male and three female care partners; and two male and two female people living with PCA. One couple, a woman with YOAD, and her spouse were recruited to the YOAD interview. An overview of demographic characteristics of group participants are provided in Table 1.

Procedure

All 25 potential participants who responded to the advertisement were offered the opportunity to participate in a focus group meeting or interview. In line with recommendations, group numbers were planned to enable exchange of ideas without discouraging others (Plummer D'Amato, 2008). Thus, a maximum of 4–6 people with communication difficulties or 8–10 people without were included in each group. In total five focus group meetings were held, one for care partners of people with LBD as no one with a diagnosis of LBD expressed an interest in the study, one for

TABLE 1 Demographic characteristics of participants in focus groups.

Participant ID	Gender	Relationship	Years since symptom onset	Years since diagnosis	Prior SLT input
bvFTD participants					
CPbvFTD01	M	Spouse	4	2	Y
CPbvFTD02	F	Spouse	3	2	N
CPbvFTD03	F	Spouse	4	2	N
CPbvFTD04	M	Spouse	4	1	N
CPbvFTD05	F	Sibling	4	0	N
CPbvFTD06	F	Spouse	6	2	N
CPbvFTD07	M	Partner	4	3	N
CPbvFTD08	M	Spouse	2	1	N
CPbvFTD09	M	Spouse	3	2	N
LBD participants					
CP_LBD01	F	Spouse	5	2	N
CP_LBD02	F	Spouse	–	–	Y
CP_LBD03	F	Adult child	6	4	N
CP_LBD04	F	Bereaved	8	7	Y
CP_LBD05	M	Spouse	7	6	N
CP_LBD06	M	Spouse	4	3	N
CP_LBD07	M	Spouse	2	2	N
PCA participants					
Plw PCA01	F	–	5	2	N
Plw PCA02	M	–	2	1	N
Plw PCA03	M	–	7	5	Y
CP_PCA01	F	Spouse	2	1	N
CP_PCA02	M	Spouse	7	4	Y
CP_PCA03	F	Bereaved	10	6	Y
CP_PCA04	F	Spouse	22	17	N
YOAD participants					
Plw_YOAD	F	–	7	5	N
CP_YOAD	M	Spouse	7	5	N

Abbreviations: bvFTD, behavioural variant frontotemporal dementia; CP, care partner; LBD, Lewy body dementia; PCA, posterior cortical atrophy; Plw, people living with; SLT, speech and language therapy; YOAD, young onset Alzheimer's disease.

people with PCA and one for their care partners, and two for care partners of people with bvFTD. The research team decided not to include people with bvFTD in the focus group meetings as the potential participants were identified as being unable to participate in an online group meeting due to behavioural issues. Hosting people with a diagnosis separately from their caregivers ensured the voice of people with the diagnosis of dementia could be heard, as well as their care partners (Volkmer et al., 2023a). Only one dyad (a person with YOAD and their spouse) responded to the advertisement for the YOAD group. Consequently, this element of the study was modified to a dyadic interview.

Each meeting or interview was facilitated by a student SLT, with a co-researcher present (either a qualified SLT

or student SLT) and lasted approximately 1 h. A different topic guide was developed for each group (bvFTD, LBD, PCA and YOAD). These were loosely based on the group topic guide developed for a similar focus group study with people with PPA (Loizidou et al., 2022). Participants were invited to discuss their experiences of communication difficulties since their diagnosis and presented with the main research question: 'How can speech and language therapy best support you?' A structured topic guide was prepared with prompting questions and visual stimuli (slides). These were intended to elevate and foreground the voices of participants with communication difficulties in line with methods developed by the first author (Volkmer et al., 2023a). Creating opportunities for people with communication difficulties to contribute equally

requires facilitators to create space and time to provide unsolicited opinions as well as providing accessible, multimodal resources to give them a voice. Visual and verbal support can enable access to, and construction of, self and identity (Braun et al., 2017) as well as enabling people to access information to express themselves more clearly (Money et al., 2016; Zusack et al., 2016). Planning these in advance (reviewing the literature on communication difficulties in each diagnostic group and providing examples of areas that might be difficult) ensured the facilitators could gather experiences and opinions, whilst also being flexible with follow-up questions, and ensuring they maintained a compassionate focus (see appendices, e.g., topic guide and PowerPoint slides). Additionally, the slides for people with PCA were developed with both communication and visual-perceptual difficulties in mind, for example, large font, short sentences, reading out all text. The researchers were aware that the support provided may have risked creating a tension between biasing responses and supporting communication. However, it was felt that student SLT facilitators (not personally known to the participants) might reduce the risk of bias somewhat, whilst participants could still benefit from their communication and facilitation skills. Student SLTs role-played facilitating in advance, receiving feedback to ensure adequate time was provided for participants to give opinions at each opportunity. Co-facilitators also practised supporting the main facilitator to give time, and create opportunities for participants to contribute (e.g., observing non-verbal communication and inviting participants to provide contributions or clarifying meanings). Each student facilitator kept a reflective log, written immediately following the focus group session, to facilitate reflection on any biases observed during the meetings.

Analysis

All meetings were video recorded and transcribed by the student SLT facilitators using a common protocol (McLellan et al., 2003) to ensure consistency. All names and identifiable information were anonymised prior to analysis.

Reflexive thematic analysis was chosen to analyse the data due to the nature of the research question, which explored participants' experiences and opinions of speech and language therapy. Reflexive thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2021). In recognition of the researchers' clinical backgrounds, reflexive thematic analysis was chosen over other thematic analysis methodologies as it uses 'the researchers' own subjectivity as a resource for analysis' (Braun & Clarke, 2021, p. 39).

Each data set for bvFTD, LBD, PCA and YOAD was analysed separately using reflexive thematic analysis over six steps (Braun & Clarke, 2021), this allowed us to allow any unique experiences or distinct needs of each group to be identified. Main themes were also identified across data sets based on commonalities of experiences

Initial data analysis was led by the student SLT who facilitated and led the relevant focus groups. The senior authors, A.V. and C.J.D.H., acted as secondary coders, supervising the analysis process, supporting and facilitating reflexive practice throughout. Please see supplementary information for a detailed illustrative example of work undertaken relevant to different stage of analysis.

