

Giving Voice to People With Dementia and Their Carers: The Impact of Communication Difficulties on Everyday Conversations

International Journal of Qualitative Methods

Volume 22: 1–15

© The Author(s) 2023

DOI: 10.1177/16094069231171096

journals.sagepub.com/home/ijq

Anna Volkmer^{1,*}, Claudia Bruns¹, Vitor Zimmerer¹, Rosemary Varley¹, and Suzanne Beeke^{1,*}

Abstract

People living with dementia are an under-served group, whose voices are often excluded from research studies due to their speech, language and communication difficulties. As part of a larger study into language processing in dementia, we invited five people with dementia and their carers to tell us about how dementia impacts on their everyday conversations. We also wanted to gain insights into their views on communication strategies to circumvent these difficulties. Aware of the limitations of a standard focus group methodology for this population, we adapted this approach to provide people with dementia the opportunity to be active research participants. To amplify their voices and to enable carers to be as open as possible we ran the groups separately. Each was facilitated by a speech and language therapist. Both groups used communication accessible materials, to create an inclusive environment that valued contributions from all participants. The topic guide remained the same for all participants, ensuring equity in posing the same core questions. Focus groups were video recorded and transcribed. Reflexive thematic analysis was selected as the most appropriate method to ensure overarching themes identified were based in the data. In our analysis the main theme was sense-making; participants experienced and tried to make sense of dementia through the lens of interaction. Four subthemes were also identified, 1. It's a journey, 2. You have to make the most of things, 3. Ask the right questions and it just flows-strategies in conversation, and 4. Dealing with people. Multimodal adaptations to a focus group methodology have given voice to people with dementia as well as their carers. They characterise dementia and identify useful strategies based on observations of what changes for them in everyday conversations.

Keywords

dementia, communication, interaction, focus group

Background

There is a growing research agenda to seek to understand the lived experience of dementia by asking people with dementia and their carers directly about issues such as strategies for coping (Bjørkløf et al., 2019), autonomy, selfhood and identity (Birt et al., 2020), post-diagnostic support (Bamford et al., 2021), and end of life care (Sellars et al., 2019). Many of these studies identified and critiqued the lack of routine involvement of people living with dementia as research participants. In a bid to upskill researchers, a recent methods review from the NIHR School for Social Care Research provides strategies to deal with ethical, methodological and practical issues when

interviewing people with dementia (Samsi & Mathorpe, 2020). In parallel, recognition of the importance of patient and public involvement in dementia research has resulted in

¹Division of Psychology and Language Sciences, University College London, London, UK

*These authors contributed equally to this work

Corresponding Author:

Anna Volkmer, Chandler House, 2 Wakefield Street, London, WC1N 1PF, Division of Psychology and Language Sciences, University College London, London, UK.

Email: a.volkmer.15@ucl.ac.uk



Creative Commons CC BY: This article is distributed under the terms of the Creative Commons Attribution 4.0 License (<https://creativecommons.org/licenses/by/4.0/>) which permits any use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (<https://us.sagepub.com/en-us/nam/open-access-at-sage>).

methods for meaningfully engaging mixed stakeholder groups (e.g. Brunskill et al., 2022s tips on keeping groups small, using sorting tasks, role play and voting for examples). Furthermore, co-production of research with people living with dementia is being facilitated by use of creative methods, such as photography by Dooley et al. (2020), to capture people's everyday lives following a diagnosis of dementia

Notably, although language impairment is a core feature of cognitive deficit in dementia, research into individuals' lived experience of communication changes after a dementia diagnosis is limited. Existing studies are narrowly focused on views on assistive devices such as communication passports (e.g. Leavey et al., 2020) and easy to use telephones (National Institute for Health and Care, 2018), or only indirectly relevant to communication because of a focus on social engagement (e.g. Birt et al., 2020). Progressive difficulties with language are a feature of all dementia types, not just those where language difficulties are the leading symptom (the primary progressive aphasia; Suárez-González et al., 2021). In their review of 73 studies on language in the dementias, Suárez-González et al. (2021) found a range of deficits were reported, including difficulties in single word and sentence processing, and narrative production. Critically, the authors found no descriptions of the impact of these impairments on everyday communication, social activities or quality of life.

The need for carers to adapt their communication to improve interactions with people living with dementia is recognised by the National Institute for Health and Care (2018) dementia guidelines and evidence synthesis, which reveals effective methods for training carers (Eggenberger et al., 2013), and subsequent outcomes for carers and people with dementia (Nguyen et al., 2019). However, the evidence referenced in these guidelines does not reflect the communication experiences of people with dementia, and neither is there much theoretical underpinning for some of the recommended strategies (Young et al., 2011).

When communication is the focus of research enquiry, the experiences and perspectives of carers and healthcare workers predominate. In their mixed methods systematic review of what is good communication for people with dementia, Alsawy et al. (2017) found only one of 15 studies actively explored the experiences of people with dementia (Day et al., 2011), and this focused on lying and its acceptability, rather than broad experiences of communication. Importantly, it highlighted that people with dementia are aware of their communication difficulties. The remaining 14 studies explored perspectives of carers and healthcare professionals, with some also making observations of people with dementia in everyday conversations to verify carers reports (e.g. Purves & Phinney, 2012/2013). Alsawy et al. (2017) concluded there is an urgent need to hear from people with dementia directly about their experiences of communication to facilitate person-centered care, enable families to live well with dementia, and inform communication training programmes.

Since the review by Alsawy et al. (2017) was undertaken, a few studies have actively sought the views of people with

dementia on communication. Alsawy et al. (2019) video recorded dyadic activity-focused interactions between nine people with dementia and their carers and used these during semi-structured interviews to enable the people with dementia to reflect on aspects of meaningful communication. Using thematic analysis, the authors identified three themes around emotional connection, empowering the ability of the people with dementia to communicate, and inhibitors to communication. Participants recognised that carers sometimes struggled to understand them, and they felt appreciative of their efforts to connect, which in turn made people with dementia feel they wanted to initiate interactions. Active listening and being heard were important to people with dementia, and people who felt unheard tended to avoid further communication. Alsawy et al. (2019) concluded that people with dementia maintain awareness of interpersonal interactions and stressed the importance of involving them in research and service development, specifically communication training for carers and staff. Crucially, for people with dementia in the Alsawy study, meaningful communication was about empathy and feeling valued, even if shared understanding remained elusive. Recommended communication strategies such as short, simple sentences and yes/no questions were viewed as less important.

In their qualitative synthesis of 13 studies reporting data on how people living with dementia engage with others in the community, Birt et al. (2020) highlight the work that people with dementia feel they need to do to interact successfully. This involves managing perceptions of others to avoid negative judgements, involvement in alternative social roles when established ones become difficult, and concern that changes in cognitive abilities (such as remembering names) lead to people not wanting to talk to them. The authors conclude "People with dementia were agentic in impression management: undertaking work to maintain recognized social roles, while being aware of when their illness led to others discrediting them." (Birt et al., 2020:23). They highlight the fact that people with dementia are acutely aware of people's responses to them and call for wider recognition of strategies used by people with dementia to maintain a 'social self'.

