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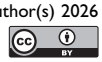
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The Experiences of Psychotherapy for People With Dementia: A Qualitative Interview Study With Family Members

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Abstract

Psychotherapeutic interventions can support people with dementia. Family members often play a pivotal role in the therapeutic process but little is known about their experiences of therapy, how they perceive the impact on their relative, and how the experience affects them directly. This study aimed to explore the experiences of family members who engage in therapy, or support someone living with dementia to attend therapy. Individuals with dementia and their family members were recruited as participants through NHS Trusts, professional networks, social media and community and support groups based in England and Wales. Semi-structured qualitative individual or dyadic interviews were conducted with 17 participants, eight of whom were living with dementia and nine were family members. Framework analysis was used. Family members highlighted "the importance of feeling seen" as distinct individuals by clinicians when engaging with psychotherapy, and not just the carer of their partner. When working with "dementia as dynamic phenomenon", therapeutic approaches needed to balance being sufficiently structured and containing whilst allowing for adaptions to each individual changeable presentation. Participants highlighted how psychotherapy presented "expected and unexpected outcomes", challenges that arose when outcomes were not agreed upon, and how therapy functioned as a support structure in ways the participants did not foresee. Psychotherapeutic

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intervention provides meaningful support to the family members of individuals with dementia. Understanding the needs of family members, alongside the needs of the individual with dementia, and taking a systemic approach is conducive to better therapeutic outcomes. The changeable nature of dementia presentation means that a therapeutic approach should be flexible based on the needs of the family. Psychotherapeutic intervention with individuals with dementia can have a range of benefits for the individual and the wider family, when sufficient considerations are made to understand each person's needs.

Keywords
dyadic support, carer, post-diagnostic support, cognitive impairment, counselling

Dementia is typically characterised by a decline in cognitive function, often impacting memory, judgement, planning, and behavioural and emotional regulation (Cheng, 2017; Pinquart & Sörensen, 2004; Wilson, 2008). Over time, individuals experience a decline in their functional capacity across various aspects of their life, typically resulting in increased need for support from others (Long et al., 2015). The medical perspective traditionally viewed dementia as resulting from neurological impairment that leads to behavioural changes, however the biopsychosocial approach also acknowledges the transformative impact that social, psychological and environmental factors have on the experience of dementia (Curran & Wattis, 2018; Kitwood, 2011). Therefore, the role of the relationship with those around the person is highly relevant for understanding how to provide person centred care.

Of the 944,000 individuals diagnosed with dementia in the UK, over 565,000 receive unpaid care (NHS, 2023), usually from family members, valued at over £10 billion annually (Wittenberg et al., 2019). Family members who provide care are often the greatest source of emotional and practical support for people with dementia, however this can significantly impact their own quality of life (Farina et al., 2017). With rates of dementia in the UK rising, understanding how to provide meaningful support to family members is important for the future (Alzheimer's Disease International, 2015; Larkin et al., 2022). Although no cure has yet been established (Cummings et al., 2022), recently licensed therapies have demonstrated modest slowing of disease progression in selected individuals with early Alzheimer's disease, representing an important advance while highlighting the continuing need for effective psychosocial and psychotherapeutic interventions (Cooper et al., 2024).

Psychotherapeutic interventions are designed to address areas of difficulty arising from psychological and behavioural challenges (Goldfried, 2013). A range of psychotherapeutic interventions have been implemented and evaluated within dementia care. With greater acknowledgement of the social and emotional needs of individuals with dementia, the value of psychotherapy for this population has been recognised (Cheston & Ivanecka, 1998). Understanding the efficacy of psychotherapy for supporting individuals diagnosed with dementia has proved challenging, acknowledging how the diagnosis impacts cognition and emotion, and how this interplays with social and interpersonal variables (Cheston & Ivanecka, 1998).

A range of psychotherapeutic approaches are used to support individuals diagnosed with dementia, and whilst the aim of intervention is often specific to the person, they typically share some of the following aims: to promote acceptance of the dementia diagnosis (Griffiths et al., 2026); support the individual to develop strategies to aid emotional regulation (Paller et al., 2015); to support memory retrieval by promoting engagement with past experiences (Lin et al., 2003); or to

strengthen social connection through group intervention (Blake, 2013). The effectiveness of psychotherapeutic interventions for individuals with dementia are mixed; with some interventions demonstrating improvements in outcomes such as depression and anxiety, and others demonstrating little or no improvements in outcomes (Orgeta et al., 2015; Shoesmith et al., 2022). The efficacy of psychotherapy is also likely to be affected by the severity of dementia, with significant variation in individuals' presentation, and practical challenges associated with implementation (Patterson et al., 2019). This requires individualised intervention plans that acknowledge the unique ways that dementia affects each individual (Spector et al., 2020), and can adapt to changeable presentations (Elvish et al., 2014).

