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Exploring Pre-Death Grief in Dementia Carers and Cognitive Rehabilitation Perspectives: Insights from Patients, Carers, and Healthcare Staff

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Chapter 1 Systematic Review

Pre-death grief experiences of family carers of people with dementia: A systematic review and meta-analysis of qualitative literature.

Prepared in accordance with the author requirements for the Journal ‘Dementia’.

Submission Guidelines

Abstract

The experience of grief while the person with dementia is still alive, known as pre-death grief (Blandin and Pepin, 2017; Lindauer and Harvath, 2014) is particularly common. Despite this, the experience of pre-death grief is not well understood, and a systematic review by Crawley et al. (2022) highlighted the need for further investigation into the distinct grief experiences of this population. This review addresses this by exploring the qualitative literature on pre-death grief in family carers of people with dementia. Embase, Medline, CINAHL, PsycINFO and reference lists of included studies were searched to identify relevant qualitative studies. 1866 records were screened for eligibility and 9 studies met inclusion criteria. Findings were extracted, critically appraised and synthesised using thematic synthesis. The Critical Appraisal Skills Programme (CASP) tool for qualitative studies was used to appraise study quality. Overall, the studies included in this review were of good quality. Themes derived from methodologically weaker studies were comparable to the stronger papers. The thematic analysis produced three themes: 'There but not there', 'Multiple Losses' and 'Coping strategies to manage pre-death grief'. Findings are broadly consistent with wider literature that highlights the complexity and variation of pre-death grief experiences in this population. This review emphasises the degree of ambiguous loss and multiple pre-death losses experienced by this population. Multiple pre-death losses refer to the various, often simultaneous, losses experienced throughout the caregiving journey and before the person's actual death. Coping strategies that carers use to help them manage their pre-death grief are also highlighted. The review highlights directions for future research and implications for service delivery.

Introduction

Dementia is the seventh most common cause of death globally, according to the World Health Organization (2017). In addition, caring for a person with dementia has been found to emotionally affect family carers and experiences of grief while the person with dementia is still alive are very common (Blandin and Pepin, 2017; Lindauer and Harvath, 2014).

As dementia progresses, those in a caring role often experience: a sense of loss; communication difficulties with their loved one; decreasing emotional closeness; and psychological distress, all/any of which can lead them to grieve. Some of these grief experiences have been identified as 'anticipatory grief' (AG) and are a reaction to perceived losses throughout the caregiving process and in anticipation of the death (Adams & Sanders, 2004; Doka, 2010; Kim et al., 2013; Marwit & Meuser, 2002; Schultz et al., 2006).

Understanding Anticipatory Grief

The complex and multifaceted nature of anticipatory or pre-death grief is highlighted by the variety of definitions and models in relevant literature. Boss (1999) introduced the ambiguous loss theory, which provides a framework for understanding the ongoing and unresolved grief experienced for someone who is physically present and psychologically absent. Boss's study emphasised that ambiguous loss creates unresolved grief, lacks traditional mourning rituals, and causes emotional stress, identity confusion, and strained family dynamics.

Rando (2000) introduced the anticipatory grief model and defined anticipatory grief as the process of experiencing normal grief reactions in advance of the actual death. According to this model, anticipatory grief can include feelings of sadness, anger, anxiety, and longing as the person anticipates the loss. Doka (2002) described anticipatory grief as a multifaceted experience that allows individuals to begin the mourning process, thereby potentially easing the adjustment to the loss once it occurs.

Anticipatory and ambiguous grief are distinct but overlapping experiences with unique challenges. Anticipatory grief, as outlined by Rando (2000) and Doka (2002), involves experiencing normal grief reactions in advance of a loss, allowing individuals to begin processing their emotions, though it still involves difficult feelings such as sadness, anger, and anxiety. In contrast, ambiguous grief, as described by Boss (1999), arises from unresolved loss when a person is physically present but psychologically absent, leading to ongoing grief without closure. Both forms of grief present specific challenges, particularly in the context of dementia, where carers face continuous and complex emotional distress due to the prolonged and uncertain nature of the condition.

Models of Grief in the Context of Dementia

More recently, Blandin & Pepin (2017) introduced the Dementia Grief Model, a theoretical model of dementia grief as a unique grief experience in dementia carers. According to Blandin & Pepin (2017), pre-death grief experienced by family carers of people with dementia is expressed in the term "dementia grief." This term highlights the ongoing emotional impact of the disease process. Unlike bereavement, which refers to grief after death, dementia grief captures the pre-death grief that carers experience as they witness the gradual decline of their loved ones (Chan et al., 2013; Lindauer & Harvath, 2014). This form of anticipatory grief is distinct due to its continuous and variable nature, compounded by the ambiguity and uncertainty inherent in dementia-related losses.

Evolving Terminology: From Anticipatory to Pre-Death Grief

While anticipatory grief has historically been the term used (Sweeting & Gillhooly, 1990), as knowledge about grief in the context of dementia increased, terminology that better encapsulates the grief experiences of this population has been introduced. Specifically, researchers have assigned the term ‘pre-death grief’ as the most accurate way to describe the losses experienced by carers of people with dementia prior to the death (Lindauer & Harvath, 2014; Crawley et al., 2022). Lindauer and Harvath defined pre-death grief as "the emotional and physical response to the perceived losses in a valued care recipient. Family caregivers experience a variety of emotions (e.g., sorrow, anger, yearning, and acceptance) that can wax and wane from diagnosis to the end of life" (p.8).

Distinguishing Between Anticipatory and Pre-Death Grief

While there are many similarities between anticipatory and pre-death grief and these terms are often used interchangeably in literature, pre-death grief specifically relates to losses that are experienced rather than anticipated and is believed to more comprehensively capture the significant aspects of grief for this population (Blandin and Pepin, 2017). In this review, both studies that focus on anticipatory grief and pre-death grief are included, recognizing that anticipatory grief may provide insights into the emotional responses to both current and future losses. However, the primary focus will be on evidence that addresses grief related to present losses, such as diminished communication and changes in relationship quality, which are common in the prolonged and uncertain course of dementia (Lindauer and Harvath, 2014).

Systematic Reviews on Grief in the Context of Dementia

A systematic review by Chan et al. (2013) synthesised 31 studies on pre-death, post-death, and prolonged grief, finding most studies were of low quality. Limited research examined the link between pre-death and post-death grief. Moderate to severe dementia was linked to pre-death grief, while being a spousal carer and having depression were major predictors of normal and prolonged post-death grief. Poor quality evidence indicated 47%-71% of carers experienced pre-death grief, and around 20% experienced complicated grief. This highlights the need for further exploration of pre-death grief as understanding these experiences can provide a foundation for supporting carers.

More recently, a systematic review conducted by Crawley et al. (2022) reported on the prevalence of pre-death and post-death grief experienced by family carers of people with dementia and synthesised the quantitative evidence on the factors associated with pre-death and post-death grief. Findings indicated that particular demographic features and psychosocial characteristics play a role in grief experienced by family carers of people with dementia and highlighted that awareness of the factors that increase the likelihood of experiencing higher levels of grief can be helpful in terms of proactively identifying those in need of support. For example, they found that elements of social support have a positive impact on grief. Whilst qualitative literature was initially meant to be included in the systematic review conducted by Crawley et al. (2022), due to the volume of the literature available, qualitative studies were excluded. This underscores a research gap in understanding how pre-death grief is experienced from the perspective of family carers.

Aims

This review aimed to build upon the above-mentioned systematic reviews and address research gaps by synthesising the qualitative literature available in relation to pre-death grief in family carers of people with dementia. More specifically, this review aimed to answer the following question:

From the perspective of family carers of people with dementia, how is pre-death grief experienced?

While a number of the studies included in this review specifically focused on exploring the nature of the experiences of pre-death grief in carers of people with dementia (Adams et al., 2004; Diwan et al., 2009; Moore et al., 2023; Sanders & Corley, 2003, Supiano et al., 2022), certain studies (Almberg et al., 2000; Frank, 2007; Hovland, 2018, Shuter et al., 2014) explored the broader emotional experiences of people caring for individuals with dementia, with some carers reporting feelings of pre-death grief.

Method

The PRISMA methodological guidance for systematic reviews was followed (Page et al., 2021). A study protocol was registered with PROSPERO on the 16th February 2024 , which can be accessed from the following link: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=508627

Search Strategy

PsycINFO, Medline, Embase and CINAHL were systematically searched up until February 2024. An expert librarian was consulted on the development of the search strategy, which used the following search terms:

1. Dementia/or Alzheimer's disease/or dementia with Lewy bodies/or presenile dementia/or senile dementia/or vascular dementia/or semantic dementia/or Alzheimer's/or frontotemporal

   AND
2. Grief or grieving or pre-death sorrow or loss or anticipatory mourning

   AND
3. Carer* or caregiv* or family or families or spous* or partner* or adult child* or parent* or mother* or father* or son* or daughter*
4. 1 AND 2 AND 3

Study Selection

All records were imported into EndNote for the removal of duplicates and for screening. Duplicate articles were removed prior to screening. The following criteria were used during the screening and selection process.

Inclusion criteria

- Peer reviewed journal articles focusing on the anticipatory or pre-death experience of family carers of people living with any type and severity of dementia, including studies that included experiences of post-death grief, providing the experiences of anticipatory and pre-death grief could be clearly distinguished and extracted.

- Qualitative studies or mixed method studies with a qualitative component.
- Written in English.
- Studies including family carers (aged 18 or over) of people with dementia. For this review, a carer is defined as someone who regularly looks after a person with dementia e.g. spouse, sibling or adult children (Carduff et al., 2014).
- Participants providing care or support for somebody living with any type and any severity of dementia in the community or in long-term care facilities. This included both participants that were currently caring for people with dementia as well as participants that had cared for people with dementia who are now bereaved.

Exclusion criteria

- Studies not written in English.
- Paid/professional carers.
- Family carers under the age of 18.
- Quantitative studies.
- Studies only focusing on post-death grief experiences.
- Grey literature.
- Studies focusing on family carers of people with a cognitive impairment not related to dementia.

The first phase of screening involved reviewing the titles and abstracts of the papers against the inclusion/exclusion criteria, and those records that did not meet the criteria were excluded. A proportion of the screening decisions (10%) were rated by a second reviewer, a Trainee Clinical Psychologist, at the title and abstract stage. Initial agreement was 100%. Following this, included records were read in full. In addition, a search of all the references of the nine included studies was conducted; this did not yield any additional papers that met inclusion criteria. Overall, nine papers were identified for inclusion.

Data Extraction and Synthesis

A data extraction tool was developed for this review and can be seen below in Table 1. The primary researcher extracted the following information from the eligible papers: title, authors & publication year, geographical location, phenomena of interest / research question/s, research study design/methodology, data collection and analysis methods.

