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Bridging Communication Gaps: Methodological Challenges and Insights in Interviewing People Living With Dementia

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Abstract

As global populations age, the prevalence of dementia is increasing, highlighting the need for research that prioritizes the voices and perspectives of those living with the disease. Historically underrepresented, people with dementia offer unique insights and valuable narratives, despite the cognitive changes that impact their communication. Obstacles remain, however, for people with dementia to participate in research, a number of which have been noted in previous studies. In this article, we discuss the specific features of communication in research interviews conducted with people diagnosed with dementia. The authors of this article have interviewed people with dementia across various research projects, and this study adopts a collaborative approach by reflecting on interview experiences in thematic meetings. In addition, the study draws directly on interviews from our projects. The participants represent diverse ages, cognitive stages, and living situations, but they share the experience of living with dementia. As dementia advances, maintaining a coherent dialogue becomes increasingly challenging, conversations become fragmented and people with dementia can confuse the past and the present in their answers. Our analysis shows that despite the best intentions of researchers, a shared understanding in interviews can, at times, be challenging to find. This underscores the importance of flexible and responsive interviewing approaches that respect participants' unique experiences. Although people with dementia may not always answer the questions posed, they might still share meaningful insights about themselves or their experiences. During interviews, the role of the interviewer is crucial, as they must navigate communication gaps and ensure that the interviewee's voice is heard. Our findings demonstrate that meaningful research participation remains possible across dementia stages when researchers adopt flexible, person-centered approaches that prioritize collaborative meaning-making over conventional interview structures.

Keywords

dementia, people living with dementia, interviews, communication, collaborative approaches, challenges, methodology

Introduction

As the global population ages, the number of people with dementia is rapidly increasing, with over 55 million people in the world currently living with the disease (World Health Organization [WHO], 2021). This means that people with dementia are a growing and increasingly significant population group whose views and experiences should be taken into account in different areas of society. First, without access to their authentic experiences, almost all of our knowledge about living with dementia is based on second-hand information. Secondly, by telling their stories, they narrate their

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own values and attitudes and thus maintain their identities regardless of the progressing and potentially stigmatizing disease. Thirdly, their knowledge is also important for family and formal carers as well as others involved in the lives of people with dementia, as it can provide crucial insights into their everyday needs, preferences, and values. This understanding is essential for ensuring good quality care and services that support the dignity of people with dementia. Without including their perspectives in research, we risk designing support systems that are misaligned with their lived realities, potentially overlooking what truly matters to them (Westius et al., 2010; Wilkinson, 2002). Hence, there is a growing recognition of the importance of incorporating the perspectives of individuals with dementia into all forms of shared knowledge formation, research included. In this study, we examine the experiences of a team of researchers in interviewing people with dementia, with a specific focus on navigating communication gaps and exploring the challenges of achieving a shared understanding in interview situations where cognitive differences create complex communicative barriers.

Dementia is an umbrella term for several different dementia-causing neurodegenerative diseases. While cognitive decline and memory problems -particularly in Alzheimer's disease - are the most widely recognized symptoms, not all people with dementia present with these difficulties initially. Depending on the type of disease, people may instead show symptoms such as personality changes, hypersensitivity, or visuospatial and perceptual problems, as seen in frontotemporal dementia (FTD) (Torrente et al., 2014).

Problems with communication, and difficulties in producing or understanding language are also common across many dementia types. These may include difficulties such as finding the right word for objects, word comprehension, incomprehensible speech, worsened understanding of complex sentences, and loss of literacy skills such as reading and writing (Klimova & Semradova, 2016). Usually, the condition results also in changed reasoning and judgment, and worsened visuospatial skills (Klimova & Kuca, 2016).

However, these problems with language skills and communication mentioned above do not apply to everyone (Beuscher & Grando, 2009), and their degree of difficulty varies depending on the stage and type of illness (Ortiz et al., 2021). Dementia gradually impairs the cognitive functions necessary for executive control. Therefore, the dementia symptoms often affect cognitively and harms doing, like social interaction in many ways. These changes increase needs for practical help. However, skills of being, such as the ability to be present in the moment and express oneself emotionally in social relationships remain strong. People with dementia can thus express prevailing observations, desires, and emotions in habituated or embodied forms (Boyle, 2014; Hautsalo et al., 2025).