Despite increased acknowledgement of the impact of interpersonal variables in psychotherapeutic interventions for dementia, little is known about how the psychotherapeutic process affects family members. Understanding the impact of psychotherapy on family members of people living with dementia is challenging as significant variation exists in their degree of involvement in therapy. While family members may not attend therapy sessions directly, they often provide support around the sessions such as transportation and session booking (Shoesmith et al., 2022). Family members may also help the person with dementia to manage the emotional and behavioural challenges that can arise from the routine changes associated with attending therapy sessions (Sutcliffe et al., 2016). Psychotherapeutic interventions for individuals with dementia and their family members together has been shown to be effective at reducing symptoms associated with depression, anxiety and for coping strategy skill development, however family member's views are not fully captured and understood within the literature to date (Shoesmith et al., 2022).

This study sits within the context of a larger programme of work aiming to explore the experiences of people living with dementia, family members, and therapists associated with psychotherapeutic interventions. Here, we aimed to explore how family members of individuals diagnosed with dementia experience psychotherapy, through either: attending with their relative; or when supporting their relative to attend independently; to understand their experiences of the whole process of engaging with therapeutic interventions.

Method

Design

A qualitative design consisting of individual semi-structured interviews conducted by a female researcher, with people living with dementia and their family members. No relationship was established between participants and the researcher prior to conducting interviews.

Sample

Participants were recruited through NHS Trusts, professional networks, social media and community and support groups based in England and Wales. We used purposive sampling (Palinkas et al., 2019) to recruit a sample with a wide range of demographic characteristics. The sample size was informed by the principles of information power, where a sample of individuals with specific experiences, who could recall detailed experiences and reflections on these, was recruited (Malterud et al., 2016). Eligible participants were people with dementia and their family members who had received any psychotherapeutic intervention since the dementia diagnosis, and were able to reflect on these experiences to participate in an interview. Two participants withdrew after completion of the interview, and their data was removed.

Table 1. Demographic Characteristics of Participants

Participant number	Age	Gender	Ethnicity	Role	Location	Form of dementia	Type of therapy received (self-reported)	Family member attended therapy (yes/no)
ID02	76	F	White british	PLWD	North England	Alzheimer's disease	Problem adaptation therapy	—
ID03	81	M	White british	Family member (husband)	North England	—	Problem adaptation therapy	Yes
ID10	61	F	White british	PLWD	South east England	Alzheimer's disease	CBT, EMDR, talking therapy	—
ID11	64	M	White british	Family member (husband)	South east England	—	N/A	Yes
ID15	36	F	White british	Family member (daughter)	South east England	—	Talking therapy	Yes
ID16	50	M	White british	PLWD	North east England	Alzheimer's disease	Counselling and talking therapy	—
ID17	50	F	White british	Family member (wife)	North east England	—	Counselling and talking therapy	Yes
ID19	75	M	White british	PLWD	East England	Lewy body dementia with Parkinson's	CBT CST	—
ID20	70	F	White british	Family member (wife)	East England	—	N/A	No
ID21	73	M	White british	PLWD	Middle England	Alzheimer's disease with Parkinson's	CBT and talking therapy	—
ID22	62	F	White british	Family member (wife)	Middle England	—	Talking therapy	Yes
ID25	76	F	White british	PLWD	North England	Alzheimer's disease	Talking therapy	—
ID26	74	M	White british	Family member (husband)	North England	—	Talking therapy	Yes
ID28	60	F	White british	PLWD	North England	Alzheimer's disease	Couples therapy	—

(continued)

Table 1. (continued)

Participant number	Age	Gender	Ethnicity	Role	Location	Form of dementia	Type of therapy received (self-reported)	Family member attended therapy (yes/no)
ID29	59	M	White british	Family member (husband)	North England	—	Couples therapy	Yes
ID42	64	M	White british	PLWD	South wales	Early onset frontotemporal dementia (FTD)	Talking therapy	—
ID43	56	F	White british	Family member (wife)	South wales	—	Talking therapy	Yes

Procedure

A topic guide was developed by the research team and a Lay Advisory Group of individuals with familial experience of dementia. This was refined in response to piloting and early interviews.

