Being Kind to Ourselves: A Qualitative Evaluation Within a Feasibility Randomised Controlled Trial of Group Compassion Focused Therapy (CFT) to Improve Depression and Anxiety in Dementia

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Part One is a systematic review and qualitative thematic synthesis of twelve studies exploring social media use amongst people living with dementia (PLWD) in relation to their condition. Results showed that social media serves as a space for processing the emotional challenges of living with dementia and as a platform for asserting autonomy, agency, and constructing identity. Barriers to use and risks were also identified. Suggestions for future research in this area were proposed, including quantitative research to better understand patterns of social media use amongst PLWD and work prioritising more diverse samples to address gaps in representation

Part Two is a qualitative evaluation embedded within a feasibility Randomised Controlled Trial of group Compassion Focused Therapy (CFT) for people with living dementia (PLWD) who have symptoms of anxiety/depression. The study aimed to explore the perspective of participants with dementia on the feasibility and acceptability of trial procedures and the intervention, as well as perceived benefits and costs, and potential mechanisms of change of the intervention. Semi-structured interviews were conducted with 11 intervention and 7 control participants and were analysed using Framework Analysis (Ritchie & Spencer, 1994). Both the intervention and procedures were found to be broadly acceptable and feasible, with several benefits and areas for improvement identified. This was a joint project with another DClinPsy trainee, Ben Loe. See Appendix 11 for an outline of both trainees' contributions to the joint project.

Part Three is a critical appraisal. It includes reflections on my personal and professional positioning, explores key considerations in conducting research with PLWD, and examines broader issues of representation and diversity.

Impact Statement

To the authors' knowledge, Part One of this thesis is the first systematic synthesis of qualitative research exploring how people living with dementia (PLWD) use and experience social media. As the prevalence of dementia continues to rise globally, and social media becomes more embedded in everyday life, this area of research is likely to become increasingly relevant. This review adds to a growing body of research that examines social media use amongst groups with health conditions. It also contributes to broader academic efforts to centre lived experience and challenge the historic marginalisation of PLWD in both research and policy. This was achieved through a focus on qualitative studies and through inclusion criteria that required studies to report separately on the perspectives of PLWD. This review outlines important limitations in the evidence base, such as a lack of diversity across samples. It therefore lays the foundation for future research by both synthesising existing research and indicating how the evidence base can be expanded.

Outside of academia, the findings of Part One of this thesis may support clinicians in understanding the experiences of people living with dementia (PLWD). This review found that PLWD actively document and share their journeys on social media, which could provide clinicians with insight into their experiences and highlight unmet needs. As interest grows in psychosocial approaches to dementia care, this review found that social media offers several psychosocial benefits. This could impact dementia care if clinicians consider appropriate ways to support PLWD in accessing and benefits from these platforms.

Part Two of this thesis presents a qualitative evaluation embedded within a feasibility randomised controlled trial (RCT) of group-based Compassion Focused

Therapy (CFT) for people living with dementia (PLWD) experiencing symptoms of depression and/or anxiety. This study contributes to a small but growing body of research exploring psychological interventions for this population. Dementia is a major and growing public health concern, and mood disorders such as depression and anxiety are common in PLWD. However, pharmacological treatments have shown limited efficacy in this context, highlighting the need for alternatives.

A small number of studies have explored the use of CFT in dementia with promising results. This study responds to the need for more robust evidence by contributing to the first feasibility RCT of group CFT for PLWD. The use of qualitative methods enabled the wider feasibility study to go beyond evaluating outcomes alone, by exploring feasibility, acceptability, and potential mechanisms of change from the perspectives of PLWD. The findings suggest that progression to a full-scale RCT is warranted and offer recommendations for delivering this.

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Part One: Literature Review

Social Media Use Among People Living with Dementia in Relation to Their Condition: A Systematic Review and Qualitative Thematic Synthesis

Abstract

Aims: There is a growing body of research exploring social media use in health contexts. However, there is limited research on its use amongst people living with dementia (PLWD). This review aimed to systematically identify and synthesise qualitative research exploring PLWD's use and experiences of social media.

Method: A systematic search was conducted across five databases. Inclusion criteria were qualitative studies reporting separately on the experiences of PLWD using social media. Twelve studies were included in the review and were appraised using the modified Critical Appraisal Skills Programme (CASP) tool (Long, French & Brooks, 2020). Data analysis followed Thomas and Harden's method for thematic synthesis (Thomas & Harden, 2008).

Results: Thematic analysis generated five master themes. These were 'Making sense of dementia: sharing and processing the journey', 'A community of shared experience and reciprocal support', 'Social media as a platform for advocacy and change', 'Navigating identity and reclaiming agency', and 'Challenges of social media'. Social media emerged both as a space for processing the emotional challenges of living with dementia and as a platform for asserting autonomy, agency, and constructing identity. Barriers to use and risks were also identified.

Conclusions: This review highlights social media's potential to amplify the voices of PLWD and challenge stigmatising narratives. Future work in this area could aim to better understand patterns of social media use among PLWD through quantitative research and prioritise more diverse samples to address gaps in representation.

Introduction

Dementia: Context and Challenges

Dementia is an overarching term for a group of progressive diseases that interfere with memory, other cognitive abilities, and behaviour, which impact a person’s ability to perform everyday tasks (Word Health Organisation [WHO], n.d.). Dementia is more common in older adults, but it is not an inevitable part of ageing. Up to 9% of people living with dementia (PLWD) have young onset dementia, where symptoms develop before the age of 65 (WHO, 2025). In 2021, an estimated 57 million people were living with dementia globally. This figure is expected to rise to 139 million by 2050, with over 60% of those affected living in low or middle-income countries (WHO, 2021).

Dementia is a leading cause of death and a major cause of disability and dependency among older people worldwide (WHO, 2021). Its impact extends beyond the individual to caregivers and broader society. In 2019, the global cost of dementia was estimated to be $1.3 trillion, with around half of this cost borne by unpaid carers (WHO, 2025). Despite its prevalence and impact, dementia research has historically been underfunded (WHO, 2022). The perspectives of PWLD have also been marginalised in research, in part due to mistaken assumptions that their cognitive capacities preclude meaningful involvement. This has been changing gradually, with a move towards including PLWD in research and policy development (Diaz Gil et al., 2023).

Digitalisation and the Rise of Social Media

In recent years, society has become increasingly digitised, with an increasing number of everyday activities, including work, study and social interaction now taking place online (Age UK, 2024; Organisation for Economic Co-operation and Development [OECD], 2019). A key aspect of this shift to living life online is the use of social media. While definitions of social media vary, this review adopts Kaplan and Haenlein's seminal definition, which describes social media as "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0 and that allow the creation and exchange of user-generated content" (Kaplan & Haenlein, 2010, p. 61). Web 2.0 represents a shift from passive content consumption to participatory, user-driven platforms. User generated content refers to publicly accessible content created outside of professional routines and involving some degree of creative input (OECD, 2007). A social element is key to Kaplan and Hainlein's definition, all though it exists on a continuum and platforms do not necessarily require direct interaction to qualify as social media. Blogs, for example, offer lower interactivity than social networking sites but are included in Kaplan and Haenlein definition due to their emphasis on self-disclosure and public self-presentation.

Recent estimates indicate that 5.24 billion, or 63.9% of the world's population, are social media users (Statista, 2025). In the UK, 94% of the population are internet users and 90% of all internet users use social media. While this number is lower in older adults, recent figures indicate that 79% of those 65 and over are internet users and of those 75% use social media (Ofcom, 2025). Social media has changed how we interact and communicate with one another (Azzaikiyah, 2023); how we construct and present social identities (Zheng et al., 2020); and how we engage in civil life, including social and political movements (Bouillane, 2019).

Social Media in Health Contexts

As social media use has grown, so has its use in health contexts. A systematic review of social media use for health purposes including 544 studies summarised how these platforms are used by health institutions, researchers and practitioners and the general public (Chen & Wang, 2021). The review included studies highlighting how individuals with mental health conditions, diabetes, breast cancer and other chronic illnesses use social media for a wide range of purposes. This includes seeking and sharing health-related information, exchanging social support, building online communities with others who face similar health challenges, and documenting their illness experience.

There is also evidence that social media is used by groups with neurological and cognitive impairments. For example, a systematic review of people with Traumatic Brain Injury (TBI) found that people with TBI use social media as a source of information, to connect socially, and to aid rehabilitation. Reported risks included concerns about internet safety, such as scams, and concerns about people with TBI sharing inappropriate content. However, social media included key benefits for this group, including accessibility (as a result of not having to travel), alternative modes of communication, and the opportunity to interact in an environment perceived to be less stigmatising (Brunner et al., 2015).

Social Media and Dementia

Despite research interest in social media use among people with health conditions, there is limited research on its use among PLWD. Many of the studies exploring social media and dementia do not centre the experiences of PLWD. For example, some examine general public discourse on social media relating to dementia (Chen et al., 2018; Domingo-Espiñeira et al., 2024; Hrcincu et al., 2022), while other studies focus on social media use amongst caregivers of PLWD (Andersen et al., 2016; Gkotsis et al., 2020; Kevern et al., 2022). In some studies that do report on social media amongst PLWD, their experiences are reported alongside caregivers, without separate analysis or results (e.g. Johnson et al., 2022).

A recent scoping review on the use of social media in dementia care stated that the studies included in the review focused on the experiences and perceptions of caregivers and PLWD (Azzarhani et al., 2025). However, none of the 20 studies included in the review focused specifically on social media use by PLWD. Instead, eight studies examined social media use in relation to dementia more generally, such as for awareness raising or campaign purposes, or analysis of social media posts mentioning dementia. Seven studies focused specifically on social media use amongst caregivers of PLWD. Only one study reported on social media use by PLWD, but this study involved a mixed sample of PLWD and caregivers without disaggregating their experiences.

The gap in research regarding the use of social media by PLWD may be due to assumptions that this group is either unwilling or unable to engage with digital technologies, including social media (Talbot & Dunne, 2024). However, while in the past PLWD have been depicted as reliant on caregivers to access technology, more recent research challenges this view. Lee at al., 2023 found that PLWD can be active and regular users of digital technology, and that technology use can support communication, enhance understanding of their diagnosis, and can promote independence.

Social media may offer a way to counteract some of the psychosocial challenges faced by PLWD, such as ‘a shrinking world’, defined by restricted geographical boundaries and social withdrawal (Duggan et al., 2008); social isolation and loneliness (Hajek & König, 2025) and changes in identity (Tang et al., 2023; Graf et al., 2025).

There is a small but growing number of studies that do explore social media amongst PLWD. A recent narrative scoping review on the use of social media by PLWD has collated some of this evidence (Talbot & Dunne, 2024). It included 11 studies and found that there are active groups of PLWD on social media who derive several benefits. These include opportunities for social connection, self-expression, identity construction and sharing lived experiences. It concluded that social media expands the ‘shrinking world’ often associated with dementia by enabling PLWD to connect to others and by fostering a sense of community. However, the review also highlighted potential risks to social media use, including exposure to negative comments and stigma, as well as challenges navigating social media due to the symptoms of dementia. Notably, out of the 11 studies included in the review, 9 were qualitative, 1 was mixed methods and 1 was quantitative.

Aims

To our knowledge, there are no systematic reviews specifically examining the use of social media by PLWD. While the scoping review cited above indicates that PLWD use social media and derive benefits from it, it provided a narrative review of the evidence and did not employ formal synthesis methods. It also included studies with mixed samples, such as studies reporting on caregivers and PLWD together. As a result, the evidence base remains fragmented and there is a gap for a focused examination of the experiences of PLWD. Further, to capture the richness of PLWD's experience and given that the literature in the area appears to be largely qualitative, it may be particularly important to synthesise qualitative literature using established methods for doing so. Consequently, this review aims to systematically identify and synthesise qualitative research exploring PLWD's use and experiences of social media.

Method

The review was prospectively registered with PROSPERO in November 2024 (registration number: CRD42024612269).

Eligibility Criteria

Inclusion Criteria

- Publication type: peer-reviewed empirical papers that described a qualitative method and analysis approach. Type of analysis did not need to be named. Mixed methods papers were eligible if they reported a qualitative component separately.
- Population: people who self-disclosed as having been diagnosed with dementia.
- Context: reports on social media, defined according to Kaplan and Haenlein's (2010) definition adopted in this review.
- Language: English language studies published anywhere in the world.
- Date range: from inception to February 2025.

Exclusion Criteria

- Publication type: quantitative studies, no original data, unpublished doctoral theses, conference papers, posters, single case studies.
- Population: studies that reported on mixed populations and did not report separate themes or sub-themes for PLWD (e.g. results were reported jointly for PLWD and carers)
- Context: Studies that reported on mixed phenomena of interest and did not report separate themes or sub-themes for social media (e.g. results section reported on technology use without reporting separately on social media).

The inclusion and exclusion criteria were developed to align with the review question and to ensure the quality and relevance of included studies. The focus on qualitative research reflected the aim of the review to capture and centre the experiences of PLWD. To support rigour, only peer-reviewed papers that described a qualitative method and analysis approach were eligible, though naming a specific analytic method was not required to maintain breadth. Mixed-methods papers were included where a qualitative component was reported separately, but only the qualitative findings were synthesised. Single case studies were excluded as they offer limited opportunity for drawing broader insights and less scope to identify patterns or develop themes beyond an individual account, which was central to the purpose of this review. Criteria relating to the population (people living with dementia) and the context (social media) were derived directly from the review question. The restriction to English-language papers was due to practical constraints, as translation was not feasible given the resources available for this review.

Search Strategy

Databases Searched

The following six databases were systematically searched in February 2025: PsycInfo, MEDLINE, Embase and Emcare via Ovid; Scopus and CINAHL Plus. A multidisciplinary search strategy was adopted due to the broad and wide-ranging nature of the review question. PsycInfo was selected as the primary database for psychology and behavioural sciences. MEDLINE was included as a core biomedical database, with Embase added to extend coverage in this area. CINAHL Plus and Emcare were chosen to capture research from nursing and allied health professions, given their central role in dementia care. Finally, Scopus was included as a large interdisciplinary database to ensure breadth of coverage and to identify studies not included in discipline-specific databases.

Review Question and Search Terms

The review question was developed with reference to the PICOD framework (Population, Phenomenon of Interest, Context, Outcome, Design), which is a recommended tool for qualitative synthesis (Soilemezi & Linceviciute, 2018). Search terms were generated for the Population (people living with dementia) and the Phenomenon of Interest (social media). The remaining elements of PICOD helped to structure the broader focus of the review, including the inclusion and exclusion criteria.

A combination of text words and MeSh terms or subject headings were used to search for studies related to the population of interest and the phenomenon of interest. Synonyms and related terms for both concepts were informed by search strategies used in previous systematic reviews addressing related topics, including a review on grief and loss in dementia (Waddington et al., 2023) and a review on social media use for health purposes (Chen & Wang, 2021). Search terms were kept as consistent as possible across databases, with adaptations made only where necessary. Qualitative filters and qualitative-specific search terms were not applied due to the risk of excluding relevant studies (such as mixed-methods papers with a qualitative component). To maximise breadth, qualitative studies were instead identified during screening using the inclusion and exclusion criteria. See Appendix 1 for the full search strategy for each database.

Study Selection

Search results were imported into EndNote and duplicates were removed manually. De-duplicated studies were then uploaded on to Rayyan. Two stages of screening followed. First, the first author (SF) screened Titles and Abstracts according to eligibility criteria. To enhance reliability, a second reviewer (BL) then screened a random sample of 10% of titles and abstracts. Disagreements were resolved through discussion.

Second, SF then screened the full texts of potentially eligible papers, recording reasons for exclusion. To ensure consistency, BL independently screened a subset of full-text articles. Discrepancies were resolved through discussion, resulting in a preliminary list of 17 studies. Uncertainty remained regarding the eligibility of five papers, as the reporting of results was unclear. Specifically, it could not be determined whether these studies presented separate themes or sub-themes for PLWD, distinct from those of other populations such as caregivers. Following discussion between SF and a third reviewer (JS), all five papers were excluded on the basis that the reporting did not provide sufficient clarity to confirm separate findings for PLWD.

SF screened the reference list of the included studies but no further studies were identified. This resulted in a final set of 12 studies for inclusion. Two of these studies were based on the same data set (Castaño, 2020 & Castaño, 2023), however the review team decided to retain both of these studies as they addressed distinct research questions. The study selection process is further detailed in Figure 1.

Data Extraction

Key study characteristics deemed relevant to the review aims were extracted and summarised in a data extraction table. Selection of characteristics to extract was informed by previous meta-syntheses relevant to the review focus, including a review on dementia (Waddington et al., 2023) and a review on online health communities (Allen et al., 2016).

Quality Assessment

Study quality was assessed using the modified Critical Appraisal Skills Programme (CASP) tool (Long, French & Brooks, 2020). While the use of quality appraisal in qualitative meta-synthesis is debated, it is increasingly seen as important for enhancing rigour (Long et al., 2020). The CASP tool was chosen because of its wide-spread use. The revised CASP tool was chosen for its flexibility, which allows it to be adapted to meet the specific needs and context of each review.

The first author assessed each study using the CASP checklist questions. As recommended, instead of calculating quality based on all 11 questions, select ‘deciding criteria’ deemed relevant to the review aims and context were used to establish study quality (Long et al., 2020). SF and JS agreed on two deciding criteria.

The first criterion was rigour of data analysis (question nine on the revised CASP checklist). The second criterion was the degree to which the study focused on social media, based on Kaplan and Heinlein’s (2010) framework of social media, which classifies social media according to social presence/media richness and self-presentation/self-disclosure. A points system was developed to rate each study as high, medium or low quality according to these two criteria and final ratings were then reviewed and revised if necessary in relation to overall CASP scores (these were calculated by totalling scores on the first 10 questions as the last question relating to value is open-ended). Further details of this process are provided in Appendix 2.

Data Analysis

A qualitative thematic synthesis approach was chosen, following Thomas and Harden’s (2008) method, as it provides a systematic and transparent way of synthesising qualitative research. It is also a flexible approach that was developed for reviews that address questions about people’s experiences. The decision was made to focus on qualitative studies for two reasons: i) A preliminary search of the literature on social media use amongst PLWD revealed a limited evidence base, much of which was qualitative in nature and, ii) the review aimed to capture rich and nuanced experiences of PWLD using social media in relation to their condition.

Main Stages

Data analysis followed Thomas and Harden’s method for thematic synthesis (Thomas & Harden, 2008), incorporating additional guidance to structure the synthesis by study quality (Long et al., 2020). This involved three main stages.