Stage 1: The student SLTs familiarised themselves with the data by watching the video recorded focus groups and reading and editing the automatically produced transcript. They then read over the transcript multiple times to fully familiarise themselves with the data (Riessman, 1993). The student SLTs also spent time revisiting their reflective diaries to remind themselves of their experiences in facilitating the meetings.

Stage 2: The student SLTs then generated initial codes by reading and analysing the final transcripts, annotating and commenting on features of the data they felt were interesting (Boyatzis, 1998). All blank transcripts were also separately coded by either A.V. or C.J.D.H. The student SLTs then compared these initial codes and met with A.V. and C.J.D.H. to discuss the codes and to aid reflexivity in the analysis process (Braun & Clarke, 2021; Richards & Hemphill, 2018) and for intercoder reliability.

Stage 3: Initial codes were collated in a table, alongside relevant quotes. Codes were grouped to establish initial themes and sub themes. This was reviewed in discussion with A.V. and C.J.D.H. to refine themes.

Stage 4: Each student produced a visual representation of the themes (see appendices for examples of the work undertaken during the reflexive thematic analysis) and presented this at a meeting to all four student SLTs, A.V. and an independent speech and language researcher, who specialises in reflexive thematic analysis present. To further aid reflexivity, the group discussed and interrogated the data, encouraging the student SLTs to reflect and revisit the original data set to ensure all themes and subthemes were authentic and related directly to the data (Braun & Clarke, 2021).

Stage 5: Each of the student SLTs finalised and defined the themes with assistance of a final meeting with A.V. and C.J.D.H. During this meeting the visual representations of the data set were also revisited to inform stage 6.

Stage 6: Each student SLT developed a written analysis of the data with feedback from A.V. and C.J.D.H. Quotes were chosen that best represented the themes and sub-themes. A.V. then synthesised the final written analysis for

TABLE 2 Themes identified in focus group data.

Main Themes				
1. Communication difficulties as a key difficulty ■				
2. Loss and loneliness ■				
3. Speech and language therapy ■				
4. The role of the caregiver ■				
	<i>bvFTD</i>	<i>LBD</i>	<i>PCA</i>	<i>YOAD</i>
1.	Communication is difficult	Communication difficulties were "the worst thing".	Loss	Memory symptoms in interactions
2.	My lone journey	"No-one wants to know"	Group support	Communication as a key challenge
3.	"They aren't capable"	"You do anything that might possibly help"	Role of the speech and language therapist	Social withdrawal and isolation
4.	Caregiver focus	Speech and language therapy support	Practical considerations for therapy	Benefits of speech and language therapy

Abbreviations: bvFTD, behavioural variant frontotemporal dementia; LBD, Lewy body dementia; PCA, posterior cortical atrophy; YOAD, young onset Alzheimer's disease.

publication, sharing it with the research team for comments and critique to ensure it remained an accurate representation of the data and reflexive thematic analysis. Part of this process included producing a final figure that could represent the entire data set and the relevance of themes to the original research question.

RESULTS

Thematic analysis

The main goal of the thematic analysis was to explore participants' experiences and perspectives regarding their language and communication difficulties and how speech and language therapy could address these needs. There are several main themes that were identified across all groups and data sets. The four main themes identified were: (1) communication difficulties as a key difficulty, (2) loss and loneliness, (3) speech and language therapy, and (4) the role of the caregiver. Equally there are several themes that do not overlap at all. Table 2 presents a list of all 16 subthemes from each of the focus group discussions, with the highlighted to illustrate how these informed the main themes. Participants in the study emphasised the importance of professionals having an in-depth understanding of their individual needs according to their individual diagnosis. Consequently, the subthemes are presented to illustrate both the main themes that span the groups and the individual needs. The main themes and sub themes identified in each of the focus group's data are explicated, the latter with appropriate quotes, in subsequent sections.

The first main theme, communication difficulties as a key difficulty, captures the emphasis that participants made on communication difficulties in their lives. Across of rare dementia groups participants reported that these difficulties have a genuine and significant impact on their lives. Participants emphasised the severity of this as difficult, key or 'the worst', despite not being the leading or main symptom of their diagnosis.

The second main theme, loss and loneliness, describes the impact of communication difficulties on the day-to-day life of people with rare dementias and their caregivers. Participants attributed the communication difficulties as being the main reason for this isolation.

The third main theme, speech and language therapy, highlights that participants felt speech and language therapy could provide support to the person with the diagnosis and/or the caregiver across the rare dementias. Participants volunteered that this type of support would be beneficial, though they were unsure if people with the diagnosis would always be capable of engaging directly.

The fourth main theme, the role of the caregiver, forefronts the fact that across the rare dementia groups people felt that the people around the person has a key role in communication. This role requires the caregiver to both support the person with a diagnosis in communicating and carry the burden of interactions, as well as being the main or co-recipients of speech and language therapy guidance.

bvFTD focus groups

Only care partners were recruited to the bvFTD focus groups. Their demographic information is presented in

Table 1. Four themes were identified from the bvFTD focus group data. These are described next:

1: *Communication is difficult*

Care partners reported that the decline in communication skills was one of the biggest challenges for them:

‘I think one of the biggest challenges is an inability to communicate at all now’. (CPbvFTD09)

They described having to decipher what the person with bvFTD said, giving a sense of having to guess:

‘I have to decode what she’s saying to understand what she wants’. (CPbvFTD04)

Deciphering or guessing was ineffective when certain language difficulties arose. This escalated to a sense of confusion and frustration as care partners described the specific symptom of binary reversals (yes-no reversal; Warren et al., 2016):

‘To say yes, yes, yes, no or no, no, no, yes. So you’re left not quite sure what on earth is going on’. (CPbvFTD07)

The sense of uncertainty extended to knowing whether people bvFTD understood what other people said and care partners were unsure whether the person with bvFTD understood any spoken language at all:

‘I don’t know how much she understands to be fair’. (CPbvFTD01)

These communication difficulties left them unable to ascertain any information about the well-being, mood or happiness of the person with bvFTD:

‘I ask her if she’s happy, she doesn’t answer things like that’. (CPbvFTD09)

2: *My lone journey*

Participant care partners describe a sense of abandonment following diagnosis, whereby they are simply left to cope by themselves. They attributed this not to individual healthcare professionals, but to the wider system in which they were treated:

‘The National Health Service pretty well washes its hand I think once it’s diagnosed the

problem and they sort of say, leave it up to you’. (CPbvFTD09).