Semi-structured interviews were conducted between December 2022 and December 2024. The communication needs of individuals with dementia mean that recruitment was often opportunistic. Dependent on participant preference, interviews were either conducted in person in a location of their choice, or via video conferencing. Interviews lasted up to 1 hour and were transcribed verbatim and anonymised. Transcripts were regularly reviewed inform later data collection and begin initial data analysis. Participants received a £20 voucher to acknowledge their time and contribution to the study.

Ethical Issues

Ethical approval (Reference Number 11311) was granted on 14 September 2022 prior to data collection from University of Liverpool and London Central NHS research ethics committees (REC Reference 23/LO/0568). All participants were assessed as having capacity to provide informed consent and gave written informed consent prior to participation. Before interviews were conducted, parti cipants were notified of potential challenging themes that may be raised throughout and reminded of their right to withdraw at any time.

Reflexivity

This research team comprised researchers with professional backgrounds in clinical psychology, systemic psychotherapy, dementia and qualitative research methodologies, and Lay Advisory Group members with lived experience of dementia within their families. Regular discussion was held throughout data collection and analysis, which enabled the researchers to help scaffold the analysis, reflect how these experiences affected the members' interpretation of themes and consider their significance in relation to the research questions.

Data Analysis

Data were analysed using framework analysis (Ritchie & Spencer, 2002), a form of thematic analysis that identifies, analyses, and reports patterns observed in qualitative data (Gale et al., 2013). We initially selected two transcripts for analysis, independently familiarised themselves with the transcripts, coded the transcript, and then discussed initial themes. The framework was uploaded to NVivo and the data were systematically indexed. Themes and subthemes were refined and finalised through discussion, including with the Lay Advisory Group.

Findings

Summary of Participants

Seventeen participants were recruited; eight people living with dementia and nine family members. Eight interviews were conducted with spouse dyads, and one with a parent living with dementia and her adult daughter (one person with dementia interviewed twice with different family members). A detailed summary of participant demographic characteristics can be found in Table 1 below.

Table 2. Thematic Structure of Findings

Theme	Subtheme
The importance of feeling seen	Identity within the carer role
	Regaining personhood
Dementia as a dynamic phenomenon	Fluidity vs structure
	Person-centred approach
Expected and unexpected outcomes of therapy	Aligning expectations
	Therapy as a resource

Overview of Themes

A total of three themes, each with sub-themes, were developed and are presented alongside supporting quotes (see Table 2 for thematic structure of findings).

The Importance of Feeling Seen. Family members' desire to feel part of the therapeutic process was discussed extensively during interviews. Where they attended therapy with the person with dementia, participants valued therapist interactions that made them feel central to the therapeutic process, otherwise referred to as 'feeling seen'. Alternatively, some participants felt their therapist did not understand the reality of caring for a person with dementia. This resulted in feeling isolation in their caring responsibilities, and unseen outside their role as a caregiver.

Identity With 'the Carer Role'. Participants highlighted often not feeling distinct from the person they care for during therapy sessions. Participants reflected feeling that they did not receive sufficient time and space to discuss the challenges of providing care and the implications that dementia had for them and their own life. A disconnect between the experience and understanding of the family member and that of the therapist was noted.

> "I think they need to live with someone twenty-four seven to know exactly what it's like and the kind of support and help that, you know, you would like" (ID03, 81-years-old, Male, Family member)

Some family members felt that their function was to facilitate the practicalities of therapy and help their relative with emotional regulation before, during, and after sessions. Participants suggested this looked like helping their family members to communicate effectively, taking notes to help with cues and reminders, and providing emotional support during challenging moments of therapy. In one example, a change in therapeutic structure had a significant impact on the relative's perception of therapy, how it affected his wife, and how this impacted his capacity to provide support to her during therapy.

> "We used to go in together and then the therapist changed it from being it to do some one-to-one stuff and, quite honestly, when I seen ID10 come out sometimes, she was coming out quite distressed, suddenly, almost broken." (ID11, 64-Years-Old, Male, Family member)

The difficulty experienced by family members around their function in the therapeutic process may reflect a lack of mutual understanding of aims and who the intervention was intended for. Ambiguity around the function of therapy often left family members feeling unseen, resigning them

to their roles as carers instead of an active participant in therapy. Participants felt that their voice was less important than the person with dementia to the therapist. This manifested conflicting emotions for family members, and whilst they acknowledged that the person with dementia was often the focal point of therapy, they could be left with unmet needs.

> "Sometimes I feel very unheard as a carer. Everything's focused on {person with dementia}, which is how it should be, but then I have a role as well." (ID22, 62-Years-Old, Female, Family member)

This also left some participants feeling that that their role as a caregiver was emphasised in therapy, rather than being given agency to identify in their preferred way, considering their relationship with the person with dementia.