The first stage involved line-by-line coding of the results section of each study by SF. The four studies that were deemed to be high quality following appraisal were coded first. This resulted in approximately 200 codes. These codes were reviewed to develop a preliminary coding framework: duplicate codes were removed, and similar codes were merged or grouped together (Thomas & Harden, 2008). SF led this process and met with BL to review and refine the framework. The coding framework was then used to code the seven medium quality studies. New codes were created when new meaningful data emerged. Following this, the coding framework was reviewed and revised. The final version of the framework was used to code the remaining low quality study. No new codes were created at this point.

In the second stage of analysis, SF examined the final code list and looked for patterns, similarities and differences. The aim of this stage was to produce a descriptive synthesis and so SF stayed close to the original data. Related codes were grouped together into categories and organised into a hierarchical tree structure. This resulted in the development of descriptive themes and subthemes.

In the third stage, analytical themes were generated by ‘going beyond’ the data in the original studies (Thomas & Harden, 2008). This involved identifying conceptual links between descriptive themes and generating novel interpretations of data in relation to the review aim (Long et al., 2019). SF met with BL to discuss and refine emerging analytical themes.

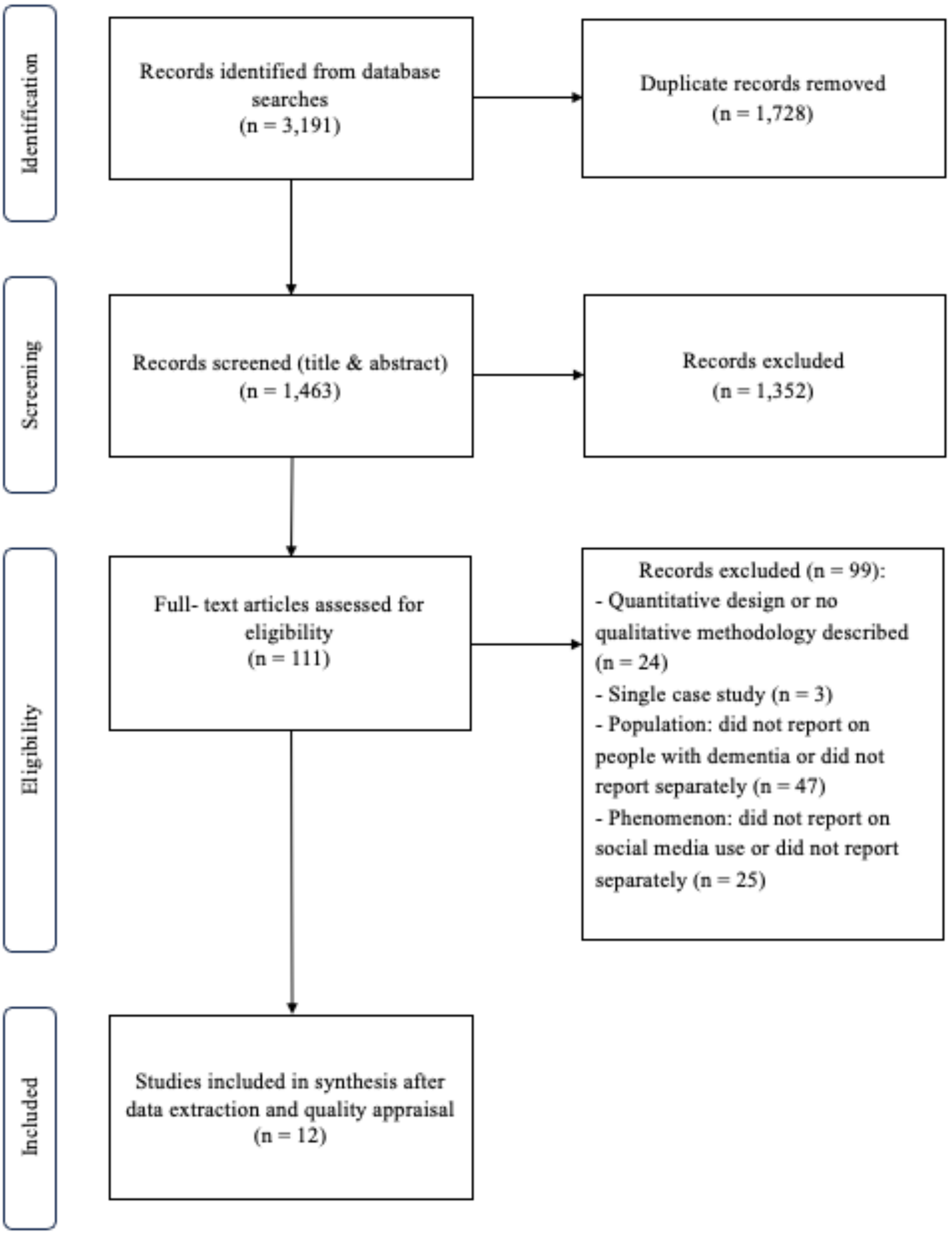
Epistemology and Positionality

SF followed an inductive approach to coding, openly coding without applying pre-specified criteria, while keeping a broad focus on experiences of PLWD. Analysis was undertaken from a critical realist position. Reviewers assumed the data could offer insights into the experiences of PLWD in relation to social media, while recognising that these accounts were shaped by context, including the interpretations of the original study authors and the reviewers. To stay close to participants' experiences, SF distinguished between participant quotations (first-order codes) and author interpretations (second-order codes) during analysis. During line-by-line coding, participant quotations were coded first, followed by author interpretations. In the code list, the two types were distinguished by formatting (first-order codes in italics; second-order codes in standard text). This ensured that participants' voices were foregrounded in the analysis. In the second stage of analysis, descriptive themes were developed mainly from first-order codes, with author interpretations incorporated subsequently to provide additional context. This approach ensured that the descriptive themes were grounded in participants' accounts while also recognising the interpretive contribution of study authors.

I (SF) reflected on how my social and cultural background, professional training and personal experiences might influence the analysis. I kept a journal throughout the analysis to facilitate this reflection. I am a woman in my early 30s from a Western background, raised in the UK, and at the time of conducting this review, in my third year of Clinical Psychology training. I approached this research with a belief in the value of digital inclusion for both PLWD and older adults.

Results

Figure 1 *Prisma Flow Diagram*



Study Characteristics

Twelve studies met the inclusion criteria for review. Key characteristics of the included studies are summarised in Appendix 3, Table 3.1.

Studies focused on online forums (*n* = 4), blogs (*n* = 3), Twitter (*n* = 2), audio-diaries (*n* = 1) and a combination of platforms (*n* = 2). Most studies analysed social media posts shared by PLWD (*n* = 8), while a smaller number of studies analysed data collected from semi-structured interviews with PLWD (*n* = 3), and one study analysed a mixture of interview and survey data. 10 studies employed named qualitative analysis methods, with the most common approach being thematic analysis (*n* = 5). Two studies used unspecified qualitative analysis techniques.

Where participant location was reported, individuals were based in English-speaking Western countries, including the UK, US, Canada, Australia and Ireland. Several studies did not explicitly report on participant location and only included social media posts written in English. Ethnicity was specified in only one study, where all participants were White British. In five studies that stated participant nationality, all participants were from English-speaking Western countries. In the remaining seven studies, participant nationality was not explicitly reported, although samples were either specified or implied to include only English-speaking participants or data written in English. Several studies explicitly focused on individuals with young-onset dementia, and in others the majority of participants were under 65.

Quality Appraisal

Four studies were rated as high quality, seven studies were rated as medium quality and one study was rated as low quality. See Appendix 4 for ratings on each item of the CASP quality criteria, and Appendix 5 for ratings on the deciding criteria specified in the methods section. Nine of the twelve papers were judged to demonstrate rigorous data analysis, two were assessed to “somewhat” fulfil this criterion and one paper provided insufficient information to assess this criterion.

Only one of the twelve studies reported clear consideration of the researcher–participant relationship. The majority of studies provided limited or no demographic data, which limits the quality of reporting. For example, ethnicity was specified in only one study and participant nationality only stated in five studies. Most studies also relied on self-identification of dementia diagnosis rather than confirmation.

Thematic Synthesis

Thematic synthesis generated five master themes. Themes and sub-themes are summarised in Table 1 below.

Table 1

Master Themes and Sub-themes

Master Themes	Sub-themes
Making sense of dementia: sharing and processing the journey	Dementia as a journey
	Sharing experience of diagnosis and disclosure
	Sharing experience of symptoms and their impact
	Reflecting on the future
	Social media as an emotional outlet and therapeutic space
A community of shared experience and reciprocal support	Connection through shared experience reduces isolation
	Collective identity and the value of dementia-specific spaces
	Seeking and sharing practical advice and guidance
	Emotional support, solidarity and encouragement
Social media as a platform for advocacy and change	Advocacy and representation
	Raising awareness and educating others
	Challenging stigma and reframing narratives
Navigating identity and reclaiming agency	Reflecting on loss and powerlessness
	Finding new identity and purpose
	Continuity of self despite change

Master Themes	Sub-themes
	Sharing what is still possible and inspiring others
	Social media supports communication and self-expression
Challenges of social media	Practical and cognitive barriers
	Social media leading to emotional distress

In the summaries below, participant quotations are presented in quotation marks and italics, while authors' interpretations are indicated by quotation marks and no italics. For longer quotations, quotations are indented, not enclosed in quotation marks, and italicised if quoting participants. An ellipsis is used where words have been removed from a quotation.

Theme 1: Making Sense of Dementia: Sharing and Processing the Journey

Dementia as a Journey. Across several studies, PLWD shared their personal journeys with the condition, using social media to document and reflect on different stages of their experience (Castaño, 2020; Castaño, 2023, Talbot et al., 2020; Talbot & Coulson, 2023; Frezza et al., 2022; Rodriquez, 2013). Participants sometimes framed diagnosis as 'the beginning of a metaphorical journey that abruptly diverted the course of their lives' (Castaño, 2023). They used journey metaphors to reflect on the terminal nature of the disease and the absence of a cure describing dementia as '*a journey of no return*' (Castaño, 2023). Participants also used metaphor to capture the uncertainty and emotional upheaval of living with dementia, describing dementia as a '*bumpy road*', '*uncharted territory*', '*a path full of pitfalls and highs and lows'*

(Castaño, 2023) and *'a rollercoaster (without seatbelts)*' (Frezza et al., 2022).

Sharing Experience of Diagnosis and Disclosure. PLWD used social media to share experiences related to diagnosis and disclosure (Castaño, 2020; Castaño, 2023; Frezza et al., 2022; Talbot & Coulson, 2023; Talbot et al., 2025; Rodriquez, 2013). Participants described the symptoms that led them to seek diagnosis, such as memory loss, disorientation and difficulty focusing (Rodriquez, 2013). They described how obtaining a diagnosis was a lengthy and frustrating process (Castaño, 2020; Castaño, 2023; Talbot & Coulson 2023), which was often delayed by denial from family members and healthcare professionals (Rodriquez, 2013). Participants shared their emotional response to diagnosis, which varied from relief at having an explanation for their symptoms (Frezza et al., 2022) to feelings of anger, isolation and fear (Castaño, 2020; Frezza et al., 2022; Talbot & Coulson, 2023). Forum users described feeling confused about the meaning and implications of their diagnosis, which was exacerbated by the lack of post-diagnostic support:

> *I was diagnosed with dementia last Friday, given a test result of 81 out of Hundred? What's this really mean [...] . . . I've not had anything in writing yet [...] Does everybody diagnosed have to contact help themselves, I just feel abandoned already*. (Talbot & Coulson, 2023, p.3)

Participants also reflected on the challenges of disclosing their diagnosis (Castaño, 2020; Castaño, 2023; Talbot & Coulson, 2023; Talbot et al., 2025). They shared deliberating and delaying telling friends and family members (Talbot & Coulson, 2023). As well as deliberating whether to disclose their diagnosis to those they knew offline, participants also deliberated over whether to broadcast their diagnosis online, where they worried about being pigeon-holed by fellow social media users:

> *I can see myself posting more about dementia in the future. But at the same time, I still want people to see me as someone my age, who still is interested in life*. (Talbot & Coulson, 2025, p.651)

Decisions to disclose varied depending on the social media platform. Designated Facebook groups and forums for PLWD were described as fostering a shared understanding and creating comfortable and open environments that were conducive to disclosure (Talbot et al., 2025).

Sharing Experience of Symptoms and their Impact. PLWD used social media to discuss a wide range of dementia symptoms, including emotional disturbances, memory difficulties, behavioural symptoms, difficulties with communication and sleep difficulties (Bailey, 2018; Castaño, 2020, Frezza et al., 2022; Talbot et al., 2020; Talbot & Coulson, 2023).

> *This disease robs people of their most precious memories. It takes away our ability to reminisce, to memorize, and recognize our loved ones. It even takes away our ability to recognize ourselves*. (Castaño, 2020, p.123)

PLWD also reflected on the impact of symptoms on daily life, describing how challenges with activities such as reading and traveling affected their ‘mood, confidence and connectedness' (Talbot & Coulson, 2023). They shared how emotional symptoms such as anxiety and confusion could be triggered by cognitive difficulties, which in turn impacted everyday functioning (Frezza et al., 2022).

Reflecting on the Future. PLWD shared their fears and concerns about the future on blogs, forums and dementia diaries (Castaño, 2020; Castaño, 2023; Frezza et al., 2022; Johnson et al., 2020, Talbot & Coulson, 2023). Dementia was described as '*unchartered territory*', reflecting the uncertainty of what lay ahead (Castaño, 2023). Fears about symptom progression were common, with participants anticipating inevitable decline: '*you don't play the what if game anymore, you play the when game*' (Castaño, 2023). Many also expressed concern about the impact of future decline on loved ones.

> *The things I read are real and uncompromising accounts of what this awful disease does to people, and their loved ones/carers ECT. Is this my future?? Is this, is what to come?? Will I be such a burden for my family??* (Talbot & Coulson, 2023, p.5)

Alongside emotional reflections, participants also discussed practical preparations for the future. Forum users reflected on how an early diagnosis gave them time to put their '*personal affairs in order*' and plan ahead, giving them '*peace of mind*' (Talbot & Coulson, 2023). Dementia diarists (PLWD who share their experiences through audio recordings on the Dementia Diaries online platform) advised others to plan ahead to prepare for the 'unknown' (Frezza et al., 2022).

Social media as an Emotional Outlet and Therapeutic Space. Several studies suggested social media platforms provide spaces for PLWD to express their emotions (Castaño, 2020; Castaño, 2023; Bailey, 2018; Brooks & Savitch, 2022; Frezza et al., 2022; Johnson et al., 2020; Rodriquez, 2013; Talbot et al., 2025). Blogs and forums were used to vent frustrations, including challenges with symptoms and medication (Johnson et al., 2020). PLWD described experiencing ‘a range of emotional states’ (Bailey, 2018), including anger, sadness, isolation and fear, with ‘*highs and lows, ups and downs*’ (Castaño, 20230). Some also expressed disappointment about perceived lack of support from friends and family (Frezza et al., 2022; Rodriquez, 2013).

PLWD reflected on how sharing their experiences online helped them to process what they were going through, likening this to ‘therapy’ (Rodriquez, 2013) or ‘counselling’ (Talbot et al., 2025).

> *It’s a way of me thinking through, this is an odd thing that is happening. Because by sharing it helps me come to terms with it [...] I’ve got so much going round in my head, when I put it to paper, it’s like a release. I suppose it’s like if you go to a counsellor*. (Talbot et al., 2025, p.652)

For some PLWD, social media seemed to be their only outlet, as indicated by one forum user: ‘*Sorry I can’t seem to keep my posts short, I haven’t talked to anyone about all this but here I guess I feel free to spill my guts’* (Rodriquez, 2013).

Theme 2: A Community of Shared Experience and Reciprocal Support

Connection Through Shared Experience Reduces Isolation. Six papers indicated that social media helped PLWD to feel less alone due to shared experience (Castaño, 2020; Castaño, 2023; Rodriquez, 2013; Talbot et al., 2021; Talbot & Coulson, 2023, Talbot et al., 2025). Participants on peer-support forums connected over shared 'social and functional losses', and in doing so 'achieved a sense of community' (Rodriquez, 2013). Key to the construction of community was 'the idea that others who had been diagnosed understood better than anyone else'. As one poster expressed, '*I found it the only place that spoke the same language*' (Talbot & Coulson, 2023).

PLWD indicated that connecting over shared experiences was normalising and reassuring:

> *You can tweet this happened and [...] somebody will tweet 'yes this happens to me'. So, you know well that must be normal*. (Talbot et al., 2021, p.2547)

Social media reduced isolation particularly for those living in rural areas, those with rarer dementias and people unable to attend in-person support groups (Frezza et al., 2022, Kohl et al., 2024; Talbot & Coulson, 2023, Talbot et al., 2025):

> *I know I'm rambling, but out of the 168 hours in a week, I see 1 person for 6*

> *hours, my home care aide! [...] It helps to know there are others going through the same things as me, and I don't feel so solitary. (*Rodriquez, 2013, p.1220)

For some, social media was their only way to connect with other PLWD (Kohl et al., 2024). Participants also valued social media because of its availability at all times: 'Twitter was considered reassuring by a diarist because it allowed for contact during night and day' (Frezza et al., 2022). In other instances, social media connected PLWD to offline opportunities, such as in-person support groups and research opportunities (Kohl et al., 2024; Talbot et al., 2021).

> *If it wasn't for Twitter nobody would have sent me a text message or knocked on my door or told me about anything. I wouldn't have known about anything that I do now without Twitter*. (Talbot et al., 2021, p.2548)

Collective Identity and the Value of Dementia-specific Spaces*.* Several studies indicated that social media platforms foster a sense of belonging among PLWD (Bailey 2018; Castaño, 2023; Rodriquez, 2013). Peer-support forum members referred to themselves as a collective, using language such as '*we'* and '*us'* (Bailey, 2018; Rodriquez, 2013):

> *Welcome to OUR family [...] we're sorry that you have had cause to join our elite group, but are delighted that you found us.* (Rodriquez, 2013, p.1220)

Bloggers also described PLWD as living in '*our hidden world*' that '*people with healthy brains cannot understand*' (Castaño, 2023).

PLWD valued spaces reserved for PLWD, away from caregivers, friends and family. In these dedicated spaces, they felt understood and felt more able to share without fear of judgment (Johnson et al., 2020; Rodriquez, 2013; Talbot et al., 2025). On forums, PLWD valued threads that were designated to be “For Patients Only”, describing these spaces as a ‘safe haven’ (Rodriquez, 2013).