The research outlined in the previous three paragraphs establishes that some people with dementia are aware of their communication difficulties and the need to manage their interactions with others to avoid negative experiences. There is some suggestion that generic strategies for carers such as 'ask yes/no questions', are less of a priority for people with dementia who wish to feel heard and remain socially connected. In these studies, there is a focus on exploring communication in the abstract; what makes communication good or meaningful. While this is important, it is during everyday activities that people feel connected and valued and so it is vital that we understand how communication works between people with dementia and families at these times. This requires us to investigate everyday conversation,

focusing on the operational components of social interaction with language skills as the building blocks. Communication training programmes will better reflect the priorities of people with dementia and their families if we understand their specific experiences and perspectives relating to retained skill and communication breakdown in natural settings (Kindell et al., 2017).

Purpose of the study

To explore the experiences and perspectives of people with dementia and their carers regarding the impact of dementia on their everyday conversations.

Methods

Design

Given the purpose of this study and its place within a larger psycholinguistic project (see Recruitment), a qualitative approach employing focus groups was a logical choice (Silverman, 2021). We wanted to access the collective sense making of our participants around the impact of dementia on the activity of having conversations, rather than leading with our observations of their conversations. We felt that individual interviews would not generate a sufficiently detailed discussion of conversation and interaction, but that in groups people would trigger each other's thoughts and reflections. Aware of the limitations of a standard focus group methodology for this population (people with communication difficulties as a result of dementia), we adapted this approach to provide participants with the opportunity to be active research participants. In our data collection we adopted what Braun et al. (2017) describe as 'pluralism', choosing not to employ a monomodal verbal form of data collection, instead using a multimodal data collection approach. This included both verbal strategies, visual and experiential components such as images and home-based activities (for a detailed list of what was used please see procedures and Table 2). This increased accessibility, providing participants the opportunity to contribute to and influence the topics under discussion. Many of these methods have existed for some time, albeit not formally employed within research. Modifying language improves accessibility

(Zuscak et al., 2016). Visual elements have been described as providing greater access to constructions of self and identity (Braun et al., 2017), and in this case visual methods also supported people with dementia to access information and express themselves in interactions (Money et al., 2016; Zuscak et al., 2016).

Another method we employed was to separate people with dementia from carers to amplify the voices of people with communication difficulties. This also optimised the opportunities for group members to contribute by keeping group numbers small (as recommended by Brunskill et al., 2022). This method is common in a clinical setting and is central to patient and public involvement as it creates environments where people can be honest and open (Volkmer, 2013; Volkmer & Broomfield, 2022), but is underutilised in research.

Recruitment

This study was part of a larger experimental psycholinguistic project investigating language and communication in dementia (Formulaic language in dementia: diagnosis, tracking and therapy; see Zimmerer et al., 2020). Participants were recruited to the main study from local dementia cafes in central London and the UK's Join Dementia Research Database. VZ and a junior researcher attended dementia cafes to present information about the main study prior to recruitment. Participants in the main study who fulfilled the inclusion criteria outlined in Table 1 were invited to participate in the current focus group study.

This pragmatic approach to recruitment from the wider pool of participants in the main study was used to identify those who could participate in group discussions about their experiences and perspectives on the impact of dementia on their conversations. Participants provided informed consent to participate in the focus groups, following the Mental Capacity Act (Office of Public Sector Information, 2005) and guidance from Royal College of Speech and Language Therapists (RCSLT). Accessible participant information sheets and consent forms were sent prior to the first focus group, and participants had the opportunity to ask questions and discuss the research with carers and the research team.

Table 1. Inclusion and Exclusion Criteria for the Focus Groups.

Inclusion Criteria	<ul style="list-style-type: none"> - Diagnosis of Dementia - At least mild cognitive impairment on a cognitive screening tool (Montreal Cognitive Assessment, MoCA; Nasreddine et al., 2005) - Judged by a member of the research team (VZ) as able to participate in group Discussions - Living at home with a support from a carer (family member, friend or paid carer) - Available carer who also consented to participate
Exclusion criteria	<ul style="list-style-type: none"> - Cognitive impairment associated with other acquired neurological condition or mental health diagnosis - Living in a care home or hospital setting

Procedure

Over 3 weeks, six 90 min focus groups were held. The objectives were to understand: i) experiences of living with dementia and of talking to people in everyday situations, ii) how conversation breaks down at home and how these issues are resolved, and iii) to ensure the views of people with dementia were represented in this discussion. Two focus groups took place concurrently each week (one for people with dementia and one for their carers), each facilitated by a trained speech and language therapist (AV and SB) aided by VZ, a language scientist, and CB, also a trained speech and language therapist. Participants were invited to attend three separate meetings, with each meeting scheduled to have refreshment breaks, to allow participants time to engage with each other and immerse themselves in the process.

Both groups followed the same topic guide and used the same communication accessible materials, to create an inclusive environment that valued contributions from all participants and ensured equity in posing the same questions. Tasks were designed to support them to reflect on their

everyday conversations, e.g. by encouraging use of a multi-modal diary to record individual experiences for discussion at the next meeting (see [Table 2](#) for an overview of three focus group sessions and supplementary materials for example topic guide). Routine communication strategies included use of written prompts (single words or sentence written on handouts or a flip chart), use of simple sentence structure, repetition and time given to respond ([Zuscak et al., 2016](#)). Participants were provided images, and invited to share images, videos, gestures and mime (see [Table 2](#) below for a detailed overview of when strategies were used in sessions). All focus groups were video recorded and transcribed orthographically by a junior researcher (and speech and language therapist), who was not present at the focus groups or involved in data analysis. Transcription followed a protocol ([McLellan et al., 2003](#)) to maintain anonymity and uniformity in the process.

Analysis

Reflexive thematic analysis was undertaken in multiple phases as described by ([Braun & Clarke, 2006; 2021a](#)). [Braun et al. \(2017\)](#)

Table 2. Overview of Three Focus Group Sessions and Multimodal Adaptations Employed in Each Session.

Session Number	Objectives	Visual and Experiential adaptations
1	<p>To understand:</p> <ul style="list-style-type: none"> i) Experiences of living with dementia and of talking to people in everyday situations ii) How conversation breaks down at home and how these issues are resolved iii) To ensure the views of people with dementia were represented in this discussion 	<p>Introductions, with name badges</p> <p>A structured session with an introduction to the context of the research using visual materials (images and simple written bullet points)</p> <p>Written summary of self-generated group rules</p> <p>Brief discussion of two central research questions to set the context</p> <p>“What are your experiences of living with dementia?”</p> <p>Then focusing on</p> <p>How do you get on with talking to people in your family and when you are out and about? (Images provided for context)</p> <p>Both questions provided in written form</p> <p>Homebased task</p> <p>Collect examples of when conversation breaks down and what helps.</p> <p>Participants invited to write a diary, take photos or videos on own phone or tablets</p>
2		<p>Re-introduction to everyone and name tags</p> <p>Recap (verbally and visually) of group rules and context of project</p> <p>Invitation to share experiences documented during homebased task, in any modality</p> <p>Provision of examples from clinical knowledge if required to prompt discussion “some people say X, have you experienced this?”</p> <p>Homebased task: Participants asked to try out strategies at home including</p> <ol style="list-style-type: none"> 1. Putting all appointments into a shared diary every week, 2. Keep appointments in a memory corner 3. Plan an event together <p>For partners</p> <p>We asked them to trial scripted responses to facilitate use of tasks outlined above e.g. “I don’t know when that is, let’s look at the diary/calendar.”</p>
3		<p>Re-introduction to everyone and name tags</p> <p>Recap (verbally and visually) of group rules and context of project</p> <p>Participants invited to share experiences of trialling homebased tasks</p> <p>Finished session by thanking participants</p>

warn that pluralist focus group methodologies require more reflexive engagement with questions of epistemology and ontology. Indeed, a critical dialogue between AV and SB informed both the decision to pursue reflexive thematic analysis methods and the processes undertaken during the six phases of thematic analysis outlined below as well as in Table 3, which provides a visual representation of the analysis process.