Other people's negative perceptions of dementia and people with it can affect their interaction with these people, for

example through dementia-related stereotypes and stigma (Farhana et al., 2023). People with dementia have often been excluded from research concerning them, and other people, usually their family members, have spoken on their behalf (Littlechild et al., 2014; Rivett, 2017). One of the primary reasons for the exclusion of individuals with dementia from research has been the concern regarding the reliability and validity of the data they provide (Digby et al., 2016). At times, people seem to think that difficulties in communicating thoughts equates with a lack of thoughts (Bottenberg, 2022). Involving people with dementia is still likely to be seen as complex and challenging due to the need for careful and critical consideration of ethical, methodological, and epistemological issues (e.g., Chandra et al., 2021; Halonen et al., 2024). Previous studies have also pointed out that cognitive assessments may not accurately reflect a person's capacity to share their experiences (Bartlett & O'Connor, 2010; Hellström et al., 2007). People with dementia can still tell their own stories, even if the progress of the illness would result in losing the details and timeline of their narration by, for example, mixing up elements from the past and present. Telling about one's own life includes talking about things that are meaningful in a person's life, one's core values, and related emotions. By telling others about themselves, their experiences and their conceptions of reality, people with dementia can express a sense of meaningfulness and continuity.

The narrations of people with dementia are rarely coherent and linear. Instead, they are multi-layered and sometimes contradictory due to various dementia-related changes in their lives (Hillman et al., 2018), especially as the disease progresses (Zwijzen et al., 2016). This opens up significant epistemological questions about the nature of knowledge. If the experiences or world of people with dementia differ from the so-called shared world, how can research capture and provide reliable insights into their experiences? What kind of interpretations of the shared world can be produced in research interviews? All interview accounts are, to some extent, constructed and shaped by social dynamics, including the desire to present oneself favorably (Bangerter, 2000; Goffman, 1959), and the quality of interview data is affected by numerous issues ranging from personal traits of the parties in interview situation to skills of the interviewer and the chosen interview method (Kuzmanić, 2009; Sparacino et al., 2025). Thus, there might actually be a risk that people with dementia are held to a higher standard regarding the validity of their answers than other interviewees. Their narratives can be more readily doubted, especially when fragmented or unexpected, whereas similar accounts by others might be seen as "incredible but true." This risks reinforcing epistemic injustice (Fricker, 2007). Rather than questioning their credibility, researchers could focus on how meaning emerges in interaction and recognise the co-constructed nature of all interviews (Boyle, 2014; Hydén, 2011).

Since people with dementia are often eager to talk about their experiences (Halonen et al., 2024), it is essential to adopt

interview methods that not only suit their needs (Cantley & Bowes, 2004; Groot et al., 2023) but also recognize their inherent communication capabilities. Conducting interviews with people living with dementia requires adaptability and sensitivity. The importance of the relationship created in an interview, the social setting, and practical strategies to make the situation easier are particularly crucial elements to consider (McKillop & Wilkinson, 2004). Researchers must navigate unpredictable thought processes, respond to signs of distress, and view the interview as a collaborative process. This involves co-constructing meaning with the participant, regardless of their cognitive limitations (Digby et al., 2016; Randall et al., 2006). Challenges such as digressions, memory lapses, and difficulties in staying on topic are inherent to these interviews, but they highlight the need for nuanced methodologies that honour the voices of individuals with dementia (Tarzia et al., 2013).

Recent scholarship has increasingly highlighted new ways to address these communication challenges in dementia research. These include methods that account for non-verbal communication, such as gestures and postures (Bottenberg, 2022; Groot et al., 2023; Spencer, 2023). Innovative approaches such as walking interviews have shown promise in facilitating more natural and empowering interactions, enabling people with dementia to express themselves more freely and maintain their sense of self (Brannelly & Bartlett, 2020; Odzakovic et al., 2020). Other qualitative methods, including ethnographic observation, photo elicitation, and various visual and sensory adaptations to interviews, have proven effective in generating rich insights while enhancing inclusion and supporting self-expression among people with dementia, aligning with participatory and emancipatory research approaches (Phillipson & Hammond, 2018). Comparable research outcomes, such as the generation of rich and self-expressive accounts, can also be achieved through interviews, provided that participants with dementia are treated as valued informants, engaged with respectfully and responsively, and that researchers adopt a flexible, person-centred approach while investing sufficient time in building rapport and trust (Beuscher & Grando, 2009; Hellström et al., 2007). Moreover, interviewing plays a central role in several emerging qualitative approaches, making it all the more important to advance research that explores its methodological potential in dementia studies.

This article focuses on research interviews, one of the most widely used methods in qualitative research. In dementia studies, there is a growing need for more nuanced uses of interviews; approaches that take into account the specific challenges related to cognitive impairment. Interviews are likely to remain central in involving people with dementia in research, not only due to their adaptability and practical advantages, such as ease of organisation and cost-effectiveness, but also because of their potential to support inclusive knowledge production. Recent scholarship emphasizes the importance of ethically attuned and epistemologically

sensitive interview practices, highlighting how relational engagement and co-constructed meaning-making can enable access to first-person perspectives on the lived experience of dementia (e.g., Beard, 2004). Despite their promise, this remains an under-researched area, and further methodological development is essential, particularly as interviews also play a crucial role in many emerging approaches.