> "I think the position that I'm seen as… my role as a carer, opposed to my role as a wife." (ID22, 62-Years-Old, Female, Family member)

Family members felt that the therapist may have not always fully understood the realities and complexity of dementia care. This perceived lack of understanding on the part of the therapist resulted in feeling that support was not sufficient, and did not resonate with family members' experiences. Therapy sessions, whilst helpful, did not always meet the needs of family members.

Regaining Personhood. Caring for individuals with dementia can affect the personhood (i.e. sense of self, identity, and autonomy) of family members, and the therapeutic process was seen as a way to help regain this. Participants described instances where therapists spoke to them directly and acknowledged, referencing their experience. Being as distinct individuals within the therapeutic space, who reflected on their own thoughts, emotions, and actions allowed participants to directly experience the benefits of being included in interventions. For one participant, this novel experience of sharing her feelings and problems with someone she did not know was helpful.

> "I wasn't sure what to expect from it, I was a bit apprehensive because, you know, it's not the type of thing that you do on a daily basis, talk to a stranger about how you're feeling or what you're going through. So that was quite tricky for me to open up to somebody I know nothing about and tell them your whole life story kind of thing. But it was quite… therapeutic, strangely enough, because you do you kind of feel like… you shared that problem with somebody."(ID17, 50-year-old, Female, Family member)

Family members reported significant benefit from spending one-to-one time with the therapist, without the person with dementia present, and for their relative to do the same. This time allowed carers to voice a different perspective on their thoughts and experience without fear of hurting their relatives' feelings, and to sit in a non-judgemental space.

> "That was an opportunity for ID02 to sort of offload to {therapist} and what she thought without upsetting me. And it was my chance to talk to {therapist} without upsetting ID02. And that, I think, was really useful. And I must admit, those five-minute chats I had with {therapist} they were very, very useful." (ID03, 76-year-old, Male, Family member)

'Dementia as a Dynamic Phenomenon'. Dementia can impact on cognition, behaviour and emotional function on a changing basis. Therefore, the capacity of individuals with dementia often looks different from day to day, and even moment to moment. Given this, carers often felt an effective

therapeutic approach was one that was dynamic and able to meet the need as it presented, which may include fluctuations in understanding and mood changes.

> "With mum and the moods, that's very fluid in the sense, you know, one minute we're laughing and joking, and then mum becomes overwhelmed and we're very much not laughing and joking anymore." (ID15, 36-years-old, Female, Family member)

'Fluidity vs Structure'. Family members sought a therapeutic approach that could adapt and work with the changing symptoms and progression of dementia. They discussed a need for fluidity in approach due to the variability in how the symptoms of dementia affect each individual, their progression, and the impact of different symptoms. When participants felt that the therapist correctly understood the approach that best suited their own and their family members' needs, balancing fluidity and structure appropriately, they could benefit more from sessions and develop a stronger therapeutic alliance. Furthermore, they appreciated a responsive approach to the needs they and the person with dementia raised in therapy.

> "He doesn't have any sort of pre-planned strategy to say, right, this is what we're going to sort out this week or this is what we're going to sort out next week. He literally lets it evolve naturally." (ID28, 60-years-old, Female, Person living with dementia)

Given the nature of dementia, large gaps between sessions may significantly reduce the efficacy of the intervention. Some therapeutic approaches may not have the flexibility to provide more intensive support, which could result in participants feeling they did not receive sufficient therapeutic input overall.

> "You've got a safe space to air whatever you need to or discuss what you're not sure of, or whatever. But with it being once a month, it's just too sparse." (ID15, 36-years-old, Female, Family member)

Family members benefitted from working with services that could act quickly to the need as it presents. They highlighted how their circumstances could change quickly, and therefore they benefitted from specialist therapeutic support and early detection.

> "If they didn't have this early onset dementia team then we'd probably still be waiting to see somebody now, do you know what I mean?" (ID43, 56-years-old, Female, Family member)

Some family members felt that therapy sessions would benefit from greater structure and from being more directive. Family members often looked for guidance for how to support their loved one and felt they lacked actionable support with clear *'take home'* points to create change outside of sessions.

> "It was more around managing stress levels for me, because obviously there's a lot happening at the same time again and it was trying to manage those stress levels and to be able to help {ID16} cope better. (ID17, 50-years-old, Female, Family member)

Where the wider family were welcome to attend therapy sessions, this led to challenges of organising individuals, due to the structure and content of the sessions being unclear. Participants hoped for direction around the overall plan for therapeutic input, and what might come next.