Phase 1: familiarisation with data. Alongside reviewing video recordings and familiarisation with transcripts AV and SB discussed the analysis approach and reflected on having collected data from a small sample size, across two separate groups (people with dementia and their carers). We reflected that we were not using a pre-existing framework or code book, and the aim was to use an inductive approach, ensuring analysis was driven by the data. Having explored the methodological guidance (Braun & Clarke, 2021a, 2021b), we also sought advice from methodological experts by messaging Braun et al. directly. They advised that given the participants had been asked the same questions, and we were interested in their experiences as a whole, we need not consider the data separately. This informed our decisions on combining the data from people with dementia and their carers for analysis.

Phase 2: Coding. Both lead authors (SB and AV) read the entire dataset independently (Hall et al., 2005; Richards et al., 2015), commenting line by line on interesting features. Importantly, the coding was completed in an inductive manner, such that both AV and SB coded in a data driven way, rather being guided by any expectations or personal views. Following discussion between them about their observations, AV then compared the comments and extracted initial codes into one common document, with extracts/quotes to inform the next stage of analysis.

Phase 3: Identification of initial themes. Using a peer debriefing process, AV and SB discussed potential initial themes from people with dementia and carers respectively, and commonalities across the two participant groups (Cornish et al., 2013; Patton et al., 2015). AV mapped these initial themes onto two diagrams and identified common themes across groups and relationships between themes.

Phase 4: Refining themes. AV then produced a single mind map, starting to finalise themes and checked each against its codes and extracts. Given the language and communication difficulties of the participants with dementia, AV and SB felt the need to represent their voices but avoid filling in the gaps and making assumptions about underlying meaning. Therefore, both agreed it was vital to refer back to the dataset to

ensure the themes represented the data. This informed the refinement and checking process in Phase 4.

Phase 5: Finalising Theme Names. In finalising the theme names AV and SB discussed the main theme: Sense Making and how this was central to the entire study. An initial diagram was developed to illustrate this (see Table 3).

Phase 6: Writing up. During the writing up phase AV and SB selected quotes to best represent and illustrate the identified themes. Quotes from carers were sometimes identified as the clearest representation of a theme, however identified themes were underpinned by data from both participant groups. The authors attempted to achieve a balanced representation from people with dementia and their carers in the quotes chosen. Lastly, a figure representing the final themes and their relationships was developed.

Results

Participants

Five people with dementia were recruited to the study. Four participants attended with family members and one participant attended with a paid carer. Of the five participants, the four with family members attended all three meetings, whilst PWD3 and CP3, a paid carer, were only able to attend the first meeting. An overview of the demographic data for all participants is presented in Tables 2–4 participants with mild cognitive difficulties, 2 with moderate and one with severe cognitive difficulties according to MoCA scores.

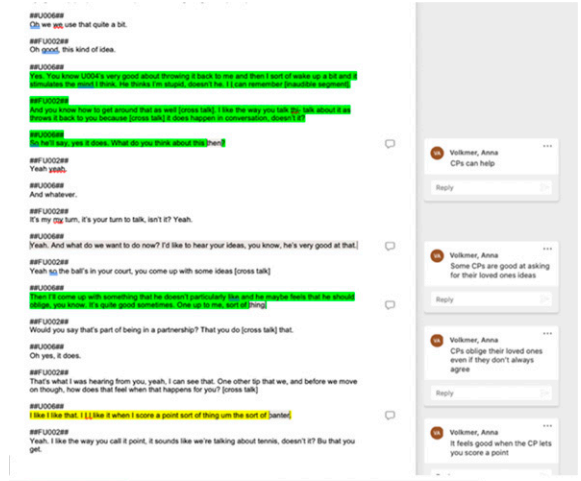
Themes

One central theme was identified in the data, Sense making, with four subthemes around it, 1. It's a journey, 2. You have to make the most of things, 3. Ask the right questions and it just flows-strategies in conversation, and 4. Dealing with people. As will be further discussed, they are dynamic themes, inter-related within the overarching main theme. Themes are illustrated with quotes from both people with dementia and their carers.

Sense making. This theme was central to all aspects of the participants' experiences of living and conversing with dementia. People with dementia also reported changes in their cognitive skills, providing reports of their communication difficulties (understanding what is said in this case), as evidence for their conclusion that they had dementia.

Table 3. Visual Representation of Work Undertaken Over Phases 2–6 of the Reflexive Thematic Analysis.

Phase 1: Familiarisation with Data AV and SB Viewed Video recordings and familiarised themselves with the transcripts.
Phase 2: Coding



Dementia is limiting

Limits where you can go and what you can do

You have to make the most of things Enjoy what you've got- be stoical

Non-language activities can still be great

QUOTE: Give it all you've got

Discovering buses and trains can allow you to make the most of things

QUOTES: we're not as bright as we used to be but so what? Just contribute, be able to laugh with others,

Emotions:

I find it physical

Physical things make you feel better e.g. yoga- its simple

Make you feel calmer

Make you feel more alive

Focuses on what you have left- cognitive strengths

Pets keep your mood up

Its irritating that i can't do things

Lights the atmosphere

Strategies

Some e.g. list writing keep you on the right track, keep routine, don't always work and things often go wrong

Strategies need to consider the person and the partner

QUOTE: Writing things down helps remember varied activities and is essential- before it was just a tool

Skills and competences

Driving

Driving is important as it means I am independent and not a burden

Change

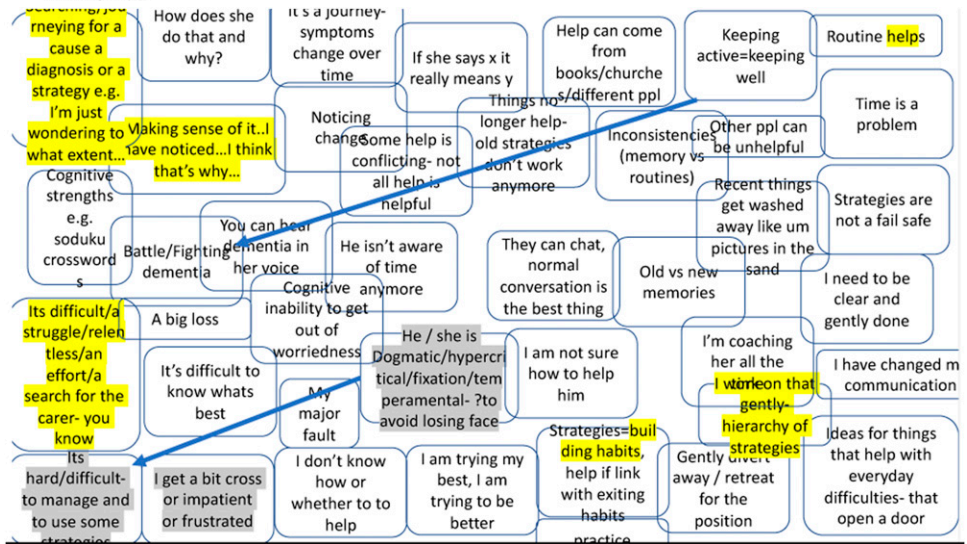
Loss of driving- more sig when you do not live in london

