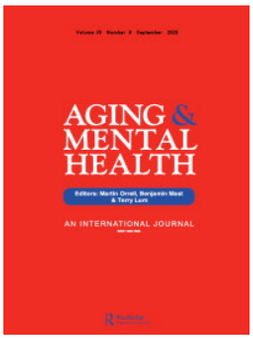

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Aging & Mental Health

ISSN: 1360-7863 (Print) 1364-6915 (Online) Journal homepage: www.tandfonline.com/journals/camh20

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To cite this article: Alys Wyn Griffiths, Louis Stokes, Divine Charura, Cara Gates, Yelena Mikhaylova-O'Connell, Sophie Jeffery, Esther Whittlesea Reed, Warren Donnellan, Emily Shoesmith, Jennifer O'Donnell, Elliot Webster & Heather Wilkinson (09 Sep 2026): How do people with dementia and their families reflect on their experiences of psychotherapeutic interventions?, Aging & Mental Health, DOI: 10.1080/13607863.2026.2729257

To link to this article: https://doi.org/10.1080/13607863.2026.2729257

Published online: 09 Sep 2026.

AGING & MENTAL HEALTH
https://doi.org/10.1080/13607863.2026.2729257

How do people with dementia and their families reflect on their experiences of psychotherapeutic interventions?

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ABSTRACT

Background: People living with dementia may experience low quality of life; some also experience symptoms of depression and anxiety. Psychotherapeutic interventions, which involve conversations with a trained therapist, allow people with dementia and their families/caregivers to receive emotional support. However, little is known about how people with dementia and their families understand, receive and respond to psychotherapeutic interventions.

Methods: Semi-structured interviews were conducted with people with dementia ($n=14$) and family members ($n=9$), either individually or in dyads. Data were analysed using framework analysis.

Results: Three themes were identified: navigating therapy with dementia, finding a place for the person with dementia in the therapeutic space, and creating and maintaining a therapeutic relationship.

Discussion: Therapists having specialist knowledge of dementia supported a meaningful therapeutic experience for people with dementia and their families. Assumptions about people with dementia being unable to develop and maintain a meaningful therapeutic relationship seem unfounded, and ensuring this is acknowledged within services is key to equitable access to interventions for families affected by dementia. Core competences are required for therapists to ensure that they are appropriately skilled to do so and feel confident in delivering this care.

ARTICLE HISTORY
Received 9 January 2026
Accepted 28 August 2026

KEYWORDS
Cognitive impairment; counselling; psychotherapy; psychosocial interventions

Background

Dementia is an umbrella term for a range of progressive conditions that may lead to a decline in cognitive abilities such as thinking, memory, and behaviour (Arvanitakis et al., 2019). Herein, we will refer to this group of conditions as 'dementia'. Around 57 million people lived with dementia worldwide in 2019, projected to increase to 153 million by 2050 (Collaborators GBDDF, 2022). Whilst currently incurable, it is imperative to provide meaningful and supportive non-pharmacological interventions (Eaglestone et al., 2023).

Following diagnosis, many individuals experience reduced quality of life, with high estimated prevalence rates of depression (37–41%), anxiety (37–41%) and apathy (43–59%; Leung et al., 2021). Identifying and providing specialised support to manage associated symptoms should be integral to post-diagnostic care (Azermai et al., 2012), and targeted psychosocial interventions (Oyebode & Parveen, 2019). However, evidence on the effectiveness and impact of interventions addressing these symptoms remains inconclusive (Abraha et al., 2017).

Learning to live with a dementia diagnosis is complex, and individuals may face difficulty processing and expressing resultant emotions (Weaks et al., 2015). Psychotherapeutic interventions, involving regular conversation between an individual and a counsellor or therapist about emotions, feelings, thinking, relationships, and life events, can support people in adjusting to life with dementia whilst reducing emotional distress (Cheston & Ivanecka 2017; Zammitt et al., 2026). Psychotherapeutic approaches, including cognitive behavioural therapy (CBT), person-centred counselling, and problem adaptation therapy (PATH) have shown promise within this population (see Cheston & Ivanecka 2017; Shoesmith et al., 2022).

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This research was funded by Alzheimer's Society, grant 585.

However, evidence for those with more severe dementia is limited (Shoesmith et al., 2022). Furthermore, poor reporting of dementia diagnoses and severity of cognitive impairment means it is unclear who is most likely to benefit from psychotherapeutic interventions (Shoesmith et al., 2022).

Psychotherapeutic interventions remain underutilised within clinical practice (Mathews et al., 2024), and provision in the UK is inconsistent, with interventions unavailable to around half of individuals post-diagnosis (Frost et al., 2019). There is often a misconception that people with dementia (Sommerbeck, 2006) and older people (Frost et al., 2019) are unlikely to benefit from such interventions. Stereotypical views and poor understanding of later life act as further barriers (Laidlaw et al., 2025). Given the limited evidence for effectiveness and limited guidance for clinicians, such interventions may not be appropriately advocated for (Laidlaw et al., 2025), which, coupled with inconsistent access, means that people with dementia do not always receive support. Furthermore, a range of adaptations may be required to ensure appropriateness for individual cognitive abilities (Tay et al., 2019), as individuals may have different perceptions of how, why, and whether they would like family members to be involved in this process {redacted}. A nuanced understanding of which therapeutic components are most meaningful and well-received by people with dementia is needed (Cheston & Ivanecka 2017).