While previous research (e.g., Cridland et al., 2016; Digby et al., 2016; Hellström et al., 2007; McKillop & Wilkinson, 2004; Novak & Wilkinson, 2019; Samsi & Manthorpe, 2020) has provided valuable insights into the development of interview methodologies, this article addresses particularities of interviewing persons with dementia which have not been systematically explored. There is critical need for a more focused examination of communication and interpretation barriers that emerge during interviews with people with dementia. The focus is specifically on exploring how researchers navigate communication barriers and work to establish shared understanding with individuals at various stages of cognitive decline.

By reflecting on our interview experiences and analysing interview data collected across multiple projects, we aim to identify and elaborate the specific communication challenges that disrupt meaningful dialogue and develop strategies for bridging these gaps. The article ultimately seeks to demonstrate how researchers can more effectively listen to and interpret the fragmented yet valuable narratives of people living with dementia, ensuring that their authentic voices are heard.

We pose the following research questions:

- (1) What kinds of communication challenges arise in interviews with people with dementia?
- (2) How can researchers bridge communication gaps and support direct communication with people with dementia and through carers?

By addressing these questions, the article aims to advance methodological approaches for navigating communication gaps and establishing shared understanding when interviewing people with dementia, thereby enhancing the meaningful inclusion and authentic representation of individuals at various cognitive stages in research.

Data and Methods

The idea of this article is based on discussions in a series of workshops by 'Listen to Me – Dementia as an Experience and a Phenomenon' which brought together researchers from different Finnish organizations in 2023 to 2024. The author team comprises researchers from social and health sciences backgrounds who have studied aging, care, and dementia including both doctoral and postdoctoral scholars. Our different disciplinary perspectives and varying levels of experience in dementia research enriched the collaborative

analysis. All the authors, except the second author, have interviewed people with dementia for their research in recent years. The work on this article began with discussions and sharing experiences of interviewing people with dementia in six Teams meetings. Notes were taken in each meeting, and these were followed up on at the next meeting. We found that it was particularly important to share our experiences and create a common understanding on the topics presented in this article.

The discussions were often related to questions of scientific theories on how knowledge is generated, how it is created in the interview situations and how interviews with people with dementia differed from other interview situations. According to Hulko (2004), there is a need to broaden the epistemological and ontological foundations of dementia research, incorporate insights from related knowledge traditions, and build theories that are rooted in the experiences and perspectives of those living with dementia.

This article is based on the authors' experiences of interviewing persons with dementia as well as on selected interviews from datasets collected by the authors. The projects that the authors have conducted in recent years include (a) interviews of persons with mild to moderate dementia living at home ($n = 19$), (b) interviews of persons with severe dementia living in nursing homes ($n = 8$), (c) follow-up interviews of persons with young-onset dementia ($n = 14$) in the initial stage of their illness, (d) interviews with very old persons with dementia in the advanced stage of their illness ($n = 8$), and (e) interviews of persons with dementia together with their spousal carers ($n = 17$).

Each of the separate research projects have been granted ethical approvals by local ethical committees (University of Jyväskylä, Tampere University and University of Helsinki) and research ethical viewpoints (ALLEA, 2023) were closely considered during the projects. This article is based on previously approved research projects and does not contain any new data collection. Therefore, this article was prepared under these existing ethical approvals. All participants in the various studies have given their written or verbal consent to the study, either personally or through next of kin. Process consent, as outlined by Young et al. (2019), refers to an ongoing ethical approach that ensures continuous and informed participation through regular check-ins with individuals living with dementia, recognizing that their capacity and willingness to participate may fluctuate over time. This approach was used specifically in one study, while others utilized traditional consent procedures.

Analysis

In this article we have used collaborative dialogue. This approach refers to processes in which researchers analyse the data together to produce an agreed-upon interpretation (Cornish et al., 2014). During the analysis we looked for similarities and differences in the data (Graneheim et al.,

2017). The main idea is that various perspectives are applied to the analysis and interpretation of the data, with the final interpretation emerging from this combination (Cornish et al., 2014).

The article originated at a meeting related to a development project aimed at strengthening the voices of people with dementia. The researchers participating in the project arranged a Teams meeting, where they began discussing interviews with people with memory disorders and related issues. The discussion gradually narrowed down to focus specifically on analyzing the interview situation.

In the second phase of the analysis, each author selected quotations from their interviews related to the research questions, bearing in mind the preceding discussions and shared notes. These excerpts were then grouped and thematized. We continued this process for two rounds before agreeing on the content of the analysis and the appropriateness of the excerpts. We chose interviews that contained unexpected points, gaps, anomalies or other points that the researcher found interesting in communication. While such challenges may be present in any interview situations, we focused on those that we perceived to be particularly relevant for interviews with people with dementia.