Other illnesses eg arthritis contribute

Change can also be good e.g. discovering trains and buses

I miss things I enjoy

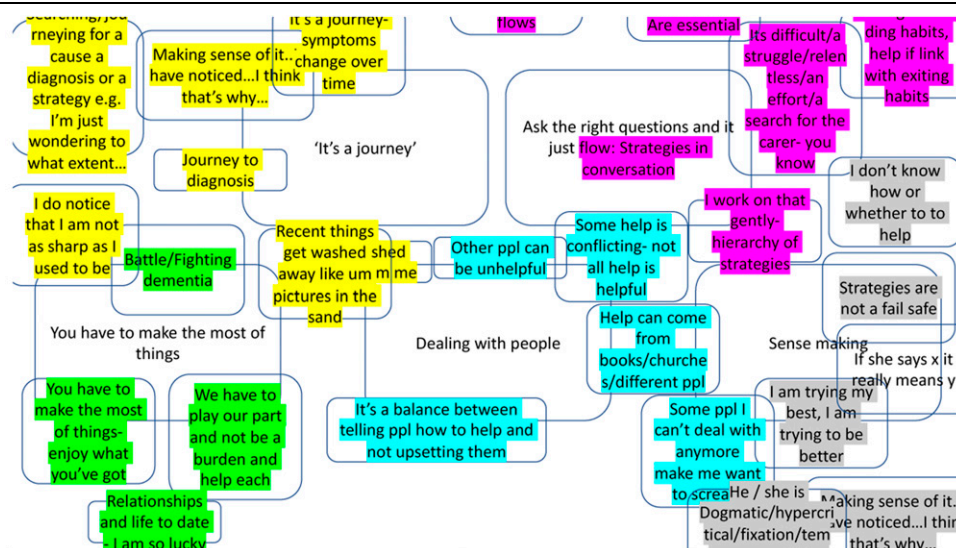
Phase 3: Identification of initial themes



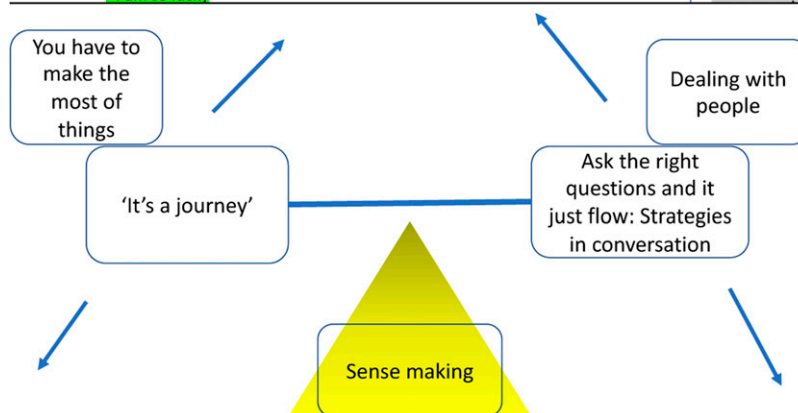
(continued)

Table 3. (continued)

Phase 4: Refining themes



Phase 5: Finalising theme names



Phase 6: Writing up

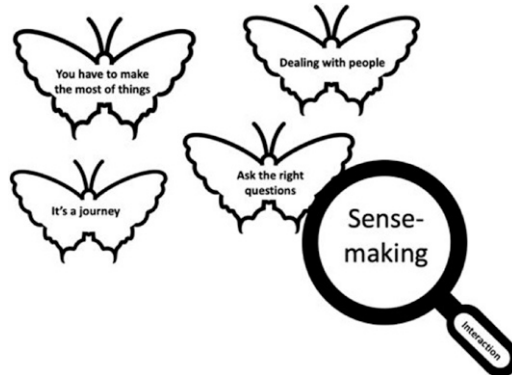


Table 4. Demographic Details of Participants with Dementia and Their Carers.

Participants with Dementia						Carer Partners						
ID	Age	Sex	Primary language use	Education	Diagnosis	MoCA score	ID	Age	Sex	Primary language use	Education	Relationship
PWD1	88	f	British English	Higher education	AD, diagnosis 1 year prior	21/30	CP1	81	m	British English	Higher education	Spouse
PWD2	79	m	British English	Higher education	lvPPA, diagnosis 2 years prior	1/30	CP2	78	f	British English	Higher education	Spouse
PWD3	70	f	British English	School until 16	AD, diagnosis 4 years prior	19/30	CP3	50	f	Hungarian	Extended education	Paid carer
PWD4	77	f	British English	School until 16	PCA, diagnosis 2 years prior	12/30	CP4	38	m	British English	Higher education	Adult child
PWD5	83	f	British English	Higher education	AD, diagnosis 1 year prior	18/30	CP5	79	m	British English	Higher education	Spouse

NB: PWD = Person with dementia; CP = Care Partner (family member or paid carer); f = female; m = male; AD = Alzheimer's Disease; PPA = logopenic variant Primary Progressive Aphasia (an atypical AD; [Rukhsanaite et al., 2021](#)); PCA = Posterior Cortical Atrophy (an atypical AD; [Crutch et al., 2017](#)); MoCA = Montreal Cognitive Assessment ([Nasreddine et al., 2005](#)). MoCA score of 18–26 = mild cognitive impairment, 11–17 = moderate cognitive impairment, 10 and below = severe cognitive impairment.

“I go to a lot of drama. And I do find that I don’t always follow what’s going on. Quite often I do but sometimes I don’t get the theme. Either I’m dim or I’ve got dementia and I think it’s dementia.”

(PWD3)

Carers provided accounts and observations that included reports of things they had said and ways in which their partners responded, thus making sense of behaviour through the lens of interaction:

“What is particularly noticeable is her short memory. Long memory can be very good. I’ll say ‘Who was that chap over there?’, ‘Oh that’s so and so’, ‘Oh thanks’. So long memory is quite good.”

(CP1)

Interactions between the person with dementia and their carers exposed changes in personality, routine, memory and language, and in order to understand these participants endeavoured to account for and make sense of their difficulties. Carers gave examples of how changes were played out through interactional behaviour, such as a person with dementia becoming “dogmatic”, “hypercritical”, “fixated” or “temperamental”:

“I mean certainly <name> has changed and become very dogmatic and very clear view on something. And so, whereas in the past, if we didn’t agree we would discuss it, I tend now to avoid it because I don’t think there’s any point.”

(CP5)

Carers also sought to account for their own interactional responses and reactions to the dementia. We observed them reflecting in order to understand and better support the person with dementia:

“I’m just wondering whether I overdo that. How far do you go to try to remind [them] what is going on or what’s happening or who’s coming to see us and that sort of thing. How far do you, you’re trying to help the memory, but I suppose maybe it’s not constructive.”