Little is known about the experiences of people with dementia who receive psychotherapeutic interventions, which aspects are seen as particularly (un) helpful, and the value placed on interventions. Therefore, this study aimed to understand the experiences of people with dementia and their families, and identify features of meaningful therapeutic experiences.

Methods

Design

This study utilised qualitative semi-structured interviews with people living with dementia and their family members (individual or dyadic). Data were analysed using framework analysis (Ritchie & Spencer 2002).

Participants and sampling

Participants were recruited through NHS Trusts, professional networks, social media and community and support groups in England and Wales. Eligible participants had accessed psychotherapeutic interventions following their, or their family member's, dementia diagnosis, within the past five years. The principles of information power were considered during recruitment, whereby the richness of data and its relevance to the research question(s) determines the ultimate size of the sample we recruited (Malterud et al., 2016).

Interviews

Procedure

Interviews were conducted *via* video or phone call and lasted about an hour. A semi-structured topic guide was co-developed with PPI representatives, exploring experiences of receiving a dementia diagnosis, living with the condition, finding and accessing psychological services and the type of support they received. Participants received a £20 voucher in recognition of their contribution.

Data analysis

Data were analysed using framework analysis (Ritchie & Spencer 2002; Smith & Firth, 2011), a form of reflexive thematic analysis (Braun et al., 2023). All co-authors contributed to initial transcript coding, and AWG and YM-O developed the coding framework. Patient and Public Involvement (PPI) representatives also coded excerpts and refined initial themes. Coded data were charted into a framework matrix (Gale et al., 2013). Collaboration with PPI representatives and co-authors at each stage ensured a systematic and transparent approach (Smith & Firth, 2011).

Reflexivity

Our team brings together clinical and research expertise in dementia and systemic approaches to psychotherapeutic work. Whilst we recognise a range of ways in which we are diverse, we acknowledge the education and socio-economic privilege we hold. Many team members have personal experience of dementia, which may have shaped our reflections on service delivery within the NHS, where some of us work. We value psychotherapeutic interventions as post-diagnostic, whilst recognising their limited accessibility at the point of diagnosis. Throughout the analysis, we engaged in discussions that challenged our perspectives.

Ethical issues

Ethical approval was obtained from the University of {redacted} and {redacted} NHS research ethics committees. All participants provided written informed consent. Before interviews, participants were informed that challenging topics might arise and reminded of their right to withdraw. All participants were assigned unique pseudonyms to protect their identities and maintain anonymity; these were selected to be broadly age- and gender-appropriate without implying a specific cultural background.

Results

Participant demographics

Fifteen interviews with 23 participants were conducted; 14 people living with dementia and 9 family members (see Table 1 for participant demographics). Five interviews were conducted with people with dementia alone, and ten interviews were conducted with dyads. Participants first noticed symptoms between 2 and 11 years prior to participation, with an average of 5.8 years; and received their dementia diagnosis between 2 and 9 years prior to participation, with an average of 4.6 years.

Participants had accessed a range of psychological interventions, including problem adaptation therapy (PATH), Cognitive Behavioural Therapy (CBT), counselling, and Eye Movement Desensitization and Reprocessing Therapy (EMDR).

Overview of themes

We developed three themes: 1. Navigating therapy with dementia, 2. Creating and finding a place for the person with dementia in the therapeutic space, and 3. Creation and maintenance of a therapeutic relationship.

Navigating therapy with dementia

The knowledge, skills and roles of the person with dementia, their family members, and the therapist were discussed and reflected upon throughout the therapeutic process.

Table 1. Participant characteristics.

Characteristic	N (%)
Type of participant	
People living with dementia	14 (61)
Family members	9 (39)
Relation to the person living with dementia ($n = 9$)	
Husband	4 (44)
Wife	4 (44)
Daughter	1 (12)
Age	
35–49	1 (4)
50–64	10 (44)
65–74	7 (31)
75–84	4 (17)
85 +	1 (4)
Gender	
Woman	12 (52)
Man	11 (48)
Ethnicity	
White British	22 (96)
Jewish	1 (4)
Type of dementia ($n = 14$)	
Alzheimer's disease	6 (43)
Frontotemporal dementia (FTD)	1 (7)
Mixed dementia	4 (29)
Posterior Cortical Atrophy (PCA)	1 (7)
Vascular dementia	1 (7)
Not known	1 (7)
Type of therapy received (self-described)	
Problem adaptation therapy (PATH)	2 (9)
Cognitive behaviour therapy (CBT)	3 (13)
Counselling	12 (52)
Eye Movement Desensitization and Reprocessing Therapy (EMDR)	1 (4)
Couples therapy	2 (9)
Not known	*3 (13)*

Therapist knowledge of dementia

Participants reflected on the importance of therapists not only knowing about dementia, but being aware of different types of dementia, particularly reflecting on the impact of non-memory-related symptoms on them as an individual, which were felt to be more impactful on relationships.