Most often, no help was provided after the diagnosis. Though where care partners were able to find support, the difficulties in accessing this were describing in terms of a long and frustrating battle:

‘You just have to batter and batter and batter down those doors to be able to get help’. (CPbvFTD02)

Care partners described long arduous searches, often on the internet, for information that was complex and difficult to understand:

‘As I said, I spend hours trawling through stuff. Stuff that may or may not be useful’. (CPbvFTD08)

The length of these battles and searches often meant participant caregivers felt they had learned information too late in the journey. This resulted in a sense of having missed vital information that could have meant they could have done a better job in their roles as care partners:

‘If I had known then how to manage the situation, I could have done probably much better’. (CPbvFTD04).

3. *‘They aren’t capable’*

Care partners did not believe that their relatives with bvFTD could benefit from participating in speech and language therapy due to their cognitive difficulties:

‘They aren’t capable of absorbing information or developing new habits’. (CPbvFTD02)

A total lack of interest in interaction was seen as a barrier to any kind of therapy:

‘He lost the power of conversation completely and he’s not interested in anything one says’. (CPbvFTD02).

Even amongst care partners who did feel therapy might have benefited their relatives, there was a lack of certainty and participants emphasised that interventions would have had to have been in the right format (words relevant to them) and at the very early stages of the disease:

‘It might have been easier at an earlier stage, I don’t know’. (CPbvFTD08)

4. Caregiver focus

Participant care partners emphasised that speech and language therapy could however benefit them:

'I think it is very clear that it's really the caregiver that needs the support in this'. (CPbvFTD03).

In fact, care partners described actively searching for guidance on communication strategies:

'I am looking for strategies, strategies to deal with situations, strategies to know how best to speak. I don't like speaking to (name) like a child'. (CPbvFTD03).

Participant care partners felt responsible for communication with their relatives with bvFTD and were open and willing to try new and novel methods of communication:

'We're not afraid to say, yeah, we're going to have to communicate in a totally different way. But the learning is on us, and it has to be on us. Unfortunately'. (CPbvFTD06)

LBD focus group

Four main themes identified in the LBD focus group data are described next.

1. Communication difficulties were 'the worst thing'

This theme describes participants' experiences of communication difficulties in their daily lives. Participants felt this was one of the most difficult aspects of their family members' disease:

'That was the worst thing, his inability to communicate'. (CPLBD05)

Communication difficulties experienced were not all attributable to one specific aspect of communication. Instead, participants identified a range of speech, language and communication difficulties. Voice volume was considered one of the main problems:

'Well, I find she's quiet, very quiet speaking now'. (CP_LBD06)

Participants reported that their family members were often unable to articulate clearly and fluently, resulting in a stammer:

'He had a kind of stuttering'. (CP_LBD04)

Word-finding difficulties were also a concern, resulting in difficulties in getting any words out, meaning people were often 'lost for words'. Importantly, cognitive difficulties were also felt to contribute to these issues:

'She goes off on a tangent, you'll talk about something and then she'll divert to something else'. (CP_LBD07)

2. 'No-one wants to know'

It was these communication difficulties that were considered the key contributors to social isolation:

'He didn't want to socialise, he didn't want to mix, he didn't want to go into crowds, and it was all to do with speech, it was the biggest hurdle we had to overcome'. (CP_LBD05)

Social isolation was also exacerbated by how friends and family members reacted to this. Friends became less engaged and interested resulting in fewer opportunities for interaction:

'A lot of the friends you used to have don't really want to know'. (CP_LBD06)

3. 'You do anything that might possibly help'

Care partners expressed a desire to do anything that could possibly help their family members in managing their LBD:

'You do anything that might possibly help'. (CP_LBD07)

However, care partner experienced their own frustrations and often found themselves isolated and grieving their past lives:

'I can't go out, so I miss walking as well because we've been all over the place on walking holidays so that's part of the frustration'. (CP_LBD02)



This adjustment was somewhat overwhelming for care partners who had more insight and awareness of the situations often than the person with LBD:

‘I think it’s worse for the carer than for the person with Lewy Bodies’. (CP_LBD06)

Although care partners flagged that some aspects of the disease were just too difficult for them to deal with yet. In particular they identified that thinking about the future progression of the disease was something they could not think about:

‘The aspect I obviously can’t deal with is the progression of the Lewy body dementia’. (CP_LBD07)

Participants attributed a lack of certainty and understanding surrounding the disease in part to the complexity of the information they had been given. Care partners identified a need for information to be presented clearly, in more accessible terms:

‘A lot of things need to be more in layman’s terms’. (CP_LBD06)

4: *Speech and language therapy support*

Access to speech and language therapy was not easily available meaning participants often had not considered it as an option. Participants identified a lack of speech and language therapy in some geographical areas compared to others and described this as a ‘postcode lottery’ [P6]. Given public knowledge of resource issues within the National Health Service (NHS), others suspected a broader funding issue, suggesting the resourcing of speech and language services within England might be limited or non-existent:

‘Unfortunately, there is a resource issue we all know with the NHS and whether speech therapists are available on the NHS I have no idea’. (CP_LBD07)

Those who had been able to access it described feeling lucky to be living in a geographical area where they could in access speech and language therapy:

‘I think we were on of the lucky ones as there was a pilot scheme going on in our area’. (CP_LBD04)

Some participants were totally unaware that SLTs might provide services to people with LBD. They had never even considered speech and language therapy as an option:

‘I’ve never even thought about speech therapy, not even entered my head’. (CP_LBD06)

A lack of awareness of the role of speech and language therapy may have influenced participants’ scepticism about the effectiveness of it:

‘Is there any point in speech therapy?’ (CP_LBD07)

Participants voiced specific concerns about cognitive symptoms such as memory, which they felt would prevent people with LBD from benefitting from speech and language therapy:

‘Would she remember what she’s just done with speech therapy?’ (CP_LBD06)