During discussions of our findings, we noticed that some excerpts and viewpoints did not align with any theme. After further deliberation, we refined the research design and excluded elements such as narratives and affective expressions from the analysis. The analysis was based on verbatim transcripts of audio-recorded interviews. We acknowledge that some aspects of communication – such as body posture, facial expressions, or eye gaze – could not be analysed. While audio allowed us to attend to tone, pauses, and hesitations to some extent, the lack of visual data limited our access to certain interactional cues. We focused instead on the communicative experiences as interpreted and recalled by the researchers, and on the verbal content and structure of interaction as reflected in the transcripts. We decided not to focus on the non-verbal communication, or contextual aspects of the interview setting (such as location, surroundings, or time of day), as these dimensions have already been addressed in previous studies and practical “how to” guides for interviewing people with dementia.

These interpretative choices also reflect the epistemological and ontological challenges of researching communication in dementia interviews. Understanding was often negotiated moment by moment, and the boundaries between shared meaning, ambiguity, and misinterpretation were not always clear. Instead of assuming a fixed or stable account of what happened in the interviews, we acknowledged that knowledge in this context is co-constructed, situated, and sometimes elusive. This was especially evident in the reflections where no direct quotation could fully capture the dynamic of the situation.

The discussion led us to ask again what issues, disruptions and differences emerged in the interview situation. We also

found that for some of our shared observations from the interview situations, we could not point directly to a suitable quotation. The observations consisted of the interview situations as a whole, not individual sentences or parts of conversations in the interviews. For this reason, the analysis section contains more of the authorial reflection than is typically found in qualitative data analysis.

Finally, the three themes were discussed together and agreed to be presented as such. Once the subthemes had been agreed upon through collaborative discussion, we searched for suitable excerpts to illustrate each of them. We do not have detailed background information on all participants, such as exact age, diagnosis or stage of disease. While our interpretations draw on all interview experiences from our collective datasets ($n = 66$ interviews), the analysis is illustrated with excerpts from eight different interviews. In the next section, we present the results with illustrative excerpts from the data. The quotes have been translated from Finnish. All the names of interviewees are pseudonyms.

Results

Navigating Linguistic Challenges of Communication

Acknowledging the stage of the disease is important, as it shapes how the interview unfolds. In the early stages of the condition, the interview may not be different from a situation with a person with intact cognition. The progression and stage of dementia affect the ability to articulate thoughts and answer interview questions. The participants may not know the exact stage of their condition and there is no particular reason why the interviewer should ask precisely about it or measure it (Halonen et al., 2024). Moreover, absence of disease awareness is common among persons with dementia. If a person with dementia does not recognize their symptoms or the impact of dementia on their daily life (Juva, 2013), they may think their life has not changed in any way and dementia does not affect their cognition. In a case like this, the interviewee might communicate in a way they consider to be coherent and describing recent events, but might from the interviewers perspective be hard to follow. This is the case with Aapeli, a person with moderate dementia and a former researcher himself, who says that he feels that dementia does not affect his life:

Researcher: Well, what do you yourself think, how does it [dementia] affect you. You said you go to shops and the like, but how does it affect your life?

Aapeli: I don't feel that it affects my life. Yes, I remember coming home and my route to come. I have accepted that it is determined by it.

During the interview Aapeli's sentences are not fully logically connected and he connects sentences in a way that is somewhat unclear to the interviewer. During the interview, it was evident that Aapeli's memory and the answers he gave

were significantly affected by his cognitive decline, although his speech was fluent. Yet, despite some inconsistencies in his speech, Aapeli talked about his life and things that were important for him as a person. For Aapeli, it was very important to keep up his identity as a researcher and continue to observe his social surroundings as an ethnographer. He even felt he was in the role of a researcher while in the hospital: *'I was doing field research in a way while I was there, talking in the hospital.'*

Based on our discussion, the stage of the disease affects the interview and advanced instances of the disease result in issues the researcher needs to be aware of. Inconsistency in the speech of a person with dementia may be related to temporal disorientation, leading to 'time jumps' in which the past and present are intertwined. Confusion about time, date, or day – or illogically connected sentences – raise the question of whose perspective on time matters most.

Eila is an elderly woman living with severe dementia in a nursing home. Eila had no communication difficulties, and the interviewer perceived her as being engaged in the conversation. She was attentive and answered the questions she was asked. She, unlike many others, recognises that she does not remember much. In the excerpt, she talks to the interviewer about her family:

Researcher: For how long were you married to your husband?

Eila: I don't remember exactly, but there is my son (points to a picture).

Researcher: Right there?

Eila: No, the last one.

Researcher: You have got one child?

Eila: One. I didn't get another.

Researcher: Does he have a child? Does your son have a child?

Eila: Look, I can't remember. The children are so big already. I think they are Jussi and Mikael. There are only two.

Researcher: So, they are adults already?

Eila: Or perhaps they were the wife's children.

Researcher: Has it been long since your husband died?

Eila: If I could only remember.