> "It would be beneficial if there was a timeline, so we can say, actually that'd be really helpful if the teenagers were there so we can get them out of school and they can understand what's happening with their grandmother. Or, actually they don't need to come because this is something that doesn't really affect them. Just, more direction would be beneficial." (ID15, 36-years-old, Female, Family member)

Family members look to professionals for guidance, assurance, and to feel someone else has their interests in mind. A therapeutic approach that places an individual's subjective experience at the centre of the process is often referred to as person-centred. Before beginning therapy, one couple expressed concerns that it might not be sufficiently person-centred; however, they later felt re-assured that the approach had been adapted to their specific needs.

> "It suits our needs.
>
> "The therapy is literally tailored to me and {ID29 - husband}."
>
> (ID28, 60-years-old, Female, Person living with dementia)

In the absence of a person-centred approach, participants often lacked understanding of the purpose, intention, and direction of therapy. This affected their desire to engage in the therapeutic process. This meant family members often felt it was harder to ensure both continuity of care and to aid the efficacy of the therapeutic process, leading to them feeling excluded from the therapeutic process, or *"in the dark"*. This also often left family members feeling that the intervention was too prescriptive and pre-planned, without allowing appropriate space for dementia-related adaptations.

> "A timeline of what topics to discuss at each session. You know, that initial session of what are you hoping to get out of this. What is everyone else hoping to get out of this? Or… this is the service that we provide, this is how long it's going to be, this is how infrequent it's going to be." (ID15, 36-years-old, Female, Family member)

Expected and Unexpected Outcomes of Therapy. The importance of discussing, defining and agreeing on outcomes for therapy was highlighted. Individuals' prior perceptions of therapy and the realities of the therapeutic experience could differ significantly. Therapy often provided an improved understanding of dementia, improved practices in providing care, and highlighted that professional therapeutic support can in some instances extend beyond the therapy room itself.

Aligning Expectations. Identifying outcomes for therapy was an integral component of the initial sessions. For family members, this might be outcomes for the person with dementia, outcomes for themselves, or both. Outcomes related to specific symptoms related to dementia, or a more general focus on improved mood or quality of life.

> "What I would like is for {ID28}'s mood to be lifted, you know, and to feel valued and to feel part of something." (ID29, 59-years-old, Male, Family member)

Where family members were explicitly asked to identify outcomes for themselves, they often struggled to express what they hoped for, especially if the person with dementia was present within the room.

> "She did ask me what I wanted out of the sessions… I suppose it's peace of mind and some reassurance or some mechanisms to cope with the stress." (ID17, 50-years-old, Female, Family member)

However, some participants reflected that as they had not previously sought psychotherapeutic interventions, they were unaware of what they wanted, needed or hoped for from the sessions. They acknowledged that awareness and understanding of potential outcomes could develop over time.

> "In the second session. Not so much in the first one, we discussed what we wanted to achieve, which 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 that you need to offload or you're not quite feeling yourself so at first, maybe you're not too sure as to what you want to achieve, but as time goes on then you figure it out." (ID16, 50-years-old, Male, Person with dementia)

For others, rather than specific outcomes, there was a general focus on feeling better. They acknowledged the limitations of therapy, but hoped for broad improvements for their family member, within the context of dementia.

> "They can't wave a magic wand. He just wanted to get better." (ID43, 56-years-old, Female, Family member)

Other participants felt that outcomes were never agreed upon, which led to challenges within and between sessions.

Researcher: And did you discuss any specific outcomes with the therapist?

ID15: Yeah… no.

ID10: No, I wasn't asked. Maybe at the beginning they could have told us, what's going to happen? And then maybe asking us if that's what we want. (ID10, 61-years-old, Female, person with dementia and ID15, 36-years-old, Female, Family member)

Therapy as a Resource. At times family members came to realisations through therapy that they had not foreseen prior to beginning intervention. Participants gained a deeper understanding of therapy which allowed them to utilise it as a resource and achieved a new sense freedom and autonomy in their lives. They reported benefitting from learning new strategies for providing more informed and higher quality care to the person with dementia, which appeared to improve their experience as both carers and family members. Through therapy, they developed practical strategies, aimed at preserving the autonomy of the person with dementia.

> "About the drawer, you know, the knives and forks things. It was little suggestions like that, really. (ID03, 81-years-old, Male, Family member)

Therapy could function as a resource for family members as they were exposed to new challenges presented by dementia. In the following example, one participant highlighted how, through the support of a therapist, they were able to access training in dementia care.