> *'Certainly with my dementia, the emotions can go up and down like a roller coaster. You can be up in the sky one minute and down in the earth the next.' (Douglas)*

Where therapists lacked this knowledge, participants appreciated honesty around current levels of understanding and an openness to learning, which was particularly pertinent to people living with rarer forms of dementia.

> *'[Therapist] did admit straight away that she wasn't an expert in any form of dementia. Great that she pointed that out at the beginning. She didn't know anything about Lewy Body dementia. She soon looked it up because the following week, she'd read up on it.' (Keith)*

Where therapists had limited knowledge of different types of dementia, this was seen as a barrier to building and maintaining a therapeutic relationship, as people with dementia viewed that explaining their condition was disruptive to the therapeutic process. This often resulted in frustration and disengagement for the person with dementia, although they acknowledged the unique ways in which dementia affects each individual and the importance of therapists not treating the experience of a diagnosis as one that is singular and homogenous.

> *'[Therapist] knew nothing about dementia, they spent a lot of time asking me questions and hoping I would teach them everything they needed to know. I got angry because I felt that they were leaning on me and they should have been taking the burden off me and helping me, and I was educating them.' (Susan)*

Participants required support navigating the emotional aspects of dementia, which were often felt to be given less consideration or prominence. These symptoms presented challenges, embarrassment and discomfort for relatives within the therapeutic space. An important aspect of the therapeutic process was navigating changing and unpredictable emotions, and how this is meaningfully supported during therapy.

> *'[Therapists] also need to understand that dementia is quite fluid, especially with the moods, one minute we're laughing and joking, and then mum becomes overwhelmed and we're very much not laughing and joking anymore. Something has been said in a way that offence has been taken. We need help to understand*

that, strategies to come back from whatever has been said, done, spoken, unspoken…' (Lauren)

Others hoped that the therapist would take a more holistic approach, having compassion for their situation and seeking to understand the individual beyond their diagnosis of dementia, rather than focusing on their diagnosis as core to their identity. The importance of a person-centred and relational approach was reaffirmed as key to feeling included and accepted within the therapeutic process.

'You can stick a label on top of your forehead and say I have dementia. I know I have dementia. You know I have dementia. But you need to know that person, let's talk about you. Let's get to know who you are and find out about you, which is what [therapist] did. We spoke about me a lot because at the end of the day, I'm the one dealing with dementia.' (Richard)

Acceptance of dementia diagnosis

Participants sought acceptance of the future, reformulating their self-identity to incorporate the progressive nature of dementia. They acknowledged there was no cure for dementia, and so acceptance of the diagnosis was challenging and complex. For some, they worked on obtaining a much smaller goal of accepting *'the next day'* with dementia.

'I just want [Julie] to be happy and that's our goal. We both know the end game. We know there's no fix and we don't want a fix, but we just don't want… everything at the minute seems so desperate and we don't want it to seem desperate. We want to be able to get our heads around living with it cause we've no option. We have to live with it, don't we?' (Jonathan)

Through acceptance of the diagnosis, some participants were able to reevaluate their lives and contributions to society. This cognitive reframing of their abilities and place within the world allowed people with dementia to experience increased confidence in their roles and responsibilities in life.

'Acceptance that… there's no cure for Parkinson's disease or any form of dementia… So they've helped me to understand, though there's no cure, I can still live a useful, productive life.' (Keith)

Some people with dementia reflected that they felt like an outsider since diagnosis, and hoped therapy could help them feel reintegrated into society they deemed themselves to be disconnected from. In turn, they felt this would allow them to not need to *'hide [their diagnosis] anymore'*.

'I wanted therapy to help me understand that I am part of the normal world out there through those lounge windows. The worst thing dementia has done is make me feel removed from the real world.' (Keith)

Therapy provided a space for difficult conversations about the future. However, for some, specific dementia-related concerns remained, including losing connections with family. These concerns could be targeted within the therapeutic process, although the unpredictable nature of dementia added complexity.

'My biggest fear is that I won't know my family. I don't care what else happens, but to forget your family, or not know who they are … at the beginning, I was in a very bad place.' (Richard)

Aligning expectations of therapy

Whilst therapists discussed expectations with the person with dementia, some participants approached therapy with very low expectations for change. This was sometimes drawn from previous therapeutic experiences, but for many participants was associated with unfamiliarity with psychotherapy, and awareness of a lack of cure for dementia.

'I didn't think it would work, she wouldn't understand. But it has worked. She's taken me back to the issue, and made me unpack what I've done and what I should have done.' (David)

Other participants were less able to express clear wishes for outcomes, and focused on general improvements, such as low mood. This could lead to poor engagement if not clearly addressed by a therapist. For some, at the starting point of therapy, they were experiencing significant distress related to living with dementia.