Eila's inability to recall details about her marriage and family highlights the impact of dementia on her ability to access past experiences. Eila's perception of time and relationships is subjective and fragmented. Losing details does not make Eila an inappropriate interviewee. She is capable of reflecting on and describing her life for the purposes of the research, but the researcher should ask different types of questions that do not rely on remembering specific details.

Asking about age, for example, may not be relevant when interviewing people with dementia. Researchers should validate the participant's experiences, recognizing the significance of what they share, even when it reflects altered temporal or spatial understanding, or mixing what is happening between human beings with cultural artifacts or mediated worlds – like the one on television.

Enni, an older woman, whose dementia has significantly progressed, is interviewed in a nursing home. When talking about her daily life in the care home, her thoughts are affected by things she sees around her during the interview:

Researcher: What do you usually do here?

Enni: There is so much to do. Anyway, there are some cars parked over there.

Researcher: Yes, we can see cars parked outside.

Enni: Yeah. Luckily the weather seems to be beautiful.

Researcher: Yes. Very beautiful. There's the sun and some blue sky ... beautiful autumn. Do you move around here? When I came here you were in the other room. So, do you move around here?

Enni: I believe I wander around here?

Researcher: Do you also go out from time to time?

Enni: Yes! It comes with the territory. You don't just.

Researcher: Can you go out by yourself or is there always someone to escort you?

Enni: I can go alone if I wish, but it would be nice if I marched like I watched those men who marched, and perhaps there were women, too. I don't know.

When Enni answers the question about going out, she goes back to what she had just witnessed on television. When the researcher arrived, Enni had been watching Queen Elisabeth's funeral on television, and the marching soldiers had probably impressed her. Perhaps when thinking about being out in the open air, the first thing to come to her mind was the marching men at the parade. Moreover, Enni is not able to go out alone anymore and the door of the care home is locked but the idea of being able to do that is probably important to her.

In the extract, Enni answers the researcher's questions by grasping at things she can see during the interview. Enni's responses reflect the cognitive and communicative challenges associated with severe-stage dementia. Her statements are often fragmented and may not directly address the researcher's questions. The question about daily activities is dismissed by simply stating that there is so much to do, and then the focus shifts to cars parked outside and the beautiful weather she sees through the window. Enni begins with a broad statement but quickly shifts her focus to a specific observation, suggesting possible difficulties in maintaining a topic or a preference for discussing concrete, immediate surroundings. The interesting

thing is how she uses her surroundings (such as cars and the weather) as a coping mechanism when she cannot handle abstract conversation. This suggests that concrete objects or items could facilitate the interview once the disease has progressed (see Hautsalo et al., 2025).

The excerpts presented here emphasize the importance of understanding the interviewees' thoughts within the context of their daily lives and experiences. The researcher's role in facilitating communication and interpreting the responses contributes to the co-construction of meaning and the validation of the interviewees' subjective experiences. Despite the challenges posed by severe-stage dementia, even Enni's engagement in conversation highlights her continued agency and presence within the social realm.

Another type of gap in communication may be the interviewee's difficulty to find words. This is not necessarily as difficult a challenge as illogical sentences because the lost words can be found with a little help from the interviewer. In her interview, Maria who has very mild symptoms of young onset dementia shares that she cannot remember words. The researcher asks a prompting question to encourage Maria to share her experiences.

Researcher: What kind of changes does memory disease lead to?

Maria: What I have noticed is that I have become a terrible cook. It's been a while now, I don't know how to... even the names of dishes, I can't remember. I made them at some point, I just can't say anymore. The kind where you put milk and flour, and you put it in the oven, and it becomes something like...

Researcher: Oven pancake?

Maria: Yeah, that kind of thing. And I made some for us at some point and I never remembered it. I've always got some kind of mnemonic, I had a pancake, I can't remember anymore. And then I forgot them, and I have all the mnemonics for so many words. For example, I have this little panda, that animal, and I never remembered its name. So, then I started saying that my son's name is Panu and then the D comes in and then I remembered the panda. I have these kinds of name memories, some of them I remember and some of them I forget.

Here, the researcher's prompt helps Maria recall the word she was searching for. This illustrates how interviewer support can facilitate communication, even when word retrieval becomes difficult.

The Role of the Researcher and Interview Dynamics

The discussion above between Maria and the interviewer demonstrates how the researcher's active engagement elicits responses about cognitive experiences. This example underscores the importance of supportive listening and shared

interpretation in facilitating communication with people living with dementia.

With people with dementia, the challenges increase as their vocabulary decreases and their understanding of words becomes more difficult as interviewing Fanni with severe dementia shows:

Researcher: So, if you could just say where you would like to live, how would you describe the place where you would like to live? What is it like? Is it the kind where you live now, like an apartment building?

Fanni: Do you mean at this age?

Researcher: At this age. Yes, or you can think of another age. You can also think of another age.

Fanni: You can think about it, but I don't...Where I've been is nothing but good to be. I can't complain. They take good care of us there. Do you know where they used to put the old people? In a home for the poor and sick.