Visual-perceptual difficulties were also considered a barrier to accessing the resources that participants anticipated SLTs would provide:

‘I find (visual resources) totally unhelpful, because of the Lewy bodies, [name] has visual problems as well’. (CP_LBD05)

Several participants had however, sought out a specific speech and language therapy intervention named Lee Silverman Voice Treatment (LSVT), an intervention known to improve voice volume in Parkinson’s disease (Sharkawi et al., 2002). Despite their desire to explore this intervention they had very little luck:

‘It (LSVT) was something I was actively trying to access, and it was impossible just not possible’. (CP_LBD05)

PCA focus group

Four main themes were identified in the PCA data:

1. *Loss*

Participants with PCA and their care partners described how PCA has affected their word retrieval skills and comprehension, and the impact this had on their mental health and wellbeing. Difficulties in word finding were described as a real issue by both people with PCA and their care partners, conveying a sense of frustration for both parties:

‘Going to address [name], and then as soon as I want to start, it just won’t come out’. (PlwPCA01)



The experience of word finding was described in more detail by participants with PCA who emphasised that they knew what they wanted to say, but that they couldn't produce it accurately:

'In my head, I know the word but when it's coming, I just can't pronounce it right'. (PlwPCA03)

Difficulties in comprehension were also reported by participants, whereby words were considered difficult to grasp, despite participants recognising them as familiar. This was described vividly as an auditory processing difficulty:

'If there was a word that could describe talking becoming a blur. Sometimes it sounds as if it's all blended into one'. (PlwPCA03)

These difficulties had a significant on the mental health of participants who reported that the communication difficulties resulted in depression:

'I was starting to get depressed with it'. (PlwPCA03)

Care partners and people with PCA recognised that they had changed as a consequence of their communication difficulties:

'He'll say to me very often, "I'm not the man I used to be"'. (CP_PCA01)

This resulted in a loss of confidence for some participants, which in turn was recognised to result in reduction in social interaction:

'I've a strong inkling it may be because of nerves or I haven't got the confidence to actually get into a conversation with somebody'. (PlwPCA03)

Changes in relationship and identify were also reported by the care partners, who reported increased isolation themselves:

'It's become quite lonely. Our conversation that we had, our sharing of books, it's like a bereavement because those things don't happen anymore'. (CP_PCA02)

2. Group support

Participants identified having tried multiple dementia support groups such as singing for pleasure but identified the

value of sharing experiences with others who also have PCA. They felt understood by people, within a safe space, and quickly established friendships based on a shared experience:

'It's friendship within people that have a rare dementia. Obviously, people that concentrate within their own, have an even bigger understanding of what it is [you are] actually going through'. (PlwPCA02)

Meeting others was considered both a space to connect and laugh about their experiences as well as meet others and understand and identify pathways and ideas for help:

'I'm hoping that this will springboard off into some kind of pathway where I can get some help'. (CP_PCA02)

Participants with PCA and care partners were keen to share 'tips' even within the focus group meeting and care partners stressed the need to seek as much advice and support as possible:

'What else anyone thinks of ... but get as much help as you can get basically'. (CP_PCA04)

Importantly, participants highlighted the value of groups being facilitated by a professional expert, who could also provide some direction and guidance:

'I would have thought if let's say we became a group and had a conversation between all of us, and we're all knowing what our problems are. That might help, I'm not sure. We've already said in another group of people with professionals, you'd get the right feedback'. (PlwPCA01)

3: Role of the speech and language therapist

Participants reported having identified many of their own strategies, but also emphasised the value of seeking expert guidance from a SLT who they identified as more expert than care partners making suggestions to the person with PCA:

'He didn't trust me as an expert speech therapist, which I'm obviously not so he didn't, he wanted an expert'. (CP_PCA02)

Participants strongly advocated that SLTs should train care partners:



'If we were to benefit from speech and language support, it's me that needs to have more tools in my toolkit to support [name] in certain circumstances'. (CP_PCA01)

They emphasised that this would enable them to, in turn, encourage maintenance of communication skills and empower their family members with PCA to feel more confident:

'How we interact could help our loved one to feel more confident about maintaining that communication through speech'. (CP_PCA01)

4: Practical considerations for therapy

Understanding PCA but equally taking a person-centred approach was considered vital. This was described as taking into consideration the social and emotional needs outside of the diagnosis. Participants felt there could not be a single approach to supporting be with PCA:

'You can't just find one sort of solution because there's all those outside things as well. You know some people are on their own but have a carer come in. There's so many dynamics in there. I think it's looking at the broader picture of something that kind of meets all those needs'. (PlwPCA02)

They also identified a need to modify therapies over the course of the disease, whereby different interventions might be more appropriate at different times. This was raised by one participant whose partner had experienced speech and language therapy themselves:

'She had speech and language therapy. And it was very sort of "right, say this word say that word" back and forth. And I think it did help in the early stages. I think that probably comes to a point where it starts to be a bit frustrating'. (CP_PCA03)

Care partners also highlighted that their family members with PCA have visual-perceptual and sequencing difficulties that need to be taken account of when planning communication strategies. Acquired dyslexia is a known characteristic of PCA (Yong et al., 2016), yet they described experiences of having been advised to trial written communication which they could not do:

'Then people said about 'well can he write' but he couldn't write because he couldn't work out the movement of his hand'. (CP_PCA02)

Participants suggested a one size fits all approach would not work, but that SLTs needed to have a range of options or solutions, that that could persevere with trying over time:

"And if it doesn't work fine, but you've just gotta keep finding possibilities or other solutions". (CP_PCA03)

Participants discussed how much speech and language therapy would be helpful, how intense this should be and at what time during their journey. Participants felt that being seen early this would be the most beneficial:

'Surely if you're having problems to speak, is it not beneficial to get it sorted out straight away?' (PlwPCA03)

However, the service models for speech and language therapy did not always fit the needs of people with PCA, and additionally, there were waiting times to contend with. Participants described having experienced short blocks of therapy once a week for 4–6 weeks. Participants suggested alternative models of service to meet the needs of people with PCA, such as fewer sessions but maintaining contact over time:

'So, I think it's the maintenance of those conversations. And that doesn't necessarily mean what's going to be six weeks. It's likely more beneficial for it to be broken down into once a fortnight and then maybe months right... you have got a live contact who is sort of working with you in the long term'. (PlwPCA02)

YOAD dyad focus groups

Four themes were identified in the interview data

1. Memory symptoms in interactions

Both members of the dyad identified the first and main symptoms they had to deal with as short-term memory and the resultant repetitive questions:

'I think the very first things that you notice are when you're asked a question repeatedly. [name] would ask me a question and then a few minutes later she's ask me the same question'. (CP_YOAD)

The person also described needing prompt answers as she found it difficult to recall the questions she had asked, which was perceived as a lack of tolerance by the CP:

'You're less tolerant of a delayed answer'.
(CP_YOAD)

2. Communication as a key challenge

Repetitive questions were not the only communication difficulty described by the dyad, the person with YOAD reported specific difficulties with word finding which resulted in both word errors and hesitations:

'I stumble over words'. (Plw_YOAD)

In making sense of these difficulties in word generation, her CP attributed these to difficulties in retrieving the word from her mental lexicon:

'Part of that is not calling to mind the right word'. (CP_YOAD)

The CP also reported changes in her handwriting, specifically the formation of letters and spelling. These specific difficulties weren't something the person living with YOAD had noticed herself, despite observing discrepancies between what she intended to write and what she did write:

'My hand has changed it doesn't do what I tell it to sometimes'. (Plw_YOAD)

Despite these communication difficulties, the CP attributed his spouses difficulties in interacting in a group context as related to her hearing difficulties:

'I do sense sometimes that its because you haven't heard clearly what's been said is perhaps why you don't join in in a conversation'. (CP_YOAD)

The person with YOAD identified specific environmental factors that exacerbated communication difficulties:

'Most of the other people were at the other end of the table ... positionally that wasn't good ... the set up was difficult'. (Plw_YOAD)

She also described experiences where the communication skills of the interlocutor made interaction more difficult for her. She identified speed of speaking as a specific issue:

'The instructions from the front were delivered too quickly'. (Plw_YOAD)

The person with YOAD also identified that many people do not provide opportunities for her to speak:

'There were other people who were perfectly happy to talk non-stop'. (Plw_YOAD)

The person with YOAD experienced these as them not really wanting her or needing her in the conversation:

'They didn't need my conversation'. (Plw_YOAD)

3. Social withdrawal and isolation

The CP observed a decline in his spouse's confidence as a result of her communication difficulties:

'This is all sort of tied up with losing confidence in conversation'. (CP_YOAD)

The CP tied the loss of confidence to his spouse's withdrawal from certain social situations, particularly those she did not know so well:

'ou withdraw from certain types of conversation ... when it's with people you don't know so well or when its in a group, you tend to be more reluctant to take part'. (CP_YOAD)

The person with YOAD also described a change in ability to remain part of the group, this could be attributable to a lack of motivation or a cognitive changes:

'I seem to have switched off'. (Plw_YOAD)

Yet when the person with YOAD spoke with people she knew well, and had known them for many years they were able to provide the right support:

'I have enough friends who know me well enough to provide that sort of support just through knowing each other for years'. (Plw_YOAD)

4. Benefit of speech and language therapy

The person with YOAD was unsure whether she needed speech and language therapy support yet. Specific interventions such as word practice or communication aids were not something she felt she needed at this stage in her

disease journey, though she anticipated requiring them in the future:

'I think it must be very useful for many people, I don't think I need that yet'. (Plw_YOAD)

In contrast her spouse felt there might be technological support that could be useful in day-to-day life:

'I'm wondering whether there is room for some dementia friendly devices'. (CP_YOAD)

However, they both agreed that connecting with others in similar situations, in the context of group settings would be beneficial. They prioritised groups where they would be able to meet people specifically with the same diagnosis as they had:

'What would be more beneficial is to join with others facing similar challenges and particularly the young onset form of Alzheimer's'. (CP_YOAD)

DISCUSSION

The aim of this study was to explore the experiences and perspectives of people with bvFTD, LBD, PCA and YOAD and their care partners regarding their language and communication difficulties and how speech and language therapy could address these needs. Focus groups held with care partners of people with bvFTD and LBD, people with PCA and their care partners and an interview with a dyad with YOAD were analysed using Reflexive Thematic Analysis. Themes identified in the four data sets demonstrated that all participants with a diagnosis of dementia experienced communication difficulties that impacted significantly on their ability to participate in social situations. A variety of communication difficulties were described, which all impacted on both the person with the diagnosis and their care partner, with loss, lack of confidence and social isolation identified across all groups. Participants reported additional factors interacting with and impacting on their communication difficulties arising from symptoms specific to their diagnosis as well as environmental factors. Importantly, participants felt that they needed support in managing these communication difficulties, identifying both peer group support and specific speech and language therapy, as vital sources of guidance.

People affected by bvFTD, LBD, PCA and YOAD described experiencing a range of speech, language and communication difficulties. Consistent with the current

research evidence (Crutch et al., 2013; Yong et al., 2023) word assembly difficulties, akin to those experienced by people with logopenic PPA, were described by participants affected by PCA in this study who reported knowing a word but being unable to pronounce it correctly. These vivid descriptions align with the theory of logopenic PPA as a phonological buffer disorder whereby the person struggles to assemble the phonological representation of the word (Ruksenaite et al., 2021). Additionally, participants with PCA explained that words sound 'blurred' or 'blended into one', suggesting the auditory processing and parsing of speech sounds may be difficult (Johnson et al., 2020).

Similarly, care partners of people with bvFTD report both expressive and receptive language difficulties. In contrast to Suárez-González's review, little was reported about specific naming difficulties, instead participants described having to decode what their partners with bvFTD meant, suggesting difficulties in organising narratives or grammar. These types of difficulties have been described previously, (Ash et al., 2019; Saxon et al., 2017); and impaired comprehension of words and sentences is also previously described (Saxon et al., 2017). The latter comprehension difficulties are consistent with participant care partners experiences of being uncertain whether their partners with bvFTD understood them or understood specific concepts such as 'happiness'. Additionally, care partners affected by bvFTD report binary reversals of yes and no, which has been identified as a hallmark symptom of nfvPPA (Warren et al., 2016). Given the underlying pathological relationship between nfvPPA and bvFTD, both being associated with frontotemporal atrophy (Ruksenaite et al., 2021), this is perhaps unsurprising.