Although the epistemological underpinnings of synthesis approaches are a contentious field, Barnett-Page and Thomas (2009) argue that approaches including thematic synthesis are more directly relevant to inform policy and practice because results are reproducible and correspond to a shared reality. According to Booth et al. (2016) qualitative evidence synthesis can inform service provision through exploring how people experience interventions, as well as barriers and facilitators of accessing services. Therefore, thematic synthesis would fit best with the review aims of integrating information to inform practice and service provision. The three stages of thematic synthesis outlined by Thomas and Harden (2008) were followed by the primary researcher. All text labelled as 'results' or 'findings' was coded line by line. Similarities and differences were identified across codes, in order to group them into descriptive themes. Subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary. The final stage involved returning to the original research aims, in order to generate analytical themes from the descriptive themes and develop a deeper understanding of the findings in the literature.

Quality Appraisal

The Critical Appraisal Skills Programme tool for qualitative studies, which is the most commonly used quality assessment tool for qualitative studies (Majid & Vanstone, 2018), was used to appraise the quality of the included studies; see Table 2. Ratings of "yes," "no" or "unclear" were used to indicate whether the 10 items of the tool were clearly demonstrated (Critical Appraisal Skills Programme, 2018). The lead author conducted the quality appraisal of the studies, and a second rater critically appraised a portion of the studies (n = 2; 22.2%). Initial agreement was 90%. Discrepancies in ratings were discussed and resolved resulting in full agreement. Quality appraisal was not used to exclude studies based on a threshold but to interpret the possible impact of study quality on findings (Thomas & Harden, 2008).

Researcher Reflexivity

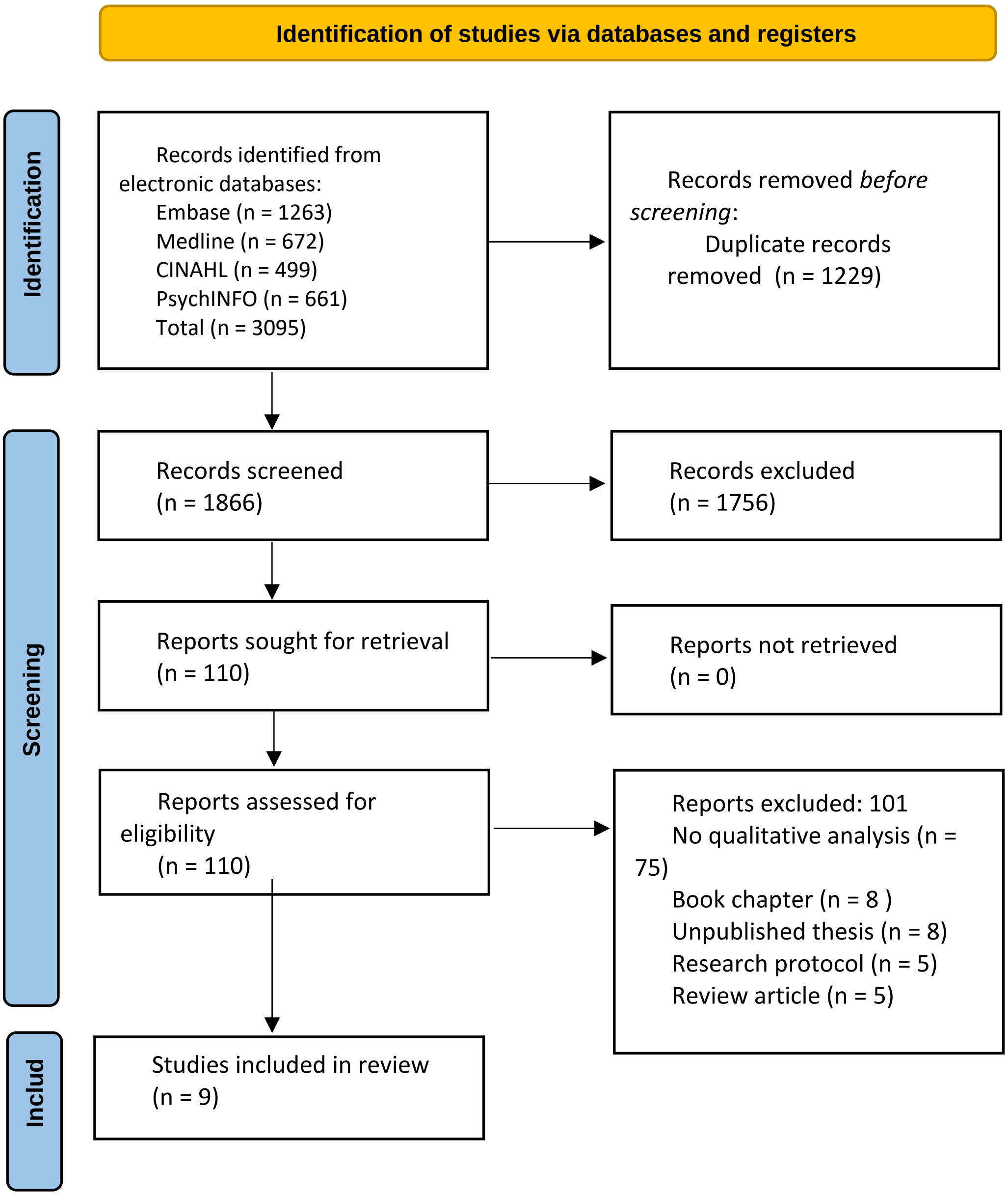
Thematic synthesis involves interpretation by the researcher and is influenced by the researcher's prior experiences and conceptions. The primary author was a Trainee Clinical Psychologist, who had experience of working with carers of people with dementia that have experienced feelings of pre-death grief. A reflective diary and supervision were used to reduce bias through increasing awareness of reactions and reflections evoked during analysis.

Results

A total of 3095 studies were identified following a search of4 different databases. Following de-duplication, 1229 articles were removed, resulting in 1866 unique references. Using the eligibility criteria, first the tile and the abstract were screened and papers which clearly did not meet criteria were removed. This then yielded a total of 110 papers for full-text screening. Upon full text screening against the inclusion and exclusion criteria, a total of nine included studies met eligibility criteria. All nine studies were retrieved. This process is illustrated in Figure 1 below.

Figure 1.

PRISMA Flow Diagram (adapted from Page et al., 2021)



Study characteristics and quality assessment

Table 1 illustrates key information that was extracted from the included studies, relevant to the aims of this review. Participant and study design information were extracted from the full text versions of the eligible studies. This information included: title, authors & publication year, geographical location, phenomena of interest / research question/s, research study design/methodology, data collection and analysis methods.

Overall, the experiences of 975 family carers of people with dementia were synthesized. The term 'carers' referred to any family member caring for a person with dementia in an unpaid capacity. They included spouses, partners, sons, daughters and siblings of people with dementia. The sample included a wide age range from 18 to 88. Living circumstances also varied, with some participants still living with and caring for the person with dementia, while others were bereaved carers whose loved one had passed away. Studies were carried out in four countries. This review included carers of people with any type and severity of dementia. In five studies (Hovland, 2018; Almberg et al., 2000; Diwan et al., 2009; Moore et al., 2023; Shuter et al., 2014) data were gathered via individual participant interviews while in four studies data were collected via focus groups or open-ended survey questions (Supiano et al., 2022, Sanders & Corley, 2003; Adams & Sanders, 2004; Frank, 2007). The studies employed a range of analytic methods including thematic analysis (Moore et al., 2023; Sanders & Corley, 2003; Supiano et al., 2022; Adams & Sanders, 2004; Almberg et al., 2000; Frank, 2007), content analysis (Hovland, 2018; Shuter et al., 2014) and cross case analysis (Diwan et al., 2009).

As shown in Table 2, all studies described the scope and purpose of their research, and all gave a clear statement of aims. Qualitative methodology was justified, and study design was apparent and appropriate to address the research aims in all studies. The recruitment strategy was appropriate for all studies. There was no mention of data saturation or other basis for ceasing data collection in any of the studies. Only four studies adequately discussed the relationship between the researcher and the participants (Hovland, 2018; Moore et al., 2023; Sanders & Corley, 2003; Almberg et al., 2000). Ethical issues were considered in varying detail. Four studies did not explicitly mention whether they had sought or received ethical approval (Adams & Sanders, 2004; Sanders & Corley, 2003; Frank, 2007, Diwan et al., 2009). There was no mention of how studies were explained to participants or if and how the effects of the research on participants were managed and addressed. Furthermore, the rigorousness of data analysis varied across studies and reflexivity reporting was limited. All but one study gave a clear statement of findings (Diwan et al., 2009) and all studies provided critical appraisal.

Overall, studies included in this review were of high quality with clear research aims, appropriate methodology, and comprehensive data collection and analysis. Based on this quality appraisal, the study by Diwan et al. (2009) stands out as potentially methodologically flawed due to limited discussion in relation to data collection and analysis. This could potentially affect the depth and reliability of its contributions to the systematic review. In relation to the other studies, the absence of explicit ethical approval statements and limited discussion on researcher-participant relationships are noted but do not constitute major methodological flaws that would significantly undermine the validity of their findings.

Table 1

Data extraction

Author Year Country	Analysis	Sample	Characteristics	Main Themes
Hovland, 2018 UK	Content Analysis	N = 36	Bereaved carers asked to reflect on experiences of pre-death grief Spouse/Significant Other/Partner N = 20 Adult Child N = 15 Sibling N =1 81% women	• Welcoming Death - To avoid unwelcome alternatives - To send him/her to a ‘better place’ - It was a ‘relief’

				- Because it ‘wasn’t him’
Moore et al., 2023 Australia	Thematic Analysis	N = 150	Non-bereaved carers asked to reflect on experiences of pre-death grief and coping strategies Spouse/Partner N = 70 Adult child N = 72 Other N = 8 77.3% women	- Embracing carer identity - Psychological strategies - Seeking support
Sanders & Corley., 2003 USA	Thematic Analysis	N = 173	Non-bereaved carers asked to reflect on experiences of pre-death grief	• Ambiguity • Loss of previously established roles • Loss of intimacy • Feelings of desperateness and loss of control • Self- awareness of grief

Supiano et al., 2022 USA	Thematic Analysis	N = 100	50 non-bereaved and 50 bereaved carers asked to reflect on experiences of pre-death grief Spouse/Partner N = 2 Adult child N =39 Other = 59 76% women	• Adequate preparedness for death • Inadequate preparedness of death
Adams & Sanders, 2004 USA	Thematic analysis	N = 58	58 non-bereaved carers asked to reflect on experiences of pre-death grief Spouse/Partner N = 2 Adult Child N = 39 Other N = 58 69.7% women	• Loss of shared activity • Mourning of previous relationship • Frustration in relation to difficulty communicating

Almberg et al., 2000 Sweden	Thematic analysis	N = 30	30 bereaved carers asked to reflect on experiences of pre-death grief Spouse/Partner N = 7 Adult Child N = 16 Other N = 7 70% women	• Pre-death grief and positive memories • Burden before death
Diwan et al., 2009 USA	Cross case analysis	N = 62	62 bereaved carers asked to reflect on experiences of pre-death grief	• Why did caregivers grieve at that time?
Frank, 2007 USA	Thematic analysis	N = 353	353 bereaved and non-bereaved carers asked to reflect on experiences of pre-death grief	Personal grief and loss • Ambiguous loss • Anticipatory mourning • Disenfranchised grief