'Researcher: What were you hoping to achieve through therapy?

Sharon: I don't know, just to improve my mood, cause my mood was so low, to the point that I wanted to hurt myself so… to change that. And it did.'

Others did not have clear expectations or goals, but hoped for reassurance, the development of coping mechanisms, or someone to talk to outside of their immediate family. They hoped to adapt their thinking to reduce maladaptive coping strategies, but required specific support and guidance from a therapist on how to do this.

'Daniel: It was just a way to talk, to refocus.

Rachel: Some reassurance?

Daniel: Yes, reassurance just working through issues like not getting stuck in the present or the past, you know… Learning to adapt.'

Some families went into therapy with *'an open mind'*, hoping to be guided by the therapist as to what they needed to adapt to life with dementia. This could interact with referral routes, where people with dementia may not be fully aware or informed about why their healthcare professionals felt they would benefit from therapy.

'Geoffrey: I don't think I wanted to achieve anything.

Christine: You were open-minded though.

Geoffrey: Yeah, I was open-minded enough to give it a whirl.'

Aligning expectations was important for understanding the aims and direction of therapy. Because this was often difficult during the first session, families appreciated ongoing collaborative discussion and reflection.

'We discussed what we wanted to achieve and that gave us some direction. It wasn't a long discussion because sometimes you don't quite know what you're looking for. You just know you need to offload or you're not quite feeling yourself so at first, maybe you're not too sure what you want to achieve, but as time goes on you figure it out.' (Daniel)

Expectations often centred on accepting the diagnosis, but also reflected wider family circumstances, including other health conditions, and how the dementia diagnosis fits within this broader context. Participants acknowledged that dementia did not exist in isolation, and that unresolved trauma existed prior to the diagnosis, which could be brought to the surface within the therapeutic process.

'Well, I wanted to feel better… I felt in my head that I had no dementia diagnosis. Then I was a wreck because of the [cancer] diagnosis my husband had, it was all too much. I couldn't cope, I wanted to feel better.' (Janet)

Where family members tried to direct the focus of therapy, this could create new relational tension. Such conflict could infiltrate home life, which was especially difficult when the person with dementia could not recall conversations within sessions that had upset others.

'I don't think the session was long enough, because we opened the can of worms and then it was: right, your hour's up, off you go. And it did leave a void for a few days because things were brought up, things were said, and it wasn't explained very well as to what they expected from the session or what we should expect.' (Lauren)

Supporting the person with dementia with uncertainty

People with dementia sought therapy to understand themselves post-diagnosis and to gain clarity on their thoughts, particularly the power their thoughts had over them. They anticipated being guided by the therapist to reduce their feelings of uncertainty or confusion. Therapy was seen as a potentially confronting, but necessary, intervention.

'If I talk to myself, I'm only telling things I want to hear. Hearing something that you don't want to hear is sometimes the best medicine. Because it makes you face facts. I want to learn about myself, how I deal with things.' (Richard)

Loss of control since being diagnosed with dementia was a significant concern for participants, who looked to the therapist to reduce this, acknowledging this was a complex and ongoing process. Participants experienced cognitive dissonance between the control they believed themselves to have over their own thoughts and life, and the ways that dementia impacted on this.

'Something that I've always had, is being in control and at times with dementia now, I don't have control. That hurts me greatly because I'm losing something which is part of me. I have no control when my mind just disappears. It's just… not there' (Richard)

Some participants felt a sense of *'abandonment'* following diagnosis, owing to a perceived lack of post-diagnostic support. The need for services or individuals to communicate with the person with dementia to help them make sense of the diagnosis, coupled with a sense of isolation, was recognised across participants.

'You're not ill in any other sense of the word to go and have anyone to talk to or anything. You're very much by yourself suddenly.' (Barbara)

Therapists supported the person with dementia to process new, and at times overwhelming, emotions. Dementia could affect the way participants experienced and responded to emotions, looking inward and placing blame on themselves.

'I used to get so frustrated and angry when I'd forget something or didn't know what I was talking about, and [therapist] turned that around for me.' (Richard)

Understanding the impact of therapy

Therapy encouraged people with dementia to confront distressing life events. This required understanding and sensitivity from the therapist, particularly when considering how dementia affects memory and recall. For some individuals, this could mean reexposure to distress across multiple sessions, which required careful management to ensure that the person with dementia felt safe to engage in the process, with confidence that they would be able to experience positive outcomes associated with therapy.

'Sometimes [therapy] wasn't always for the good, because things had to come out. I had to own some of the things that have been done to me. For so long I had just pushed it to the back of my head and then there it was all out, so that was quite hard in a lot of ways but then in other ways… having faith in myself that I could get through things.' (Janet)

Therapy enabled individuals with dementia to learn skills to assist with the identification and regulation of emotion. Where these had not been present across the lifespan, this could be challenging for

participants, and helped them to understand their own thought processes.