Participants with LBD and their care partners describe difficulties with fluency, word finding and topic maintenance. This is consistently with language difficulties reported in the current research evidence describing reduced speech rate, pausing and grammar difficulties (Grossman et al., 2012), as well as topic maintenance difficulties (Ash et al., 2011). Little has been reported about the severity of these difficulties (Suárez-González et al., 2021), although the finding that voice volume is identified as the most difficult of these communication symptoms, is well recognised in Parkinson's disease (Donaghy et al., 2017).

Finally, the dyad with YOAD described repetitive questions and word finding difficulties, characterised by word errors and hesitations. Additionally, the dyad reported problems with spelling. This contrasts with the small research literature on communication difficulties in YOAD reviewed in Suárez-González et al. (2021), which reported a variety of findings across only four studies, variously describing a range of language symptoms from none at all to severe receptive difficulties. More recent work has shown the specific burden of repetitive questioning

in conversation with people with Alzheimer's dementias (Volkmer et al., 2023b).

Participants with non-language-led dementias examined here emphasised the impact of communication difficulties on both their confidence and ability to participating in social activities. Suárez-González et al. (2021) found no papers that explored the impact of language difficulties on activities of daily living or quality of life for people with bvFTD, LBD, PCA or YOAD in their scoping review. The findings from this study therefore extend previous research on communication difficulties in these groups by highlighting the direct relationship between communication difficulties and participating in social activities. We also shed light onto the emotional impact of these communication difficulties. It is reasonable to assume that participants may be hindered by other symptoms in social contexts, such as physical motor symptoms in LBD, yet communication was cited as the specific reason their partner didn't socialise: 'It was all to do with speech' [P5]. The partner of the person with YOAD directly associated communication difficulties with a loss of confidence in conversation, and it was a direct source of low mood for a person with PCA. Given the evidence that communication in stroke can result in negative mental health outcomes for a person with aphasia (Baker et al., 2018), this is perhaps unsurprising. Negative health outcomes have also been reported for care partners of people with dementia (Jeste et al., 2021). In our study, care partners of people with bvFTD also reported that communication difficulties were a source of great frustration for them. Care partners of people with LBD reported loss and social isolation similar to care partners of people with PCA who described feeling lonely as a consequence of their spouse's communication changes. Thus, communication difficulties in people with bvFTD, LBD, PCA and YOAD have implications above and beyond their main, or leading, symptoms, and result in negative mental health outcomes, reduced participation and social isolation for them and the people around them.

Participants with PCA, LBD and YOAD and care partners of people with these conditions felt that speech and language therapy could benefit them. Yet previous work (Suárez-González et al. (2021) found no papers describing language-based interventions for people with bvFTD, LBD, PCA and YOAD. People with LBD and their care partners in this study reported a desire for specific support addressing voice-volume. This is a well-described symptom in Parkinson's disease, so it is not surprising to find this in people with LBD, which comprises Parkinson's disease dementia as well as the closely related dementia with Lewy bodies. It is known to respond well to the LSVT. This is a well-known evidence-based intervention for addressing voice-volume for people with Parkinson's disease (Guidi

et al., 2023; Pu et al., 2021). Despite there not being specific evidence available on the effectiveness of this approach for people with LBD, one participant with LBD reported having accessed this intervention via a novel pilot study in their local area.

People with PCA stated they would like speech and language therapy to focus on providing care partners with additional skills to support interaction. This aligns with a recent case study describing how a person with PCA and their care partner benefitted from communication partner training (Volkmer et al., 2022). This is the only speech and language intervention study, known to the authors, to address the communication needs of people with PCA. This intervention, Better Conversations with Primary Progressive Aphasia, was originally developed for people with PPA (Volkmer et al., 2021). Previous research has highlighted similarities in the language difficulties of people with lvPPA and PCA (Yong et al., 2023) and svPPA/nfvPPA and bvFTD (Hardy et al., 2016). Some researchers have also suggested overlaps between lvPPA and YOAD, with language difficulties being relatively common amongst people with YOAD (Mendez et al., 2012), endorsing research describing the multidimensional nature and overlapping phenotypes of these diseases (Ramanan et al., 2022). Some of these researchers have suggested that interventions developed for people with PPA may therefore benefit people with PCA and bvFTD (Yong et al., 2023). There is thus a need for research to explore speech and language interventions for people with bvFTD, LBD, PCA and YOAD, starting with exploring the impact of LSVT for LBD and Communication Partner Training for bvFTD, LBD, PCA and YOAD.

Limitations

The focus groups described in this study were designed, run and analysed by speech and language therapy researchers, which is likely to have resulted in some bias. Braun and Clarke (2021) acknowledge this type of bias will inevitably shape conceptualisation of themes and conclusions. Moreover, the communication support given may be described as leading, and therefore influence the participant responses. However, communication support certainly enabled people with communication difficulties to contribute to the discussion, thus perhaps maintain a sense of equipoise was important in this study. To assist in this process the SLT students kept a reflective journal throughout the data collection phase. As a result of the COVID-19 related restrictions these groups were held remotely via video conferencing, which likely excluded some individuals from participating. Yet, several carers commented on this facilitating their attendance as they

	bvFTD	LBD	PCA	YOAD
Beginning	Get to know people deeply and take a person centered approach			
Symptom specific needs	Binary reversals (saying yes for no and no for yes) are especially difficult, and people need guidance on how to manage this.	Need to take into consideration visual-perceptual difficulties when designing stimuli/visual information. Voice may be more important to work on than language and communication.	Need to take into consideration visual-perceptual difficulties when designing stimuli/visual information and when exploring strategies or solutions for communication.	Repetitive questions (often arising from memory related difficulties) can have a significant impact on interaction and can be the focus of therapy.
Environment	Work with care partners/family members may be the main or a high priority for therapy. This should focus on practicing strategy use to support interaction.			
Education	Empower people to access speech and language therapy by educating both people living with the diagnosis and other professionals (gatekeepers).			
Groups	Prioritise incorporating, offering or supporting people to access groups with people with the same diagnosis.			
Therapy focus	People with bvFTD may (only) benefit from direct SLT right at the early stages.	Advocate for equitable access to interventions such as LSVT.	Focus intervention on strategies to support conversation and interactions as communication is often the primary compensatory strategy in PCA.	Offer a range of supports, including technology.
Care pathway	Employ a person-centred approach and offer a range of supports. Offer people support at any time during the care pathway and help them re-access when they need it. Work with people to modify approaches over time.			
Services and funding	Services should not be ringfenced to exclude rare dementias. Advocate for funding. Be creative and change service models - not 1x weekly for 6 weeks, perhaps less frequently for longer.			