When it was evident that non-PLWD were posting on dementia-specific threads or forums, PLWD posted reminders that the space was designed for them in a bid to reclaim it (Johnson et al., 2020; Rodriquez, 2013).

> *Hi fellow PWDers. We need to reactivate this Board. It is designed for folks of about 60 and older who have been diagnosed with some form of dementia..* (Johnson et al., p.127)

On the other hand, PLWD found platforms such as Facebook ‘constrained self-expression due to family members using this platform’ (Talbot et al., 2025).

> *With Twitter, it’s more open and I don’t really need to be so careful because I can say what I want. If I have a really crappy day I can be as open as I want to on Twitter, whereas on Facebook I have to be a bit cagey because my family don’t want to hear my bad days*. (Talbot et al., 2021, p.2549)

Seeking and Sharing Practical Advice and Guidance. Almost all the studies reviewed indicated that PLWD used social media to exchange practical advice (Castaño, 2020; Castaño, 2023; Johnson et al., 2020, Kohl et al., 2024, Rodriquez, 2013; Talbot et al., 2020; Talbot et al., 2021; Talbot & Coulson, 2023; Talbot et al., 2025). Bloggers described fellow bloggers as '*coaches and onlookers*' and thanked them 'f*or shining the light on your path, in order for us to better see ours*' (Castaño, 20232). PLWD used peer-support forums to seek information related to post-diagnostic support, disease progression, symptom management, medication, accessing clinical trials and planning for the future (Johnson et al., 2020; Talbot & Coulson, 2023).

In addition to seeking practical advice, PLWD also provided it. They shared the latest research on clinical forums and gave advice to the newly diagnosed on how to interpret their diagnosis and how to navigate the medical system (Johnson et al., 2020, Talbot et al., 2025). Advice extended to navigating the online world, such as how to avoid scams (Johnson et al., 2020). Participants signposted other PLWD to sources of support beyond the social media platform they were communicating on, such as other threads on a forum or in-person support groups and charities (Talbot et al., 2025).

Emotional Support, Solidarity and Encouragement. PLWD used peer-support forums and platforms such as Twitter to share empathy, validation and encouragement (Johnson et al., 2020; Rodriquez, 2013; Talbot et al., 2020; Talbot et al., 2021; Talbot & Coulson, 2023). After sharing their feelings on social media, PLWD sometimes asked '*do others feel the same'*, seeking reassurance they were not alone in their emotions (Talbot & Coulson, 2023). In response to forum users sharing challenges, other PLWD would often reciprocate with their own stories, highlighting shared experience as a key form of emotional support. At the same time, ‘users also expressed empathy in response to experiences they did not share’ (Talbot & Coulson, 2023). PLWD validated one another’s struggles, emphasising how hard experiences can be:

> *I’m sorry for all you have been through. It’s a very difficult road. I’m VERY sorry that you are unable to drive anymore! That must feel awful!!* (Rodriquez, 2013, p.1221)

Despite only connecting online, PLWD emphasised their unwavering support for fellow social media users: *‘I may not know you, but I care about all of you [...] I will always be here’* (Johnson et al., 2020).

PLWD also used social media to encourage other to stay positive and pursue goals, such as several forum users who supported a forum user to travel independently:

> *Let us know how you make out. YOU CAN DO IT!!” [...] whenever you take your first trip [...] many of us would be willing to think of you at that time. To ‘be’ there with you.* (Rodriquez, 2013, p.1223)

Theme 3: Social media as a Platform for Advocacy and Change.

Advocacy and Representation. Studies indicated that PLWD engaged in advocacy and activism through social media platforms such as Twitter, blogs and Facebook (Brooks & Savitch, 2022; Castaño, 2023; Kohl et al., 2024; Talbot et al., 2020, Talbot et al., 2021; Talbot et al., 2025). Twitter in particular was used for political lobbying with PLWD aiming 'to influence the policies that affect their lives' (Talbot et al., 2020). Participants in some studies made it clear that they primarily used social media to bring about change, rather than for personal reasons (Brooks & Savitch, 2022; Kohl et al., 2024).

> *I'm writing for an audience, I'm not writing just because I want to write [...] I'm writing as an activist, I want people to read it and re-examine what they think and what they do*. (Brooks & Savitch, 2022, p.2411)

PLWD saw social media as a way to make sure people with dementia's voices were heard, and to highlight lack of representation amongst NHS trusts and conference organisers (Brooks & Savitch, 2022; Talbot et al., 2020, Talbot et al., 2025).

> *One half of the consumer coin is there - a carer. The other half is obviously missing in action*. (Talbot et al., 2020, p.115).

Participants described social media as a powerful tool to reach a wider audience, '*I was interested in having my voice heard [...] media is frigging powerful*' (Talbot et al., 2025). Bloggers saw themselves as communicating on behalf of those who '*are less able to communicate*' (Brooks & Savitch, 2022).

On the other hand, some PLWD expressed frustration when they felt their voices were ignored; *'I started writing to try and encourage the council [...] which has fallen on deaf ears*' (Talbot et al., 2021).

Raising Awareness and Educating Others. One reason PLWD used social media was to raise awareness about dementia (Brooks & Savitch, 2022; Kohl et al., 2025; Talbot et al., 2020; Talbot et al., 2021). This included raising awareness about what it's like to live with dementia (Brooks & Savitch, 2022; Talbot et al., 2025) and highlighting needs of certain groups, such as those with young-onset dementia:

> *Making people aware that there are young people with dementia that need help [...] and not just when you reach 65. (*Talbot et al., 2021, p.2550).

PLWD chose to disclose their diagnosis and post online to improve public understanding about the complexities of dementia and to foster empathy (Kohl et al., 2024, Talbot et al., 2021; Talbot et al., 2025). They shared information about a range of topics, including tips for interacting with PLWD and guidance to caregivers (Talbot et al., 2020).

Some studies showed how PLWD used social media to educate healthcare professionals and researchers (Brooks & Savitch, 2022; Talbot et al., 2020). For example, PLWD used Twitter to signpost GPs to dementia resources (Talbot et al., 2020). Several bloggers were 'invited to give talks to medical students' as a result of their blogs:

> *Ken described how his blog was being used as a 'teaching tool' at several universities [...] where nursing students were encouraged to search for specific topics on his blog*. (Brooks & Savitch, 2022, p.2410)

Finally, PLWD also used social media to raise awareness and fundraise for dementia-specific organisations (Kohl et al., 2024; Talbot et al., 2021).

Challenging Stigma and Reframing Narratives. Participants across many studies used social media to combat the stigma associated with dementia (Castaño, 2023; Frezza et al., 2022; Kohl et al., 2024; Talbot et al., 2020; Talbot et al., 2021, Talbot et al., 2025). Twitter users criticised the use of stigmatising language such as '*suffering*' or 'd*emented*' and instead 'tweeted suggestions for appropriate language' (Talbot et al., 2020).

Other PLWD hoped that by posting openly about their experiences, they would reduce the shame attached to dementia (Kohl et al., 2024; Talbot et al., 2020).

> *To break down the stigma that's attached to having a dementia diagnosis (...) that it's okay to talk about it. Because it's a bit like the C word would have been at one time. You know, nobody mentioned cancer. It was taboo*. (Kohl et al., 2024, p.7367)
>
> *Having a Twitter account is one way of actually saying look, I'm not ashamed of having a diagnosis, and all the stigma around it is wrong*. (Talbot et al., 2021, p.2550)

Participants used social media to try to challenge misconceptions and negative stereotypes promoted by the media (Frezza et al., 2022) and held by the general public (Talbot et al., 2020). Beyond what PLWD posted, simply having a presence on social media was seen as challenging stigma:

Participants recognised that they were already challenging dementia stereotypes by simply being active on Twitter. For example, Robert explained: *'People are surprised that you're actually on social media'* (Talbot et al., 2020)

Theme 4: Navigating Identity and Reclaiming Agency

Reflecting on Loss and Powerlessness. PLWD used blogs, forums and dementia diaries to reflect on loss in relation to dementia (Castaño, 2020; Castaño, 2023; Bailey, 2018; Frezza et al., 2022; Rodriquez, 2013). While this subtheme has some overlap with the earlier subtheme *Reflecting on The Future,* particularly in relation to concerns about anticipated decline, it is analytically distinct in its focus on how PLWD reflect on both past and future losses as threats to identity and agency. In blogs, PLWD mourned the memories and skills they had lost already, such as aspects of their writing ability (Castaño, 2023). PLWD on peer support forums reflected on 'defining moments' of loss, including losing the ability to drive or being forced to give up work' (Rodriquez, 2013).

Participants across several studies linked loss of skills and activities to a loss of identity. For example, forum users introduced themselves in relation to the skills they had lost or retained: '*I am 54, unable to work but can still drive'* (Rodriquez, 2013).

As well as mourning what they had lost already, bloggers worried about the loss that lay ahead. They expressed fears about losing themselves as their cognitive abilities declined:

> *I am what I know, remember and feel. I am the pictures and sensations stored in my brain. When I lose them, who will I be?* (Castaño, 2020, p.123)

PLWD used metaphors to convey a sense of powerlessness and loss of autonomy, suggesting their identity was being stolen and subsumed by dementia. Bloggers framed dementia as an active and malicious agent, comparing it to a '*stealthy equal opportunity thief*', and a monster that '*likes to eat brain and eats at you slowly'* (Castaño, 20232), while forum users described it as a '*beastly illness [...] that eats thoughts and memories'* (Bailey, 2018).

Finding New Identity and Purpose. As well as using social media to reflect on loss, some PLWD found a new identity and purpose on social media in the face of loss (Kohl et al., 2024; Talbot et al., 2021, Talbot et al., 2025). One of the ways that PLWD found a renewed sense of identity and purpose was through finding a sense of community belonging, as described in the earlier subtheme *Collective Identity and the value of dementia-specific spaces*. However, this was not the only route: PLWD also found purpose through new routines, such as blogging, or by taking on new roles. Some PLWD turned to social media to pass the time after giving up work and found that it provided a new occupation:

> *I suppose it gives me a purpose because I've always worked full time, and it was giving me something to do. It's also keeping my brain occupied because*

> *I'm having to think of where I've been, what I've done [...] I blog every day apart from weekends, I have two days off [laughing].* (Kohl et al., 2024, p.7369)

Other PLWD found that campaigning and educating others helped them find new identities as authority figures, advocates and experts by experience (Talbot et al., 2021, Talbot et al., 2025):

> *I'm not a do-it-yourself-er anymore, I'm far less a husband and father than I was, so this is concentrating on something I can do and that's talking about dementia and knowing about dementia. It's about giving yourself confidence, value, and a sense of purpose*. (Talbot et al., 2021, p.2548)

Continuity of Self Despite Change. Across blogs, forums and Twitter, PLWD reflected on ways they were able to maintain a continuous sense of self, with social media often helping them to stay connected to who they were before their diagnosis (Castaño, 2023; Bailey, 2018; Brooks & Savitch, 2022; Frezza et al., 2022, Kohl et al., 2024; Rodriquez, 2013; Talbot et al., 2021, Talbot et al., 2025). Bloggers reflected on how they were '*a new version'* of the same self, describing dementia as masking rather than destroying their identities:

> *What you can see on the outside can often be a poor representation of the "me" that is on the inside*. (Castaño, 2023, p.115)

PLWD suggested that social media helped them retain their identity *'it's a continuation of who I was [...] this is still me*' (Talbot et al., 2025). Several studies indicated that social media platforms acted as '*memory repositories'* (Talbot et al., 2025), helping PLWD to keep a record of their experiences (Bailey, 2018;, Talbot et al., 2021; Talbot et al., 2025). Some PLWD found that looking back on their social media accounts helped them to remember (Brooks & Savitch, 2022; Talbot et al., 2025). Others hoped that their identities would be preserved in their blogs and posts:

> *For somebody to be able to look back on a blog that is [...] an event by event expression of who you really were, that's still inside*. (Brooks & Savitch, 2022, p.2408)

PLWD across several studies found that social media helped them to sustain aspects of their former identities (Brooks & Savitch, 2022; Talbot et al., 2020, Kohl et al., 2024,). For example, participants indicated they were able to apply skills they acquired at work to social media, such as a Twitter user who linked his previous work in policy to his advocacy work on Twitter (Talbot et al., 2025), and a blogger who sustained her identity as a writer through her blog (Brooks & Savitch, 2022). Other participants found that social media helped them pursue their hobbies without being reduced to their dementia diagnosis, such as a PLWD who posted photos on Facebook:

> *People who didn't know me then began to call me the camera lady instead of Linda with dementia*. (Talbot et al., 2025, p.654).

Sharing what is still possible and inspiring others. A common theme amongst studies was participants using social media to show how they could still live a full life and find joy (Castaño, 2023; Frezza et al., 2022; Johnson et al., 2020; Talbot et al., 2020; Talbot et al., 2021; Talbot & Coulson, 2023; Rodriquez, 2013). On blogs and forums, PLWD portrayed themselves as '*fighting'* against dementia, suggesting that they were making a conscious effort to retain autonomy (Castaño, 2020; Castaño, 2023; Talbot & Coulson, 2023).

PLWD shared how they adapted activities so they could still continue doing them, such as using audiobooks instead of reading or getting help from a friend to organise sheet music so they could continue singing in a choir (Brooks & Savitch, 2022; Frezza et al., 2022; Talbot & Coulson, 2023). PLWD shared what they were still capable of on social media, such as advocacy work, publishing books or passing a driving test:

> *Passed my driving assessment today [...] Dementia not taking me off road yet.* (Talbot et al., 2020, p.116)

Across several studies, PLWD used social media to share their creative outputs, including craft and photography (Frezza et al., 2022; Kohl et al., 2024, Talbot & Coulson, 2023; Talbot et al., 2025). They reflected that focusing on living in the moment helped them to find joy (Castaño, 2020; Castaño, 2023; Talbot & Coulson, 2023).

In many studies, a motivation for posting on social media was to inspire and reassure others with dementia, particularly the newly diagnosed (Brooks & Savitch, 2022; Frezza et al., 2022; Kohl et al., 2024; Talbot et al., 2021; Talbot & Coulson, 2023; Talbot et al., 2025; Rodriquez, 2013).

> *It’s letting people know that it's not going to just deteriorate like I got my diagnosis and then tomorrow I’m going to be sat in a chair. So, I wanted to take them on my journey showing them that you can live and enjoy your life*. (Talbot et al., 2025, p.651)

> *So that’s why I’m always on social media, really. It’s just to inspire people to keep going and have a go at doing things*. (Kohl et al., 2024, p.7370)

Social Media Supports Communication and Self-expression. Four studies indicated that some PLWD found it easier to communicate on Twitter, forums and blogs than face-to-face (Brooks & Savitch, 2022; Rodriquez, 2013; Talbot et al., 2021; Talbot et al., 2025). Across all of these studies, participants valued the asynchronous nature of social media, which provided them with time to think before communicating:

> *I’m not so good at speaking off the cuff.... [Blogging] gives me time to reflect, to think out exactly how I want to say something (George)*. (Brooks & Savitch, 2022, p.2407)

Studies also indicated that participants appreciated the ‘multimodal communication facilitated by social media platforms, including text, images, emojis and videos’ as it ‘provided multiple avenues for self-expression’ (Talbot et al., 2025). Some PLWD found Twitter particularly accessible because of the brevity of tweets:

> *It’s a nice way of communicating. Short sentences* (Talbot et al., 2025, p.655)

> *I can’t do Facebook because there’s too many sentences [...] whereas Twitter is to the point*. (Talbot et al., 2020, p.2549)

In addition to making communication more manageable, studies also indicated that social media provided a platform for creative expression. PLWD expressed themselves through poems, short stories and metaphors (Castaño, 2020; Castaño, 2023; Kohl et al., 2024; Talbot & Coulson, 2023).

Theme 5: Challenges of Social Media

Practical and Cognitive Barriers. Two studies reported that PLWD faced practical challenges using social media as a result of their dementia (Brooks & Savitch, 2022; Talbot et al., 2021). Some bloggers found ‘the blogging interface difficult to navigate’, while others struggled with typing and some found that sudden emotional shifts could affect their writing. PLWD developed strategies to overcome these difficulties, such as writing out a list of instructions for carrying out different tasks, and getting a friend to check over blog posts:

> *Sometimes I get angry! [laughing] And... I see everything very black and white, that's dementia... and Dave has to try and tone it down, so we’re keeping the frustration there, but taking the explosive anger out!* (Brooks & Savitch, 2022, p.2407)

PLWD who used Twitter found that the platform required more effort and concentration on days where they were struggling more with their dementia. This would sometimes lead them to make mistakes in their tweets, requiring them to check what they wrote before posting:

> *I sent a tweet this morning, the other day, and it was all gobbledegook because my brain wasn't working very well*. (Talbot et al., 2021, p.2550)

Social Media Leading to Emotional Distress. Studies reported that PLWD were sometimes exposed to aggression or hostility on Twitter when they shared aspects of their experience that were atypical. This included people with young-onset dementia and PLWD who shared positive experiences (Talbot et al., 2021; Talbot et al., 2025). While some fought back against those who questioned their legitimacy, others started questioning themselves:

One participant described her experience of responding to a dementia doubter: '*I came back with something, and I said: 'I think we're all the true faces'.* Others questioned the legitimacy of their diagnosis:

> *It has a negative effect on you because then you can start questioning. Have I got dementia? Am I being a fraud? It sends those questions through your mind*. (Talbot et al., 2021, p.2441)

Some PLWD received responses from 'trolls' on Twitter in response to sharing their experiences, with other users sending messages intended to provoke distress:

> *He said you're all mad [...] You know, 'can tell you're all demented'. Because some people just they come on and say all people with dementia are lunatics*. (Talbot et al., 2021, p.2552)

One study reported that PLWD found being exposed to others' negative experiences of dementia shared on social media was upsetting:

> *One participant discussed [...] challenges in Facebook groups, where they were repeatedly exposed to negative experiences of dementia, which they did not identify with and found distressing*. (Talbot et al., 2025, p.656)

Discussion

This study systematically reviewed and synthesised qualitative research on the use of social media amongst PLWD, using established methods to endeavour to capture the richness of their experience. To our knowledge, this is the first systematic review focusing on this topic. We identified 12 studies that met the inclusion criteria for our review and analysed these using thematic synthesis (Thomas & Harden, 2008). The findings add to wider research on social media use among people with health conditions and extend the smaller body of work on groups with cognitive impairments. For PLWD specifically, this review synthesises a fragmented but growing evidence base, highlighting both the opportunities and challenges that social media presents. In doing so, it contributes to the broader movement within dementia research to centre the perspectives of PLWD, which have historically been marginalised (Diaz Gil et al., 2023).