While Fanni does not directly address the specific housing question, her response demonstrates meaningful engagement with the topic. She seeks clarification about timeframe, expresses satisfaction with her current care situation, and contextualizes her experience within historical knowledge about elder care. This example illustrates how participants with dementia construct responses that, though they may not directly answer research questions, often reflect their ability to use language meaningfully and share their lived experiences and understanding of their world.

In our experience, what often happens in interview situations is that, although the interviewer is pursuing a particular agenda, an interviewee's answers may open completely new perspectives or reveal things that were not expected and provides a new way of understanding the world.

Translating research concepts into everyday language is challenging, especially when doing so for people with dementia. Questions must be both understandable and respectful (Hulko, 2004), but even then, participants may interpret or respond in unexpected ways. For example, Eero, who has moderate dementia, responds to a question he likely doesn't understand by describing a picture on the bookshelf.

Researcher: Do you feel, Eero, that you can influence your own life and the things in your life?

Eero: By the way, I've been fishing, and I can see that one of my friends was with me at the time and still is, but we rarely meet. He caught an 11- and a 12-kilo salmon within 15 minutes.

This requires flexibility and a willingness on the part of the researcher to accept that the information they receive may differ from what a question originally intended. This flexibility applies, of course, to all interviews conducted in all kinds of research, but when interviewing people with dementia the

issue is more pronounced. Here, the role of the interviewer is particularly sensitive: one must allow the interviewee to tell their story without excessive direction, while also ensuring the interview remains relevant to the research. Moreover, this quote demonstrates the importance of accepting, as part of the process, that a person with dementia may answer something quite different from what the interviewer would like to hear or what they consider to be important for the research.

The Role of the Carer in Interviews

A person with dementia may participate in a research interview with their carer who can help in overcoming communication barriers, finding lost words or interpreting meanings. In the next excerpt, Tuulikki is being interviewed with her sister, who she also lives with. Tuulikki has moderate or severe dementia, and she has difficulties in communication especially in the evening when the interview took place, as her sister has previously informed the researcher. However, Tuulikki does not get confused even when the researcher asks questions that she does not fully understand or for which she cannot produce an answer with so-called conventional logic:

Researcher: Well, what do you think Tuulikki, what should people, other people know about dementia? Or what would you like to tell people about it?

Tuulikki: Well, I don't know. I mean, it's also something that you can think that now they're, now they're bla...I'm in the black darkness over there and I can't get home, and something like that. So then...No, what I mean is.

Sister: Yes, it's good that at least the neighbours know...

Tuulikki: Yes, the neighbours know, yes.

Sister: ...that they know how to help you inside, if...

Tuulikki: But I don't usually go into the dark.

Tuulikki articulates her thoughts about dementia despite her cognitive challenges, demonstrating how participation in conversation remains a fundamental way of connecting with others. It is difficult to know whether Tuulikki mentions being in 'black darkness' and unable to get home because she is thinking about occasions when she had literally been at her front door but could not get in because the key was lost in her purse – something her sister reported in the interview. Alternatively, being in the 'black darkness' may also be a metaphor of her experience of confusion and disorientation. Tuulikki is perhaps trying to say that 'you can think that now they're in black darkness'.

In another part of the interview, Tuulikki suddenly changes from talking about going for walks to talking about pink houses and how she would not like to live in her current location anymore. Later, outside the interview, it emerged that Tuulikki and her sister had been forced to move six months

ago to a more affordable apartment, which was not as comfortable as their previous one.

Sister: Not every day, but several times a week we go for a walk. But they're short, the walks, the walks themselves, they're about an hour and a half.

Tuulikki: We had a bit of a miserable time too, when there were three of these pink houses. So then, well, these were very difficult, when they were so many, how many months we had to be there, so that...(sister), tell me now, so that we couldn't...Uh.

Sister: Now I'm totally exhausted.

Tuulikki: Yes, when (laughs) how...how...But the fact that...Hm. Why don't I get that word. That it's not really...It's just that we shouldn't have to live here anymore, because I don't like it here...to be here.

Tuulikki reaches out to her sister to fill in the missing parts of her thoughts and the sister often acted as Tuulikki's 'interpreter' in the interview, but at this point she is unable to match her sister's thoughts. Tuulikki laughs, but at the same time she is annoyed at not being able to express her thoughts as she would like to. Anyway, Tuulikki is able to say something about houses and how having to live in a place that is not to her liking bothers her. She introduces a topic that is important to her into the conversation, even if it comes out in an unconventional way and needs some interpretation from the interviewer.

Anja has moderate dementia and lives with her husband, who was also Anja's carer. In the following excerpt from Anja's interview, she has some difficulties in explaining exact issues or details, partly due to missing words and partly because she is confusing different periods of time.

Researcher: How often do you go out for walks or spend time outdoors?