bvFTD = behavioural variant Frontotemporal Dementia; LBD = Lewy Body Dementia; PCA = Posterior Cortical Atrophy; YOAD = Young Onset Alzheimer's Disease; SLT = speech and language therapy; LSVT = Lee Silverman Voice Technique

FIGURE 1 Recommendations for clinical practice. bvFTD, behavioural variant frontotemporal dementia; LBD, Lewy body dementia; LSVT, Lee Silverman Voice Technique; PCA, posterior cortical atrophy; SLT, speech and language therapy; YOAD, young onset Alzheimer's disease.

could more easily manage caring responsibilities alongside participation. A selection bias is inevitable in this study, as participants who volunteered to participate in the study likely represented people who experience communication difficulties arising from their rare dementia diagnosis. Despite estimates that language difficulties are common second symptoms for some, if not all, of the included groups (e.g., PCA, Yong et al., 2023) specific estimates as to the number of people who experience these difficulties are lacking, and our results may therefore not be representative of the entire population of people with these rare dementias. Additionally, the small number of participants who participated, did not represent diverse socioeconomic, ethnic or linguistic groups, given most were white, English speaking and from professional backgrounds. This study describes a first step in providing an invaluable picture of unexplored needs in these dementias, and highlights biases that will need to be explored in future research.

Future implications

Given the current lack of research on interventions for people with non-language-led dementias, this study provides

insights to potential intervention avenues. Development of novel interventions that genuinely meet the needs of the people they are designed for, must be designed with their views and opinions at the centre of this process. This also applies to service development with the clinical setting. Current service models for speech and language therapy are based around a 4–6 session dosage, delivered through a weekly scheduled of 1-hour sessions (Volkmer et al., 2020). Yet this has clearly not met the needs of people with PPA and SLTs have advocated for alternative models of care that provide a continuity of care (Volkmer et al., 2023b). Reports from participants in this study demonstrate speech and language therapy services are also not meeting the needs of people with non-language-led dementias. There is therefore a need to revise traditional models of care and write specific care pathways that address the needs of people with progressive language difficulties.

Specific considerations for speech and language therapy, synthesised from the thematic analysis data in this study and stratified to represent both disease specific and more universal needs across non-language led dementia, have been presented in Figure 1. This highlights the needs to get to know people deeply, before embarking on bespoke interventions that take into account the needs of the person, their diagnosis, the people supporting them in



their specific context and their needs over the long term. This is likely to reduce both the negative mental health outcomes for these people as well as minimising social isolation and dependence. Importantly, participants in this study did not identify healthcare support for language and communication needs to be solely the responsibility of the SLTs. Rather, alongside speech and language therapy, participants advocated for therapists to connect them with groups of people with the same diagnosis with whom they could share experiences, tips and ideas. Group interventions are often de-prioritised in favour of impairment-based interventions that target the restitution and repair of communication difficulties (Volkmer et al., 2023b). Yet the participants in this study advocated those ecological interventions, such as communication partner training, and group support should be prioritised, sometimes over impairment focused interventions. This serves as an important reminder that working with people with progressive diseases requires a different approach from traditional models of communication rehabilitation. Thus, revising the potential order of events that may populate a care pathway. Care pathways must therefore be co-produced in conjunction with people with bvFTD, LBD, PCA and YOAD and their care partners and families.

CONCLUSIONS

People with bvFTD, LBD, PCA and YOAD and their care partners experience speech, language and communication difficulties that have a negative impact on their social participation and mental health. The data collected in this study indicate that participants felt they could benefit from speech and language interventions. There is an urgent need for research exploring speech and language interventions for people affected by bvFTD, LBD, PCA and YOAD that must be co-produced to ensure they meet their needs. This, in turn will support the development of much needed care pathways for people with non-language led dementia within speech and language therapy settings.

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CONFLICT OF INTEREST STATEMENT

The authors report there are no competing interests to declare.

DATA AVAILABILITY STATEMENT

Videorecorded data sets generated and/or analysed during the current study are not publicly available due to ethical restrictions related to sharing of video data.

PATIENT CONSENT STATEMENT

Potential participants were invited to attend an individual consent session, held and recorded digitally on the video conferencing platform GoToMeeting, in line with RDS Impact Study protocol (Brotherhood et al., 2020).

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APPENDIX 1: EXAMPLE TOPIC GUIDE AND SLIDES

Topic guide

Those with PCA

Date -

Time []

Facilitator: C.S.: lead and facilitate the discussion, sustain conversation, prompt, clarify

Co-facilitator: C.W.: facilitate the discussion, prompt, when necessary

Platform: GoToMeeting

Welcome:

Hi everyone thank you for joining the focus group

My name is Chloe, I am a Master's student at UCL. And this is Connie, another masters student who is also with us today. *Connie introduces herself.*

Before we start I think it would be nice to introduce ourselves to the group by telling us your name. Let's start with ...

Thank you all for sharing it's lovely to meet you all. I would like to assure you that this is a safe space, where everyone is free to share and be honest. Your opinions will be respected by everyone in the group.

We are very grateful to you for participating in this research. Firstly I want to explain a little about this research.

[Share slides]

I work on this project with Anna Volkmer and Chris Hardy, who run the project. We all work with UCL and the Rare Dementia Support.

Before we start, I would like to remind you that this meeting will be recorded. If you don't wish to be recorded, you can leave the meeting now. **I'm going to start recording the meeting now**'.