This review identified five master themes that capture how PLWD used social media to document their experiences, connect with others, and advocate for change. *'Making sense of dementia: sharing and processing the journey'* highlighted how PLWD use social media to express emotions and make sense of their diagnosis. *'A community of shared experience and reciprocal support'* described how social media fostered collective identity and supported the exchange of practical advice and emotional encouragement. *'Social media as a platform for advocacy and change'* reflected how PLWD engage in advocacy by raising awareness, educating others and challenging stigma. *'Navigating identity and reclaiming agency'* explored how individuals reflected on loss while also maintaining a sense of self and constructing new identities through social media. Finally, *'Challenges of social media'* captured the practical, cognitive, and emotional barriers that can hinder engagement.

Many of the themes outlined above are closely connected, with blurred rather than distinct boundaries, for example, the sub themes *'Reflecting on the future'*, and *'Reflecting on loss and powerlessness'*. When participants considered the future, they also shared their feelings of powerlessness in relation to the progressive nature of dementia. Similarly, the subtheme *'Finding new identity and purpose'*, situated within *'Navigating identity'*, is linked to the theme *'Social media as a platform for advocacy and change'*, as some PLWD discovered a renewed sense of identity through their involvement in advocacy. These overlaps between themes reflect the complex, multi-layered ways in which PLWD use social media.

A consistent thread across the review was the dual role of social media: as a space for processing the emotional challenges of living with dementia, including experiences of loss and uncertainty, and as a platform for asserting autonomy, agency, and constructing identity. This dual function was evident both across and within themes, highlighting the nuanced and dynamic role social media plays in the lives of PLWD. One area in which this was reflected was the finding that PLWD use social media to document and process their experiences, both positive and negative. This mirrors broader research on social media use for health purposes, which has shown that individuals with long-term and life-altering conditions, such as cancer and chronic diseases, use social media platforms to track and share illness experiences (Chen et al., 2021).

The challenges that PLWD shared on social media both reflect and add to those documented in the wider literature. These included difficulties obtaining a diagnosis, an issue that has been identified as a major global concern (Alzheimer’s Disease International, 2021), and lack of post-diagnostic support, which has been documented as an issue in the wider literature (Alzheimer’s Society, 2022). In addition, some reflected on how denial from others, and the normalisation of symptoms as part of ageing created further barriers to receiving a diagnosis, patterns also documented in the literature (Parker et al., 2020).

Participants also reflected on the complexities of disclosing their diagnosis. While research on self-disclosure among PLWD is growing, it remains limited (Kohl et al., 2024). This review adds to existing evidence on the challenges of disclosure to family and friends and extends it by showing that these concerns also apply to online settings. Some participants expressed hesitation about disclosing their diagnosis on social media due to fears of stigma.

Other challenges shared included fears about symptom progression, difficulties coming to terms with the progressive nature of dementia and uncertainty about what lies ahead. These concerns are reflected in wider research, which shows that loss of independence, loss of skills and abilities, uncertainty about the future, and changes to one's sense of self are major sources of distress for PLWD (Wehrman et al., 2021; Hillman et al., 2023; Waddington, 2023; Mentzou, 2023).

While this review found that PLWD use social media to share the difficulties of living with dementia, it also highlighted how they challenge narratives of decline and powerlessness. By simply being present on social media and by voicing their experiences (both positive and negative), PLWD combat the one dimensional 'tragedy discourse' of living with dementia, which focuses on loss of ability and identity (Reed et al., 2017). This aligns with Talbot & Dunne's (2024) observation that social media amplifies the voices of PLWD and in doing so disrupts portrayals of them as passive 'sufferers'. Broader dementia research has described the stories of PLWD as 'narratives of resistance' and as valuable 'currency' in a 'narrative economy of dementia' that focuses mainly on loss and decline (Hilman et al., 2018). This review shows that social media provides a platform through which alternative narratives can be constructed and shared.

This review found that the format of social media supported communication and self-expression for some PLWD. Features such as asynchronous and multimodal communications and shorter messages enhanced accessibility. On Twitter in particular, the brevity of posts was valued by some PLWD as reducing cognitive demands. Participants also valued the convenience of being able to connect at any time without needing to travel. These findings align with research on people with traumatic brain injury, who also valued social media for these reasons (Brunner et al., 2015). This review indicates that social media therefore not only provides a platform for the voices of PLWD but offers specific affordances that help enable that expression.

Alongside enabling PLWD to tell their own stories, a key finding of this review was that social media can be a space for PLWD to connect with and support one another. This finding is echoed in the broader literature on social media use among people with health conditions. Chen et al. (2021) found that individuals with a range of long-term health conditions use social media to exchange medical information and emotional support.

This review found that PLWD especially valued connecting with others who shared their diagnosis and that a sense of mutual understanding fostered belonging and gave rise to a collective identity. Notably, social media offered PLWD access to dementia-specific spaces where they could participate meaningfully, support one another and find a sense of purpose. In particular, closed forums and “patients only” threads were described as creating safe environments for sharing, in contrast to platforms such as Facebook, where users felt less comfortable due to the presence friends and family. Findings from studies from research on other online health communities describe how users of online patient forums often transition from an “I” to a “we” perspective (Fayn et al., 2021). In these settings, individuals move from seeking and accepting support to providing it, becoming active members of a virtual society. Accompanying this shift is a move from individual to collective empowerment.

While this review documented several benefits for PLWD using social media, four of the twelve studies synthesised also documented challenges. Some PWLD faced cognitive and practical difficulties navigating social media, such as typing, managing complex interfaces, and concentrating on days when symptoms were more pronounced. These barriers echo findings from the TBI literature, where cognitive and behavioural impairments, alongside accessibility issues, such as technical complexity, frequent platform updates, and the need to remember passwords, have been shown to hinder social media engagement (Brunner et al., 2015).

This review also found that PLWD can be subject to negative comments on social media, which can cause emotional distress. This was most often reported in relation to Twitter, where participants described greater exposure to hostility. Consistent with findings from Talbot & Dunne's (2024) scoping review on dementia and digital selfhood, several PWLD reported having their dementia diagnosis questioned online by others who perceived their presentation to be atypical. This finding stands in contrast to the broader pattern identified in this review, that social media often serves as a space where PLWD can express the nuanced realities of living with dementia.

Strengths and Limitations

This was the first systematic synthesis of qualitative research exploring how people living with dementia (PLWD) use and experience social media. The topic is of growing relevance given the rising global prevalence of dementia, the increasing use of social media among older adults, and the expanding body of research on how people with health conditions, including dementia, engage with these platforms. The review employed recognised and rigorous methods for qualitative synthesis, including a comprehensive search strategy; clearly defined inclusion and exclusion criteria; use of the modified CASP qualitative checklist as a reputable quality appraisal tool (Long, French, & Brooks, 2020); and thematic synthesis following the established method outlined by Thomas and Harden (2008).

While reflexivity was built into the process, for example through the lead researcher keeping a reflexive journal, the inclusion of other stakeholder perspectives, particularly those of PLWD, might have further strengthened the review. Furthermore, a decision was made to limit the review search to studies published in English due to resource constraints. It is therefore unclear whether research on social media use by PLWD exists in other languages, as these were not captured by the search strategy. More deliberate reflection at this stage might have prompted reconsideration given that statistics indicate that the majority of people living with dementia reside in low and middle-income countries, many of which are non-English speaking (WHO, 2025).

A strength of the review is that it only included studied that reported separate findings on the experiences of PLWD, rather than combining the experiences of PLWD with other groups, such as caregivers. This review therefore centred the perspectives of PLWD, which have often been marginalised in research (Diaz Gil et al., 2023).

A limitation of this review is that the conclusions are constrained by the limited demographic detail in the included studies. For example, only one study reported on the ethnicity of participants. Most studies did not specify how dementia was diagnosed and relied on self-identification of dementia diagnosis. While the lack of demographic information is to some extent expected in studies using naturally occurring data from social media and online forums, it nonetheless limits the conclusions that can be drawn from this review, as it is unclear whose perspectives are represented.

This review is further limited by the age profile of participants across the included studies, Many studies reviewed including samples where the majority of participants were under 65. While this reflects an important and often underrepresented group, it means the review may not fully capture the perspectives of adults over 65, who make up the majority of people living with dementia globally (WHO, 2025). While recent statistics indicate high levels of internet and social media use among adults aged 65 and over, they often treat this group as a single category and do not break down usage by narrower age bands (Ofcom, 2025). Preliminary quantitative research also indicates that social media use amongst people with dementia is higher amongst those who are 65 and under (Kohl et al., 2024). Therefore, the review may reflect a limited pool of voices, namely, younger PLWD who are more likely to be digitally literate and active on social media.

Implications and Recommendations

PLWD often have unmet needs, partly due to their limited involvement in decision-making and research (WHO, 2017; Diaz Gil et al., 2023). This review shows that social media is a space where PLWD document and process their experiences. Clinicians and researchers could draw on these accounts as a valuable resource to better understand the experiences of PLWD and to identify unmet needs and gaps in care.

In recent years, psychosocial interventions have become an increasingly important part of dementia care, aiming not just to manage symptoms but to support people with dementia to ‘live well’ (British Psychological Society, 2022). This review suggests that social media may offer psychosocial benefits for PLWD. Given these findings, clinicians might consider whether it is appropriate to safely signpost PLWD to such platforms and/or develop interventions that leverage these platforms as part of living well. However, given the reported barriers as well as the potential for emotional distress, further research is needed to explore how risks can be mitigated and access better supported.

While several benefits identified in this review were consistent across platforms (e.g. continuity of self through posting photos on Facebook, or recording experiences on blogs), the findings also suggest that different platforms may be suited to different needs. Dementia-specific forums or closed groups may be particularly valuable for peer support and disclosure, offering PLWD spaces away from caregivers, friends, and family. By contrast, more public-facing platforms such as blogs and Twitter appeared to facilitate advocacy and political lobbying. Twitter’s brevity was noted as helpful for communication by some PLWD, yet it was also the platform where negative interactions were most often reported. These distinctions highlight the importance of considering differences between platforms when supporting PLWD to engage with social media and suggest that some platforms may be more suitable than others depending on individual needs.

There is a pressing need for primary studies to collect and clearly report fuller demographic data, not only to reflect the diverse experiences of PLWD, but also to enable transparency about whose perspectives are being represented and whose may be missing.

While this review focused on qualitative studies and included some mixed-methods research (analysing only the qualitative components), studies relying solely on quantitative methods were excluded as they fell outside the scope of the synthesis. Quantitative research in this area, while limited, is beginning to emerge and may provide useful insights. For example, Kohl et al. conducted an online survey of 143 internet-using individuals with dementia and found that younger participants (under 65) used social media more frequently than their older counterparts. Larger-scale quantitative studies, perhaps drawing on the issues and potential research questions identified in this review, would be valuable to better understand patterns of social media use among PLWD, particularly when disaggregated by demographic factors such as age.

Conclusion

This review synthesised qualitative research exploring how PLWD use and experience social media. Findings show that social media offers a space for PLWD to document and process the challenges of living with dementia, while also serving as a platform to assert autonomy, identity, and agency. Some studies also reported cognitive barriers and emotional risks. Importantly, the review highlights social media’s role in amplifying the voices of PLWD, voices often excluded from research and policy, and in challenging stigmatising narratives. Future work should aim to better understand patterns of social media use among PLWD through quantitative research, and to prioritise more diverse samples in terms of age, ethnicity, language, and geography to address current gaps in representation.

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Part Two: Empirical Paper

Being Kind to Ourselves: A Qualitative Evaluation Within a Feasibility Randomised Controlled Trial of Group Compassion Focused Therapy (CFT) to Improve Depression and Anxiety in Dementia

Abstract

Aims: Depression and anxiety are common among people living with dementia (PLWD). Psychological approaches show promise but the evidence base remains limited. Compassion Focused Therapy (CFT), developed for individuals high in shame and self-criticism, may be particularly well suited to PLWD experiencing depression and/or anxiety. This qualitative study was embedded within a larger feasibility randomised controlled trial (RCT) of group CFT for this population. It aimed to explore the perspective of participants with dementia on i) the feasibility, acceptability, perceived benefits and costs, and potential mechanisms of change of the CFT intervention; and ii) the feasibility and acceptability of the trial procedures.

Method: This study was embedded within a mixed methods feasibility RCT for people with mild to moderate dementia with anxiety and/or depression. Participants were randomised to receive either group Compassion Focused Therapy (CFT) and Treatment as Usual (TAU), or TAU alone. Semi-structured interviews were conducted with 18 participants in total, including 11 participants from the intervention arm and seven participants from the control arm. Data were analysed using Framework Analysis (Ritchie & Spencer, 1994).

Results: Results generated 15 themes which were grouped into four domains, guided by the research questions. The group based CFT intervention and trial procedures were broadly acceptable and feasible, with areas for improvement identified. Reported benefits included improved mood, increased compassion, and greater confidence. Mechanisms of change included CFT practices, theory, and the group format.

Conclusions: Findings support progression to a full-scale RCT and indicate areas in which the trial procedures and intervention can be improved and refined.

Introduction

Dementia is an umbrella term for a group of “diseases that affect memory, thinking and the ability to perform daily activities” (World Health Organisation [WHO], 2025). 982,000 people are estimated to be living with dementia in the UK, approximately 1.5% of the population. This number is predicted to rise to 1.4 million by 2040. The societal and economic impact of dementia is substantial, with the UK cost of dementia forecast to rise to £90 billion by 2040. This includes the cost to the NHS and social care, private spending, and the significant contribution of unpaid carers, who make up the largest share of the total cost (Alzheimer’s Society, 2024). Globally, dementia is recognised by the WHO as a major public health priority. In 2021, an estimated 57 million people were living with dementia worldwide, and in 2019 the total global economic cost was $1.3 trillion, with unpaid carers accounting for 50% of that cost (WHO, 2025).

Depression and anxiety are common among people living with dementia (PLWD). A systematic review and meta-analysis including 20 studies from 10 different countries reported that depressive symptoms in PLWD ranged from to 10-78%, with an overall pooled prevalence rate of 39%. Anxiety symptoms ranged from 13% to 67%, with a pooled prevalence also of 39% (Leung et al., 2021). These rates are substantially higher than those observed in the general population — global estimates suggest that the current prevalence of depression is 3.8% of the population, while the prevalence of anxiety is 4% (WHO, 2023a, WHO, 2023b)

Depression and anxiety amongst PLWD have been associated with worse outcomes in a wide range of areas. These include higher rates of institutionalisation (Kales et al., 2005), more rapid cognitive decline (Foxworth et al.,2022; Rapp et al., 2011) greater functional impairment (Kales et al., 2005), behavioural disturbances (McCurry, et al, 2004), reduced quality of life (Shinn et al., 2005) and increased mortality (Watt et al., 2021).

Although it has changed more recently, dementia care has historically been shaped by the medical model, with an emphasis on pharmacological treatments (Spector & Orrel, 2010; Poz, 2018). However, pharmacological interventions for depression and anxiety in PLWD have shown limited efficacy and have been linked to adverse outcomes (Allain et al., 2000; Dudas et al., 2018; Watt et al., 2021). National Institute for Health and Care Excellence (NICE) guidelines recommend considering psychological treatment for PLWD who have depression and anxiety rather than antidepressants (NICE, 2018). However, NICE does not recommend any named psychological therapy.

A small but promising evidence base indicates that psychosocial and psychological interventions may be beneficial for PLWD experiencing depression and anxiety. An overview of 14 systematic reviews of Randomised Controlled Trials (RCTs) evaluating nonpharmacological interventions for depression and anxiety in PLWD found that music-based therapeutic interventions had a small effect on depression and a medium effect on anxiety; while psychological treatments, primarily CBT, showed a small overall effect on depression (Kishita et al., 2020). However, the overview concluded that the small number of studies and methodological limitations across reviews underscored the need for more robust evidence in this area.

More recent evidence focusing specifically on psychological therapies for PLWD with anxiety and depression also suggests potential benefits but again underscores the need for higher-quality evidence. A meta-analysis of 29 RCTs found small but beneficial effects for CBT-based approaches for depression (Ortega et al., 2022). Supportive or counselling interventions showed little or no effect on depression, although the confidence in this finding was limited by low-certainty evidence. For all other psychological interventions targeting depression or anxiety, the review concluded that there were too few studies, and the evidence was too uncertain to support any meaningful conclusions. Collectively, these reviews highlight the potential benefits of psychosocial interventions targeting depression and anxiety in PLWD, while also indicating a need for more robust RCTs to evaluate novel and promising approaches.

Compassion Focused Therapy (CFT) is designed to help individuals foster compassion for themselves and others, defined as a “a deep awareness of the suffering of oneself and of other living things, coupled with a wish and effort to relieve it” (Gilbert, 2009a, p.xiii). CFT was developed by Paul Gilbert after he observed that individuals high in shame and self-criticism were not benefiting from traditional CBT. Gilbert hypothesised that lack of self-compassion was an obstacle to emotional change (Gilbert, 2010).

CFT is influenced by Eastern philosophy, attachment theories, neurophysiology, and evolutionary theories (Gilbert, 2014). A key concept in CFT is the ‘three circles model’, which outlines how humans have evolved to develop three emotion regulation systems: the Threat system, Drive system and Soothe system. The Threat and Drive system are often dominant in individuals high in self-criticism and shame, while the Soothe system is underdeveloped. CFT aims to restore balance among these three systems (Gilbert, 2009b).

Evidence for CFT is growing rapidly and it is being increasingly applied across a range of psychological difficulties. A recent systematic review and meta-analysis of 15 studies in clinical populations found CFT to be effective in improving compassion-based outcomes and reducing clinical symptoms, including depression, relative to waitlist control (Millard et al., 2023). The majority of studies reported on group CFT, with only two reporting on individual CFT. The review highlighted unclear methodological rigour in many studies and outlined a need for more transparent, rigorous RCTs. It also noted a lack of diversity in study samples, with most participants being White and from Western countries.

A series of meta-analyses examining the efficacy of CFT including both clinical and non-clinical samples also found that CFT significantly reduced negative mental health symptoms, including depression (Petrocchi et al., 2024). In line with previous meta-analyses (Craig et al., 2020; Millard et al., 2023), studies mainly reported on group CFT. Moderation analysis showed that therapist led CFT was more effective than self-help.

CFT, an intervention designed for individuals high in shame and self-criticism, appears well suited to the needs of PLWD. A dementia diagnosis can lead to individuals experiencing stigma, shame and self-criticism (Alzheimer’s Society, 2013; Cheston et al., 2005). Dementia has been described as “a threat to life, a threat to function, a threat to finances, a threat to self-identity, and a threat to social inclusion” (Poz, 2018, p.127). At the same time as activating the Threat system, dementia can reduce opportunities to engage the Drive and Soothe system, for example by removing access to activities such as employment and contributing to social exclusion (Poz, 2018).