Shuter et al., 2014 USA	Content analysis	N = 13	13 bereaved and non-bereaved carers Spouse/Partner N = 7 Adult Child N = 6	Grief • Acknowledged • Anticipatory • Ongoing

Table 2

Quality Ratings with CASP Qualitative Checklist

CASP Criteria	**Hovland, 2018**	**Moore et al., 2023**	**Sanders & Corley, 2003**	**Supiano et al., 2022**	**Adams & Sanders, 2004**	**Almberg et al., 2000**	**Diwan et al., 2009**	**Frank, 2007**	**Shuter et al., 2014**
Clear state of aims?	√	√	√	√	√	√	√	√	√
Is qualitative methodology appropriate?	√	√	√	√	√	√	√	√	√
Was the research design appropriate to address research aims?	√	√	√	√	√	√	√	√	√
Was the recruitment strategy appropriate to research aims?	√	√	√	√	√	√	√	√	√
Was the data collected in a way that	√	√	√	√	√	√	√	√	√

addresses the research issue?									
Has the relationship between researcher and participants been adequately considered?	√	√	√	-	-	√	-	-	-
Have ethical issues been taken into consideration?	√	√	√	√	√	√	√	√	√
Was the data analysis sufficiently rigorous?	√	√	√	√	√	√	√	√	√
Is there a clear statement of findings?	√	√	√	√	**X**	√	**X**	√	√
Will the results help locally?	√	√	√	√	√	√	√	√	√

Note: √ (Yes), χ (No), - (unclear)

Thematic Synthesis

Three analytic themes emerged from thematic synthesis: ‘There but not there’, ‘Multiple Losses’ and ‘Coping strategies to manage pre-death grief’.

These themes attempt to describe the distinct and complex experiences of pre-death grief as experienced by carers of people with dementia. While some carers may experience all these themes, others might relate to only some of these, reflecting the diverse nature of pre-death grief experiences in this population.

‘There but not there’

Ambiguity was a prevalent theme in the pre-death grief experiences of carers of people with dementia (Almberg et al., 2000, Sanders & Corley, 2003; Adams & Sanders, 2004; Frank, 2007; Shutter et al., 2014; Hovland, 2018; Supiano et al., 2022; Moore et al., 2023;). The theme ‘there but not there’ reflects the uncertain, ongoing nature of loss where the person with dementia is physically present but feels psychologically and emotionally absent.

Participants of the studies included in this review often reported experiencing ambiguous loss, characterized by the physical presence but psychological absence of the person with dementia. This unique form of grief was described as ongoing and unresolved, complicating the carers' emotional responses. This is in line with Boss (1999) who highlights that the grief of caregivers is compounded by ‘not knowing whether a loved person is absent or present, dead or alive’ (p. 4). The ‘goodbye without leaving’, as defined by Boss (1999), creates confusion for carers about roles and status within relationships.

The study by Hovland (2018) highlighted the ambiguous nature of this grief, where caregivers struggle with the duality of presence and absence. A poignant example of the psychological impact of ambiguous loss and the emotional turmoil faced by carers is captured in the words of a participant from this study who reported that “*I wanted him to die [crying] cause it wasn’t him. I loved the guy that he was and not the guy that he became… it wasn’t him.*"

Sanders and Corley (2003) highlighted how caregivers cope with the continuous, accumulative nature of loss, reinforcing the concept of the long goodbye as they mourn each progressive loss of their loved one's abilities and personality. This feeling was exemplified by the words of a 36-year-old daughter caring for her mother with a diagnosis of dementia:

> *She is not the way she used to be as my mother. Just looking in her bedroom at home, it is feeling like she is gone, but yet she's still alive. Her things are still where they have been for years, even when she was well. She sits and looks at the things that once made up her life and to her that life never existed. I ask myself daily, is my mother alive or dead.* (Sanders & Corley, 2003).

This struggle in caring for someone who is 'there but not there' is also captured in the study by Frank (2007). One daughter caring for her mother stated that the biggest barrier she has faced as a caregiver is *"letting go of the person we used to know"*, highlighting a feeling of loss for the person that her mother was before the diagnosis of Alzheimer's.

The ambiguity of losing someone gradually causes significant emotional and psychological distress. In the study by Almberg et al. (2000) the emotional toll of ambiguous loss is highlighted by a participant that noted, *"I feel like I'm grieving every day. It's a constant state of mourning for what was and what will never be again".* Similarly, Supiano (2022) highlighted how the emotional turmoil is exacerbated by the prolonged nature of caregiving. One caregiver reflected, *"There are moments when I feel like I'm drowning in grief, and then I remind myself that he's still here, which makes it even harder".*

A 63-year-old wife caring for her husband described in a similar vein the difficult ambiguity of having the loved one there, but not there. She said: *"I look at him sometimes and think the "he" I know is no longer there. Once in a while, there is a flash of the person he once was and then it is gone. This makes me sad. I would rather have him all here or all gone."* (Adams & Sanders, 2004).

In the study by Almberg et al. (2000), almost all participants (n = 21) reported experiences of pre-death grief and reflected on slowly losing their loved one's personality being almost as traumatic as not being recognised by the person and described feelings of wanting the person to be who they were before the disease despite knowing this was not possible. One carer in this study stated that *"to see mother slowly disappearing mentally, but still being physically present. It was terrible".*

Furthermore, additional layers of ambiguity and loss are introduced due to the impact the cognitive decline has on relationship dynamics. For example, the study by Shuter et al. (2014) highlighted the impact on spousal relationships. A participant noted that "*he's my husband, but it feels like I'm married to a stranger. The man I knew is gone, and yet, he's still here".* One carer summed up her experience when she stated that her biggest barrier as a caregiver is *"realizing and facing that it truly is a "long goodbye"* (Frank, 2007).

As one participant caring for their father with dementia described:

> *It is a constant reality shock every day to still see him and not communicate. It's like being teased. He's here, but not.* (Adams & Sanders, 2004).

A central component of the carers' pre-death grief experiences was the overall sense of ambiguity that they were experiencing as a result of the changes their loved one was faced with due to their diagnosis. Many of the carers commented that their loved ones physically looked the same but were cognitively or mentally different. Thus, the caregivers questioned their relationship with the care recipients and the feelings that they had for these individuals.

The studies referenced above highlight the complexity and ambiguity that characterise the pre-death grief experiences of carers of people with dementia. It is possible that as a result of these experiences, this population may find it more challenging to cope and resolve their grief than individuals that perhaps experience less ambiguity.

Multiple losses

In all studies, individual participants linked their experiences of pre-death grief while caring for people with dementia to experiencing multiple losses, such as witnessing their loved one lose their cognitive and functional abilities, loss of previously established roles and intimacy (Sanders & Corley, 2003; Adams & Sanders, 2004; Diwan et al., 2009, Supiano et al., 2022), loss of communication (Adams & Sanders, 2004; Diwan et al., 2009) loss of control (Sanders & Corley, 2003; Frank, 2007) and loss of the person their loved one was before their diagnosis of dementia (Hovland, 2018; Adams & Sanders, 2004; Frank, 2007, Almberg et al., 2000, Shuter et al., 2014, Moore et al., 2023). Participants described experiencing multiple losses, including the loss of their relationship with their loved one and a sense of missed opportunities for closure, illustrating the complex nature of pre-death grief.

Loss of previously established roles was a central theme in most studies included in this review. In the study by Sanders and Corley (2003) participants who identified themselves as grieving (n = 173) despite the cared for person still being alive, highlighted the impact of role reversal on their pre-death grief experiences. Furthermore, these carers attributed the grief as being caused by the changes in roles. For example, a 49-year-old participant attributed her grief to the fact her father was becoming more child-like and described:

> *I am slowly watching the man who was my father, and all that role implies turn into a child. Sometimes it is difficult to conjure up the man I knew as my father for all of my life. This version of the man is now my father. He cries, wets himself and now I rock him like a baby. It is so sad; heartbreaking.* (Sanders & Corley, 2003)

Many carers in this study indicated that their grief would become more intense at times when other individuals noticed the role reversal. For instance, an 83-year-old husband stated:

> *My granddaughter asked me why I now do the ironing and bathe grandma. My heart broke because suddenly the rest of the family recognized that she was now dependent on me. That is*

> *why I grieve. I see that others know she will never return.* (Sanders & Corley, 2003)

A different study (Diwan et al. 2009) suggested that individual carers report a variety of losses that are experienced simultaneously. The majority of participants described experiences of pre-death grief in varying degrees (n = 62) and linked these to experiencing distinct losses, such as the loss of personhood (memory, recognition, functional ability). Findings of this study were in line with earlier studies that reported a variety of losses experienced by caregivers (Sanders & Corley, 2003).

Coping strategies to manage pre-death grief

All studies included in this review highlighted various strategies that carers use to manage pre-death grief. These strategies encompass seeking social support, utilising emotion regulation and acceptance as well as problem-focused strategies, engaging in positive reframing and meaning-making strategies and maintaining positive memories. These strategies were described as helping carers navigate the complex emotional landscape of caregiving, providing them with the tools to manage their grief effectively while they were still caring for their loved ones.

A recurring theme in the literature is the role of positive memories in coping with pre-death grief. Several studies (Hovland, 2018; Supiano, 2022; Moore, 2023; Sanders & Corley, 2003; Alberg et al., 2000) illustrate how positive memories helped carers cope with pre-death grief by enhancing emotional resilience and a sense of continuity and connection with their loved ones. Positive memories were described as an emotional buffer, facilitating meaning-making, aiding in psychological adaptation, and sustaining relationship continuity. By focusing on positive past experiences, carers found solace and resilience.

For example, in the study by Almberg et al. (2000) twenty-one carers reported experiences of pre-death grief but linked these to positive memories and rewarding shared experiences with their loved ones during this period. This study focused on how carers use positive memories as a coping mechanism to manage stress and anxiety, providing moments of emotional relief from the current challenges of caregiving. In addition, in the study by Supiano et al. (2022) carers that were able to access and reflect on positive past experiences with their loved one often reported a more adaptive grief process and better emotional outcomes. As one participant explained:

> *There are days when I feel completely drained, but remembering the way she used to laugh gives me the strength to keep going.* (Supiano, 2022)

Another strategy involves finding positive aspects within the caregiving role and constructing meaning from the experience. This strategy was related to providing emotional resilience and a sense of purpose to carers in their caregiving role, helping them cope with their ongoing grief. For instance, participants in Moore et al. (2022) reported that holding onto memories of significant life events, such as their wedding day, helped them maintain a deeper sense of purpose in their caregiving.