'Today, we are interested in hearing about your communication needs and suggestions about what speech and language therapies you believe would be most useful to you'.

WFD:

[Next slide]

'Some people with PCA have difficulty finding the right word or saying it correctly. Have you experienced this?'

[Stop sharing to allow for discussion]

'Thank you everyone, that is really interesting. I can imagine these difficulties really impact you daily.

I am wondering, what would be helpful when you cannot find the right word? Maybe something like a vocabulary list? Or other support strategies such as gesture and predictive text?'

Discuss

'Thank you for those ideas, it is really insightful information. I am going to move to the next slide now'.

Phonemic errors

[Share slides]

'Some people, when they say the word, get the soun mixed up. Instead of saying animal, they say manimal. Does this happen to you?'

[Stop sharing to allow for discussion]

'Following on from that, what therapy would you find helpful for this difficulty? Maybe practise rehearsing words you find tricky?'

Discuss

‘Thank you for those brilliant ideas. I am conscious of time so I want to move on to the next question.’

Comprehension difficulties

[Share slides]

‘Some people have difficulty understanding others even though they can hear them, do you experience this difficulty?’

[Stop sharing to allow for discussion]

‘Thank you, that’s raised some interesting points. Again, what support would you like for this, listening exercises for example?’

Discuss

I would like to thank you for your time today. It was lovely to meet you all. You shared some very interesting ideas with us. We are really grateful for your participation and honesty. We are happy to answer any questions or comments, so please get in touch.

Stop recording

Example slides for dyadic interview:

UCL

What communication difficulties do people with young-onset Alzheimer's disease (YOAD) experience?

How can speech and language therapy best support individuals and their carers?

Rare Dementia Support

UCL

Have you experienced any difficulties with your communication?

What do you find challenging?

What impact does this have on your daily life?

Rare Dementia Support



Understanding what another person is saying

Finding the **words** you want to use

Remembering what you want to say

Putting words together in a sentence

Paying attention in conversations

Blocking out background **noises**

Reading & writing



Rare Dementia Support



How do you think speech and language therapy could best support you?

What kinds of interventions would you like to see developed?



Rare Dementia Support

APPENDIX 2: REFLEXIVE THEMATIC ANALYSIS

Initial analysis of data was led by the student speech and language therapist (SLT) who facilitated and led the relevant focus groups. The senior authors, A.V. and C.J.D.H., acted as secondary coders, supervising the analysis process, supporting and facilitating reflexive practice throughout. Please see supplementary information for detailed examples of work undertaken relevant to different stage of analysis.

Stage 1: The student SLTs familiarised themselves with the data by watching the video recorded focus groups and reading and editing the automatically produced transcript. They then read over the transcript multiple times to fully familiarise themselves with the data (Riessman, 1993). The student SLTs also spent time revisiting their reflective diaries to remind themselves of their experiences in facilitating the meetings.

Stage 2: The student SLTs then generated initial codes by reading and analysing the final transcripts, annotating and commenting on features of the data they felt were interesting (Boyatzis, 1998). All blank transcripts were also separately coded by either A.V. or C.J.D.H. The student SLTs then compared these initial codes and met with A.V. and C.J.D.H. to discuss the codes and to aid reflexivity in the analysis process (Braun & Clarke, 2021; Richards & Hemphill, 2018).

Stage 3: Initial codes were collated in a table, alongside relevant quotes. Codes were grouped to establish initial themes and sub themes. This was reviewed in discussion with A.V. and C.J.D.H. to refine themes.

Stage 4: Each student produced a visual representation of the themes (see Table 4. Below for examples of the work undertaken during the reflexive thematic analysis) and presented this at a meeting to all eight other student SLTs, A.V. and an independent speech and language researcher, who specialises in reflexive thematic analysis present. To further aid reflexivity, the group discussed and interrogated the data, encouraging the student SLTs to reflect and revisit the original data set to ensure all themes and subthemes were authentic and related directly to the data (Braun & Clarke, 2021).

Stage 5: Each of the student SLTs finalised and defined the themes with assistance of a final meeting with A.V. and C.J.D.H. During this meeting the visual representation of the data set was also revisited to inform stage 6.

Stage 6: Each student SLT developed a written analysis of the data with feedback from A.V. and C.J.D.H. Quotes were chosen that best represented the themes and subthemes. A.V. then synthesised the final written analysis for publication, sharing it with the research team for comments and critique to ensure it remained an accurate representation of the data and reflexive thematic analysis. Part of this process included producing a final figure that could represent the entire data set and the relevance of themes to the original research question

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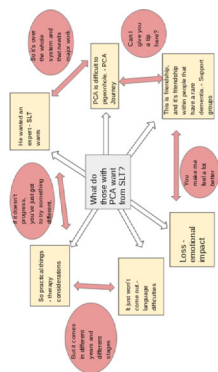
Young onset Alzheimer's disease

Posterior cortical atrophy

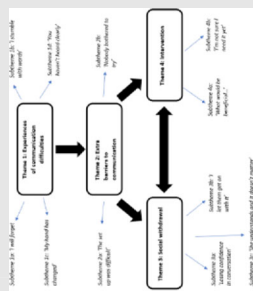
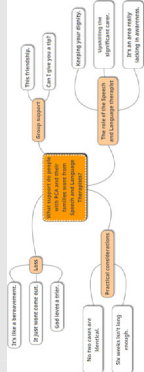
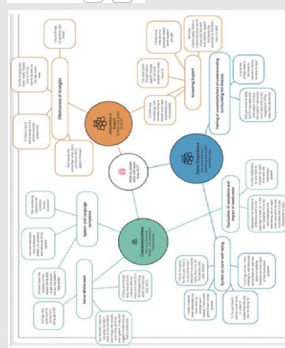
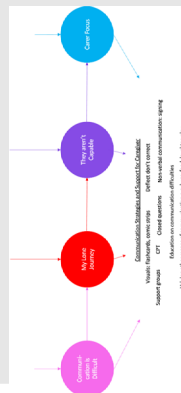
Lewy body dementia focus groups

Behavioural variant frontotemporal dementia groups

Finishing themes



Exploring relationship between themes



Abbreviations: LBD, Lewy body dementia; PCA, posterior cortical atrophy.