A small number of studies have explored the application of CFT for dementia, with promising results. Craig et al. (2018) conducted a mixed methods case series feasibility study involving seven PLWD with symptoms of depression and/or anxiety. Manualised CFT was delivered individually over 10 weeks, for one hour per week. Symptoms of depression and anxiety were reduced at the end of the intervention compared to baseline, and levels of self-compassion increased. The intervention appeared feasible, with low attrition and most participants were able to engage in exercises and discussion. Qualitative interviews indicated that CFT was acceptable and well-liked. Notably, while five participants completed all 10 sessions, none completed the intervention in the planned time frame. Researchers recommended building on this study with a larger trial and comparing CFT to a wait-list control group. They also recommended delivering CFT over a longer time-frame and exploring the efficacy of CFT for dementia in a group, given that most existing evidence for CFT relates to group delivery.

Rationale for the Current Study

As noted above, there are high rates of depression and anxiety in dementia, with limited evidence for pharmacological approaches, and a small but promising evidence base for psychological approaches. CFT is an approach that seems well suited to PLWD and early evidence indicates that it has potential. Most existing research into CFT demonstrates efficacy in group formats (Craig et al., 2020; Millard et al., 2023; Petrocchi et al., 2024), which are not only more cost effective, but may offer therapeutic benefits, such as reducing shame (Clapton et al., 2018).

Given the lack of RCTs evaluating CFT in people with dementia, despite theoretical relevance and promising pilot findings, there is a strong need for well-designed, robust research in this area. The broader research project, of which this study forms a part, is a mixed methods feasibility RCT of group CFT to improve symptoms of depression and/or anxiety in dementia. Medical Research Council (MRC) and National Institute for Health and Care Research (NIHR) guidelines on developing complex interventions recommend assessing feasibility and acceptability of both trial procedures and the intervention itself, before progressing to a full-scale RCT (Skivington et al., 2021).

This study forms part of the qualitative evaluation embedded within the larger feasibility RCT. Guidelines for developing complex interventions recommend mixed methods approaches to enable research to go beyond simply evaluating whether an intervention has achieved its intended outcome (Skivington et al., 2021). There are two parts to the qualitative evaluation in this study, one focusing on the perspectives of people with dementia (this project) and the other on the perspectives of carers, NHS staff and CFT group facilitators (an associated Dclin Psy project).

The aims of this study are thus: i) to gather the perspective of PLWD on the feasibility, acceptability, perceived mechanisms of change and perceived benefits and costs of a group CFT intervention; and ii) to gather PLWD's perspective on the feasibility and acceptability of the trial procedures.

Feasibility and acceptability are overlapping concepts that can be difficult to distinguish. Our exploration of these concepts will be informed but not dictated by the Office for Health Improvement and Disparities (2020) definitions of feasibility and acceptability; as well as recommendations for maximising the impact of qualitative research in feasibility trials (O'Cathain et al., 2015).

This research aims to explore the following broad primary research questions, from the perspective of participants with dementia:

1) Are the CFT trial design, procedures and intervention acceptable and feasible?
2) What are the potential mechanisms of change?
3) What are the perceived benefits and costs of the CFT intervention?

Method

This study is part of an embedded qualitative evaluation within a larger feasibility RCT. This thesis and the following methods section focuses on one component of the qualitative evaluation: interviews with PLWD. Contextual detail from the wider study is provided where relevant.

Study Design

The broader study was a multi-site feasibility RCT designed to assess the feasibility, acceptability and outcomes of a group based CFT intervention for people living with mild to moderate dementia experiencing symptoms of depression and/or anxiety. A total of 74 participants were randomised to receive either group Compassion Focused Therapy (CFT) and Treatment as Usual (TAU), or TAU alone. The trial employed a mixed methods design. Semi-structured interviews were conducted with PLWD from both the treatment and control group.

Ethics

Ethical approval for the study was granted by the London Riverside Research Ethics Committee (Ref: 23/LO/0535), with Health Research Authority (HRA) and Health and Care Research Wales (HCRW) approval obtained via the Integrated Research Application System (IRAS ID: 327086) (see Appendix 6). Research and Development approval and Letters of Access were secured from all participating NHS sites.

Participants

Wider Trial Context

Participants were recruited to the feasibility RCT from seven NHS Trusts (sites) across the UK. The study was promoted through local NHS services, third sector organisations, care homes and supported living accommodation. Participants were also recruited through ‘Join Dementia Research’, an online recruitment platform. A total of 74 participants were recruited over a period of 15 months and randomised to either the treatment group or the control group (TAU).

Participants with dementia needed to meet the following inclusion criteria:

1. Meet Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) for dementia of any type (American Psychiatric Association, 1994).
2. Mild to moderate dementia as determined by the following: A confirmed dementia diagnosis based on DSM-IV criteria for any type of dementia, and a Clinical Dementia Rating (CDR) score of 0.5, 1, or 2 (Morris, 1997).
3. Experience symptoms of depression and/or anxiety as determined by either: a HADS score ≥ 8 on the anxiety and/or depression subscale (Zigmond & Snaith, 1983), or a HADS score of 5–7, accompanied by evidence of low mood as reported by a caregiver or clinician, or significant psychological distress, as assessed by a clinician or researcher, regardless of the HADS score.

4. Have capacity to consent to take part in research.
5. Can communicate in English.
6. Have access to WiFi, enabling them to partake in online CFT groups, or the ability to attend a face-to-face group.
7. Are not participating in another interventional research programme concurrently.
8. Aged 18 and over.
9. Participants could be included whether or not they have a caregiver.

To minimise travel-related barriers for participants allocated to the treatment group, practical steps were taken during recruitment and trial setup. At recruitment, participants were asked how they would feasibly attend an online or face-to-face group in line with the inclusion criteria (e.g., through independent travel, with support from a carer, or by joining online groups where WiFi access was available). At some sites, participants were recruited from a specific local area to ensure proximity. At other sites, researchers reviewed participants’ addresses prior to randomisation and selected a mutually convenient venue for the group.

Qualitative Evaluation

Participants for the qualitative evaluation were recruited across both arms from four sites: two within North East London NHS Foundation Trust (NELFT), one within Black Country Healthcare NHS Foundation Trust, and one within Oxford Health NHS Foundation Trust. The original sampling strategy aimed to purposively recruit and take into account characteristics often underrepresented in research (e.g.

sex, ethnicity, socio-economic status and session attendance), using sampling matrices to ensure sufficient representation. In practice, a more pragmatic purposive sampling approach was taken, given the need to recruit a sufficient number of participants within the study timeline. We approached all participants from both trial arms from the first four sets of treatment and control participants who completed the intervention within the study timelines. Researchers contacted participants by phone in the week before the CFT group concluded or shortly after to ask if they would be willing to take part in an interview. Across all sites, 32 participants with dementia were eligible and invited to take part in a qualitative interview. Of these, 18 were interviewed: 11 from the treatment group and seven from the control group. The remaining 14 did not complete interviews for pragmatic reasons, such as difficulties arranging a suitable time due to participant availability and study time constraints. See Table 1 for details of participant demographics.

Table 1

Participant Demographic Characteristics by Trial Arm

Characteristic	Intervention	Control	Total
	n	*n*	*n*
Gender			
Female	8	5	13
Male	3	2	5
Age Range			
<65	1	2	2

65–74	4	0	4
75–84	6	4	10
85+	0	1	1
Ethnicity			
White British	11	4	14
White Other	0	2	2
White and Black African	0	1	1
African	0	1	1
Diagnosis			
Alzheimer’s	9	3	12
Vascular dementia	2	2	4
Mixed dementia	0	2	2

Procedure

Wider Trial Context

Following recruitment, blinded baseline assessments lasting approximately 1.5 hours were carried out in participants’ homes and memory clinics. These gathered demographic data and included standardised measures assessing a range of areas, including symptoms of depression and anxiety, quality of life and cognitive function. Following assessment, participants were then randomised to either the treatment group or the control group using a procedure carried out by NWORTH

University of Bangor. The 12-session CFT intervention was delivered across a period of 12–15 weeks, depending on the scheduling needs of each group. Follow-up assessments were conducted at approximately 16 weeks and six months post baseline.

Control group (TAU). Participants allocated to the control group received TAU, defined as the standard care available to people with dementia and depression and/or anxiety. This varied between participants and could include medication, other therapies, support from health and social care professionals or no treatment.

Treatment group (CFT plus TAU). Participants in the treatment group received TAU, alongside 12 sessions of group based CFT. Sessions lasted 60 minutes and were delivered in person in NHS or community sites. While sessions were held weekly, some groups included a scheduled break, extending the intervention beyond 12 weeks. A manual was developed to guide delivery, adapted for group delivery from a ten-session individual CFT programme for PLWD (Craig et al., 2018). Groups were limited to approximately seven people.

The initial CFT intervention (Craig et al., 2018), which formed the basis for this group version, was co-developed with Patient and Public Involvement (PPI) contributors, including four PLWD and three family caregivers. Their input shaped core elements such as caregiver involvement and the feasibility of home practice. For this trial, a PPI advisory group, comprising four PLWD and one caregiver, met on multiple occasions to review and adapt the intervention for group delivery. They contributed to refining the CFT manual, psychoeducation materials, CFT exercises, and home practice and session summaries to enhance clarity and accessibility. They also advised on session structure and frequency.

The sessions were split into three phases. Phase one introduced participants to the group and to CFT. This included psychoeducation on key CFT concepts and activities such as goal setting. Phase two centred on developing self-compassion and included discussions such as common blocks to self-compassion, and exercises such as compassionate letter writing. Phase three explored how to manage difficult feelings and also focused on ending the sessions and maintaining benefits long-term.

Each session included a core CFT practice, such as soothing rhythm breathing, a recap of previous content and introduction of new content. The manual provided prompts for group reflection on the emotional experience of living with dementia. Adaptations were made to accommodate cognitive difficulties, including increased use of visual cues and repetition. Home practice was encouraged, with flexible options offered to support engagement. The CFT manual suggested a home practice task, usually linked to the exercise practised in the session, but also advised facilitators to not be prescriptive and to offer alternatives where participants might not enjoy or be able to engage with a particular exercise. The lead research assistant on the trial (MM) communicated with participants or their carers in between sessions to remind them of the home practice. In some groups, participants were given a CD which had recordings of the CFT practices to aid engagement at home. Handouts with session summaries were provided at the end of each session.

Each group was delivered by two facilitators. One facilitator needed to be clinically trained, while the second could take a supportive role. All clinical professionals attended a two-day Introduction to Compassion Focused Therapy workshop to ensure they were adequately trained in CFT. They were also sent an additional training video with guidelines for adapting CFT for people with dementia. One of the groups was delivered by the first author (SF), together with another Trainee Clinical Psychologist (BL).

Qualitative Evaluation

Interviews were conducted between August 2024 and March 2025. As mentioned above, interviews were conducted soon after each group finished to assist recall for the treatment participants. Most interviews were conducted within two weeks of groups finishing, with many conducted on the same day. Where possible, interviews with the treatment group were conducted in person at the group location immediately after the final session. All other interviews took place in participants’ homes.

Interviews were conducted by three researchers: MM, SF and BL. SF and BL did not carry out interviews for the group that they facilitated. Participants were presented with an information sheet which gave details about what the interview would involve, the purpose of the interview, possible advantages and disadvantages of taking part and details about how their information would be used (see Appendix 7). Participants were then asked to sign a consent form if they wished to continue (see Appendix 8). The information sheet and consent form outlined that participation was voluntary and then participants were free to withdraw at any time. Across the study, participants were expected to be able to provide informed consent in accordance with the guidance in the Mental Capacity Act (2005) and consent was treated as an ongoing process, with re-affirmation sought at each study visit.

Interview format and Data Collection. Interviews were audio-recorded on a Dictaphone. Duration ranged from 15 to 56 minutes, with a mean length of 32 minutes. While participants were encouraged to speak for themselves, caregivers were permitted to remain in the room to support them if the participants chose.

Separate semi-structured interview schedules were developed for treatment and control group participants. Topic guide development was informed by the study research questions. In addition, relevant literature and guidance was drawn upon. This included guidance on designing feasibility studies (Office for Health Improvement and Disparities 2020; NIHR, 2023) and the role of qualitative research in feasibility trials (O'Cathain et al., 2015); literature on the acceptability of healthcare interventions (Sekhon, 2017); and frameworks for process evaluation (Moore et al., 2015; O'Cathain et al., 2019). Broader guidance on developing and evaluating complex interventions was drawn from Skivington et al. (2021), along with theoretical models for implementation, such as Normalisation Process Theory (May et al., 2007).

Questions for the treatment and control group topic guides explored the acceptability and feasibility of trial procedures, such as recruitment and assessments. The treatment topic guide also included questions about the acceptability and feasibility of the intervention itself, including: session content and exercises, home practice, practical aspects (such as the location, number and length of sessions) and views on the CFT facilitators and group format. The treatment topic guide also included questions about the perceived impact of the intervention, perceived mechanisms of change and suggestions for intervention improvement.

SF and MM chaired a meeting with the study's Patient and Public Involvement Advisory Group (PPI Group) to gather feedback on the draft interview guides. Three members with dementia and one caregiver attended. In response to PPI recommendations, the number of questions asked was reduced and the order of questions was rearranged to assist recall. Reminders and visual prompts were also added to the guides in an effort to make the questions feel less like a memory test (see Appendix 9 for the finalised interview schedules for the treatment and control group).

Analysis

Data were analysed using Framework Analysis (Ritchie & Spencer, 1994; Gale et al., 2013). This approach was well suited to the applied nature of the current study and its focus on informing future intervention development. An abductive approach was followed in this study, whereby final themes were developed through a combination of open coding and analysis guided by the research questions. Analysis occurred across seven stages (Gale et al., 2013):

1. Transcription
2. Familiarisation
3. Coding
4. Developing a working analytical framework
5. Applying the analytical framework (indexing)
6. Charting data into the framework matrix
7. Interpreting the data

Recordings were transcribed by SF and other members of the research team. SF then familiarised herself with the data, which involved re-reading transcripts, listening to sections of audio-recordings and making initial reflective notes.

Stages 3, 4 and 5 were applied iteratively. First, SF randomly selected five transcripts for initial coding. SF went through these transcripts line by line, noting down labels or ‘codes’ in the right-hand margin. At this stage, a broadly inductive approach was taken, with anything of interest being coded, while keeping the research questions in mind. SF and MM held two further meetings with the PPI group and collaboratively coded sections of these transcripts together, helping to ensure that a range of perspectives fed into the initial analytical framework. This process helped to reduce researcher bias and enhanced the credibility of the analysis, while also leading to the addition of new codes and the refinement of some existing ones.

Following initial coding of the first five transcripts, SF and BL met to review the 83 codes generated. These codes were distilled and organised into categories, informed by both the research questions and new areas of interest that had emerged from open coding. This formed the initial working analytical framework. SF then used this framework to code five more transcripts (a process called indexing). At this stage, new codes that did not fit existing categories in the framework were added to a temporary 'miscellaneous' category. After this set of five transcripts were coded, the indexing framework was reviewed and refined and miscellaneous codes were incorporated. This process of iterative indexing and framework refinement was repeated until no new codes were generated. The final version of the indexing framework was then applied to the remaining four transcripts. All previously coded transcripts were reviewed and reindexed to ensure consistency with the final framework.

A spreadsheet was used to chart and summarise the coded data in a framework matrix. Data were organised by category and participant, enabling comparison both across and within cases. See Appendix 10 for an excerpt of the final analytical framework and framework matrix. In the final stage, the framework matrix was reviewed and themes were developed by examining connections between participants and categories, and mapping the range of experiences, including both similarities and polarities. SF also considered possible explanations for patterns in the data.

All stages of the analytical process were documented to enhance dependability and transparency. This included keeping a record of coded transcripts, successive iterations of the analytical framework, and the framework matrix.

Epistemology and Positionality

This research was undertaken from a critical realist stance. This assumes that participants’ accounts can offer genuine insights into their experiences, while recognising that these accounts are shaped by broader social and personal contexts, as well as the characteristics and perspectives of the research team.

I (SF) reflected on the influence of my social and cultural background, clinical training and personal experiences throughout the research process. In order to enhance credibility and transparency, I kept a reflexive diary. I am a woman in my early 30s from a Western background, raised in the UK, and at the time of writing, in my third year of Clinical Psychology training. I have clinical, research and personal experience interacting with PLWD and a belief in the importance of expanding therapeutic support for this population. This research formed part of my doctoral thesis, and I also co-facilitated one of the CFT groups from which several interview participants were drawn.

The reflexive diary was used to document initial impressions of the data and record reflections on how my previous experience and current role might have shaped the analysis. This practice helped me to acknowledge potential biases and bracket assumptions throughout the analytic process. For example, I noted occasions when I was particularly drawn to transcripts from participants in the group I had co-facilitated, and used this awareness to deliberately revisit transcripts from other groups to counterbalance this tendency.

Results

Analysis of interviews with 11 treatment participants and seven control participants revealed 15 themes. Themes were grouped into four domains, which were guided by the research questions. A summary of domains, themes and sub-themes is displayed in Table 2. The first domain, ‘Trial Procedures Acceptability and Feasibility’, includes themes relevant to both control and treatment participants. The remaining three domains only apply to treatment participants. Themes within ‘Perceived Mechanisms of Change’ do not always align directly with those under ‘Perceived Benefits and Costs of the Intervention’. Not every reported cost or benefit has a clearly corresponding mechanism or vice versa. Some themes, such as self-compassion, appear as both an outcome and a mechanism of change, highlighting the blurred line between these two domains.

Quotations from participants have been anonymised. Participants in the treatment group are labelled with ‘T’ followed by a number (e.g. T1), and participants in the control group are labelled ‘C’ followed by a number (e.g. C1). Quotations from the researcher conducting the interview are labelled ‘R’. Ellipses (...) have been used to indicate the removal of non-essential material from quotations.