(CP1)

Similarly, people with dementia reflected on the support their carers gave them, recognising this support was provided through interactional responses:

“He’s tremendous, you know and he doesn’t fuff around me at all. He says ‘You get on and do, it you can do it yourself’, which I appreciate. I prefer that but when I do need help he’s always there, we’re very lucky.”

(PWD1)

Subtheme 1: It’s a journey. Dementia is not a static entity, meaning people with dementia and their families experienced a gradual progression of symptoms. Participants had travelled this journey for some time, experiencing many changes over months and years. The symptoms they observed were often viewed through interaction, for example repetitive questions or stories were interpreted as a change in memory:

“First, I think we thought that the stress was causing her memory to slip or maybe becoming quite er moody...but we noticed that she was talking like repeating stories quite a lot, you know, quite often minutes after she’d said them, which she doesn’t do so much now actually, it’s very strange. I guess because maybe she’s on medication it’s diagnosed as well.”

(CP4)

Changes were compared to a gradual erosion

“I did use the computer, for notes and things like that and now I do it and it’s basically washed away from me, I find it very difficult.”

(PWD5)

Certain things were more vulnerable to being lost on this journey, particularly recent memories or experiences:

“And of course, the longer ago memories is what he remembers better. Recent things you know get washed away like pictures in the sand really.”

(CP2)

This pilgrimage to a place of understanding, to make sense of what was happening, commenced the very first time participants observed a ‘sign’ of dementia. This journey continued during the process of getting a diagnosis and beyond, entering a period of strategy identification. Early in the journey people with dementia and their families actively searched for a reason to explain their symptoms. This long and rather drawn-out process was often time-consuming and difficult, as illustrated by this extended quote which again reveals sense making through interactional scenarios. Here, the response to an instruction to turn right when driving was interpreted as misunderstanding or not remembering:

“We all thought that he might be getting dementia and about three years ago he went to the GP and he had all the tests, you know, where they ask you, your name and address, what day it is and all that and they said ooh you know there might be some mild cognitive impair-, you know, likely nothing to worry about, come back in a year. Well I went back the following year and they said that’s the thing, I didn’t think there was much going on, and by that time we were quite worried, you know because he was driving and but even if you said ‘Turn right’ he’d go straight on, he could nearly always turn left, you know, things like that. I mean, he was

fairly safe, he wasn't driving too close to people or doing anything dangerous but he was just, I don't know, misunderstanding or not remembering the directions which was odd because he used to drive all over the country and he'd have a map in his head he'd know exactly where he was going and which way was north and everything, you know, much better than anybody else. So I said to the doctor, it's not good enough, I wanted tests [inaudible segment] MRI scan and they found considerable deterioration. So those tests at the doctor, about what day it is, don't reveal everything. So then we started going to the memory clinic and they put him on medication, which doesn't seem to make a lot of difference and so he's just gradually getting worse."

(CP2)

After receiving a diagnosis people with dementia and their families continued their journeys, often wearily. At this point the journey was less focused on an answer, and more on the hope of identifying support and strategies to help them manage the day to day of living with dementia:

"I suppose it's difficult, isn't it, to know when are you helping someone, when you try to remind them of something too often perhaps or let it ride. Are you helping them not to be upset or are you helping them with memory? I don't know."

(CP1)

This process was frustrating and difficult for people with dementia, as well as their spouses:

"Sometimes I write stuff for myself and I can't read my own writing. But everything has to be very specific when someone else writes it down for me. And I find that very difficult. That really irritates me"

(PWD1)

Subtheme 2: You have to make the most of things. Despite the dementia, people had many things in their lives that they valued. By making the most of these things (e.g. yoga in one participant's case), they could continue to enjoy a quality of life:

"You have to make the most of things - enjoy what you've got."

(PWD5)

Being a potential burden to people around them was, however, a real concern for people with dementia. They were aware that they needed to help themselves and one another to reduce this very real risk:

"We have to play our part and not be a burden and help each other"

(PWD1)

Carers recognized this effort, describing their partners as fighting against the symptoms:

"She's quite good and she can sit down quietly for an hour or two and I think she's aware since she was diagnosed, she had the early phase of dementia, that she is quietly trying to fight against it."

(CP1)

Relationships are formed and maintained through interactions and conversations, and people with dementia continually returned to this. They felt they had been lucky in their relationships to date and wanted to preserve and maintain these:

"So having other people there to help you, it's a lucky thing."

(PWD5)

Subtheme 3: Ask the right questions and it just flows - strategies in conversation. Maintaining the flow of a conversation is a collaborative effort and requires both participants within the interaction to take turns. Yet some people may be more or less skilled in adapting their conversation skills to support a person with dementia. No matter whether family, friends or acquaintances, people were described as differently skilled in asking the right questions and knowing how to support the flow of conversation in a way that a person with dementia would want:

"I mean I think struggling to think of a word it helps if the other person guesses."

(PWD1)

Building on previous habits was considered a useful way to embed new conversational strategies into everyday life. Participants stressed, however, that where they had previously used strategies as tools on occasion throughout life, they now depended on them:

"Writing things down helps remember varied activities and is essential - before it was just a tool."

(PWD1)

Unfortunately, some strategies were not always appropriate to use in all social situations, requiring people with dementia themselves to have a range of strategies:

"Yes, I lose the thread, you know, it's at a big drinks party and I have to pay attention at the big city dinners because I can't write anything down so when I'm talking to Mr So and So on one side because you'll invariably will have a man so I the great thing is to let them talk."

(PWD5)

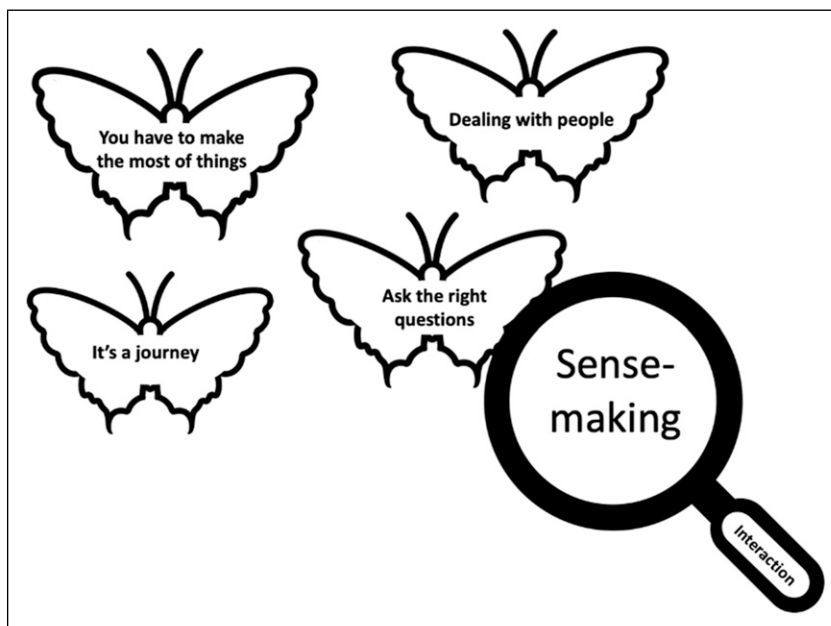


Figure 1. The themes identified from the focus group data with people with dementia and their carers.