> *I hold onto the memories of our wedding day and the life we built together. It reminds me why I'm doing this and gives my caregiving a deeper purpose.* (Moore et al., 2022)
>
> *Even though it's hard now, I know that caring for my mother is part of honouring her life and our relationship.* (Adams & Sanders, 2004)
>
> *Caring for my father has deepened our bond. It's hard, but it's also brought us closer in ways I never expected.* (Supiano et al., 2022)

Most participants (n = 88) in the study by Moore et al. (2022) reported that they found positive outcomes as part of their pre-death grief experiences, such as celebrating caring for their relative with dementia, finding value in supporting other people including carers, and recognising their caring role and the need to address their own personal needs. Some participants identified positive aspects of being able to reciprocate care to a loved one who may have supported and cared for them in the past. Some found the caring role had brought them closer to their relative with dementia and had highlighted characteristics in the person with dementia that they had not noticed before (Moore et al., 2022). Similar studies, including those by Supiano et al. (2022) and Almberg et al. (2000), reported that carers often find meaning in reciprocating care, deepening their emotional connection, and recognizing the value in their caregiving role.

As one participant caring for their father with dementia put it:

> *Many parts of our lives have… are now kind of interwoven with dad in a way that wasn't the case before… there's been, you know, positive things that have come out of this… in some ways it's felt like we've had an opportunity to form this new relationship (with dad).* (Moore et al., 2022)

Supiano et al. (2022) highlighted how the long illness trajectory allows carers to give and receive forgiveness and reconciliation, improving their relationship with the person with dementia. This relationship resolution contributes to carers readiness for their loved one's death by addressing emotional and relational aspects, managing experiences of pre-death grief, and providing closure before the death of the person with dementia.

As one carer reported:

> *I have no regrets—I had time before the disease was severe to really talk to my dad…I became an ongoing caregiver with my mom…nothing was left unsaid.* (Supiano et al., 2022)

Seeking social support was also emphasized as a critical strategy. Participants reported that connecting with others who understand their experiences provided significant emotional relief. As some participants reported:

> *Talking to others who understand what I'm going through has been a lifeline. It makes me feel less alone.* (Supiano, 2022)
>
> *My siblings and I take turns caring for Mom. It helps to know I'm not doing this alone.* (Moore, 222)

Emotional regulation and acceptance strategies, including acceptance of the disease trajectory, were also reported as being helpful by participants in supporting them to change their outlook on their situation and making it more manageable. However, in contrast, some carers reported an inability to identify anything positive or helpful about their circumstances, highlighting the variation in pre-death grief experiences for carers of people with dementia (Moore et al., 2022).

Discussion

This review synthesised the pre-death grief experiences of carers of people with dementia. Pre-death grief is a complex and multifaceted concept and is defined in various ways across the studies included in this review.

Supiano et al. (2022) describe pre-death grief as emotional distress in anticipation of a loved one's death, especially due to dementia progression. Hovland (2018) defines it as grief experienced due to the ambiguous loss associated with dementia. Almberg et al. (2000) refer to it as chronic sorrow from continuous mourning of the gradual losses over extended periods while Moore et al. (2023) define it as the cumulative emotional impact on carers witnessing their loved ones' decline and preparing for their final loss.

Thematic analysis identified three interrelated themes: ‘There but not there,’ ‘Multiple Losses,’ and ‘Coping strategies to manage pre-death grief.’

Most studies (Almberg et al., 2000; Sanders & Corley, 2003; Adams & Sanders, 2004; Frank, 2007; Shuter et al., 2014; Hovland, 2018; Supiano et al., 2022; Moore et al., 2023) highlighted ambiguity in carers' experiences of pre-death grief, linking it to feelings of hopelessness, guilt, and despair. Carers reported a 'long goodbye,' grieving for their loved one throughout the disease trajectory. The theme ‘there but not there,’ aligning with the Ambiguous Loss Model (Boss, 1999), emphasizes unresolved loss before death.

‘Multiple losses’ was a central theme in the included studies, and it highlights the gradual decline in loved ones’ abilities, affecting carers' sense of loss and shifting relationship dynamics (Supiano et al., 2022). The continuing multiple losses experienced by carers while the person with dementia is still alive contribute to a complex experience and highlight the need for support systems to help carers manage these challenges.

The review also highlighted strategies used by carers to manage pre-death grief within their caring roles. Certain studies (Almberg et al., 2000; Supiano et al., 2022; Moore et al., 2023, Shuter et al., 2014) emphasised positive outcomes from these experiences, such as relationship resolution and closure, which provided carers with a sense of peace. Important coping strategies included embracing the carer identity, use of acceptance and humour, and seeking support.

These approaches align with the Dual Process Model (Stroebe & Schut, 1999), which outlines how people manage grief through two types of stressors: loss-oriented and restoration-oriented. Loss-oriented stressors involve directly dealing with the emotional pain of the loss, such as grief work and confronting feelings of grief. Restoration-oriented stressors focus on adapting to life after the loss, including managing new roles and engaging in new activities. Study participants included in this review utilized social support and positive reframing, consistent with the model's restoration-oriented coping.

Walter's (1996) grief model, which suggests that sharing memories and creating biographical narratives of loved ones can benefit carers, is also relevant, given the anticipatory nature of dementia-related loss. Supporting carers in this process could be beneficial.

Limitations

Studies included in this review incorporated wide heterogeneity in family carers' age, dementia subtype and living circumstances, including both spouses/partners, siblings and adult children caring for a person with dementia. These details were not always clearly distinguishable in the studies and therefore it was difficult to determine their influence on the findings of the studies.

The synthesis is also likely to have been influenced by studies being carried out in different countries. Different countries utilise distinct education, health and social care systems, influencing participants' experiences. For example, perspectives on the support available may differ between public funded and private systems. Based on the studies included in this review, in the USA (Frank, 2008) formal support services, such as counselling and support groups, were crucial and more prevalent, contributing to better emotional outcomes for caregivers while in Sweden (Almberg et al., 2000), there was a greater emphasis on informal support networks.

In addition, perceptions toward disease and dying among dementia caregivers may vary based on cultural, social, and healthcare contexts in different countries. Based on the studies included in this review, caregivers in the USA (Hovland, 2018) often focused on understanding and being prepared for the disease trajectory including end of life care and access to professional support. Swedish carers (Almberg, 2010) emphasized the emotional strain of the caregiving journey and the critical need for social support. The healthcare system's provision of support services was seen as essential to alleviating caregiver burden.

Furthermore, studies conducted in the USA highlighted a tendency towards an individualistic perspective. For example, Supiano (2022) emphasized the importance of formal support services and the psychological preparedness of carers, which resulted in a smoother transition through grief. On the other hand, the caregiving experience in Sweden often involved a collectivist view, relying heavily on family and community support networks. For example, Almberg et al. (2000) noted the importance of family and community support in alleviating the emotional burden of caregiving. These differences are influenced by cultural norms, healthcare systems, and the availability of support services. Understanding these variations can help tailor interventions and support mechanisms to better meet the needs of carers in different cultural contexts.

A limitation of this systematic review is the lack of a second rater during data extraction, which could introduce potential biases and reduce the reliability of the extracted data. However, efforts were made to enhance rigour, including discussing developing analytic themes through academic supervision and a second rater for quality appraisal. The purpose of quality appraisal was to highlight limitations in study quality, as opposed to excluding low quality studies, as this remains contentious (Thomas & Harden, 2008). Methodologically flawed studies may have influenced findings; however, themes derived from methodologically weaker studies were comparable to the stronger papers.

Implications for service provision and future research

The findings of this review have implications for services supporting carers of people with dementia. Studies included in this review highlight the dual nature of grief, acknowledging that it is a normal and expected reaction to loss (Diwan, 2009), while also recognising how grief can become prolonged and impact on daily functioning (Shuter, 2014).

This review highlights how carers of those with dementia may grieve throughout the long disease trajectory and may experience a number of pre-death losses. Therefore, education in relation to pre-death grief would be helpful in supporting them to prepare for the losses they may experience while their loved one is still alive.

There was variation in the experiences of carers, which emphasises the need for services to be more attuned to the diversity among carers and why and when they may grieve. The finding that some carers cope well with the loss of a person with dementia, even while providing care, is promising. These carers can identify positive outcomes linked to their experiences of pre-death grief. This highlights how managing the challenges of caregiving, grief, and loss can offer opportunities for personal growth and development.

Positive memories and opportunities to form a new relationship with the person with dementia were highlighted as particularly helpful by participants in this review. This finding is in line with Neimeyer’s (1988) model that focuses on meaning making in the grieving process, which uses a narrative approach to understanding the impact of loss on each individual’s life. Thus, interventions for this population could consider focusing on supporting carers to explore the significance or meaning of pre-death losses as well as supporting them to create a narrative of their loved one’s life and a way to find new meaning or form a new relationship with them. In addition to this, support in relation to coping with losses over time as well as safe spaces to share their complex pre-death grief experiences and have these acknowledged and normalised could be particularly helpful.

Conclusion

This synthesis provides an insight into the experiences of pre-death grief of family carers of people diagnosed with dementia. The review outlines the experiences of pre-death grief through three themes: ‘There but not there’, ‘Coping strategies to manage pre-death grief’ and ‘Multiple Losses’. Findings highlight the complexity and variation of pre-death grief experiences in this population and emphasise the pre-death losses this population may experience. The findings of this review provide implications for service delivery and future research.

Statements and Declarations

There was no funding associated with this review and the authors have no competing interests to declare.

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Chapter 2: Major Research Project

A qualitative examination of the experiences of people with dementia, carers and healthcare staff participating in a cognitive rehabilitation programme.

Prepared in accordance with the author requirements for the Journal Dementia.

Submission Guidelines

Plain Language Summary

Title: A qualitative examination of the experiences of people with dementia, carers and healthcare staff participating in a cognitive rehabilitation programme.

Background: Dementia is a brain condition that causes problems with thinking and memory, making daily activities difficult. Cognitive rehabilitation can help people with dementia manage their everyday tasks more effectively (Kudlicka et al., 2023). However, there is limited research on the experiences of people receiving and delivering cognitive rehabilitation.

Aims: To explore the experiences of people with dementia, their carers and staff participating in a cognitive rehabilitation intervention designed specifically for people with dementia. A key focus was on examining the impact of the intervention on participants' confidence in managing the condition.

Methods: Semi-structured interviews were conducted with people with dementia, their carers and staff participants who were recruited from Older People's Community Mental Health Teams (OPCMHT) or Young Onset Dementia (YOD) services in NHS Greater Glasgow & Clyde. Interviews were conducted before and at the end of the intervention and transcripts were analysed to identify themes in relation to the research aims, such as confidence of people with dementia in managing their difficulties and facilitators/barriers to participating in the intervention.

Findings: A total of 19 interviews were completed with people with dementia, their carers and staff participants. Out of these, 11 were pre-intervention and 8 were post-intervention interviews. Three main themes were identified. The 'role of the therapeutic relationship' showed that the relationship with the therapist influenced how participants' experienced the intervention. The 'relationship with the condition' theme highlighted how the intervention impacted on participants' views about dementia and the 'facilitators or barriers' theme explored what elements of the intervention were viewed as helpful or unhelpful.