> "There's quite a well organised carers organisation and I have linked up with them. They organised two workshops to do with the impact for dementia carers on… the practical issues around caring and those were really helpful. (ID26, 74-year-old, Male, Family member)

Participants benefitted from receiving support from a therapist on aspects of dementia care that they may not have initially expected the therapist to offer. One person with dementia experienced

nightmares brought about by a medication change. The couple benefitted significantly from advice given to them during a session about how to take the medication.

> "{ID02} was put on some tablets, weren't you? Donepezil, they were called. And she was having these horrendous nightmares, weren't you? {Therapist} was brilliant, reassuring. She said "don't take them overnight, take them of a morning"." (ID03, 81-years-old, Male, Family member)

Discussion

This study aimed to explore how the family members of individuals diagnosed with dementia experience psychotherapy, either as a person attending with their relative, or supporting their relative to attend alone. Despite the increased recognition of psychotherapy as a means of supporting individuals with dementia, the role of family members in this process is poorly defined and recognition of these individuals by services is inconsistent. This paper identified three main themes: the importance of feeling seen; dementia as a dynamic phenomenon; and unanticipated outcomes.

Family members reported inconsistencies in how the therapist approached their sessions, often creating feelings of uncertainty about their role in the therapeutic process and the intended direction of therapy. This impacted family members' perceptions of their own autonomy, typically making them not feel heard or understood, and feel isolated during sessions. Interventions aimed at supporting family members directly have demonstrated 'immediate positive effects' for reducing caregiver burden, symptoms associated with depression, and social isolation (Au et al., 2010; Brodaty et al., 2003). However, family members experience a pervasive lack of social contact and support, and report elevated feelings of social isolation (Holt Clemmensen et al., 2021), and these may not be addressed within this context. Conversely, exclusion from the therapeutic process left family members struggling to ensure both continuity of care and to support the therapeutic process for their relative. Caregiver support can significantly improve experiences and emotional reactions to the caregiver role (Hepburn et al., 2001). Therapeutic approaches that utilise multiple components, including family support and specific skill development together have more significant effects than components conducted in isolation (Cheng et al., 2019). This research demonstrates the need for greater caregiver integration into the therapeutic process. Future research should explore how to more effectively and explicitly define the role of the family member within therapy, agree and communicate this with the person with dementia, and understand how to increase family involvement where clinically appropriate.

The term 'psychotherapy' is often poorly defined (Markowitz, 2022), varying significantly in underlying philosophy, intentions, and intended outcomes. Participants described variation in how psychotherapy is defined and understood, often being unsure about what kind of therapy they received and what its goals and intentions were. For participants that understood the approach they received, many highlighted Cognitive Behavioural Therapy (CBT) based approaches, which may incorporate allied therapies that included Dialectical Behavioural Therapy and Acceptance and Commitment Therapy, amongst others (Mansell, 2008). Although not unique to this demographic, it is likely that many seek therapy to support a sense of clarity and security into their lives that may be otherwise absent (Elvish et al., 2014). This need was seemingly met by different therapeutic functions, such as psychoeducation about dementia (Frias et al., 2020), knowledge that their relative was receiving professional support, the unofficial respite that therapy sessions provided (Vandepitte, et al., 2016), and in the shared experiences of learning from others who provide dementia care (Chien, 2011).

Many family members felt the approach they received lacked flexibility and failed to be dynamic when working with a condition characterised by cognitive decline and changeable presentation. The traditional 'goal focused' nature of interventions such as CBT, that place emphasis on 'self-development and growth' may be challenging to maintain throughout treatment with a disease that can create rapid cognitive decline. Research supports this, with clinicians reporting participants may require a higher volume of sessions than is typically offered through CBT, and that the structure of CBT may require significant adaptation to work with the impacts of cognitive decline (Baker et al., 2022). Family members in this research showed a preference for approaches grounded in relational approaches and psychoeducation, that enabled them to develop a greater understanding of dementia, gave validation around the challenges of dementia care, and supported them and their family member to understand each other. Comparisons between the effectiveness of CBT and psychoeducational based approaches found no significant difference in effectiveness for the treatment of depression or anxiety (Fossey et al., 2021). Therapeutic frameworks that maintain clinical rigour while offering flexibility to accommodate the fluctuating cognitive, emotional, and behavioural demands of dementia care, supporting family members to navigate this, are most likely to be successful.