Strategies were not always able to resolve or compensate for interactional difficulties associated with dementia:

“If I can’t gently steer it [the conversation] somewhere else, I’ll say ‘Oh you know, hold on a second, you know, where’s my phone?’. It just kind of, it just jolts it to a stop and that can work-ish.”

(CP4)

In fact, carers returned often to this idea of what conversational strategies worked and didn’t work, giving examples of how they dealt with frustrating or difficult communication, such as repetitive questions. Some participants had developed a hierarchy of strategies that they could employ. Yet, this relentless responsibility for managing conversation was difficult for carers:

“My major fault as I said I suppose is my patience. I’m ordinarily a patient sort of person, but at times I might get rather ..., now that she’s diagnosed, I try to row back on that because I must be part of that team spirit as it were. I used to say, ‘Well you should know about that we’re going out at this time’, and so on. But I don’t do that anymore, I tend to remind her more beforehand, building up on that, you know.”

(CP1)

Subtheme 4: Dealing with people. People with dementia and their families sought to make sense of the unhelpful behaviours of other family members or friends, experiencing these and describing them as everyday conversational exchanges.

They recognized the value of help even when what was offered did not actually help. This quote illustrates how a person with dementia experienced her friend’s behaviour in an everyday conversation, providing a scenario encapsulated via reported speech:

“And she’ll be there. And then she’s going, ‘How much have you put in there?’. And you know, I want to scream and I am really struggling not knowing how to deal with it because I do want her to help me, but I don’t want her to stand too close to me. It’s very odd.”

(PWD4)

The logical next step, instructing people how to help, wasn’t always considered the best way to maintain a relationship. Dealing with other people requires a delicate and balanced approach:

“I didn’t want to rock the boat. That’s why you tread gently. It can be tricky, can’t it. Because you’re right because sometimes people think they’re doing the best they can.”

(PWD4)

People with dementia also recognised that they had previously been the stronger communicators, supporting friends in conversations prior to the diagnosis and could no longer do so. Thus, they felt they had to make decisions about who to spend time with, and their social networks changed as they found some people harder to be around:

“She’s a very singular person at work and I think, you know, okay well I could deal with her before, you know, I’d say ‘Oh stop being so bossy’ or whatever, you know. But now I’m finding it very irritating and hard. You know, she comes and sees me but I think oh god’s sake sit down, while I’m sort of like walking round and she goes ‘Have you got that right?’, you know. ‘Shall I do that?’.”

(PWD4)

Despite some interactional losses, support and help was identified in different places. People reported starting new hobbies:

“It limits where you go and your accessibility to places so within the new framework that you’ve got, you’ve got to give it all you’ve got and really enjoy. I mean I do a breathing yoga class for two hours once a week”

(PWD6)

Participants described assistance from audio books that enabled them to continue to enjoy reading:

“And I do a lot of listening. Listening books”

(PWD8)

One participant felt able to explore the community via public transport, having lost her driver’s license. She felt this provided her access to a whole new world:

“But I have a new world now because I go everywhere on trains and buses and things and I’m very happy to do it.”

(PWD8)

Summary of results. The themes identified from the focus group data with people with dementia and their carers are presented in [Figure 1](#).

The magnifying glass represents sense-making, the main theme. In this study participants experienced and tried to make sense of dementia through the lens of interaction. This was illustrated through participant accounts of how they experience living with dementia, which revolved around reports of interactions they had experienced (e.g. ‘He says you get on and do it, you can do it yourself’) or considered hypothetically (e.g. ‘I’ll say ‘Oh you know, hold on a second, you know, where’s my phone?’). The butterflies demonstrate the dynamic nature of everyday communication, the constant change in focus for participants, depending on their previous and continuing journey with dementia. The subthemes weigh heavily at different times, meaning what is under the magnifying glass can change and is examined according to current context.

Discussion

Using a novel multimodal methodology to give voice to people with dementia, employing visual and experiential adaptations,

this study explored the experiences of people with dementia and their carers, and their perceptions concerning the impact of dementia on everyday conversations. The study contributes to an understanding that people experience living with dementia through interaction with others, and they characterise dementia based on observations of what changes for them in everyday conversations. In seeking to make sense of their experiences they report scenarios that involve explicit references to talking and (mis)understanding, often quoting what themselves and others might say in particular situations. Interestingly, despite finding repetitive questioning frustrating and difficult to manage, carers did not view this behaviour as a communication difficulty per se, but rather as a difficulty related to living with and interacting in the presence of dementia.

The multimodal techniques employed in this study, involving communication accessible materials, created an inclusive research environment that valued contributions from all participants. This approach meant that people with dementia could be asked the same questions as their carers, and given an equitable opportunity to respond. Giving voice to both people with dementia and their carers in this way improved the trustworthiness of the findings, which genuinely reflect the views of both groups of participants.

These findings extend our knowledge by providing an additional perspective on communication in dementia. Current research often describes language impairments in dementia ([Suarez-Gonzalez et al., 2021](#)) but has much less to say about their impact on the ability to communicate in everyday life. The few studies that have asked people with dementia and their families about perceptions and experiences of communication and social connections have revealed broad understandings of what people with dementia feel makes a good conversation. This has included, for example, feeling heard, and also that people with dementia work to manage the perceptions of those around them ([Alsawy et al., 2019](#); [Birt et al., 2020](#)). Similar to these studies we found that people with dementia in the mild to moderate stages were acutely aware of their communication difficulties and the responses of others.

Importantly, the findings of this study allow us to begin to appreciate how communication works between people with dementia and families during everyday activities. Participants described the ways in which dementia affects them from day to day as being played out in and through their interactions with others, both positive and negative. Carers raised concerns about whether their interactional responses such as reminding of appointments were really helping. People with dementia identified the effect that a person’s conversational strategies and prompts could have on them, which could mean the difference between carrying on with existing social relationships or curtailing them. This highlights the centrality of conversation – the vehicle for much of our interaction with others – to the lived experience of dementia. It also highlights the interdependence of the communication skills of both people with dementia and those around them, and the

importance of the context of everyday activities. Although primarily understood by people as a disease of the brain and memory (Langdon et al., 2007), dementia appears to be experienced as a disease of interaction, interfering with everyday activities and slowly robbing people of their relationships. McGee et al. (2023) argue that positive psychological interventions for people with dementia can improve quality of life, but only if tailored to leverage individuals' virtues and character strengths. We concur with Alsawy et al. (2019) and McGee et al. (2023) that researchers cannot design effective communication training programmes until we understand from people with dementia and their interactants how dementia plays out in their lives and relationships, enacted through daily conversations.

This study adds to the emerging repertoire of methods developed to capture aspects of people's lives with dementia, such as photography (Dooley et al., 2020) and video (Alsawy et al., 2019). Braun et al. (2017) have described these approaches as pluralism, enabling participants greater access to constructions of self and identity within the narrative. Whilst there might be differences of identity between participants in this study, such as carers' weight of responsibility in conversation versus people with dementia's awareness of diminishing conversational skills, these point to the same perception encapsulated by subtheme three; asking the right questions enables conversation to flow. Thus, employing this multimodal approach enabled equitable access to expression of self for people with dementia (Braun et al., 2017) and their carers, leading to the identification of common themes. Importantly, our participants with dementia were supported to share their experiences of dementia and conversations through group discussion, leading to rich data and new understandings. An approach such as ethnographic observation of people with dementia and their carers in conversation followed by clarifying interviews might be considered to be more supportive of people's ability to reflect given their dementia, but at least for our participants this would have underestimated their potential to participate in research. We acknowledge that a next step in this research could usefully involve observational methods to provide a complimentary individualised approach to reflection on conversation, using examples of specific interactional sequences as triggers for discussion. Communication disorders research is the site of much current innovation in techniques for research participation and patient and public involvement that give adults and children with communication difficulties and needs a voice, which could be further harnessed to enable the participation of people with dementia (Wilson et al., 2015; Lyons et al., 2022).