> *'David: We identified my triggers and discussed techniques, either to avoid them or to minimise the reaction.*
>
> *Researcher: And you would practice those techniques then on your own?*
>
> *David: Yeah, and I've succeeded so far.'*

Participants reflected on how engagement with therapeutic intervention protected them from experiencing a greater deterioration in their mental health, which they anticipated may be a component of the future with dementia.

'You can live a successful, independent life for as long as possible, that's the thing I've learnt. If it wasn't for those sessions, I would have gone into terrible depression' (Keith)

Creating and finding a place for the person with dementia in the therapeutic space

Where people with dementia could communicate their needs and preferences, therapy could be delivered, adapted and tailored to ensure that the person could experience meaningful change. Where this was not possible, expectations were not always well aligned, and therapeutic change was more challenging to achieve.

Negotiating a safe space for the person with dementia and their family to communicate

Therapy offered people with dementia a safe space to discuss issues their family were unable or unwilling to discuss. This helped to reduce feelings of anxiety, isolation and frustration that could usually be targeted towards family members.

> *'I tried to talk to my family about [death], they said, 'dad, we don't want to talk about that'. Well, I do. I need to talk about these things and with therapy I can.' (Richard)*

For others, therapy provided important scaffolding and a space to hold conversations with their families at home, where previously they lacked confidence or knowledge of how to hold these conversations.

'Sometimes you become blind to certain things, or you don't want to acknowledge them. That just opened up some things to me about how she was feeling and thinking. It helped us to open up a bit more, be honest with each other within the four walls.' (Daniel)

Tailoring therapy to the individual

People with dementia appreciated a tailored approach to their individual needs and preferences for therapy. This included scheduling sessions on preferred days and times to support engagement with therapy and minimise the impact of symptoms of dementia on the therapeutic process. Individuals felt listened to when therapists used learning from their previous experiences to consider which modalities or techniques could be more or less successful. For some, flexibility was also offered around where and how therapy was delivered; reducing concerns about being within the therapeutic space.

> *'At the time when I wanted to do [therapy] I just felt so low I think I didn't want to see anyone… a phone call was easier.' (Sharon)*

Some participants reported a preference for receiving therapy in the home. The home environment offered participants a form of comfort that may not be accessible in traditional therapy settings, which was felt to be particularly important within the context of challenges with confusion and orientation. This allowed participants to feel more able to express their feelings without the traditional power dynamics of a healthcare setting, leading to a sense of equality between therapist and client.

> *'[Therapist] came to my home, and helped me find a place to deal with this problem. I talked about my problems over a cup of coffee, I was very lucky.' (Etta)*

Awareness of the number of sessions available to them helped participants utilise these to be most effective for their needs. Participants appreciated the flexibility to increase time between sessions, allowing the family to spend time practicing techniques, ensuring they could gain the greatest impact from them. Flexible referral processes were well received, where families could request additional sessions; however, this was not standard practice.

'I've had a few sessions over the last three years with psychologists, and I can tap in and out of them as I want to. So if I start to feel down, I just speak to a psychologist, and we'll book in a few sessions.' (Daniel)

Navigating the involvement of family members

Acknowledging the many ways family members supported the person with dementia helped facilitate meaningful therapeutic experiences, particularly in the challenging context of navigating caring relationships. Some family members attended therapy as clients, as a dyad or a family, allowing a focus on their changing relationship and roles within the therapeutic space.

> *'I think they understood the dynamics, how our relationship can get frustrated or… anger might come in when you can't do things anymore.' (Susan)*

Some family members attended only to support communication rather than actively participate. Here, therapists might direct questions to the person with dementia but look to the family member for clarification, additional detail, or to ensure shared

understanding. This was particularly important where dementia affected clarity of communication. The importance of a clearly defined and boundaried role for family members who attended to support communication ensured that the focus of therapy could remain on the person with dementia.

> *'I join my husband's [sessions], but I'm just there to help him understand the conversation.' (Helen)*

In some cases, family members were included in early sessions, but therapists later chose to work solely with the person with dementia. This shift appeared driven by therapist preference, and could be challenging for family members to accept. They perceived that this change reduced their ability to understand the therapeutic process. This could reduce the quality of support they could offer to their family member with dementia, given increasing unpredictability in their emotional state.

> *'We used to go in together, then the therapist changed it to do some one-to-one stuff and, quite honestly, when I've seen [wife] come out sometimes, she was quite distressed, suddenly, almost broken.' (Stephen)*

Family members supported their relative by recalling discussions occurring between sessions. People with dementia found this helpful, but could become dependent on this recollection, at times questioning its accuracy.

> *'I find that quite difficult because that's all gone by the next month… My husband fills me in on what we had been speaking about.' (Janet)*

However, for families attending as a group, not all members contributed equally. This could inadvertently cause relational challenges, where some family members felt they were being more vulnerable than others.

> *'I don't know what [son-in-law] took away from [therapy], he didn't participate as such. I think it's an awkward position for a son-in-law to be in, I think he was just observing and hearing.' (Janet)*

One couple attended therapy together, which they considered appropriate given the nature of the dementia diagnosis, which was felt to be a shared experience.