Anja: We have been outdoors, but now it's this pa, pa, pa...now it got mixed up. Anyway, we haven't been on walks in that sense for a long time. But, for example, when we were in the city, we went outdoors with the little ones, and we were very careful, and then it went well.

Researcher: Yes, yes, when you're outdoors with grandchildren.

Anja: They're quite big already. But anyway, I don't know how to put it, I can't say...In my opinion, it's just regular everyday life.

When beginning to answer the question about going for walks, Anja tries to say something about a current issue ("but now it's this pa...") but she could not find the words and got frustrated and left the story short. In a separate interview with Anja's husband, it became clear that Anja was having more hip pain than before and that the pain had reduced their outdoor activity. Anja was probably trying to express this in her interview. In this case, the interview with the spouse opens the door to an interpretation that would not otherwise be available.

In addition to helping the interviewer to interpret the meanings of possibly fragmented speech, a carer participating in the interview may help the person with dementia to understand the questions or discussed issues. In our experiences this often happened when interviewing a person with dementia together with their spouse carer. However, it sometimes remained uncertain whether the person with dementia truly understood what was being discussed, despite the carer's help.

It is not unusual in joint interviews for the carer to begin speaking on behalf of the person with dementia, either out of habit or to support them. This represents a critical challenge, but it is difficult to illustrate directly with a clear data quote, as it often manifests in what remains unsaid by the person with dementia when their carer speaks instead. In such cases, the person with dementia may not respond at all in the presence of their spouse, while in individual interviews they would likely have answered in their own words.

Perhaps on some occasions it is rather the spouse carer who answers the interview questions, and it is unclear whose voice is being represented. This dynamic can affect the entire interview discussion, as the person with dementia may be sidelined while the spouse carer, who communicates without difficulty, takes a more dominant role. In these situations, couple interviews may become challenging for the interviewer to redirect. Therefore, when planning the interviews and considering inviting the carer to join also, it should be noted that although interviews conducted solely with the person with dementia may not be as logically structured and may contain communication gaps, they may more likely reflect the authentic voice of the person with dementia. One possible approach is to conduct the interview in two parts or hold two separate interviews, as some of the authors of this article have done: the first including both the person with dementia and the carer, allowing for shared context and support, and the latter focusing solely on the person with dementia to ensure their individual perspective is heard.

Conclusion

In this article, we have explored experiences of interviewing people with dementia, focusing explicitly on the communication gaps that emerge during research interactions. We have reflected on how researchers can navigate these challenges in ethically and epistemologically informed ways and how they can bridge gaps and enhance mutual understanding in interview situations.

By building on our own experiences, we have shown how interviews with people with dementia are different from other interviews and have special features that the interviewer should be aware of and prepared for. The unique communicative dynamics require researchers to develop flexible and adaptive strategies. Our findings underscore the importance of viewing communication in dementia research as a collaborative process, where fragmented responses are not obstacles, but valuable insights into the participant's inner world.

The stage of a participant's dementia usually has a significant impact on the interview. In our experience, interviews with people in the early stages of dementia are almost identical to those with cognitively intact people. Difficulties increase as the disease progresses: the logical flow of conversation deteriorates, the ability to engage with abstract concepts diminishes, and responses become fragmented and illogical, making it harder for researchers to follow the participant's line of thought. Similar changes have been observed in previous studies. The speech of people with memory loss is rarely coherent and linear, and sometimes contradictory, as the disease progresses (Hillman et al., 2018; Zwijsen et al., 2016). Our study extends this understanding by highlighting how such changes not only present challenges but also open up alternative ways of understanding lived experience through affective and moment-bound expressions.

Based on our experiences, common research practices, such as asking for specific background information, may no longer be relevant or accessible, underscoring the need to adopt techniques that respect the participant's current abilities. We agree with previous research that unstructured and semi-structured interviews, alongside active listening, are preferred so that varying cognitive abilities can be accommodated (Cridland et al., 2016; Digby et al., 2012, 2014). We further argue that researchers must be ready to shift their expectations about coherence and linearity, and instead engage with the narrative in a supportive, exploratory manner. This invites researchers to rethink the types of questions posed. Instead of relying on memory-based prompts, questions can focus on feelings, preferences, or sensory and embodied experiences. Such questions support the participant's ability to contribute from within their current cognitive and emotional frame, and encourage spontaneous expression. This approach reframes the interview not as a test of memory, but as an opportunity to share perspective, experience, and meaning in the moment. Also using pictures or photographs in interviews may encourage the person with dementia to initiate their story-telling (Hautsalo et al., 2025).