Limitations

A significant limitation of qualitative research methods such as focus groups (Galdas, 2017), particularly those involving

people with communication difficulties, where meanings may be interpreted rather than stated, is the risk of bias. This was anticipated and addressed through the use of pre-planned topic guides and trained speech and language therapy facilitators. Despite this, speaking about living with dementia is a stigmatized issue and people may not have felt able to be completely open and honest within a group setting.

In valuing all participant contributions, one risk is the over-interpretation and thus over-intellectualisation of what people with dementia tell us, given the presence of language impairments. Perhaps this over-interpretation or filling in the gaps is unavoidable as we strive to represent their voices, but it could lead us to attribute more than they are saying. However, the method of reflexive thematic analysis requires the analyst to seek deeper, latent interpretations than the purely semantic (what was said). One solution may be to paraphrase interpretations of the opinions of people with dementia given by another speaker during the focus group, that are then confirmed by the people with dementia, as a way of ensuring against overinterpretation (see for example Johnson, 2015).

It is important to acknowledge that as group facilitators AV and SB may have been susceptible to bias in the analysis process. The reflexive thematic analysis approach acknowledges bias and provides significant opportunity for discussion and peer debriefing, and the detailed description of the processes undertaken to maintain reflexivity are outlined in detail in the methods section.

Another obvious limitation to this study is the small sample size and the lack of diversity in terms of stage of disease, culture, ethnicity, socioeconomic status and languages spoken. All participants who fulfilled the inclusion criteria were included in the study and were not discriminated against based on any of these domains. However, future larger research studies should actively seek the opinions of people with different stages and types of dementia and their carers, who may have different experiences and perspectives. This should include investigating how residents in nursing homes may perceive communication difficulty compared to those living at home independently. Additionally, research needs to be undertaken with those from diverse communities to ensure that we can adequately meet all needs and generalize results to a diverse society.

Conclusions

This study proposes a novel multimodal, inclusive methodology, that gives people with dementia a voice, to share their experiences in qualitative focus group research. The study contributes to an understanding that people with dementia and their carers experience living with dementia through the lens of interaction and they characterise dementia and identify useful strategies based on observations of what changes for them in everyday conversations. Future research developing interventions for people with dementia and their carers needs to take account of the lived experience to better meet these needs.

Acknowledgments

We would like to thank the people with dementia and their family members and carers who participated in this study, and Sara Bunker for transcribing the focus group video recordings.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Alzheimer's Society Project Grant: AS-PG-16-004. AV is funded by an NIHR Advanced Fellowship (NIHR302240).

Ethics

The study was granted ethical approval by the UCL Research Ethics Committee (6015/001).

ORCID iD

Volkmer, Anna  <https://orcid.org/0000-0002-4149-409X>

Supplemental Material

Supplemental material for this article is available online.

References

- Alsawy, S., Mansell, W., McEvoy, P., & Tai, S. (2017). What is good communication for people living with dementia? A mixed-methods systematic review. *International Psychogeriatrics*, 29(11), 1785–1800. <https://doi.org/10.1017/S1041610217001429>
- Alsawy, S., Tai, S., McEvoy, P., Mansell, W., & Tai, S. (2019). 'It's nice to think somebody's listening to me instead of saying "oh shut up"'. People with dementia reflect on what makes communication good and meaningful. *Journal of Psychiatric and Mental Health Nursing*, 27(2), 151, 161. <https://doi.org/10.1111/jpm.12559>
- Bamford, C., Wheatley, A., Brunskill, G., Booi, L., Allan, L., Banerjee, S., Denning, H., Manthorpe, J., & Robinson, L, et al, PriDem Study Team. (2021). Key components of post-diagnostic support for people with dementia and their carers: A qualitative study. *Plos one*, 16(12), e0260506. <https://doi.org/10.1371/journal.pone.0260506>
- Birt, L., Griffiths, R., Charlesworth, G., Higgs, P., Orrell, M., Leung, P., & Poland, F. (2020). Maintaining social connections in dementia: A qualitative synthesis. *Qualitative Health Research*, 30(1), 23–42. <https://doi.org/10.1177/1049732319874782>
- Bjørkløf, G. H., Helvik, A. S., Ibsen, T. L., Telenius, E. W., Grov, E. K., & Eriksen, S. (2019). Balancing the struggle to live with dementia: A systematic meta-synthesis of coping. *BMC geriatrics*, 19(1), 295. <https://doi.org/10.1186/s12877-019-1306-9>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2021a). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative research in psychology*, 18(3), 328–352.
- Braun, V., & Clarke, V. (2021b). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, 21(1), 37–47.
- Braun, V., Clarke, V., & Gray, D. (2017). *Innovations in qualitative methods*. In the *Palgrave handbook of critical social psychology*, (pp. 243–266). Palgrave Macmillan.
- Brunskill, G., Wheatley, A., Bamford, C., Booi, L., Costello, J., Herbert, J., Tucker, S., & Robinson, L. (2022). On behalf of the PriDEM study project team how do we meaningfully engage stakeholders in developing a best practice approach to post-diagnostic dementia support? *Journal of Dementia Care*, 30(2), 24–27. <https://journalofdementiacare.co.uk/issue/march-april-2022>
- Cornish, F., Gillespie, A., & Zittoun, T. (2013). Collaborative analysis of qualitative data. In U. Flick (Eds.), *The SAGE handbook of qualitative data analysis* (p. 10). Sage.
- Crutch, S. J., Schott, J. M., Rabinovici, G. D., Murray, M., Snowden, J. S., van der Flier, W. M., Dickerson, B. C., Vandenberghe, R., Ahmed, S., Bak, T. H., Boeve, B. F., Butler, C., Cappa, S. F., Ceccaldi, M., de Souza, L. C., Dubois, B., Felician, O., Galasko, D., & Graff-Radford, J., Alzheimer's Association ISTAART Atypical Alzheimer's Disease and Associated Syndromes Professional Interest Area (2017). Consensus classification of posterior cortical atrophy. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association*, 13(8), 870–884. <https://doi.org/10.1016/j.jalz.2017.01.014>
- Day, A. M., James, I. A., Meyer, T. D., & Lee, D. R. (2011). Do people with dementia find lies and deception in dementia care acceptable? *Aging and Mental Health*, 15(7), 822–829. <https://doi.org/10.1080/13607863.2011.569489>
- Dooley, J., Webb, J., James, R., Davis, H., & Read, S. (2021). Everyday experiences of post-diagnosis life with dementia: A co-produced photography study. *Dementia*, 20(6), 1891–1909. <https://doi.org/10.1177/1471301220973632>
- Eggenberger, E., Heimerl, K., & Bennett, M. I. (2013). Communication skills training in dementia care: A systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics*, 25(3), 345–358. <https://doi.org/10.1017/S1041610212001664>
- Galdas, P. (2017). Revisiting bias in qualitative research: Reflections on its relationship with funding and impact. *International Journal of Qualitative Methods*, 16(1). <https://doi.org/10.1177/1609406917748992>
- Hall, W. A., Long, B., Bermbach, N., Jordan, S., & Patterson, K. (2005). Qualitative teamwork issues and strategies: Coordination through mutual adjustment. *Qualitative Health Research*, 15(3), 394–410. <https://doi.org/10.1177/1049732304272015>
- Johnson, F. M. (2015). What works in conversation therapy for aphasia, and how? Searching for mechanisms of change and active ingredients using tools and theory from behaviour change research [Doctoral dissertation, University College London]. https://www.researchgate.net/publication/333811016_What_works_in_conversation_therapy_for_aphasia_and_how_Searching_for_