> *'[Therapist] asked how does it affect her, how does it affect me, because, at the end of the day, this disease is affecting us, not [Julie], not me, it's affecting us.' (Jonathan)*

Family involvement was sometimes flexible, depending on the focus of the session. For one couple, this approach led to important breakthroughs in understanding the behaviour of the person with dementia.

> *'Sometimes it was just one-to-one, but other times [therapist] asked if I would come in. It was during those therapy sessions that I learned things about [Janet] and what she had gone through that she'd never disclosed in forty-two years of marriage.' (Stephen)*

Another couple benefited from brief individual conversations with the therapist at the end of each joint session. This allowed for a check-in with each individual's emotional state and ensured containment of emotions within therapeutic sessions.

> *'She [therapist] did something which I thought was great at the end of each session, she said: right. I want five minutes alone with each of you. It's difficult, isn't it? To get the balance right when we're both talking together. But that was an opportunity for [Margaret] to offload to [therapist] what she thought without upsetting me and it was my chance to talk to [therapist] without upsetting [Margaret].' (Stanley)*

However, the impact for family members of seeing their loved one experiencing distress was also acknowledged. They looked to the therapist to bring awareness of and make sense of the person with dementia's emotions, which could be overwhelming to them.

> *'She has anxiety and lack of self-worth, she's always waiting for somebody else to do the things that she thinks she should easily be able to do. And when you can't do them things you think: well, what's my point? Why am I here?' (Jonathan)*

Managing the therapeutic process

Therapists needed patience with the slower processing speed some people with dementia experience, which affected participants' ability to engage in conversation and hold multiple perspectives simultaneously. Being able to bring the person with dementia back to the topic of discussion sensitively was deemed important.

> *'Give me time to express myself, because when you ask me questions I start to answer and I've immediately forgotten the question, I'm probably going to go off on a tangent.' (Keith)*

In retrospect, some people with dementia felt they had not been ready for therapy when it began, and appreciated the therapist's perseverance in supporting their readiness to change. Engaging in this process could be confronting, and required patience and openness from the person with dementia.

> *'Even though I was saying nah, rubbish… I learned very quickly you don't always get the answers that you want to hear. You've got to be big enough and ugly enough to say to yourself, actually, what they're saying is right, you don't want to hear it.' (Richard)*

Opening sessions with a weekly recap or reflection was difficult for many people with dementia. Family members often felt uncomfortable; unwilling

to speak on their behalf, but also concerned about them feeling embarrassed when unable to recall details.

'[Therapist] would start off and say to [Margaret] 'how have you been this week?' And I'm thinking she won't remember.' (Stanley)

Creation and maintenance of a therapeutic relationship

Whilst the therapeutic relationship is a core component of all therapy, this was felt to be particularly pertinent for people with dementia to ensure they felt emotionally safe to engage in the therapeutic process.

Creating and maintaining a sense of safety

Many people with dementia had not received therapy pre-diagnosis and were unfamiliar with the concept of psychological safety. Quickly feeling safe to share their issues with a trusted individual was essential.

> *'She just came in, sat down next to me and talked about my problems. She was comfortable and listened to me.' (Etta)*

When trust was established early in the therapeutic relationship, people with dementia were reassured that any intervention offered was appropriate, believing the therapist would prioritise their well-being when they could not advocate for themselves. Where participants were experiencing significant emotional distress, they gave control over to the therapist. Developing, trusting and maintaining a sense of safety was key to this.

> *'I'm so well looked after by that team, I felt they were only ever going to do what was good for me and I ran with it because I was in such a dark place that anything would have been better than staying where I was.' (Janet)*

For others, the idea of therapy initially provoked concern or fear, often linked to preconceptions about mental health support. A sense of physical and psychological safety emerged only after meeting the therapist, experiencing warmth and openness, and engaging in the intervention.

> *'It frightened me, when you went through the main [hospital] doors there was a sign that said 'psychiatric'… that word put me right off. I thought, what am I heading into here, am I going mad, crazy? I didn't know what to expect. But it was the best move, it was completely the opposite, everybody was so friendly, so helpful, so informative… so caring… And that made a huge difference.' (Keith)*

Endings were particularly challenging for people with dementia, and required therapists to manage discussions about the transition with particular care, sensitivity and skill.

> *'As you near the end of therapy, they say, OK, we're coming to the end now, and then the end session is a bit like taking the rubber ring away from you when you're swimming. You've then got to decide, am I going to drown or am I going to swim?' (Janet)*

For some, limited clarity and discussion about endings left them feeling unable to detach at the close of therapy. They felt the therapist should have managed this differently to support them better, identifying signs of dependence or reliance on the therapist and actioning a plan to address this.

> *'I noticed that I became dependent on them, which was not healthy at all. When I had to say goodbye to the CBT therapist, it really threw me.' (Susan)*

This was especially difficult when participants felt they had not received enough sessions to address their concerns and were left without a clear plan for further support.