Conclusions: This study explored how cognitive rehabilitation is experienced by people with dementia, their carers and staff. The themes identified highlight the elements of cognitive rehabilitation that are viewed as important and the significance of a person-centred approach in meeting the needs of people living with dementia. Further research is needed into the longer-term benefits of cognitive rehabilitation within the context of disease progression.

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Abstract

There is growing interest in developing interventions that can equip people with dementia and their carers to respond to dementia related challenges (Prince, Wimo, & et al., 2015). A Cochrane review (Kudlicka et al., 2023) concluded that cognitive rehabilitation can help people with dementia manage everyday activities. However, the evidence suggested that the impact on broader cognitive and psychological outcomes is less clear and requires further research. Furthermore, self-efficacy and its role in determining positive outcomes for people with dementia has been recently highlighted (Tonga et al., 2020). This study explored the experiences of people with dementia, their carers and staff participating in a cognitive rehabilitation intervention. A key focus was on examining the impact of the intervention on participants' confidence in managing the condition. The study utilised a qualitative design. Participants were recruited from Older People's Community Mental Health Teams (OPCMHTs) and Young Onset Dementia (YOD) services in NHS Greater Glasgow & Clyde. Semi structured interviews were conducted before and at the end of the intervention, audio recorded, transcribed verbatim and analysed using reflexive thematic analysis. The design allowed for an in-depth exploration of participants' experience of the intervention and aimed to investigate participants' perceptions of the impact of the intervention on their sense of self-efficacy and confidence in responding to dementia related difficulties. A total of 19 interviews were completed; 11 were pre-intervention and 8 were post-intervention interviews. Three superordinate themes emerged from the findings: 'the role of the therapeutic relationship', 'the relationship with the condition' and 'facilitators or barriers'. The themes identified highlight what elements of cognitive rehabilitation are viewed as important by participants as well as potential facilitators and barriers to intervention delivery. Further research is needed into the longer-term benefits of cognitive rehabilitation within the context of disease progression.

Keywords: Dementia, Cognitive Rehabilitation, Self-Efficacy, Carers, Qualitative

Introduction

Dementia is a progressive, neurodegenerative condition affecting millions of people around the world. The trajectory of dementia involves deterioration in cognitive, behavioural, emotional and physical functioning. In recent years, there has been an interest in creating interventions to effectively prepare individuals with dementia and their carers for these changes and to help them address dementia-related challenges (Prince, Wimo, & et al., 2015).

Cognitive rehabilitation is a personalized, solution-focused approach designed to help individuals with cognitive impairments to manage everyday activities and maintain as much independence and quality of life as possible. It involves working on specific goals identified as important by the person with dementia and may include using compensatory techniques, developing new habits and routines, and using enhanced learning methods to improve recall of crucial information (Kudlicka et al., 2023).

Amieva et al. (2016) conducted a randomized control trial comparing cognitive training, reminiscence therapy, and individualized cognitive rehabilitation in Alzheimer's patients to usual care. The study found that individualized cognitive rehabilitation led to better clinical outcomes, with patients experiencing less functional decline after 24 months compared to other groups. Furthermore, this approach significantly reduced the rates of institutionalization, suggesting it should be considered to delay institutionalization in patients with mild to moderate Alzheimer's disease.

A recent Cochrane review on cognitive rehabilitation for people with mild-to-moderate dementia evaluated the effectiveness and risks associated with this intervention (Kudlicka et al., 2023). The review concluded that cognitive rehabilitation can help people with mild to moderate dementia improve their ability to manage everyday activities and can be a valuable part of dementia care. However, the evidence suggested that the impact on broader cognitive and psychological outcomes is less clear and requires further research. The findings were predominantly driven by one large, high-quality RCT (Clare et al. 2019) and the review highlighted that the long-term effects of cognitive rehabilitation beyond a year remain uncertain and there is a need for more high-quality studies to strengthen the evidence base and explore the mechanisms by which cognitive rehabilitation works.

NHS Education for Scotland (NES) have developed a training package (a resource book and workshop) that aims to provide health and social care staff in Scotland with the knowledge and skills to apply Cognitive Rehabilitation strategies for people with Dementia in a consistent and evidence-based way. The resources developed by NES are based on the Cognitive Rehabilitation in Dementia evidence base, particularly on work by Clare and colleagues (2019). However, the clinical utility of the NES intervention and its acceptability with staff, people with dementia and their carers has not been formally investigated.

The Current Study

This study is part of a wider project investigating the clinical application of the NES Cognitive Rehabilitation in Dementia workshop and staff resource. The wider project consists of two studies, one focused on evaluating the efficacy of the intervention and the present study which took a qualitative approach in exploring the personal experience of participating in the cognitive rehabilitation intervention from the perspective of people with dementia, their carers and staff members delivering the intervention.

A particular focus for this study was to explore whether there is a relationship between engagement with a cognitive rehabilitation intervention and self-efficacy reported by participants. There is growing interest in the role of self-efficacy, defined as the perception of one’s capacity to manage responsibilities and tasks (Bandura, 2005), in determining positive outcomes for people with dementia (Tonga et al., 2020). Self-efficacy has been suggested to be related to overall quality of life (Luszczynska, 2005), a finding that was also supported by a systematic review conducted by Crellin et al. (2014) who highlighted the association between self-efficacy with health-related quality of life in carers of people with dementia. The fact that self-efficacy is not a fixed trait but can be changed through psychosocial interventions (Bandura, 1992) adds to the importance of exploring and gathering evidence regarding the relationship between engagement with a cognitive rehabilitation intervention and self-efficacy.

Research aims

The aim of this project was to explore the personal experience of participating in an intervention using the NES cognitive rehabilitation in dementia resources from the perspective of people with dementia, carers and staff members.

Specifically, the study aimed to investigate the impact of this intervention on the areas outlined below:

i) From the perspective of people with dementia and their carers, what was the experience/satisfaction of the assessment and goal identification process at the initial stages of the intervention?

ii) From the perspective of people with dementia, is there an impact on reported self-efficacy in managing tasks following participation in a cognitive rehabilitation in dementia intervention?

iii) From the perspective of carers, is there an impact on reported self-efficacy and confidence in responding to the behaviours and needs of the person with dementia? What are carers' views on whether the self-efficacy and confidence of the person with dementia they are caring for has changed?

iv) From the perspective of people with dementia and their carers, is there an impact on communication and mood during and after the intervention?

v) From the perspective of people with dementia, their carers and staff members, what are the facilitators and barriers to engagement with the intervention? Are there any adaptations required.

Method

Design

This study utilised a qualitative design. Semi structured interviews were conducted at two time points, at the assessment and goal identification process in the initial stages of the intervention and at the completion stage of the intervention. Interviews were conducted at two time points to accommodate the cognitive impairments experienced by people with dementia, by giving them the opportunity to share their views sooner rather than attempting to retain all their thoughts and views in relation to the intervention until the completion stage. Furthermore, there was a possibility that the outcome of the intervention may impact on participants' experience and therefore conducting interviews both at initial and final stages of the intervention may offer some insight into how their views are potentially shaped by this. Semi structured interviews were audio recorded, transcribed verbatim and analysed using reflexive thematic analysis (Braun and Clarke, 2022).

Ethical Approval

Approval was sought and obtained from the West of Scotland Research Ethics Committee (23/WS/0144) and NHS Greater Glasgow and Clyde (GG&C) Research and Development Department (UGN23NE239). For further information see Appendix B.

Recruitment Procedure

Patient participants were people with dementia known to and identified by Older People's Community Mental Health Teams (OPCMHT) or Young Onset Dementia (YOD) services in NHS Greater Glasgow & Clyde (NHSGGC). Participants needed to meet the following inclusion criteria: a diagnosis of a mild/moderate dementia in the last 12 months, having been assessed by members of the OPCMHT/YOD service as eligible for cognitive rehabilitation as well as having a carer who is also able to engage in the intervention. People who lacked the capacity to consent in research were excluded. Staff participants were OPCMHT or YOD members of staff who had access to the NES Cognitive Rehabilitation in Dementia workshop resources and access to clinical supervision to support their implementation of the NES resources in clinical practice. Participants were approached either face-to-face, by telephone or email.

Sample Characteristics

Participants were recruited between December 2023 and March 2024. This study was part of a wider project, split into two studies, investigating the clinical application of the NES Cognitive Rehabilitation in Dementia workshop and staff resource. The first study undertook a Single Case Experimental Design and a sample size of 6 people with dementia was deemed sufficient to investigate whether staff assisted use of the cognitive rehabilitation resources leads to goal identification, goal attainment and satisfaction for patients with dementia and their carers. The present study aimed to explore the experiences of those 6 participants and their carers and staff members involved in their care, thus aiming to conduct semi-structured interviews with 18 people.

Eighteen participants were initially invited to participate in the study. Of these, two people with dementia and two carers did not meet the eligibility criteria. Out of the 14 participants who met the criteria, two people with dementia and two carers withdrew from the intervention due to personal reasons following the initial assessment and goal identification process - one person with dementia and their carer agreed to complete the pre-intervention interviews before withdrawing from further participation, while the other dyad (one person with dementia and their carer) withdrew entirely before completing any interviews.

In total, three people with dementia and three carers proceeded with the intervention. Of these, one person with dementia chose not to complete the pre-intervention interview, while the other two people with dementia and the three carers completed the pre-intervention interviews.

Post-intervention interviews were completed by all three people with dementia and the three carers who participated in the intervention. Additionally, two staff members completed post-intervention interviews. One staff member was responsible for delivering the intervention to two of the three people with dementia who completed the intervention.

The final sample of participants is summarised in Table 1. Pseudonyms were assigned to maintain anonymity.

Table 1.

Sample Characteristics

Pseudonym	Gender	Participant Group	Dementia Type	Interview Location
Nina	Female	Person with Dementia	Alzheimer's	Home
Kate	Female	Person with Dementia	Alzheimer's	Home
Derek	Male	Person with Dementia	Alzheimer's	Home
Robert *	Male	Person with Dementia	Alzheimer's	Home
Mark	Male	Carer	N/A	Home
Josh	Male	Carer	N/A	Home
Natalie	Female	Carer	N/A	Home
Alison *	Female	Carer	N/A	Home
Karen	Female	Staff	N/A	Online
Mary	Female	Staff	N/A	Online
Valerie	Female	Staff	N/A	Online
Jane	Female	Staff	N/A	Online

Note. *Robert and Alison completed the pre-intervention interviews but decided not to proceed with the intervention. All other participants proceeded with the intervention.

Participants typically met with their therapists on a fortnightly basis over a duration ranging from 1 to 11 weeks. Each session lasted approximately 60 minutes and encompassed a range of standard cognitive rehabilitation activities aimed at enhancing cognitive functioning. These activities primarily targeted domains such as memory, attention, executive functioning, and problem-solving, and were individualized to address specific cognitive difficulties.