Clinical Implications

Participants within the present study had accessed a range of modalities, and in some cases, broad psychotherapeutic interventions that from their perspective were not aligned with a single modality. However, the development, maintenance and strength of therapeutic relationship is a key predictor of therapeutic outcome, characterised by trust in the therapeutic process, agreement on intervention goals, and effective collaboration between client and therapist (Baier et al., 2020; Charura & Paul, 2014). Traditionally, many people with dementia have been considered 'beyond therapeutic reach' (Sommerbeck, 2006), meaning they cannot establish and maintain a therapeutic relationship. Such assumptions likely reduced referrals, access and take-up of therapy. Our work challenges this perspective by demonstrating that people with dementia can develop and maintain therapeutic relationships, navigating this with their family members, to benefit from psychotherapeutic interventions. Critically, when family members are integrated meaningfully into the therapeutic process, this can result in more positive outcomes for the individual with dementia (Griffiths et al., 2021). Individuals with dementia often depend on family members to facilitate the practical and emotional aspects of therapy, and support from clinical services is required to ensure timely access to psychotherapeutic interventions. Furthermore, significant inequalities exist in the access to post-diagnostic therapeutic interventions based on location (Frost et al., 2020), which requires consideration in service design and delivery.

The importance of family members supporting with the practicalities of attending therapy was discussed within interviews. Family members often facilitate the person with dementia attending therapy appointments, so these concerns are important when thinking about family member experiences. The literature around practical barriers to attending therapy and how these can significantly impact on therapeutic outcomes is well established (Kelly & Innes, 2016). However, this can be exacerbated by the complex needs presented by dementia care, particularly as individuals caring for those with dementia may be older, bringing further challenges around mobility and comorbid health conditions (Kelly & Innes, 2016). As these views are well represented elsewhere, they are not discussed in this paper.

Some psychotherapeutic modalities are theoretically orientated to work solely with the individual with dementia, and having a family member present may add complexity and deviate from

service delivery. However, it is important to ensure that the voices of family members are well represented, given the benefit of informing progress and development of novel therapeutic approaches, or in improving pre-existing interventions to enhance therapeutic efficacy and outcomes for people with dementia (Jeffery et al., 2025). Interestingly, many positive outcomes reported from therapy related to practical strategies or psychoeducation. This highlights the importance of ensuring goals for therapy are outlined with people with dementia and their families, to ensure that they see meaningful benefit tailored to their needs (Ghosh et al., 2023). However, this may lead to a focus on outcomes that are easier to define and name, compared to improvements in symptoms associated with depression or anxiety, for example. This requires careful consideration and discussion between the therapist and all individuals present in the therapeutic space, to help people to acknowledge, name and share their desired outcomes.

Inconsistences were present in the experiences of psychotherapy in the sample recruited here. In some instances, families were welcome to attend sessions as clients or as supporters, and in other instances, they facilitated the person with dementia to attend sessions but could not attend themselves. Despite the many potential benefits of a relational approach, services are typically offered to the individual with dementia, with few services offering models that invite family members into the therapeutic space (Frost et al., 2020). The evidence for couple-centred or family-centred (i.e. systemic) approaches for families affected by dementia is growing. However, systemic therapy is infrequently offered to older adults (both with and without dementia) and there is a lack of later-life content in therapist training (Jeffery, 2019; Jeffery et al., 2025), potentially reducing both awareness of and confidence in working with this population. Furthermore, concerns have been raised that within these spaces, the views of individuals with dementia can be overlooked (Bielsten & Hellström, 2019). This can lead to a poor understanding of relational issues, particularly from the perspective of those with dementia. Therefore whilst the inclusion of family members within the therapeutic space is encouraged, this must not risk the exclusion or silencing of the person with dementia.

Delivery of psychotherapeutic interventions to families affected by dementia may require additional considerations. Given the often rapid and unpredictable changes in symptoms, therapists must be prepared to adapt their approach (Ries, 2022). Challenges with memory deterioration may mean that revisiting the 'contracting' (i.e. formally agreeing a plan for working together therapeutically) multiple times throughout intervention may be required to ensure all parties remain aware of the goals of therapy, and to ensure that the consent provided at the beginning of intervention remains valid. It is also important when contracting to think about the role of the family member in the therapeutic process, to reduce ambiguity and preserve confidentiality within families where appropriate (Abrams et al., 2019). Whilst some people with dementia may appreciate their family member being welcomed into the therapeutic space, for others this may offer additional challenges. Sensitivity is needed to support families to navigate this, and to clearly specify a role for the family member, for example facilitating attendance, supporting memory retrieval and narrative development, or guiding the direction of therapy over time. Furthermore, as dementia advances during the therapy, the goals and outcomes of therapy may change and need renegotiation. Service managers should accommodate this in-service planning to enable therapists to collaborate with their clients and wider families. Furthermore, therapeutic models and therapist training that is responsive to the shifting biological, psychological, and social variables that characterise the experience of dementia and dementia care are required.