> *'They opened this can of worms and then were like, go and get on with it.' (Janet)*

Selecting an appropriate therapeutic approach

Therapists often suggested novel approaches, which required clear explanation and reassurance to build willingness among people with dementia. Participants felt reluctance towards, concern about or lack of belief in certain modalities before trying them. They reflected on the importance of openness to new techniques and experiences.

> *'[Therapist] said please, please try mindfulness. Scanning my whole body in a relaxed position, lying down. And I thought this is absolutely brilliant.' (Keith)*

Participants with prior therapeutic experience felt this could inform modality choice, as they felt empowered to discuss this with confidence and advocate for their preferences.

> *'They didn't offer me CBT cause I'd had it before and it didn't work for me.' (Sharon)*

However, participants were not always aware of the therapeutic modality or its purpose. For some, expectations did not align with the therapist's chosen approach, which affected their experience and their sense of the therapy and therapist's suitability for them.

'She hadn't got a clue about dementia, how you feel and how it affects you. She didn't go through the route of bereavement and loss. She just seemed really at a loss to know what to do. She did try CBT… these are your feelings, this is why you are feeling this and that, but dementia doesn't always work like that.' (Susan)

Trusting the process

Therapists needed to clearly communicate the complex emotions that therapy may bring, especially for those with low mood and confidence. For some, initial reactions to therapy could increase these feelings, and create concern that therapy was not 'working' for them.

> *'I suppose you've got to go a certain way before you can start coming back through the other side of the tunnel.' (Stephen)*

Participants trusted therapists to help them navigate therapy without creating more distress, despite knowing life with dementia will get *'harder and harder'*. For some, attitudes towards therapy were based on whether they saw noticeable changes. Without this, they were unlikely or unwilling to continue.

> *'We didn't really have any sort of preconceived ideas. It was just a case of, we'll see what they've got to say and if we like what they're saying, we'll carry on. If we don't, we'll stop.' (Jonathan)*

For others, change occurred quickly once they began seeing a therapist, leading to noticeable shifts in their perspectives and beliefs about living with dementia.

'I noticed the change quite rapidly. It sent me down a different avenue, made me believe I can live successfully. This is why I'm so grateful for all the psychological intervention.' (Keith)

Discussion

This study explored the experiences of people with dementia and their families who had received post-diagnostic psychotherapeutic interventions, from their own perspective, to identify and understand features of meaningful therapeutic experiences.

Navigating therapy with dementia was often complex. Aligning expectations of therapy ensured that both the therapist and client agreed on what might be feasible as an outcome of therapy, but also what this process might look like (Mathews et al., 2024). People with dementia emphasised the importance of addressing losses in ability or changes in identity that had arisen since their diagnosis, developing and implementing coping strategies, and identifying sources of support that could ensure they were able to stay psychologically well (Birtwell & Dubrow-Marshall 2018). Participants viewed therapy as a space to reconnect with the world that they felt disconnected from since their diagnosis. A sense of loss was shared by participants, and many focused on uncertainty in their place in society, hoping therapy could support them to resolve this. However, caution is needed when promoting the dominant narrative around living well with dementia (Bartlett et al., 2017), as whilst many people with dementia may be striving for or achieving this, the experiences presented here suggest that significant distress can also be present, which should not be minimised or ignored.

The positioning of the person with dementia within the therapeutic space depended on their capacity to engage with the process, their communication abilities, and on the role of family members. Individualised, formulation-led, person-centred approaches, which centre the experiences of the person with dementia, were essential for meaningful change, and participants reflected on this as a surprising part of the therapeutic process (Mathews et al., 2024; Shoesmith et al., 2022). Family involvement varied: some were welcomed, others felt excluded, despite clear clinical benefits to their inclusion (Cheston & Ivanecka 2017; Webster et al. in press), and systemically informed approaches may offer a way to ensure each family member feels included in a way that the person with dementia is comfortable with (Ball, 2024; Jeffery et al., 2026). Whilst adaptations within sessions are often required, such as changes in communication style or simplifying techniques (Tay et al., 2019), participants here valued tailored support delivered with patience and kindness. This aligns with evidence that people with dementia benefit most from therapy that is tailored to their abilities, preferences and wishes (Mathews et al., 2024).

Establishing a strong therapeutic relationship was central to positive experiences. These findings challenge widely held assumptions that people with dementia cannot form or sustain such relationships, echoing recent evidence that this is feasible, although this requires a sensitive, highly skilled therapist (Griffiths et al., 2021; Mathews et al., 2024). Core therapeutic skills, including empathy, unconditional warmth, and psychological flexibility (Mathews et al., 2024; McKenzie & Brown, 2021), are fundamental. Whilst these are core skills that would support development of a therapeutic relationship with any individual, the progressive and unpredictable symptoms associated with dementia combined with the communication, language and speech challenges many people experience (McKenzie & Brown, 2021), mean that these core skills are particularly important when working with people with dementia (Charura et al., 2026).