Table 2:

Summary of Domains, Themes and Sub-Themes

Domains	Themes	Sub-theme
Trial procedures Acceptability and Feasibility	Navigating the unknown	Apprehension
		Openness
	Interaction and social opportunity matter	Researchers put participants at ease
		Social opportunity valued
	Unclear or forgotten trial procedures	Assessments felt like tests
		Difficulties with recall
		Confusion regarding randomisation
Intervention Acceptability and Feasibility	Focusing and taking a pause: 'It's not simple'	
	Identity alignment	Identifying with the diagnosis
		Identifying with CFT
	Facilitators created a supportive environment	
	Group affected engagement	Group as a facilitator
		Group as a barrier
	Practicalities	
Perceived mechanisms of change	Finding a sense of calm and control through CFT exercises	
	Increased emotional understanding and awareness as a result of CFT theory	

	Group as a source of connection, motivation and insight	Feeling less alone leads to feeling better
		Seeing others benefit was motivating
		Sharing and hearing new perspectives helped participants grow
Perceived benefits and costs of Intervention	Changes in mood and emotion regulation	
	Increase in confidence and compassion	Developing self-confidence
		Developing compassion
	Changes in perspective on dementia	
	Unmet hopes and limits of intervention	

Trial Procedures Acceptability and Feasibility

Navigating The Unknown

Participants expressed a range of attitudes toward joining the research project. While some described hesitation and discomfort linked to the uncertainty of what to expect, others approached the unknown with openness and curiosity.

Apprehension. Some participants expressed apprehension in relation to signing up to the project and fear of the unknown. One control participant described reluctance at the recruitment stage, while several treatment participants described feeling anxious about joining the group after they had been allocated to it:

> *Anxious, I was a bit anxious, concerned. Who was going to be there? What was I going to talk about? Did I really want to speak to people in an open forum*? (T7)

Openness. Some participants reported having no reservations about joining the project, despite feeling that they were not sure of what it would involve.

> *I didn't know much about it, so I didn't have a lot of thoughts. I thought I would rock up and see what happened* (T11)

Several stated that they would have been open to joining any kind of project related to dementia. Some were driven by *'curiosity'* (C3) and wanting to find out more about dementia, while others were motivated by a desire to contribute to research.

> *I was eager to join any kind of research [...] Anything to do with Alzheimer's because I wanted to be part of something, to be a contributor (C7)*

Interaction and Social Opportunity Matter

Participants indicated that positive interactions with researchers increased acceptability of trial procedures. They also valued the social connection that arose from these.

Researchers Put Participants at Ease. When asked about their experience of baseline and follow-up assessments, several participants said they felt comfortable and enjoyed the meetings because of how researchers interacted with them. Researchers were described as '*friendly*' (T10), '*calm' (*C3), '*nice*' (C4, C3, T10), and '*lovely' (*T10, C2*)*. Some participants struggled to recall details of the assessments but remembered what the researchers were like:

> *It was nice, that girl that came, she was nice, she was calm, she had all the patience in the world (C4)*

Social Opportunity Valued. Several control participants indicated that they enjoyed taking part in the trial procedures because of the social interaction these experiences provided:

> *For me, it is all the different people I've been involved with. Somebody to talk to, because I was getting very depressed very easily [...] otherwise, if I hadn't been answering those questions, I would just be sitting watching TV (C1)*

Some participants explicitly stated they enjoyed researchers visiting them because it gave them a chance to talk:

> *I didn’t mind because I could talk, and nobody stopped me* (C3)

Others spoke about topics unrelated to the research during the interviews, such as previous occupations and hobbies, indicating that for them the interviews were more than just a data collection exercise.

Unclear or Forgotten Trial Procedures

Assessments Felt Like Tests. Some participants suggested that they found the baseline and follow-up assessments pressurising. This pressure seemed to be linked in some cases to uncertainty as to the purpose of the assessments. For example, one participant suggested they saw the baseline assessments as linked to diagnosis, while another described feeling pressure to perform well:

> *I suppose I was just hoping they’ll say oh you'll be fine, you know and try not to worry about that* (T10)

> *Frightening — for me personally [...] just wanted to get the questions right.* (T7)

For some, the assessments triggered feelings of inadequacy, which seemed to be compounded by confusion as to the purpose of the questions:

> *Oh I just thought I dunno I just thought why are they asking me this you know [..] I can't remember but yes I was rubbish [...] I felt a bit stupid at first* (C6)

Another participant responded with relief when they were told many people struggle during the assessments:

> *Oh my god I didn't know, I thought something was wrong with me* (T4)

Difficulties with Recall. Most participants struggle to recall elements of trial procedures when asked about them in the interviews. This applied to recruitment, randomisation and assessments. Some could answer with the help of prompts, however others were clear they did not feel comfortable answering questions related to procedures they struggled to remember:

> *So now I don't remember an awful lot of it, that's the problem isn't it. So I can't really give an honest answer because that would be unfair. I don't really. You know, I can fake. I can remember sort of bits of it, but not enough at all that would be of any relevance* (T1)

Confusion Regarding Randomisation*.* Several participants said that they were unaware of the randomisation process. It was unclear whether these participants did not remember being told or whether this process was not clearly explained to them. Two control participants were aware that they were allocated to a control group but indicated they assumed this meant that they would be offered the intervention later, with one participant stating they were waiting for more information.

Intervention Acceptability and Feasibility

Focusing and Taking a Pause: ‘It’s Not Simple’

Participants described practical, cognitive, and emotional barriers that made it difficult to engage with the CFT exercises, particularly at home. Nearly half of those interviewed reported that they did not manage to complete any home practice. Participants reported being too busy and finding it hard to remember to practice:

> *Sometimes home got a bit hectic. So I didn’t have the time to suddenly stop and think, “Oh, hold on a minute—I’ve got to do this”. (T10)*

Others reported struggling to concentrate on the exercises, describing their minds as ‘*wandering*’ (T10) or ‘*whirring away*’ (T11). One participant reflected that it was only possible to engage with the exercises when already feeling calm:

> *Often you take it on board when you’re calm, but when something happens you get upset about something, or you can’t remember something it all goes out the window, and you get into panic mode. (T10)*

Another participant described how upsetting thoughts about dementia got in the way of imagery exercises:

> *You need to be careful, because memories, the good ones come and you can get that you can't have those things, so they can be negative. They say sit there and imagine a nice occasion, well I am thinking I am not going to be*

> *sitting on a beach anymore because I can't get there, I can't drive like I could [...] so it is not simple. (T11)*

In comparison, the smaller number of participants who engaged in exercises at home suggested facilitators to this included support from carers and use of materials. One participant worked on exercises together with their partner and listened to the recordings provided:

> *I am still doing it at home. Still got my CD, I still play it three or four times a day (T4)*

Identity Alignment

The extent to which participants identified with the dementia diagnosis and the nature of the CFT exercises affected their engagement with the intervention.

Identifying with the Diagnosis. A small number described struggling to accept their dementia diagnosis and suggested this impacted their engagement. One participant described how avoiding using the word dementia sometimes made it hard to take part in group discussions:

> *Did you find it difficult in sessions, having to speak about that word? (R)*
>
> *Yes, I still do, yes I did. I just can't accept that I've got it. I told them, I just call it "it. (T4)*

Another participant, who was unsure if they were correctly diagnosed, described not wanting to write a compassionate letter, suggesting this might somehow make their diagnosis more tangible:

> *I wouldn't do the letter idea [...] I don't know whether I would write anything down really about it. (T10)*

Identifying with CFT. Some participants described how they were familiar with aspects of CFT, such as breathing exercises and meditation, and indicated that this acted as a facilitator for them. Another participant indicated that CFT felt more alien to them because they were less familiar with activities they felt were similar to CFT:

> *I am not very good at it, one of the girls gets a lot from it, but she does Pilates and all that stuff and I don't do Pilates [...] I mean it gradually built up but when you first sort of sit there doing these breathing you are like "what the heck is this all about?" (T11)*

Facilitators Created a Supportive Environment

Most participants were positive about the facilitators leading the CFT groups. They described how facilitators appeared to be well trained and intuitive and felt they created a welcoming and friendly atmosphere, while also explaining CFT concepts and exercises well.

> *They were friendly to us and did the nitty gritty as well, they'd explain it properly and calmly.* (T10)

> *They were really sensitive. Compassion was in the air, you know [...] they created a really good working atmosphere.* (T2)

In contrast, one participant expressed less positive views, suggesting that the content was a '*bit basic*' and '*repetitive*', and that the facilitators could have done more to vary their delivery. However, their feedback appeared to relate the design of the sessions as much as it did to the facilitators themselves:

> *They relied on that [the board] an awful lot. I think it would have been nice if perhaps they could have had some sort of, I don't know whether it's pictures or something else [...] I just think if you're going to do something like that, it needs to have more meat. (T1)*

Group Affected Engagement

All participants were accepting of the group format and most suggested it helped them engage with the intervention. A minority mentioned aspects of the group that could be challenging.

Group as a Facilitator. When asked whether they would prefer to attend a group in future or individual therapy, most expressed a preference for the group format. This included participants who initially felt nervous about joining a group. Two participants valued the group setting because they found it less pressurising than one-to-one therapy:

> *I would prefer in a group because you feel more comfortable, more chilled (T4)*

Several described the group as a safe and supportive space where they felt able to share their thoughts and emotions openly.

> *I've never been a person that could stand up and really command an audience [...] I found I didn't have to have that down. Just you know, we could all speak so freely (T7)*

> *It was easy to talk to people. And it was easy to cry. If you wanted to cry, you could cry. You'd get a cuddle if you needed one (T8)*

Some shared how the small group size helped them feel more at ease and able to share and reflected that this might have been harder in a larger group.

Group as a Barrier. A small number of participants described barriers linked to the group format. These participants felt they had little in common with other group members –- one participant suggested that they developed a deeper connection with the facilitators. Participants also described how inconsistent attendance and limited contribution from other group members affected their experience:

> *Some people have been here hardly, you know, they sort of keep very quiet of themselves. So it tends to be more about two or three of us that perhaps would contribute anything [...] I have to be honest, I started to get a bit bored.* (T1)

Practicalities

Most participants reported that the location of the group worked well for them. Many participants walked or used public transport. One participant relied on NHS-funded transport, while another relied on a family member driving them. Only one participant described difficulties with travel, reporting the cost of the taxi to be prohibitive. All expressed a strong preference for face-face sessions.

Most participants described the rooms where the CFT sessions were hosted as fit for purpose. Participants felt the rooms were a suitable size and reported that they were able to hear and see.

Views on the number and length of sessions varied. Five participants felt the number of sessions felt appropriate, four wanted more sessions and one wanted fewer sessions. Six participants felt the length of the sessions was appropriate, four wanted longer sessions and one wanted shorter sessions. Four participants mentioned missing sessions as a result of holidays or ill health, which they described as ‘*disappointing’* (T7) and ‘*upsetting*’. (T8)

Perceived Mechanisms of Change

Finding a Sense of Calm and Control through CFT Exercises

Many participants described how they found the CFT exercises helped them to relax and find a state of calm. While some struggled to distinguish between specific exercises –- one participant reflected *‘it all merges into one*’ (T6) –- breathing exercises were the main type of exercise named by participants as being beneficial.

One participant described how he played the CD of the CFT recordings to help soothe himself during stressful moments:

> *I’ve done that 3 O’clock in the morning because my next door neighbour keeps me awake [...] it just chills me out. It gives me like, as I call it, an hour's chilling out and you just listen to it and you just as I call it, you float.* (T4)

Other participants described how breathing exercises helped them to manage their emotions and reactions during moments when they felt under threat or out of control. They suggested that these exercises helped them to pause, slow down and reset. One participant described how breathing helped them not to ‘*panic’* when they struggled to remember something (T10), while another described how breathing exercises helped them to take time out when feeling stressed:

> *Now, if I get a moment I'm not sure about — or I feel a bit uptight — I just take a few minutes out to close my eyes, relax, and just breathe [...] I like breathing exercises very much. Yeah, and it does help. I found it works for me because it helps me to calm myself down (T7)*

Increased Emotional Understanding and Awareness as a Result of CFT Theory

Several participants suggested that learning about CFT concepts and theory helped them better understand and make sense of their emotions. Two participants described how the Three Circles Model helped them become more aware of the reasons for their emotional responses and provided them with the vocabulary to reflect on this. One participant described how it enabled him to identify when he was under threat:

> *It kind of brought everything together for me [...] If we hadn't done that, I probably wouldn't have known myself whether I was under threat*. (T7)

Another participant described how both he and his partner were able to describe his reactions as being driven by the Threat System. He suggested this enabled him to take a step back and analyse his reactions, potentially giving him some distance from them:

> *[Carer’s name] has caught me out when I have said how I reacted and she pointed out that is your threat system because I get angry [...] I have tried saying it is my threat system, overreacting, I think it does help* (T11)

Some participants reported valuing learning about the concept of self-compassion. As described earlier in the results section, some became kinder to themselves as a result of the intervention. Participants described how being told that you can be compassionate towards yourself and not just others was a novel idea, indicating that this knowledge alone perhaps planted a seed, giving them the permission to start practising self-compassion:

> *It helped me understand that I can be compassionate to myself as well, which is probably something I’ve never really thought of or done before* (T7)
>
> *I think it's nice that they taught us to think about ourselves, which normally you wouldn't do [...] normally you make other people happy but you don't think about yourself (T5)*

Group as a Source of Connection, Motivation and Insight

Almost all participants kept returning to the impact of the group throughout the interview, showing it to be a mechanism of change in a range of areas.

Feeling Less Alone Leads to Feeling Better. Many participants reflected on the value of shared experience and the realisation that group members ‘*were all in the same boat*’ (T5). One participant shared how they enjoyed hearing others read their compassionate letters because they found ‘*a bit of me inside each one*’ (T5). Several commented on how hearing about other people’s problems made them feel less alone, and some suggested that this led to them feeling more able to cope with their difficulties:

> *Because they're like me. I'm not the one on my own. Because that's how I felt, like I was on my own. But I wasn't, you know, because I'd got everybody with me [...] They change my attitude towards things [...] I'm not the only person on the earth who hurts (T8)*

Seeing Others Benefit was Motivating. Some participants described how seeing others engage with the intervention and benefit was motivating. One participant spoke about how seeing others engage with the exercises helped him:

> *Doing those exercises in a group, do you think that helped in any way? (R)*
>
> *Yeah, because you have got others and how they benefit from it helps you, it helps me definitely (T11)*

Another participant spoke in depth about another group member who grew in confidence over the course of the group and the impact that this had on her:

> *He went from a very, very sick man who was kind of within himself — like in a shell — and then all of a sudden, he brought himself out of this awful place, I think it did him really good. It was great seeing him do that. It brought tears to*

> *my eyes. I think it did him really good. It did me really good. And it did the others in there, you know [...] he was a fantastic role model (T8)*

As mentioned earlier, a minority indicated that inconsistent attendance and lack of contribution from other group members negatively impacted their experience of the group. For these few, other group members appeared to be demotivating and negatively impacted their experience:

> *It's been a strange group, it started off with lots of people and then drop, drop, drop [...] the people were nice but some were very quiet* (T1)

Sharing and Hearing New Perspectives Helped Participants Grow*.* Many participants spoke about the value of sharing their feelings and thoughts with others, as well as the value of hearing from others. As mentioned earlier, some participants reported growing in confidence over the course of the sessions. Participants indicated that being in a group was key to this. One participant described how developing the courage to share with others led them to develop greater faith in themselves:

> *It enabled me to trust them, myself. And it helped me. I got a lot from that -- having been a person that's quite inward in lots of ways, by trying to protect myself [...] I wouldn't normally say things to people, in front of people I didn't know. But it helped me to come through that (T7)*

While they valued their shared experience of living with dementia and what they had in common, participants also described how listening to different perspectives had benefits because it led to new ways of thinking:

> *In a group is better because you can listen to other people's opinions, you put your side, they put their side, you listen to each other, even the staff say things (T4)*

> *We all clubbed together and it would give you a different thing altogether and a different attitude* (T6)

One participant suggested that the group was as important as the active components of CFT in enacting change:

> *We are all very different, different backgrounds and what we got from listening to each other and things like that's been good [...] the Psychiatrist thinks that these exercises are helpful for calming you down and I think they probably are, I mean I could do with some calming, but I think just hearing what other people's experiences are and how they you know do and don't cope with things I think that is as much rather than the pure experience*

This sentiment was reflected across the interviews, with many participants repeatedly returning to the impact the group had had on their experience.

Perceived Benefits and Costs of the Intervention

Changes in Mood and Emotion Regulation

Some participants reported noticing improvements in their mood as a result of attending the CFT group. Participants described feeling '*happier*' (T7, T8), '*more positive'* (T10) and becoming '*angry and frustrated*' (T3) less often. One participant described changes in their emotions using concepts they learnt during the intervention. When shown the Three Circles Model, they pointed at the Threat system:

> *I don't like this at all because it's anxiety, anger, disgust. That's frightening, that one, to me. But then those [feelings] came down and made it better. Not fully better. But you felt better* (T8)

Participants indicated they were more able to regulate their emotions and reactions. In some instances, participants also reported that carers noticed these changes, while in others carers themselves interjected to confirm noticing them. One participant described how their wife had noticed a change while they themselves were less aware:

> *My wife's noticed it, but I can't [...] she thinks when I'm talking I'm not getting as angry* (T4).

Another participant described how they felt more able to manage their temper, and his wife who was sitting with him during the interview corroborated:

> *I used to be a person that could lose my temper quite quickly — or lose… not my temper, but I’d lose… my patience (*T7)
>
> *But you've got it under control now* (Carer)
>
> *Yeah, I've got it under control now. (*T7)

Increase in Confidence and Compassion

Participants described growing in confidence and developing greater compassion, both for themselves and others, as a result of the intervention.