Research Procedure

Written informed consent was obtained from all participants prior to interviews. Interviews were conducted largely individually, however on two occasions the person with dementia requested that their carer remained present during their interview. Interviews took place at two time points, at the initial intervention stage and as close to the final intervention session as possible and the researcher took a note of the elapsed time between completion of the intervention and interviews. Interviews were conducted flexibly, and participants were reminded that they could stop the interview at any point. Regular breaks were offered, and the researcher adapted their communication style to accommodate the patient participants' cognitive impairment. Consideration was given to the order in which the questions were asked to ease the patients into the interview and questions were kept as concise as possible. Interviews were arranged for when the person with dementia was more alert. The interviews were conducted in a non- distracting environment and the researcher allowed for extra time before the interviews to build rapport. Patient participants were advised that if they required further support following the interview, they could contact their OPCMHT or YOD service.

A semi-structured interview schedule was developed and used to facilitate access to participants' experience more pertinent to participants rather than researcher assumptions (Larkin et al., 2006). The interview schedule was developed by the lead researcher in consultation with the researcher's Academic and Field Supervisors. Questions were open-ended and prompts were used to facilitate access to participants' experience (see Appendix E).

Researcher Reflexivity

Thematic synthesis involves interpretation by the researcher and is influenced by the researcher's prior experiences and conceptions. The author and interviewer is a female Trainee Clinical Psychologist, who had experience of working with people with dementia and their carers and was in the process of completing a Doctorate in Clinical Psychology. A reflective diary and supervision were used to reduce bias through increasing awareness of reactions and reflections evoked during analysis.

Data Analysis

Individual interviews lasted approximately 20-30 minutes, were audio recorded and transcribed verbatim. Field notes were not made during and/or after the interviews and repeat interviews were not carried out. Data saturation was not discussed, and interviews were completed with all study participants. Transcripts were not returned to participants for comment and/or correction due to time constraints in relation to study completion and write up. The author analysed the qualitative data using reflexive thematic analysis (Braun & Clarke, 2022). Interviews were analysed individually. Initial line by line comments were made and initial coding was generated. The author examined the codes developed to identify broader patterns of meaning (potential themes). Data relevant to each potential theme were collated. Once initial themes were developed, these were examined in relation to the coded data to determine whether the research aims were addressed. The themes were reviewed and further developed by being split, combined or discarded. The researcher aimed to ensure that themes were refined and defined by developing a detailed analysis of each theme, working out the scope and focus of each theme and deciding on an informative name for each theme. Given information was gathered from multiple perspectives, the researcher was aware that certain themes that were identified may be individual to certain participant groups whilst others may be identified across all participants. The researcher systematically looked for commonalities and overlaps amongst themes and used a bottom-up approach in grouping codes together and identifying patterns. The final phase included the writing up and presentation of the analytic narrative in relation to existing literature. Participants have not provided feedback on the findings up to this point, but a summary of the findings will be shared with them in due course.

Results

Cognitive rehabilitation was received positively by the majority of the participants. Key themes were developed reflecting factors that influenced the experience of the intervention and whether it was considered beneficial. Given information was gathered from multiple perspectives, certain themes that were identified were individual to certain participant groups whilst others were identified across all participants. Given interviews were conducted both before and at the end of the intervention, there were distinct themes that emerged at the two time points. Three superordinate themes which represent participants' experiences of cognitive rehabilitation are summarised below in Table 2. Divergent experiences are discussed in cases where subthemes applied differently to a participant's account.

Table 2.

Summary Table for Superordinate Themes and Subthemes

Superordinate Themes	Subthemes
The role of the therapeutic relationship	'Somebody's helping me
	Establishing a connection
	Impact of support
Relationship with the condition	'It hits home'
	Changing attitudes
	Acceptance and Adaptation
Facilitators and barriers	Meaningful goal
	Logistical issues

The role of the therapeutic relationship

The first theme encapsulates the role of the therapeutic relationship in the effectiveness of the intervention, which can be understood in three subthemes: ‘somebody’s helping me’, ‘establishing a connection’ and ‘impact of support’. The first theme was identified across all participant groups and at both interview points.

‘Somebody’s helping me’

This subtheme describes how information that therapists gave about dementia and the intervention were largely considered to be helpful for both people living with dementia and their carers. The relationship with the therapist in most cases made asking questions and communication comfortable and easy. Most participants looked forward to the therapist visiting, enjoyed their interactions and expressed feelings of disappointment when the intervention ended.

For example:

> *I’ve had somebody to ask questions, although there were questions, I did not have to ask. I was told them before I asked them. I used to think all week of Karen coming and not in a frightening way, definitely not in a frightening way, and that I need to make sure this is okay, and I thought ‘somebody’s helping me, which is a good thing’ and I am quite disappointed it’s finishing.* (Kate, person with dementia, post-intervention interview)

A carer also shared how he believed that his wife *“is probably pleasantly surprised by how much support there is now, that wasn’t there before, so, that’s very obvious and it’s good that that’s there, and that we have someone helping us”*. (Mark, carer, pre-intervention interview)

Establishing a connection

Building a positive relationship with the therapist was perceived to be crucial. Most people living with dementia described feeling comfortable, relaxed and at ease when talking to their therapist and both people with dementia and their carers highlighted the significance of 'having the right person' delivering the intervention and identified key therapeutic skills that impacted on their experience.

As one carer described:

> *I think it's important to have the right person doing the intervention. Mary, as far as I could see, was very kind and very gentle and took her time and her and Derek immediately clicked. He was pleased to see her. Yeah, I think having the right person would be really important. It's like with anything, in psychology etcetera, you need to have the right person that presses your buttons, yeah, so, I think probably that.* (Natalie, carer, post-intervention interview)

The impact the therapeutic relationship may have had on their perception of the intervention was also reflected upon by one couple that decided to withdraw from the intervention stage of the study following the initial assessment and goal identification stage. During their pre-intervention interviews, this couple reflected on feelings of distress that they experienced during the initial stage of the intervention. While the couple was not able to identify what it was exactly that they found difficult about the whole experience, the carer wondered whether perhaps the therapist's therapeutic style impacted on their experience.

As the carer put it:

> *As I say, I have no idea, I don't know where it came from, it just got us really sad, and we were crying, the tears were really bubbling. I don't know, I don't know what caused it. And I think it was also, that she kept, it was like an inquisition rather than just asking questions and getting to know us. But it didn't work that way and I felt she was just getting on him all the time. And I was sitting here, and she was sitting there, and I had to go over and sit with him. He was so distressed.*
> (Alison, carer, pre-intervention interview)

The same carer shared how *"It's just something happened that day, I don't know… But something was fractured",* highlighting how potentially a lack of rapport ultimately impacted on their decision to withdraw from the intervention.

Impact of support

In some cases, the support provided through the therapeutic relationship and the skills acquired through the intervention were linked to positive changes in relation to mood and overall psychological wellbeing. For example, people with dementia described how through their relationship with their therapist and learning new skills, they noticed a more positive outlook on things and improvements in their mood. Thus, while the therapeutic relationship was crucial, the intervention itself also contributed to these positive outcomes.

> *I am much more happier, yeah… because I've got a new skill.* (Derek, person with dementia, post-intervention interview)

Some people with dementia described previously experiencing feelings of anxiety and agitation in relation to dementia related difficulties and highlighted how through their relationship with their therapist they were supported to learn new strategies to help them manage these feelings:

> *If I get something wrong, I tend to keep looking and looking, so she has said 'stop that' and 'what you do is leave it and go back to it' or 'forget about it, look at your phone, do something else'. Cause I get very agitated if I can't do something so it's just to stop my agitation*. (Kate, person with dementia, post-intervention interview)
>
> All three participant groups reflected on how the confidence of the person with dementia increased, often in relation to the strength of the therapeutic relationships.

For instance, one person with dementia demonstrated growing confidence in using technology and this appeared to be directly linked to his positive interactions with his therapist. He started with basic tasks and gradually progressed to more complex activities, showing significant improvement. As the staff member described: *"...he knew just by looking at me what we would be working on and as things* *progressed, he would be like 'oh this is how you do it' and could find everything…"* (Mary, staff member, post-intervention interview)

Participants described how this increased confidence expanded out with the intervention and the specific goal they were working on to other aspects of their lives. Staff members highlighted what elements of the therapeutic relationship empowered the person with dementia and increased their confidence. For example, Karen, a staff member delivering the intervention, emphasised how the intervention increased the confidence of the person with dementia while also highlighting the importance of managing people's expectations and being mindful of the pressures they may put on themselves to reach their goals.

> *I think in some ways it has increased her confidence with having structure, something to do, you know, working towards this and I can see that she has been doing really well so I can see the positive impact. And it has also been about managing her expectations and not being too hard on herself...* (Karen, staff member, post-intervention interview)

Mary also recalled noticing that when the person with dementia started feeling more confident in their new skills, their confidence in other areas grew as well. As she reported:

> *…it was just really nice to see the impact that it had on his life and watch his skills generalise out to other things, his confidence grow in [activity] and connecting with people and planning things. Yeah, just watching that spread throughout his family too cause definitely it had an impact on them.* (Mary, staff member, post-intervention interview)

From one of the carers' accounts, it is apparent how this increased confidence enhanced her husband's sense of independence and made her feel more secure and safe.

> *And he has had his phone more often, it's been easier for us to communicate, so like before the only way to find out where Derek was by looking at 'find my phone' whereas now I can phone him. And he will answer the phone. Before he often didn't have the phone charged or he wouldn't use it so there was no point of him taking it with him so it's nice that we've got a bit more security and*

> *he has got more independence, I think.* (Natalie, carer, post-intervention interview)

One person with dementia described how she felt confident enough to go out on her own, something that she had not felt the confidence to do in a long time. She highlighted how the skills and strategies she learnt as part of the cognitive rehabilitation supported her to manage feelings of anxiety. As she described:

> *I hear her in my ear saying things like 'right, just stop, don't panic, do something else and then go back' so what I did is I went into this little shop I know people. Well, I know them from going into the shop, I don't know them. And I spoke to them and then I carried on.* (Kate, person with dementia, post-intervention interview)

Relationship with the condition

The second theme highlights how the intervention challenged the relationship and the beliefs people with dementia and their carers held about the condition. This was apparent within three interrelated subthemes: 'it hits home', 'changing attitudes' and 'acceptance and adaptation' and it was particularly highlighted in the post-intervention interviews.

'It hits home'

Some carers of people with dementia described how the intervention operated as a reminder of the progressive nature of the condition and the losses their loved one was experiencing in terms of their functional abilities. One carer, Mark, used the phrase 'it hits home' to describe how the intervention affected him. This was also illustrated by another carer:

> *It's difficult because sometimes you just want to ignore what is happening and it's bringing forth things that he can't do. And that is almost like a bit of a car crash every time it happens. You are reinforcing that because you are writing it down, but I am up for anything that is going to help him.* (Natalie, carer, pre-intervention interview)

Changing attitudes

Changing perceptions and outlook on supporting their loved one was reported by carers of people with dementia. All three carers that completed the post intervention interviews highlighted how the intervention enhanced their understanding of their loved one's abilities and difficulties and challenged some of the beliefs they held in relation to what it meant to be living with dementia.