- [mechanisms_of_change_and_active_ingredients_using_tools_and_theory_from_behaviour_change_research](#)
- Kindell, J., Keady, J., Sage, K., & Wilkinson, R. (2017). Everyday conversation in dementia: A review of the literature to inform research and practice. *International Journal of Language and Communication Disorders*, 52(4), 392–406. <https://doi.org/10.1111/1460-6984.12298>
- Langdon, S. A., Eagle, A., & Warner, J. (2007). Making sense of dementia in the social world: A qualitative study. *Social Science and Medicine*, 64(4), 989–1000. <https://doi.org/10.1016/j.socscimed.2006.10.029>
- Leavey, G., Corry, D. S., Waterhouse-Bradley, B., Curran, E., Todd, S., McIlpatrick, S., Coates, V., Watson, M., Abbott, A., McCrory, B., & McCormack, B. (2020). Acceptability and use of a patient-held communication tool for people living with dementia: a longitudinal qualitative study. *BMJ open*, 10(5), e036249. <https://doi.org/10.1136/bmjopen-2019-036249>
- Lyons, R., Carroll, C., Gallagher, A., Merrick, R., & Tancredi, H. (2022). Understanding the perspectives of children and young people with speech, language and communication needs: How qualitative research can inform practice, 24(5), 547–557. *International Journal of Speech-Language Pathology*. <https://doi.org/10.1080/17549507.2022.2038669>
- McGee, J. S., McElroy, M., Meraz, R., & Myers, D. R. (2023). A qualitative analysis of virtues and strengths in persons living with early stage dementia informed by the values in action framework. *Dementia*, 22(1), 46–67. <https://doi.org/10.1177/14713012221131857>
- McLellan, E., MacQueen, K. M., & Neidig, J. L. (2003). Beyond the qualitative interview: Data preparation and transcription. *Field Methods*, 15(1), 63–84. <https://doi.org/10.1177/1525822X02239573>
- Money, D., et al (2016). *Inclusive communication and the role of speech and Language therapy*. Royal College of speech and Language therapists position paper. RCSLT: This document was viewed on the RCSLT website August 2022. www.rcslt.org
- Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, J. L., & Chertkow, H. (2005). The montreal cognitive assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, 53(4), 695–699. <https://doi.org/10.1111/j.1532-5415.2005.53221.x>Chertkow.
- National Institute for Health and Care Excellence. (2018) Dementia: assessment, management and support for people living with dementia and their carers. NICE Guideline 97. Accessed 12/03/2020 <https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#supporting-carers>
- Nguyen, H., Terry, D., Phan, H., Vickers, J., & McInerney, F. (2019). Communication training and its effects on carer and care-receiver outcomes in dementia settings: A systematic review. *Journal of Clinical Nursing*, 28(7-8), 1050–1069. <https://doi.org/10.1111/jocn.14697>
- Office of Public Sector Information. (2005). *Mental Capacity Act 2005*. London: OPSI.
- Patton, M. Q. (2015). Variety of qualitative inquiry frameworks: paradigmatic, philosophical, and theoretical orientations. *Qualitative research and evaluation methods* 4th Eds. SAGE Publications; p. 109.
- Purves, B. A., & Phinney, A. (2012/2013). Family voices: A family systems approach to understanding communication in dementia. *Canadian Journal of Speech-Language Pathology and Audiology*, 36(4), 284–300.
- Richards, K. A., & Hemphill, M. A. (2018). A practical guide to collaborative qualitative data analysis. *Journal of Teaching in Physical Education*, 37(2), 225–231. <https://doi.org/10.1123/jtpe.2017-0084>
- Ruksenaite, J., Volkmer, A., Jiang, J., Johnson, J., Marshall, C. R., Warren, J. D., & Hardy, C. J. (2021). Toward a pathophysiological synthesis. *Current Neurology and Neuroscience Reports*, 21(3), 1–12. <https://doi.org/10.1007/s11910-021-01097-z>
- Samsi, K., & Mathorpe, J. (2020). Interviewing people living with dementia in social care research. *NIHR School for Social Care Research*. https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-methods-review_MR022.pdf
- Sellars, M., Chung, O., Nolte, L., Tong, A., Pond, D., Fertherstonhaugh, D., McInerney, C., Sinclair, C., & Detering, K. M. (2019). Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies. *Palliative medicine*, 33(3), 274–290. <https://doi.org/10.1177/0269216318809571>
- Silverman, D. (2021). *Doing qualitative research*. Doing qualitative research, 1–100. Sage Publications Ltd
- Suárez-González, A., Cassani, A., Gopalan, R., Stott, J., & Savage, S. (2021). When it is not primary progressive aphasia: A scoping review of spoken language impairment in other neurodegenerative dementias. *Alzheimer's and Dementia*, 7(1), article12205. <https://doi.org/10.1002/trc2.12205>
- Volkmer, A. (2013). Assessment and therapy for language and cognitive communication difficulties in dementia and other progressive diseases. Guildford J&R Press.
- Volkmer, A., & Broomfield, K. (2022). Seldom heard voices in service user involvement: The how and why of meaningful collaboration. Guildford J&R Press.
- Wilson, S., Roper, A., Marshall, J., Galliers, J. R., Devane, N., Booth, T., & Wolf, C. (2015). Codesign for people with aphasia through tangible design languages. *CoDesign*, 11(1), 21–34. <https://doi.org/10.1080/15710882.2014.997744>
- Young, T., Manthorp, C., Howells, D., & Tullo, E. (2011). Developing a carer communication intervention to support personhood and quality of life in dementia. *Ageing and Society*, 31(6), 1003–1025. <https://doi.org/10.1017/s0144686x10001182>
- Zimmerer, V. C., Hardy, C. J. D., Eastman, J., Dutta, S., Varnet, L., Bond, R. L., Russell, L., Rohrer, J. D., Warren, J. D., & Varley, R. A. (2020). Automated profiling of spontaneous speech in primary progressive aphasia and behavioral-variant frontotemporal dementia: An approach based on usage-frequency. *Cortex; a Journal Devoted to the Study of the Nervous System and Behavior*, 133, 103–119. <https://doi.org/10.1016/j.cortex.2020.08.027>
- Zuscak, S. J., Peisah, C., & Ferguson, A. (2016). A collaborative approach to supporting communication in the assessment of decision-making capacity. *Disability and Rehabilitation*, 38(11), 1107–1114. <https://doi.org/10.3109/09638288.2015.1092176>