The social GGRRAAACCEEESSS framework highlights how an individual lived experience is shaped by Gender, Geography, Race, Religion, Age, Ability, Appearance, Class, Culture, Ethnicity, Education, Sexuality, Sexual Orientation, and Spirituality (Burnham, 1992, 1993; Roper-Hall 1998, 2008). It is important to recognise the many ways in which families affected by dementia experience

diversity and how their experiences are shaped by their own social GGRRAAACCEEESSS. Additional consideration may be required to ensure that therapeutic spaces feel accessible and welcoming for individuals, who may have had poor experiences previously within healthcare services. This may interact with potential safeguarding issues, and therapists must communicate this clearly and ensure this is understood by all individuals within the therapeutic space. Furthermore, therapists delivering psychotherapeutic interventions must engage and respond to individuals, families and communities in ways that are appropriate for them, whilst maintaining core therapeutic components (James et al., 2021). This means understanding and valuing different conceptualisations of mental and physical health across the lifespan, and how this may interact with the values and beliefs of individuals. It is therefore important to ensure therapists are sufficiently skilled in adapting their approach to work with these differences.

Strengths and Limitations

This study forms part of a wider programme of work exploring the therapeutic experiences of people with dementia and their family members. Here, we specifically considered the views of family members. However, there were inconsistencies in whether the relative attended therapy or supported the person to attend, which offered a challenge within analysis, to ensure that the focus remained on family members' experiences, within a context that often centred around the person with dementia. At times these experiences were inseparable, which may not be aligned with how participants perceive their role. This was further complicated by interviews being conducted with the dyad or family, meaning that reflections were offered with the person with dementia present. Future research should consider the benefits of conducting further, individual interviews with family members alone.

Whilst we made significant effort to recruit a diverse sample, our participants were all White British individuals, and spouses were particularly well represented. There was an absence of voices of people from diverse or minoritised communities within the UK. There is also limited representation of young onset dementia within the sample, which is particularly important, given these individuals are likely to be diagnosed with rarer forms of dementia, face additional barriers to and longer waits for diagnosis, and poorer access to appropriate post-diagnostic support (Hussey & Butler, 2019; Spreadbury & Kipps, 2018). Where couples were recruited, these were all heterosexual dyads. Future research should seek to include a great diversity of experience when exploring the impact of psychotherapy for families affected by dementia, acknowledging the specific barriers to access determined by ethnicity, culture, gender identity, sexuality and relational dynamics.

It should also be noted that many participants receied psychotherapy several years prior to interview, and were uncertain about what specific form(s) of psychotherapeutic intervention they had received. Challenges with participants recalling what therapeutic intervention they received is reflective of a general lack of therapeutic literacy, and the challenges that people have accessing therapy. Many participants are grateful to be receiving any form of support without much thought for the specific modality. Future research should corroborate self-reported information with an understanding of service delivery or therapist approaches, triangulating this to understand how different individuals delivered and received interventions.

Conclusion

This study offers a unique exploration of how family members of individuals with dementia experience psychotherapy, facing distinct challenges when dealing with the additional complexity

that dementia brings, the emotional burden of providing care, and their often-ambiguous position within the therapeutic space. Whilst this work helps build the evidence base for psychotherapy within this cohort, it suggests that to be truly effective, therapists must consider the family member wherever clinically appropriate. Current therapeutic approaches can fail to recognise the dual role played by the family member, both as the carer and as a distinct person with their own psychological needs (Elvish et al., 2014). Although not unique to this demographic, our findings suggest the need for a more person-centred, responsive, and inclusive approach. We emphasised the ongoing struggle faced in delivering a structured therapeutic approach that remains sufficiently flexible to accommodate the evolving needs and challenges of the individual. Clearly defining and understanding the important role of family members within a psychotherapeutic context for people living with dementia can help to focus, improve, and tailor interventions. Drawing on a framework grounded in a systemic relational approach, that emphasises the role of interpersonal relationships and relational patterns provides a robust framework for such implementation whilst also offering a clear rationale for involving family within treatment. In conclusion, a person-centred, flexible therapeutic approach, that is well communicated with all individuals, and tailors therapy to the unique ways that dementia affects each individual, is required to ensure that both the person with dementia and their family members feel welcomed and supported within the therapeutic space.

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Ethical Considerations

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