As one carer described it:

> *Well, I think it gives you a strong realisation of the challenges that Nina's affected by, the condition, certainly opens that up to you. I think the intervention was very useful in understanding how if you compartmentalise things, it's easier to sort of deal with something opposed to maybe looking at everything together.* (Mark, carer, post-intervention interview)

Some carers felt that the intervention demonstrated that their loved one could still learn new skills and regain independence if the right tools and strategies were used and highlighted the usefulness of this in supporting people with dementia and their families. As one carer described:

> *I just think that understanding how people think, and work is quite important to being able to achieve, you know… And I don't think there is enough insight into that, the general public wouldn't know how to do that, you know, and it probably would really help people instead of saying things twenty times and shouting, which is what I think happens to people, which is a real shame. Because Derek has proved that he can re-learn*. (Natalie, carer, post-intervention interview)

People with dementia also reported how the intervention challenged their views about their own abilities to manage dementia related challenges. For example, Derek reported that: *"I fairly quickly found out that I can still learn a new skill"* (Derek, person with dementia, post-intervention interview).

A carer also reflected on how the intervention to some extent encouraged other family members to be involved, which in turn made her feel more supported in her caring role. As she explained:

> *We managed to get everyone involved and probably for me there is a lot of denial going on in Derek's family at the moment, there is not a lot of help. So, it kind of opened a door to that. Would I say it encouraged the conversation about it? No, cause they wouldn't have a conversation about*

> *it. But it just made them a wee bit more involved which helped me, you know.* (Natalie, carer, post-intervention interview)

Furthermore, participating in this intervention appeared to enhance understanding and patience among carers. For instance, one person with dementia noted that her husband became more patient and supportive: *"I actually think he is better with me, going back to the [activity] he is better with me… He is more patient with me".* Similarly, a carer explained how the intervention helped him understand and respond better to his wife's needs: "*It's helped me understand what she needs."* This improved communication not only facilitated better care but also strengthened the relationship between carers and their loved ones with dementia.

Acceptance and adaptation

Carers of people with dementia reported that it was helpful to learn strategies and new skills that can support them to adapt and meet the needs of their loved one. The intervention was described as helping carers better understand and accept dementia, which in turn facilitated their adaptation to new routines and coping strategies. As some carers described:

> *If I had known about the process or thought about the process earlier, then life could have been easier, quicker, because instead of getting frustrated that Derek wasn't following instructions and was finding things difficult, I might have used that technique quicker.* (Natalie, carer, post intervention interview)
>
> *I think just the intervention itself, listing out a process is great to just have that identified, because sometimes the obvious is not that obvious when you are in the swamp with the alligators, so it's good to have these things pointed out and I think that's a big help going forward as a tool.* (Mark, carer, post-intervention interview)

Facilitators and barriers

The third theme refers to the factors that were perceived to be acting as facilitators or barriers in delivering cognitive rehabilitation and it emerged from participants' accounts at both interview points. It can be understood in two subthemes: 'a meaningful goal' and 'logistical issues'.

Meaningful goal

There was a shared belief among staff delivering the intervention that the goal identification process was a key element impacting the success of the intervention. Staff described how goals that aligned with the participants' values had a positive impact on engagement with the intervention. For instance, one staff member described supporting two people with dementia: one was highly motivated by a meaningful goal, while the other pursued a less meaningful goal. She explained:

> *What they agreed on was the [activity]. I am just not sure that this was something she really felt motivated about to achieve…*

And:

> *I feel that's the difference, she had a really meaningful goal, you know, it's to [activity] to communicate with her granddaughter. So, there's this real kind of meaning behind it and seeing how this is influencing her motivation to engage with it, and I think it has maybe boosted her confidence in the strategy and knowing she can do things and learn the [activity] she is quite, you know when she is doing well with it, you can see she is kind of pleased and enjoying it as well so that's been nice.* (Karen, staff member, post-intervention interview)

Both people with dementia and carers also reflected on choosing goals that were meaningful and had a positive impact on their family. For example:

> *I thought, well, it is something useful to me and it is useful to the family, and it will help my mind I hope if I can remember it just trying to remember all of it cause my memory is not very good.* (Kate, person with dementia, post-intervention interview)
>
> *It means it's been a really good goal cause its impacted on the whole family because he is joining in with the family what's app chat sometimes and erm he is getting really positive feedback; it's really helped his mum. Because he is texting his mum and we've had people come to visit because he's been texting them.* (Natalie, carer, post-intervention interview)

When recounting her experience of the goal identification process, one carer explained how this was perceived as ‘positive’ because she was able to observe her husband’s abilities change over time:

> *I actually think doing the goals was quite helpful because it was positive. Derek’s ability changed. It was obvious it was very static and then it really changed. I suppose realising that he can learn. It was positive, it was really positive when things began to change, which is really nice.* (Natalie, carer, post-intervention interview)

Staff highlighted how the level of motivation the person with dementia demonstrated about meeting their goals either supported or hindered progress with the intervention. As some staff members described:

> *I think although the intervention is supposed to be very goal focused for the person, I think still their motivation on picking something that is meaningful to them and they really want to do is the biggest, the biggest challenge.” (Mary, staff member, post intervention interview)*
>
> *“So, did it improve her confidence? I don’t think so, but I don’t necessarily think she was that motivated in the first place to get the most out of it maybe. (Karen, staff member, post intervention interview)*

Participants found the process of goal setting challenging at times due to the extensive information required and the need for self-reflection. This process sometimes evoked strong emotions. A carer described how *“I thought arriving at the goal was initially kind of tricky”* and staff members reflected on how the goal identification process required a lot of paperwork to be filled in and questions to be asked, which at times was potentially “overwhelming” for both people with dementia and their carers.

Logistical issues

One person with dementia reported concerns about the number, length and frequency of meetings and shared how this added to their burden and sometimes led to frustration and disengagement. As they explained**:**

> *I found the number of meetings a bit of a pain but obviously you've got to sacrifice something.* (Nina, person with dementia, post-intervention interview)

Coordinating appointments around existing commitments, especially for working carers, was sometimes challenging and added to their stress. One carer reported how initially they felt *'I had to be here every week so for me, because I am working as well, erm, it probably added to the burden of what we were doing"* but that they then realised they did not need to be present for each appointment.

Staff members delivering the intervention reflected on helpful intervention elements and potential improvements for future delivery. They reported that they found the initial assessment and goal identification appointment overwhelming for them to deliver and the participants to experience due to the complexity and amount of information that needed to be covered. The structured nature of the intervention was recognised as helpful, while staff reported they would welcome more support in the form of peer supervision to help them shift through some of the challenges in delivering this intervention.

> *I feel like that's quite a good thing to have when you are going into delivering an intervention is having something that is kind of a bit more structured, and you have got the tools there for you, you got the values sheet to use, and you've got the handouts to fill out so you are going in with materials ready to use so I think that is quite good.* (Mary, staff member, pre-intervention interview)
>
> *I feel like a group information session with like all of the therapists would have been very helpful to have…* (Karen, staff member, post-intervention interview)

Discussion

This study explored the experiences of people with dementia, their carers, and staff participating in goal-oriented cognitive rehabilitation. Thematic analysis revealed three main themes: 'the role of the therapeutic relationship', 'relationship with the condition', and 'facilitators or barriers'.

The first key element identified was the role of the therapeutic relationship. A strong, supportive, and consistent therapeutic relationship enhanced the experience for people with dementia and their carers, leading to better engagement and outcomes. Miscommunication or lack of rapport, on the other hand, caused distress and reduced the intervention's effectiveness. Trust-building and support were highlighted as helpful factors. People with dementia noted their partners became more patient and understanding, while carers valued learning skills from therapists, improving communication. This finding aligns with the GREAT trial (Warmoth et al., 2020) and previous research (Moebs et al., 2017), emphasizing the importance of a collaborative and safe therapeutic relationship (Sohlberg & Mateer, 2017) in achieving better compliance and functional outcomes (Schönberger et al., 2006). Participants reported increased confidence and a changing self-view, which extended beyond the intervention into other life aspects. Staff found the structured, goal-oriented intervention rewarding, noting the generalizability of the outcomes.

Secondly, the study highlighted how cognitive rehabilitation challenges participants’ relationship with dementia, including their beliefs and attitudes. The intervention highlighted the difficulties faced by people with dementia while supporting them in learning new skills, aiding in acceptance, adaptation, and coping with emotional challenges. The balance between hope for improvement and acceptance of the condition's progression was a central aspect.

Lastly, participants identified certain facilitators and barriers. The goal identification process was crucial, linking meaningful goals to motivation. Staff appreciated the structured nature of the intervention and suggested that group supervision and support would be beneficial.

During the pre-intervention interviews, participants primarily focused on the challenges of identifying meaningful and appropriate goals, as well as the emotional complexities associated with the goal-setting process. In the post-intervention interviews, reflections centered on the therapeutic relationship and its role in fostering increased confidence in individuals with dementia for managing tasks, alongside carers' enhanced ability to meet their loved ones' needs. These post-intervention discussions also provided deeper insights into the facilitators and barriers to intervention delivery, particularly highlighted by staff participants. Notably, while the therapeutic relationship emerged as a consistent theme across all participant groups, themes related to emotional adaptation were predominantly voiced by people with dementia and their carers, whereas logistical concerns were primarily raised by staff participants. This highlights the need for further research to better integrate these distinct perspectives, particularly in addressing both emotional and practical challenges in cognitive rehabilitation delivery.

Overall, in relation to the specific aims of this study, the assessment and goal identification process was highlighted as a key element of cognitive rehabilitation. Participants reported how it can be both a positive and an emotive experience and a link between identifying a meaningful goal and effectiveness of the intervention was highlighted. Many participants reported increased self-efficacy in managing tasks following the intervention and the strong link between therapeutic relationships and increased confidence highlights the importance of fostering positive, supportive interactions to facilitate successful outcomes. Carers also reported experiencing an increase in their confidence in responding to the needs of the person with dementia. Lastly, improved communication between carers and people with dementia, with carers becoming more patient and understanding, underscores the intervention’s role in enhancing the overall caregiving experience and relationship quality.

Participants included in this study were people diagnosed with Alzheimer’s disease, with one participant having a diagnosis of early-onset Alzheimer's. Early-onset Alzheimer's often presents with more pronounced executive function deficits, which may have influenced the type of cognitive difficulties addressed during the cognitive rehabilitation intervention compared to late-onset Alzheimer’s. It is important to note that this sample did not include individuals with other types of dementia, such as frontotemporal dementia (FTD), which typically manifests with different cognitive and behavioural impairments, particularly in language, social cognition, and executive functioning. Interventions for individuals with FTD might require more focus on managing behavioural symptoms and language-related tasks, suggesting that the findings from this study may not be directly generalizable to other dementia subtypes. This distinction should be considered when interpreting the results, as cognitive rehabilitation strategies may need to be tailored differently for non-Alzheimer's populations.