Language skills deteriorate as dementia progresses, creating a gap between the researcher's structured questions and the participant's ability to respond meaningfully. Interviewers can better adapt to these communication challenges if they have knowledge of dementia symptoms and experience in interacting with people living with the condition. Our interviews revealed how participants struggle to recall common words or recognize familiar places. In such cases, the interviewer can help the interviewee by guessing what the interviewee is trying to say or by asking for more information. In addition, someone who knows the person can help with the interviews. We discovered that there are many ways in which carers can fill in and interpret the speech of the person with dementia. However, a third person present can change the dynamic of the interview (Nygård, 2006). The third party can also take too dominant a role and complicate the interview process, as it raises questions about whose voice is truly being

heard. Conducting interviews with only the person with dementia, despite the potential loss of logical coherence, may offer a more authentic representation of their voice. However, it is difficult to know in advance whether the presence of a third person is a threat or an opportunity. It may be a good idea to agree in advance, if possible, to interview the person with dementia alone.

In interview situations, there may be situations where it is difficult to find common understanding. Our article illustrates how people living with dementia and researchers often operate in different cognitive and experiential realms. For instance, participants may respond to questions in ways that reflect their lived experiences or memories rather than providing direct answers to the researcher's queries. The fact that people with dementia may live in a different temporal or spatial reality than the interviewer makes the interview process complicated. Participants may talk about past events as if they are occurring in the present, mixing different time periods in their responses. While this can make it challenging for researchers to follow the narrative, it also highlights the importance of focusing on the participant's meaningful experiences, as has been shown in previous studies (Beuscher & Grando, 2009). These narratives can reveal how individuals make sense of their changing world.

In our interviews, people with dementia sometimes described what they were capable of, even if other people knew it was not true. This raises important epistemological questions: must the interview account be "true" in the conventional sense to be meaningful? On the other hand, one might ask if everything is always true in an interview with a person who does not have dementia. Are we telling a similar interpretation of the reality when talking about something to a friend, to a researcher or to an occupational medical doctor? As in any interview, reality is partly co-constructed depending on the situation and the interlocutor. The meaning can also vary depending on what is being asked. Rather than trying to seek an objective truth, interviews should focus on meanings co-created between the participant and the interviewer – it is not the facts but the interviewees' experiences that count (Westiun et al., 2010). Understanding the intersubjective nature of the interview situation is crucial to obtain genuine knowledge of people with dementia.

While interview questions need to be formulated in an understandable and respectful way for people with dementia (Hulko, 2004), their responses may be unexpected, fragmented and irrelevant from a research perspective. Interviews with people with dementia may not always provide clear answers to research questions or results that are immediately applicable to the research at hand. Such variability emphasizes the importance of flexibility in interviews. Future research should also consider potential vicarious trauma for researchers working closely with people with dementia, as participants may share distressing experiences. Researchers must validate the responses of people with dementia, recognizing that fragmented or emotionally driven answers provide insight into

their lived experiences. This approach maintains the dignity of people with dementia as active research participants. Hubbard et al. (2003) has emphasized how, in order to acknowledge the varied experiences of dementia, there is a need for diverse strategies tailored to individuals.

Cultural and social norms affect research aims and shape research practices, reflecting broader discourses and debates. To ensure that participants' voices are included and heard meaningfully when interviewing people with dementia, even as their cognitive abilities decline, an interviewer must demonstrate sensitivity, respect, and flexibility (Digby et al., 2016). This approach enhances the ethical validity of research and strengthens the representation of people with dementia. Success in such interviews requires the researcher to be well-prepared, adaptable in framing questions, open-minded, and flexible in their approach.

Although this study benefits from the authors' diverse backgrounds and direct experience of interviewing, it lacks the voices of racialized, ethnic, and sexual minority groups (Hulko, 2004), with participants primarily being drawn from the Finnish majority population. Addressing this gap remains an important direction for future research. Previous research has focused on the experiences and world of people with dementia in the early stages of the disease (Novak & Wilkinson, 2019; Zwijsen et al., 2016), but the data in this study also include people with middle- and late-stage disease, which is the strength of this study.

The number of people with dementia is already significant on a global level, but their voices have not been heard in societal issues as much as they should be. This article demonstrates that interviewing people with dementia is not only feasible at any stage of the disease, but can yield authentic insights when approached with appropriate methodological sensitivity. In our experience, as we have shown in this article, information obtained from interviews with people with dementia differs from that gathered from individuals without dementia. Because the person with dementia lives in the moment, responses are also bound up with the interview moment, the words used in it and the immediate, visible environment. We invite other researchers to consider epistemological and ontological questions about the knowledge that can be accessed in interviews with people with dementia.

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Ethical Considerations

Each of the separate research projects have been granted ethical approvals by local ethical committees (University of Jyväskylä 498/13.00.04.00/2023, Tampere University and University of Helsinki) and research ethical viewpoints (ALLEA, 2023) were considered accurately during the projects. All participants in various research have given their written or verbal consent to the study, either personally or through next kin.

Consent to Participate

The article uses a variety of data. All of them have collected consent either in writing or orally and used observation to assess the participant's willingness to take part in the study.

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

Data Availability Statement

Some of the data is already openly available, but some is still used by research projects or researchers themselves.

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