Clinical and research implications

This study reinforces the need for therapists to have specialist knowledge of dementia, consistent with recent work to define core competences for therapists working with people with dementia (Shoesmith et al., 2022). This work has recently taken place (Charura et al., 2026), resulting in core competences

in four areas: knowledge of dementia, therapeutic techniques and skills, therapeutic relationship and scope of practice; at three levels, generic, specialist and leading (Charura et al., 2026). Evaluation of their implementation in practice is now needed.

There is concern that people with dementia may enter therapy without understanding why they were referred, what realistic expectations look like, or what therapy can offer them, leading to unclear expectations. Therapists should elicit or co-develop expectations to clarify goals, using relational communication skills, and ongoing training and specialist supervision (Mathews et al., 2024). Further work is needed to understand which components of therapy are most meaningful for people with dementia (Cheston & Ivanecka 2017), to clarify which modalities may be particularly beneficial (Mathews et al., 2024). Longitudinal research, working closely with families from referral, and understanding barriers and facilitators to meaningful engagement could inform service design. This is particularly important as assumptions and stigma surrounding the suitability of people with dementia for psychotherapeutic interventions, may unintentionally create inequalities of access (Charura et al., 2026).

Future research should also investigate systemic barriers and facilitators to referral, including the effects of waiting lists or unclear referral pathways. Specific training needs for staff working in services where people with dementia are regularly seen, such as older adult services, should be clearly identified. However, given people with dementia, particularly those diagnosed with young-onset dementia, may have children and young adults in their families, the needs of staff working in non-specialist services, such as Child and Adolescent Mental Health Services, should be explored.

Limitations

This study has several limitations. Although we aimed to capture experiences across different therapeutic approaches, many participants were unaware of the specific modality they had received, and some had engaged in multiple interventions both before and after diagnosis. Nonetheless, participants consistently emphasised the primacy of the therapeutic relationship over modality, aligning with the evidence that the therapeutic-client relationship is more influential than the specific approach used (Paul & Charura, 2014). This has important implications for practice, and ensuring that people with dementia are offered a range of therapeutic approaches, where appropriate. Future research should consider seeking permission to contact participants' therapists, in order to gain clarity on which modalities they would seek to use with clients with dementia.

The limited diversity of our sample also raises limitations. Whilst we sought to obtain a sample who were diverse in many ways, our sample was overwhelmingly White British, and those with dementia tended to be younger. Inequalities in access to psychotherapeutic services for Black, Asian and minority ethnic service users are well established (Naz et al., 2019), and attitudes towards psychotherapy may differ. This is particularly important where disclosure of mental health concerns outside of the family are unusual, or services are mistrusted (Brijnath et al., 2022). These inequalities, when combined with poor dementia diagnosis rates within these populations (Pham et al., 2018), may mean that individuals are less likely to be receiving appropriate assessment, diagnosis and post-diagnostic care. Significant work is required to address these inequalities in care, specifically when considering psychotherapeutic interventions (Zammitt et al., 2026).

Participants first noticed symptoms four to eleven years prior, bringing a range of experiences of dementia, time to obtain and receive a diagnosis, and access to a range of service provision. However, all participants were able to engage meaningfully in a semi-structured interview; therefore, they were not experiencing the most significant symptoms of dementia. The collected data were self-reported and therefore could be influenced by factors such as self-reflection, relationships with family members, and understanding of dementia. This may limit in-depth understanding of the sample or the ability to draw comparisons with other cohorts. Given concerns about poor reporting of dementia severity and the influence this has on our knowledge of who may benefit most from psychotherapeutic interventions, future research should seek to collect data around dementia stage or the severity of cognitive or functional status in a standardised format, or triangulate self-reported data with clinical data such as formal diagnosis and use of validated psychometric measures, such as the Montreal Cognitive Assessment (Nasreddine et al., 2005), which are currently utilised within healthcare services.

Whilst offering an inclusive approach, conducting remote interviews with people living with dementia and their family members posed challenges. In telephone interviews, it could be difficult to involve the person with dementia as family members sometimes repeated the interviewer's question and answered on behalf of both participants, incorporating their own interpretation or views. Therefore, the voice of people with dementia was at times not heard within interviews, despite attempts to centre this. Managing this required sensitivity from the researcher to ensure that the family member did not inadvertently feel silenced, whilst centring the experience of the person with dementia.

Conclusion

People with dementia and their families access a range of psychotherapeutic interventions, at different points post-diagnosis, often through non-standard referral pathways. People with dementia generally find these interventions valuable, and are able to tolerate the uncertainty and emotional challenges associated with therapy. Assumptions that people with dementia cannot form or sustain a meaningful therapeutic relationship appear unfounded, and ensuring that this is recognised within services is key to providing equitable access to psychotherapeutic support for families affected by dementia.

Acknowledgements

We wish to thank the people with dementia and their family members who shared their personal experiences so willingly with us, in order to help improve care for people living with dementia more widely.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by Alzheimer's Society, 585.

Data availability statement

Data related to this study are available upon reasonable request to the corresponding author.

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