In addition, while relational complexities were not explicitly noted within the patient-carer dyads in this study, it is important to consider that these relational dynamics could significantly influence the outcomes of cognitive rehabilitation. Established or longstanding tensions between people with dementia and their carers may complicate the intervention process, potentially affecting engagement and the overall effectiveness of the therapeutic relationship. When such complexities are present, cognitive rehabilitation may require a more nuanced approach, as these relational factors could heighten emotional challenges or create barriers to achieving meaningful goals and fostering positive outcomes. Future research should explore how these dynamics may further complicate the intervention process.

Strengths and Limitations

One of the particular strengths of this study is that interviews were conducted at two time points, at the initial intervention stage and as close to the final intervention session as possible. This approach helped mitigate the risk of memory related difficulties by allowing participants, particularly people with dementia, to reflect on their experiences when these were fresh in their memory and their perceptions of the initial assessment and goal identification stage were not influenced by their overall experience of the study. Similar approaches have been validated by existing literature, which emphasizes the benefits of capturing evolving experiences through multiple data collection points. This method was informed by studies such as Clare et al. (2008) and Spector et al. (2003), which highlight the value of capturing participants' reflections at multiple time points, particularly in dementia research. By minimizing recall bias, this approach allows for more accurate insights. This approach may be beneficial in similar contexts, especially with populations prone to memory challenges, to better capture evolving experiences.

In terms of the limitations, interview transcripts were not returned to participants for comment and correction, due to time constraints related to the study write-up. However, participants were asked whether they wished to receive a written study summary following study completion and the research team will make arrangements for this in due course. In addition, the sample may not be representative of all experiences of cognitive rehabilitation. Participants were recruited via OPCHMTs and YOD services and there may have been biases in clinician judgment that affected who was approached and nominated to participate in the study. Furthermore, in relation to the staff participants, the sample is not representative of all health professionals that deliver cognitive rehabilitation to people with dementia, thus the views expressed may not reflect those of other staff groups. Canvassing and inclusion of a wider range of views could lead to the identification of additional themes.

Steps were taken to reduce positive response bias. There was not an established relationship with the participants prior to the study and the interviewer was also not involved in delivering the intervention and this was made clear to the participants so they could reflect and feedback what they truly thought about the intervention. Participants were informed that the interviewer was part of the study team and that their role was to gather information about their overall experience of taking part in the intervention. However, it is possible that participants’ may not have shared the entirety of their perspectives. Nevertheless, the interviews elicited varied and nuanced experiences of the intervention which mitigates against these concerns.

Implications for Clinical Practice

This study emphasized the significance of the therapeutic relationship in cognitive rehabilitation and suggests that this aspect could possibly be further highlighted in the NES cognitive rehabilitation workshop, along with guidance and support for staff on building rapport. Additionally, the study highlighted how staff delivering the intervention model effective interaction and responsiveness to the needs of people with dementia for carers. This underscores the importance of holding sessions involving all three parties for the benefit of both the carer and the person with dementia.

Future Research

This study looked at the perceived immediate impact of participating in cognitive rehabilitation from the perspective of people with dementia, their carers and staff delivering the intervention. More research is required to investigate whether there is a longer-term impact on functioning and care. It would also be helpful to investigate people's experiences of cognitive rehabilitation with different characteristics, such as dementia subtype and ethnic background. While the study sample consisted of only people with a diagnosis of Alzheimer's disease, this included both people with late and early onset of the condition. The role of the therapeutic relationship was highlighted as a key element of cognitive rehabilitation in this study. Future research could potentially explore how this relationship is developed and the role it plays in the context of cognitive rehabilitation for people living with dementia and their carers so healthcare providers can maximize this effect when planning dementia care packages.

Conclusions

The present study explored the experiences of people with dementia and their carers as well as staff who participated in a goal-oriented cognitive rehabilitation intervention. The original aims of the study were revisited, and the findings suggest that cognitive rehabilitation was viewed positively by most participants. Many participants reported improved mood and increased self-efficacy in managing tasks following the intervention and the role of the therapeutic relationship and the importance of meaningful foals were highlighted as key elements influencing the effectiveness of the intervention. Further research is required into the possible longer-term benefits of cognitive rehabilitation within the context of disease progression.

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Appendices

Appendix A:

ENTREQ Checklist

Item No.	Guide and Description	Report Location
1. Aim	State the research question the synthesis addresses	Page 15
2. Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis)	Page 19
3. Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved)	Pages 16 - 18
4. Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type)	Pages 16 - 17
5. Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources	Page 16
6. Electronic Search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits)	Pages 16 - 17
7. Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies)	Pages 16 - 17
8. Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions)	Pages 23 - 27
9. Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development)	Page 18
10. Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g.	Page 19

	assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings)	
11. Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting)	Page 19
12. Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required	Page 19
13. Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale	Pages 28 - 29
14. Data extraction	Indicate which sections of the primary studies were analyzed and how were the data extracted from the primary studies? (e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software)	Page 18 - 19
15. Software	State the computer software used, if any	None used
16. Number of reviewers	Identify who was involved in coding and analysis	Pages 18 - 19
17. Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts)	Pages 18 - 19
18. Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary)	Page 19
19. Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive	Page 19
20. Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation	Pages 30 - 36
21. Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct)	Pages 37 - 41

Appendix B:

Ethical Approval Documents

Ethical Approval Documents removed due to confidentiality issues

Appendix C:

Participant Information Sheets

Accessible from these links:

https://osf.io/7q4xz

https://osf.io/nwug2

https://osf.io/mz7np

Appendix D:

Participant Consent Forms

Accessible from these links:

https://osf.io/p52fg

https://osf.io/fgrek

https://osf.io/qr8pg

Appendix E:

Interview Schedule

Interview Schedule (PwD)

Assessment and Goal Identification Process

1. Can you tell me what your thoughts are in relation to the process of setting goals?
   1.a Did you feel well supported during the goal identification process?
   1.b Was there anything that could have been done differently?
2. How did you find the process of identifying the goals you wanted to work towards?
   2.a What feelings did this process bring up for you?

Intervention

3. Can you tell me how the intervention affected the way you manage tasks?
   3a How do you feel about that?
4. How did the intervention change your beliefs about your abilities to accomplish difficult tasks/challenges?
5. How did the intervention affect how you communicate with your partner?
6. How did the intervention affect your mood?

Facilitators and barriers to engagement

7. What did you find helpful about your experience?
8. What did you find unhelpful/what could have been done better?

Interview Schedule (Nominated People)

Assessment and Goal Identification Process

1. Can you tell me what your thoughts are in relation to the process of identifying the goals of this intervention?
   1.a Did you feel well supported?
   1.b Was there anything that could have been done differently?

2. How did you find the process of identifying the goals this intervention would be focusing on?
   2.a What feelings did this process bring up for you?

Intervention

3. Can you tell me how the intervention process affected you?
   3a How did the intervention affect your confidence in responding to the needs of the PwD?
   3b How do you feel about that?
4. How did the intervention impact on how you communicate with the PwD?
5. How did the intervention affect the mood of the PwD?

Facilitators and barriers to engagement

6. What did you find helpful about your experience?
7. What did you find unhelpful/what could have been done better?

Interview Schedule (Staff Participants)

Assessment and Goal Identification Process

1. Can you tell me what your thoughts are in relation to the initial stage of this intervention (initial assessment and setting up goals)?
   1a What worked well and what didn't?

Intervention

2. How did the intervention affect the PwD confidence in managing tasks/challenges?
3. How did the intervention affect how they communicate with their partner?
4. How did the intervention affect their mood?

Facilitators and barriers to engagement

5. Can you tell me what are the facilitators to engagement?
6. What are the barriers to engagement?
7. Any adaptations required to facilitate engagement?

Appendix F:

Sample Theme and Exemplar

Superordinate Theme	Subtheme	Exemplar	Representation
Facilitators and barriers	Meaningful goal	*"So, there's this real kind of meaning behind it and seeing how this is influencing her motivation to engage with it and I think it has maybe boosted her confidence in the strategy and knowing she can do things and learn the [activity] she is quite, you know when she is doing well with it, you can see she is kind of pleased and enjoying it as well so that's been nice."* (Karen)	Karen Natalie Mary Kate Mark
		"…then it means it's been a really good goal cause its impacted on the whole family because he is joining in with the family what's app chat sometimes and erm he is getting really positive feedback; it's really helped his mum. Because he is texting his mum and we've had people come to visit because he's been texting them." (Natalie)	
		"I think still their motivation on picking something that is meaningful to them and they really want to do is the biggest, the	

		biggest challenge." (Mary) *"…I thought, well, it is something useful to me and it is useful to the family…"* (Kate) *"As I said initially we weren't quite sure what goal to choose but I think having arrived at that one it was a useful and sensible one to go with."* (Mark)	
	Logistical issues	*"I found the number of meetings a bit of a pain but obviously you've got to sacrifice something".* (Nina) *'I had to be here every week so for me, because I am working as well, erm, it probably added to the burden of what we were doing."* (Natalie) *"I feel like a group information session with like all of the therapists would have been very helpful to have…" and "I just felt that maybe completing all those worksheets was maybe a little bit overkill for the one goal and ermm I don't know if I am putting that on the patients, how I was feeling and projecting that to them."* (Karen) *"Yeah, so I think maybe the first thing that I would say is that it was quite a lot to try and do*	Nina Natalie Karen Mary Jane

in such a short period of time." (Mary)

"Erm so I did find like overall it was quite a lot to get through being the first time that I met the client and his wife…" (Jane)

Appendix G:

Final Approved MRP Proposal

Accessible from this link:

https://osf.io/2amcb

Appendix H:

COREQ checklist

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	56
2. Credentials	What were the researcher’s credentials? E.g. PhD, MD	56
3. Occupation	What was their occupation at the time of the study?	56
4. Gender	Was the researcher male or female?	56
5. Experience and training	What experience or training did the researcher have?	56
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	71
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	71
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	71

Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	56
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	53 - 54
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	53
12. Sample size	How many participants were in the study?	54
13. Non-participation	How many people refused to participate or dropped out? Reasons?	54
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	55
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	55
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	55
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	56
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	56
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	56
20. Field notes	Were field notes made during and/or after the inter view or focus group?	56
21. Duration	What was the duration of the inter views or focus group?	56
22. Data saturation	Was data saturation discussed?	56
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	56
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	56

25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	56 – 57
27. Software	What software, if applicable, was used to manage the data?	N/A
28. Participant checking	Did participants provide feedback on the findings?	57
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	58 - 68
30. Data and findings consistent	Was there consistency between the data presented and the findings?	69 – 70
31. Clarity of major themes	Were major themes clearly presented in the findings?	69 – 70
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	69 – 70