Developing Self-confidence. A few participants described how they initially felt nervous about speaking in front of others but grew in confidence over the course of the sessions: ‘*It helped me get over my fears in talking to people*’ (T7). One person suggested that participating in the group led them to feel more generally self-assured and capable:

> *I’m so very shy, should I say? But while I was there, we were all together, speaking and working together, I felt better. (T3)*
>
> *You felt better in yourself? (R)*
>
> *Yeah, I got some courage [...] I feel more secure. I can do things, speak (T3)*

Developing Compassion. Several participants suggested that the intervention had helped them to develop self-compassion. The impact of this was participants being kinder to themselves when difficulties arose as a result of their dementia:

> *If something goes wrong, not to beat myself up about it [...] take a step back it's not the end of the world.* (T11)

Some reported developing greater compassion for others. One participant described how they felt they had become a '*more understanding person*' (T6), while another shared how he and his wife had become more '*accepting of each other*' (T4). Another participant described how the intervention had led them to reflect on how they had lived their life and treated others before their dementia diagnosis:

> *I think it has made me understand and think more about my behaviour always, it is not just the dementia. You know I have been thoughtless, I have been too much focused on career. (T11)*

Changes in Perspective on Dementia

A small number of participants who found it hard to accept that they had dementia suggested that the group had helped them start to come to terms with their diagnosis. One participant spoke about not being able to '*accept what I've got'* throughout the interview. However, when asked about whether they met their goals, they answered:

> *I've got to accept that I've got it, that's the goal [...] I'm still accepting, I've got to accept it, try and work with it (T4)*

While this participant did not state that they had fully accepted they have dementia, describing their diagnosis as a goal that they are working on signifies a shift in attitude. Another participant who had not yet fully accepted their dementia diagnosis also indicated that they had come closer to acceptance, and reflected that if their symptoms worsened, they would be more open to seeking help as a result of attending the group:

> *If I have got it [...] I realise that if I was worse, I would ask for more help* (T10)

Other participants reflected that the group had changed how they felt about living with dementia. One described feeling differently about the progressive nature of the disease:

> *There is no sort of going back to where you were [...] You know, I don't have to think negative about it. I was at first, but I don't feel negative about it now* (T7)

Several participants reflected that they felt less alone in their dementia as a result of attending the group:

> *You don't feel as lonely I think. The fact that others have sort of gone through it and then you know there are ways of dealing with it to a degree. (T11)*

Unmet Hopes and Limits of the Intervention

While participants generally felt that the intervention had value, several suggested that intervention’s impact was limited by the incurable nature of the disease. When asked whether they had met the goals that they had set at the outset of the intervention, two participants reflected that this was not possible because their ultimate goal would be to be free from dementia:

> *I’ve not reached a whole goal. Because I can’t — I’m not going to go back from this, am I? To be truthful* (T7)

> *I mean what I want to do is get a treatment that cures it, but everything else is additional* (T11)

One participant shared that he was hoping to get more information about the ‘*potential outcomes*’ of the disease and how it progresses. He shared feeling frustrated because no medical professionals would answer his questions and described how he had asked the group facilitator but had been ‘*cut off*’ (T11).

Many participants described still feeling anxious or sad about living with dementia during the interview. Participants often reflected on the emotional impact of living with a progressive and incurable disease, sometimes suggesting that the intervention could not alleviate this:

> *Did you notice any changes in your feelings since attending the group? (R)*

> *No, I think it's the same, because the dementia is getting worse, I feel it's more of a hole in me (T2).*

Discussion

This study formed part of a feasibility RCT evaluating the acceptability and feasibility of group based CFT for PLWD with symptoms of depression and/or anxiety. The qualitative component reported here explored the perspectives of PLWD on the acceptability and feasibility of the trial procedures and intervention, potential mechanisms of change, and the perceived benefits and costs of the intervention. A total of 18 semi-structured interviews were conducted with 11 treatment participants and seven control participants and were analysed using Framework Analysis. Analysis generated 15 themes which were grouped into four domains informed by the research questions: *acceptability and feasibility of trial procedures; intervention acceptability and feasibility; perceived benefits and costs of the intervention; and perceived mechanisms of change*. The first domain draws on data from interviews with participants from both trial arms, while the remaining three domains are based solely on interviews with treatment participants.

Summary of Results in the Context of Wider Literature

Trial procedures appeared broadly acceptable. While some participants expressed apprehension about signing up to the project, many reported feeling curious and motivated to contribute to dementia research. This mirrors findings from a recent systematic review of facilitators and barriers to trial recruitment for PLWD which identified a desire to learn and to contribute to society as key facilitators to trial participation (Hirt et al., 2024). In this study, positive interactions with researchers also increased acceptability of trial procedures. Hirt et al. (2024) also found that researchers' interpersonal skills are crucial to building trust and engagement.

However, some elements of the trial procedures appeared to be confusing or anxiety provoking. Many participants were unaware of or could not recall the randomisation process and a small number of control group participants assumed they would receive the intervention at some point. Some participants also misunderstood the purpose of the assessments and indicated they viewed them as cognitive tests and found them pressuring. This highlights the need for clear and accessible communication at all stages of a trial. Previous research has identified insufficient study information as a barrier to participation and has shown that regular updates throughout an intervention are valued by PLWD (Hirt et al., 2024; Zammitt et al., 2024). Participants' experiences of assessments as pressurising also suggests that anxiety linked to diagnosis is an important consideration. Previous research has found that responses to diagnosis, including feeling overwhelmed and in denial of the dementia diagnosis, can act as barriers to research participation (Lee et al., 2022).

Practical aspects, as well as the structure and format of the intervention appeared generally acceptable and feasible. Few participants reported issues with travel, whereas other studies have highlighted travel time as barriers to participation (Bouranis et al., 2023; Zammitt et al., 2024). This may in part reflect the trial design: at recruitment, participants were screened to ensure they could feasibly attend in line with the inclusion criteria, and additional steps were taken to minimise travel demands, such as choosing mutually convenient venues for the group or recruiting from specific local areas. All participants expressed a strong preference for face-to-face sessions. Many felt that 12 sessions was appropriate, with some wanting more and only one wanting fewer. This is consistent with findings from Craig et al. (2018), who concluded that 10 sessions of individual CFT for PLWD was insufficient. Participants were generally positive about the facilitators, valuing both their interpersonal qualities and their ability to explain CFT concepts. This again aligns with findings from Craig et al (2018) who found that participants valued that facilitators were compassionate as well as knowledgeable.

Most participants indicated that the group format was well received. This aligns with a recent meta-synthesis reporting high levels of acceptability for group CFT across diverse clinical populations (Garret et al., 2025). Other group-based interventions, such as Cognitive Stimulation Therapy (CST), have also been found to be acceptable to PLWD (Gibbor et al., 2021). Similarly, a study of group based CFT for PWLD and their partners also found that participants felt positively about the group format (Collins et al., 2017). While most participants indicated that the group setting enhanced their experiences, a minority reported difficulties with this format, such as feeling that they had little in common with other group members. Research on CST has highlighted the importance of shared identity in helping PLWD feel comfortable in groups (Bailey et al., 2017). For some participants, difficulties accepting their diagnosis may have contributed to a reduced sense of connection with others, making it harder to engage fully in the group setting.

Participants described practical and cognitive barriers to engaging with the CFT exercises. This included being too busy, struggling to remember to practice and difficulty concentrating. These findings are consistent with Craig et al. (2018) who found memory and cognition made it hard for participants to engage with aspects of CFT. In this study, these barriers were a particular issue with regard to home practice, with most participants reporting that they faced challenges engaging with home practice over the course of the intervention. Upsetting thoughts about dementia and difficulties coming to terms with their diagnosis also made CFT exercises and discussion difficult for some participants. However, these responses were not reported by all. These findings could indicate that in this context it would be helpful to consider psychological processes of adjustment, and the different ways in which people respond to a dementia diagnosis (Clare et al., 2022).

Participants reported several perceived benefits from attending the CFT group. These included improvements in mood, better emotion regulation, development of self-confidence; and increased compassion, both towards themselves and others. Some participants also suggested the intervention helped them to accept their diagnosis and the effects of living with dementia. These findings are again consistent with those of Craig et al. (2018), who reported improvements in mood, emotional regulation, self-compassion and acceptance.

While most treatment participants indicated that they benefited from the intervention in some way, results also revealed limits and unmet hopes. Several participants reflected on how the intervention could not alleviate the emotional difficulties of living with an incurable disease. Others expressed feeling disappointed because they were hoping to receive more practical information and advice regarding the progression of dementia. Research has identified ‘motivational misconceptions’ as a risk in dementia studies, whereby participants' reasons for signing up to a research study might not align with the study goals. Hoping for clinical benefits such as slowing of disease progression is a documented example (Benson et al., 2021). Our findings, together with this literature, indicate the importance of clearly communicating study goals and limitations and checking that these are understood.

Results revealed several potential mechanisms of change. However, the distinction between mechanism of change and outcome was often blurred. For example, improved emotion regulation can be seen as both a positive effect of the group and a mechanism leading to other benefits, such as increased self-compassion. Some participants suggested that active components of CFT were mechanisms of change, for example by describing CFT exercises as helping them to manage their emotions. This suggests that CFT worked as intended, helping participants to downregulate the threat system and activate the soothing system (Gilbert, 2007). Additionally, some participants reported that CFT concepts, such as the Three Circles Model, led to greater awareness and emotion regulation. This echoes findings from other studies where participants were able to meaningfully engage with CFT theory (Poz, 2018) and indicates that CFT is feasible with this population.

A mechanism of change that participants often mentioned was the group format itself. Participants described how the group helped them feel less alone, inspired them to engage with CFT, and was a source of insight and alternative perspectives. These findings align with other research on CFT which has found the group format can transmit and reinforce principles of CFT by providing a deshaming, compassionate and psychologically safe space (Garrett et al., 2015; Clapton et al., 2018).

Strengths and Limitations

A strength of this study is that it was designed in line with MRC and NIHR guidelines, which recommend assessing feasibility and acceptability of a trial before progressing to a full-scale RCT (Skingvington et al., 2021). Using qualitative methods, this study gathered important insights that will inform and strengthen the design of a future full-scale RCT.

Another strength of this study was the involvement of the Patient and Public Involvement (PPI) group. The PPI group have been involved from project inception, helping to design the intervention and review key materials, including the intervention manual. Feedback from the group led to important adaptations to the interview guides, including reordering of questions and adding prompts to support recall. Members of the PPI group also contributed to data analysis, helping to ensure that the interpretation of findings was informed by a range of perspectives.

One limitation of the study was that the qualitative interviews relied on control and treatment participants recalling their experiences of trial procedures and on treatment participants' recall of the intervention. Efforts were made to aid recall, by including reminders in the interview guides, and by scheduling interviews as soon as possible after the intervention ended. However, almost all participants struggled to remember aspects of the trial procedures and some struggled to remember parts of the intervention. This was particularly the case for trial procedures such as recruitment and baseline assessments, which had taken place several months prior to the interviews.

Another methodological consideration was the presence of carers or supportive others during some interviews. In most cases, participants indicated that they preferred to be interviewed with their carer present. Carers often played a helpful role by providing practical or emotional support and occasionally prompting or reminding participants during their responses. Despite these benefits, the presence of carers may also have influenced what participants felt able to disclose, particularly in relation to sensitive topics or the participant–carer relationship. Previous research highlights the complexity of carer involvement, noting that while the presence of carers may make PLWD reluctant to speak openly about sensitive topics, some PLWD may still prefer to have the option of a carer present during interviews (Cridland et al., 2016)

Another limitation relates to the sampling strategy and the diversity of the sample. While the study initially aimed to recruit participants representing a range of characteristics often underrepresented in dementia research, a more pragmatic approach was adopted due to time constraints. The sample lacked diversity in key characteristics, with most participants identifying as White British and female. This may limit the transferability of findings, particularly as demographic factors likely shape how interventions such as CFT are experienced (Millard et al., 2023). In addition to this, reliance on participants volunteering to take part in interviews after being approached may have introduced bias. Participants who had a less positive experience may have declined to take part in interviews, meaning that important barriers to engagement may not have been captured.

A further limitation relates to the fact that interviews and subsequent analysis were conducted by researchers who were involved and invested in the broader project. Research on ethical and methodological considerations in studies with PLWD highlights the issue of 'role ambiguity', where participants may struggle to distinguish between clinical and research roles (Benson et al., 2021). SF and BL conducted this research as part of their doctoral theses and facilitated one of the four CFT groups included in the qualitative evaluation. MM was the lead research assistant on the project and so had interacted with most participants at varying stages of the project before interviewing them. Efforts were made to mitigate bias; for example, MM conducted interviews with participants from the group facilitated by SF and BL; and SF kept a reflective diary while undertaking analysis. However, the position of the researchers may have influenced interview delivery, participant responses, and analysis.

Finally, the analytic approach may have placed some constraints on the findings. The analytical framework and matrix both organised data into pre-determined categories based on the research questions, and results were also presented within these categories. This sometimes led to overlap between domains, particularly between 'Perceived Mechanisms of Change' and 'Perceived Benefits and Costs of the Intervention'. While keeping the research questions in mind ensured the analysis addressed the study aims, the distinction between outcomes and mechanisms may at times have been artificial.

Implications for Research

Overall, findings indicated that both the trial procedures and the group based CFT intervention were broadly acceptable and feasible to PLWD, with a potential range of benefits. While these findings should be interpreted alongside quantitative data, they suggest that progression to a full-scale RCT is warranted. In line with MRC and NIHR guidance (Skivington et al., 2021), results from this study will help inform the development and delivery of a future RCT, including the outcome measures, trial procedures and the CFT intervention.

Findings indicate a need to improve communication in relation to trial procedures. It would be advisable to consider how to improve communication regarding randomisation, both when it is first explained to participants and throughout the trial. In particular, researchers should consider how to clearly communicate to control participants what to expect, as a minority indicated that they were expecting to receive the intervention at a later date. Changes should also be made to make the purpose of assessments clearer to participants and to emphasise that they are not diagnostic tests. Outcome measures should be reviewed to ensure they are appropriate for this population and modified to reduce discomfort if possible.

Given that we found participants had difficulty remembering trial procedures and to a lesser extent aspects of the intervention, the timing of qualitative interviews could be further considered in a future trial. For example, multiple shorter interviews could be conducted at different stages to reduce reliance on long-term recall. Alternative approaches could also be explored that do not reply on retrospective recall, such as methods that capture experience and participation “in the moment” (Algar-Skaife et al., 2014; Dowlen et al., 2022; Smith et al., 2022). These might include observational methods, collecting short reflections during sessions, or videoelicitation interviews, where video recordings of sessions are used to help participants re-experience and reflect on specific moments (Dowlen et al., 2022).

Future research should also consider how best to manage carer involvement during interviews. Offering PLWD the choice of whether a carer is present, together with a conversation about the benefits of private space and confidentiality, may help ensure that participants feel both supported and able to speak freely.

With regards to the intervention itself, as most participants found the number and length of sessions acceptable, with some expressing a preference for more, a minimum of 12 one-hour sessions should be trialled in the future. While all participants expressed a preference for face-to-face delivery, virtual delivery is being trialled with other participants in this wider feasibility trial and so these findings should be considered together with feedback from participants who have attended virtual groups. While travel was not reported as a barrier in this sample, this likely reflects the feasibility trial design, which involved screening for ability to attend and locating groups in convenient venues. Future research should consider whether such adjustments can be maintained at scale.

Findings indicate that the group format should be retained. While a minority of participants described some barriers to engagement arising from the group format, it was acceptable to almost all participants and appeared to facilitate several therapeutic benefits. Participants who were initially nervous about being a part of a group also seemed to enjoy and benefit from this format and so it might be worth highlighting this trajectory during recruitment to encourage others who might feel apprehensive to join the project.

Cognitive, practical and emotional barriers should be considered when designing the full-scale RCT. CFT exercises may need to be shortened or further adapted in other ways to accommodate concentration difficulties. If home practice is retained, consideration should be given to how participants can be better supported to engage with it. This could include more consistent provision of materials to aid home practice; and increased involvement from carers (if possible), both of which appeared to support home practice. It may also be useful to explore the impact of providing flexible options for home practice. While this approach was intended to adapt to participants' needs and preferences, the range of options may have reduced clarity and made home practice more difficult to implement. Future iterations of the intervention could balance flexibility with clearer guidance to support adherence.

While emotional distress cannot and should not be avoided entirely, it should be acknowledged and responded to in a manner in keeping with the compassionate principles underpinning CFT. For example, the intervention manual could prompt facilitators to explore with participants how certain exercises might bring up difficult emotions related to dementia or to directly address the absence of a cure. Facilitators could also be briefed on how to answer questions related to disease progression or how to signpost participants to other sources of information.

Finally, future qualitative research within the full-scale RCT could consider adapting the analytical approach. Framework Analysis was appropriate for the applied nature of this study as it ensured the findings addressed the research questions. However, themes may not need to map so directly onto pre-specified domains. A more flexible approach could still keep the research questions in mind but allow themes to emerge more freely, avoiding forced distinctions between outcomes and mechanisms. To balance this with the pragmatic aims of a feasibility trial, researchers could then reflect in the Discussion on how these themes address the research questions or use a summary table to demonstrate possible links. Future research could also explore mechanisms of change in greater depth. While some participants identified specific elements of the intervention such as CFT exercises as leading to positive outcomes, others linked benefits to more general factors, such as the group setting. Future qualitative work could explore the impact of specific intervention components versus more general therapeutic factors.

Conclusions

The group based CFT intervention and trial procedures were broadly acceptable and feasible. The intervention appeared to offer several benefits for PLWD experiencing symptoms of anxiety and depression, including improved mood, increased compassion for self and others and greater confidence. Therefore, a future full-scale RCT is warranted. Results identified elements of the intervention that were particularly well received and beneficial, such as the group format. They also indicated areas in which the procedures and intervention could be refined before proceeding to a full trial, such as clearer communication regarding trial procedures and greater attention to practical, cognitive and emotional barriers that may affect engagement.

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Part 3: Critical Appraisal

Introduction

This critical appraisal reflects on the process of conducting the two main components of my thesis: a qualitative empirical study exploring the feasibility and acceptability of a Compassion Focused Therapy (CFT) intervention for people living with dementia (PLWD), and a systematic review and qualitative thematic synthesis examining social media use among this population. I begin by outlining the experiences, interests, and assumptions that shaped my approach to the research. I then reflect on methodological decisions and the wider research process, including my choice to conduct qualitative research, the challenges of conducting interviews with PLWD, and working within the structure of a randomised controlled trial (RCT). I also consider the impact of holding dual roles as both researcher and group facilitator and conclude by reflecting on broader issues of representation and diversity in dementia research.

Experience, Interests and Assumptions Coming to the Project

I came to this project with a long-standing interest in improving care for older adults and adults with dementia**.** As I write this, I am aware that these two groups are not interchangeable, and one of the things that I take issue with is the tendency to conflate both these groups with one another. I have noticed that this happens in public discourse, in the media and in clinical settings. There can be an assumption that all older adults are cognitively impaired, or that dementia is an inevitable part of ageing. Conversely, the experiences of younger people with dementia can be overlooked because dementia is seen as an ‘older adult’ issue.

Alongside older adults and PLWD getting treated as one and the same, I came to this project aware of the stigma that leads individuals within both of these groups to be treated as homogeneous rather than recognised as individuals. I’ve always felt a bit uneasy when anyone over 65 is labelled as an ‘older adult’ because I feel like it can flatten individual differences and makes assumptions about identity, capacity, and experience. A similar issue arises in the context of dementia, where the diagnosis can overshadow the person and shape how others perceive their needs, abilities, and potential to engage in therapy.

My experiences before starting the DClinPsy made me aware of the barriers that PLWD face to person-centred care and to psychological support and I wanted to choose a research project that could in some way address these barriers. I will first outline how my experiences made me conscious of these barriers and then how this awareness led me to choose the two topics for my empirical paper and systematic review.

During my Psychology MSc, I conducted qualitative research into how personal pets affect the wellbeing of older adults in care homes. This taught me the value of person-centred care that enables care home residents to maintain a sense of autonomy and identity. I also discovered how policies can mean residents with dementia have fewer opportunities to access such care. For example, some care homes do not allow adults with advanced cognitive impairments to bring their pets with them when they move into care.

Experience as a dementia befriender providing support to the same man for five years further highlighted to me how PLWD can get overlooked by society. Navigating this relationship during COVID-19, where my befriendee was left inside his flat with limited personal contact for several months, taught me how public policy does not always respond sensitively to the needs of PLWD or their support network. Over the years, the many rich and enjoyable conversations I had with my befriendee challenged assumptions I held about dementia. They led me to understand that PLWD can engage meaningfully in conversation and reflect on emotional experiences and psychological ideas. It made me think that PLWD can engage in psychological therapies and should be offered them. While my befriending experience still informs my views, while undertaking my research project I tried to be mindful of making broader assumptions about all PLWD based on my experience with one person.

Before starting the DClinPsy my main clinical experience was as a Psychological Wellbeing Practitioner (PWP) in Improving Access to Psychological Services (IAPT). This experience, alongside further research work, made me acutely aware of the lack of provision for talking therapies for PLWD. IAPT delivers short-term, structured interventions designed to increase access to psychological therapy for common mental health problems (Veale et al., 2018). However, I found it hard to adapt this standardised model to provide adequate care for adults with additional needs, such as those with cognitive impairments. This raised significant concerns for me about how appropriate IAPT is for supporting PLWD, particularly given its central position in the NHS Long Term Plan as a key solution for delivering psychological therapies for common mental health problems (NHS England, 2019).

After leaving my PWP role, I worked on a qualitative research project exploring barriers to IAPT uptake among older adults. While I supported the project's aim of increasing access to psychological therapies for this group, the project also deepened my concerns about the limited provision for PLWD. The *Positive Practice Guide: Older People* (Age UK & NHS England, 2024) does not directly state that IAPT services exclude PLWD. However, it implies this by stating that this group often may require support in multidisciplinary settings and that IAPT services may not regularly offer support for PLWD.

I was drawn to the Compassion Focused Therapy (CFT) in dementia project when I saw it on the list of DClinPsy projects being advertised. At the time, I knew little about CFT beyond a lecture I had attended, which I had found engaging and thought provoking. However, I was undertaking a Dialectical Behavioural Therapy (DBT) placement in my first year, which sparked a more general interest in third-wave Cognitive Behavioural Therapy (CBT) approaches. I was primarily drawn to the project because of its focus on providing psychological therapy for PLWD. As outlined above, my previous experiences had made me aware of the significant gap in therapy provision for this group and convinced me this was an area in need of further attention.

The topic for my systematic review, exploring social media use amongst PLWD, emerged more organically. In my second year of the DClinPsy, I was reading *Somebody I Used to Know* (Mitchell, 2018), a memoir written by dementia campaigner Wendy Mitchell, who was diagnosed with dementia at the age of 58. Her writing made me curious about the opportunities PLWD have to share their experiences. When I researched her further, I discovered that she had a blog entitled *Which Me Am I Today?* (Mitchell, n.d.), and was also a regular poster on Twitter*.* This led me to develop an interest in how social media platforms might offer meaningful spaces for people with dementia to express themselves.

I was also drawn to this topic because it challenged some of the stigmatising assumptions I had encountered in public and clinical settings, including the idea that all PLWD are digitally disengaged or unable to use technology. In line with my belief in person-centred care, I was interested in social media platforms as a way to better understand the lived experience of dementia from the perspective of those who are actually living it.

Reflections on Methodology and The Research Process

Choosing a Qualitative Approach: Reasons and Limitations

I chose a qualitative approach for both the empirical paper and systematic review components of my thesis. One of the main reasons for this was a desire to centre the experiences of PLWD. I felt that qualitative methods would align well with this aim. For the systematic review, I was interested in what PLWD choose to share on social media and I thought this would be best captured through qualitative analysis.

I also was drawn to qualitative research because it fell within my comfort zone. My undergraduate degree was in English and I have always enjoyed analysing speech and text in depth. My Psychology MSc dissertation used Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) and I appreciated how this allowed me to analyse a small group of participants' experiences in great detail. Prior to the DClinPsy, I also held a research role in a behavioural science organisation where I worked on several mixed methods projects. However, I was always assigned to work on the qualitative components of this project. As a result, I felt confident with tasks like developing semi-structured interviews and analysing qualitative data.

Working on both projects deepened my interest in and confidence in the value of qualitative research. I enjoyed interviewing participants of the CFT project and hearing about their experiences of the trial and intervention. I valued engaging with analyses of what PLWD shared online and their accounts of using social media, and found that the qualitative studies included in my review were rich and insightful. However, throughout the project, I questioned whether I should have pushed myself more to engage with quantitative methods or indeed taken on a quantitative project. I sometimes felt that I was missing an opportunity to develop a new skill set while still in the relatively supported context of training. At the same time, I was aware of how stretched I already felt in other areas of the course. While the variety and intensity of clinical placements is stimulating, adapting to a new client group and learning new skills every six months is hard. While choosing qualitative research was driven by a desire to stay within my comfort zone, it was also a deliberate choice to hold onto something familiar in a course where I felt stretched and sometimes overwhelmed.

A final reflection I have with regards to qualitative research is that at times I may have slipped into a false sense of security. For example, I underestimated the demands of learning Framework Analysis (Ritchie & Spencer, 1994; Gale et al., 2013), assuming I would feel comfortable with it because of my previous qualitative experience. In reality, I found myself learning a new approach in a shorter space of time than was ideal.

Conducting Semi-structured Interviews with PLWD

The interviews I conducted for the empirical paper were my first experience conducting semi-structured interviews with PWLD. One of the main things I noticed was the range in the depth of responses I received, both across participants and within the same interview. Compared to other populations I have interviewed, brief responses were common. For example, when I asked participants whether aspects of the trial procedures could be improved, several replied saying no or that everything was fine without elaborating. Similarly, when intervention participants were asked if they felt they benefited from attending the group, some said yes but did not expand, even when prompted.

I undertook this research from a critical realist position, assuming that participants' accounts could offer genuine insights into their experiences. Based on this, I analysed responses as direct reflections of participants' views, without inferring latent meaning. However, I found myself questioning this response during analysis. I wondered whether there might be other explanations behind brief responses, such as cognitive difficulties relating to comprehension or communication.

Working within a Randomised Controlled Trial

Conducting the qualitative study within the broader structure of a feasibility randomised controlled trial (RCT) led me to reflect on the ethical tensions and dilemmas inherent in this type of research. When I interviewed participants in the control group, several shared that they had limited social contact or support and some explicitly stated they felt lonely. In addition to this, several control participants also stated that they had little formal support to help them with their symptoms of dementia or manage difficulties with their mood.

While it was a positive outcome that control participants reported enjoying the social interaction involved in trial procedures and contact with the research team, I sometimes found it difficult to sit with the fact that control participants were unable to access the intervention itself, particularly when it was clear that they had unmet psychological needs. While randomisation was explained to participants at several points, I still felt uneasy when some control participants indicated that they were unclear about the randomisation process, particularly as a minority appeared to believe they might still receive the intervention at a later stage.

At times, I felt concerned about whether my interactions with the control group were somewhat transactional. I was interviewing them to collect data for the trial and my thesis and when they shared that they had unmet psychological needs I felt I was unable to respond in any meaningful way. The principle of equipoise is often used to justify random allocation, based on the idea that an RCT is justified if there is genuine uncertainty about whether the intervention arm is superior to the control arm

(Freedman, 1987). However, I found it difficult to sit with this uncertainty when participants were clearly in need of support, and there was already some rationale to suggest that the intervention might be helpful. On the other hand, I understand that RCTs are valuable tools in establishing causal relationships between interventions and outcomes. I also feel hopeful based on the findings of this study that the CFT intervention shows promise and if developed further it could be a meaningful source of support for many.

Dual Role: Researcher and Group Facilitator

In addition to leading the qualitative research with PLWD, I also co-facilitated one of the CFT groups. In hindsight, I am glad that I had this experience as it deepened my understanding of both CFT more broadly, as well as the specific intervention we were delivering as part of the trial.

However, co-facilitating the CFT group alongside completing other elements of my thesis also presented a number of practical challenges. The group ran throughout the first term of my final year and took up a substantial proportion of my allocated study day each week. I found it challenging to balance delivering the group with progressing other parts of my thesis, especially the systematic review. This was partly due to time constraints and travel, but also because I found it hard to switch between clinical and research roles. After delivering a CFT session, I found I wanted some time to reflect before sitting down to work on my thesis. As a result of the time I spent delivering the CFT group, I ended up completing a greater proportion of my systematic review later on in my third year. While I feel comfortable with the final outcome of my thesis, this experience highlighted the difficulties of juggling dual roles and multiple demands when undertaking research.

As discussed in my empirical paper, a further challenge regarding the dual roles I held was the potential for bias. To mitigate this, I kept a reflective diary in order to bracket my assumptions (Tufford & Newman, 2012). This process made me more aware of how my role in delivering the group made me feel more invested in its success and may have shaped how I approached analysis. I also involved other members of the research team and the PPI group in interview analysis to try to reduce the impact of my individual bias. While these strategies supported reflexivity, I still wonder whether I could have taken further steps to bracket and challenge my assumptions.

While I reflected on the impact of my group facilitator role when I analysed data from the interviews, I was less conscious of its potential influence when I was conducting the interviews. However, when I read about ‘role ambiguity’ as an ethical challenge in dementia research (Benson et al., 2021), I began to reflect more critically on the implications of holding dual roles within the study. I am unsure whether it would have been realistic to fully separate clinical and research roles within the constraints of the trial. Nonetheless, this experience has increased my awareness of how dual roles can affect both the research process and participants and is something I will be more mindful of in future work.

Representation in Dementia Research – Whose Voices are Heard?

At the start of this appraisal, I outlined the experiences that drew me to the research for both my empirical paper and systematic review. These included conducting research with older adults in care homes who had a personal pet and my experience as a dementia befriender. The adults I interviewed in the care home study were all living in expensive private care homes, as these were the only settings that allowed residents to keep personal pets. The man I visited for befriending was university educated and White British.

The ethnicity and socioeconomic background of these individuals does not invalidate their experiences. I am grateful to have learned from them, and their perspectives have definitely shaped my thinking. However, this also reflects a wider issue in dementia research, which is the persistent underrepresentation of certain groups, particularly people from the global majority and those facing socioeconomic disadvantage (Gilmore-Bykovski et al., 2019).

Both my empirical paper and systematic review contribute to this pattern of underrepresentation. The sample in my empirical study was predominantly White British. In my review, most studies either failed to report participant demographics or focused exclusively on participants from English speaking populations from Western countries. There were practical factors that contributed to the lack of diversity within the samples in both my empirical paper and systematic review. For the systematic review, I limited included studies to those published in English due to resource constraints. For the empirical paper, I did not purposively sample on the basis of characteristics underrepresented in research due to time constraints. However, I question whether these reasons are sufficient. In research, resource and time constraints are often cited to justify methodological decisions that contribute to continued underrepresentation of certain groups. If we continue to accept these justifications without question, we risk perpetuating structural inequalities in whose voices are heard and who contributes to the evidence base.

Conclusion

This project deepened my understanding of both the value and complexity of conducting research with people living with dementia. It reinforced my commitment to person-centred research, while also highlighting areas where I need to continue growing. This includes managing dual roles, engaging with quantitative methods, and addressing issues of representation.

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Appendices

Appendix 1: Systematic Review Search Strategies

Medline, PsycInfo, EMBASE and Emcare via Ovid Search Strategy

Medline Search Date: 04.02.25

PsycInfo Search Date: 05.02.25

EMBASE and Emcare Search Date**:** 09.02.25

1. exp Dementia/
2. Dementia.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
3. "People Living with Dementia".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
4. "Alzheimer's disease*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
5. Alzheimer's.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
6. "posterior cortical atrophy".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
7. "Benson's syndrome".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
8. "primary progressive aphasia*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
9. "frontotemporal degeneration".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
10. "frontotemporal lobar degeneration".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
11. "Pick's disease".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
12. "major neurocognitive disorder*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
13. "young-onset dementia".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
14. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13
15. exp Social Media/
16. "Social media".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
17. "social networking site*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
18. "digital platform*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

19. "online forum*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
20. "online communit*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
21. "chat room*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
22. "online social space*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
23. "online space*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
24. "online social support".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
25. "online peer support".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
26. "shar* online".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
27. blog*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
28. Twitter.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
29. Facebook.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
30. Instagram.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
31. TikTok.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
32. YouTube.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
33. Reddit.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
34. Tumblr.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
35. Pinterest.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
36. 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35
37. 14 and 36
38. limit 37 to english language

Scopus Search Strategy

Search Date: 05.02.25

((TITLE-ABS-KEY ("Social media") OR TITLE-ABS-KEY ("social networking site*") OR TITLE-ABS-KEY ("digital platform*") OR TITLE-ABS-KEY ("online forum*") OR TITLE-ABS-KEY ("online communit*") OR TITLE-ABS-KEY ("chat room*") OR TITLE-ABS-KEY ("online social space*") OR TITLE-ABS-KEY ("online space*") OR TITLE-ABS-KEY ("online social support") OR TITLE-ABS-KEY ("online peer support") OR TITLE-ABS-KEY ("shar* online") OR TITLE-ABS-KEY (blog*) OR TITLE-ABS-KEY (twitter) OR TITLE-ABS-KEY (facebook) OR TITLE-ABS-KEY (instagram) OR TITLE-ABS-KEY (tiktok) OR TITLE-ABS-KEY (youtube) OR TITLE-ABS-KEY (reddit) OR TITLE-ABS-KEY (tumblr) OR TITLE-ABS-KEY (pinterest))) AND ((TITLE-ABS-KEY (dementia) OR TITLE-ABS-KEY ("People Living with Dementia") OR TITLE-ABS-KEY ("Alzheimer’s disease*") OR TITLE-ABS-KEY (alzheimer’s) OR TITLE-ABS-KEY ("posterior cortical atrophy") OR TITLE-ABS-KEY ("Benson’s syndrome") OR TITLE-ABS-KEY ("primary progressive aphasia*") OR TITLE-ABS-KEY ("frontotemporal degeneration") OR TITLE-ABS-KEY ("frontotemporal lobar degeneration") OR TITLE-ABS-KEY ("Pick’s disease") OR TITLE-ABS-KEY ("major neurocognitive disorder*") OR TITLE-ABS-KEY ("young-onset dementia"))) AND (LIMIT-TO (LANGUAGE , "English"))

CINAHL Plus Search Strategy

Search Date: 06.02.25

S37	S14 AND S36	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	484
S36	S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	49,254
S35	Pinterest	Expanders - Apply	Interface - EBSCOhost	85

		equivalent subjects Search modes - Proximity	Research Databases Search Screen - Advanced Search Database - CINAHL Plus	
S34	Tumblr	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	46
S33	Reddit	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	381
S32	YouTube	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	1,844
S31	TikTok	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	415
S30	Instagram	Expanders - Apply	Interface - EBSCOhost	1,440

		equivalent subjects Search modes - Proximity	Research Databases Search Screen - Advanced Search Database - CINAHL Plus	
S29	Facebook	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	5,801
S28	Twitter	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	4,043
S27	blog*	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	5,141
S26	“shar* online”	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	94
S25	“online peer support”	Expanders - Apply	Interface - EBSCOhost	139

		equivalent subjects Search modes - Proximity	Research Databases Search Screen - Advanced Search Database - CINAHL Plus	
S24	"online social support"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	162
S23	"online space*"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	170
S22	"online social space*"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	3
S21	"chat room*"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	236
S20	"online communit*"	Expanders - Apply	Interface - EBSCOhost	1,055

		equivalent subjects Search modes - Proximity	Research Databases Search Screen - Advanced Search Database - CINAHL Plus	
S19	"online forum*"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	589
S18	"digital platform*"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	653
S17	"social networking site*"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	1,701
S16	"social media"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	38,200
S15	(MH "Social Media+")	Expanders - Apply	Interface - EBSCOhost	25,968

		equivalent subjects Search modes - Proximity	Research Databases Search Screen - Advanced Search Database - CINAHL Plus	
S14	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	118,930
S13	“young-onset dementia”	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	328
S12	"major neurocognitive disorder*"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	158
S11	"Pick’s disease"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	157
S10	"frontotemporal lobar degeneration"	Expanders - Apply	Interface - EBSCOhost	1,423

		equivalent subjects Search modes - Proximity	Research Databases Search Screen - Advanced Search Database - CINAHL Plus	
S9	“frontotemporal degeneration”	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	96
S8	"primary progressive aphasia*"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	796
S7	“Benson’s syndrome”	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	2
S6	"posterior cortical atrophy"	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	228
S5	Alzheimer’s	Expanders - Apply	Interface - EBSCOhost	54,008

		equivalent subjects Search modes - Proximity	Research Databases Search Screen - Advanced Search Database - CINAHL Plus	
S4	“Alzheimer’s disease*”	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	49,850
S3	“People Living with Dementia”	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	1,685
S2	Dementia	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	Display
S1	(MH "Dementia+")	Expanders - Apply equivalent subjects Search modes - Proximity	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus	

Appendix 2: Quality Assessment Deciding Criteria

Quality Assessment Deciding Criteria

Rigour of Data Analysis: We agreed that this was a strong indicator of overall methodological rigour, which we felt was important to prioritise, especially given this is a relatively under-researched area.

Social Media Classification: The second criterion was the degree to which the phenomena discussed in the studies aligned with Kaplan and Hainlein's classification of social media. Kaplan and Heinlein define social media in terms of social presence/media richness, and self-presentation/self-disclosure. According to their framework, blogs score highly on self-presentation but low on social presence. In contrast, social networking sites and forums score middling on both dimensions. We ranked platforms that were middling on both dimensions higher than those that were high on only one dimension. Therefore, blogs were ranked as low, while social networks and forums were ranked as medium. Studies that included a range of different types of social media were ranked as high, as they represent a broader spectrum of social media experiences.

We developed a points system whereby studies were assigned as high, medium or low quality according to the degree to which they met these two criteria. We then reviewed these quality ratings in the light of the total CASP scores. Studies that scored 8 or above (out of 10) on the CASP quality checklist that were ranked as high according to our deciding criteria stayed as high ranking and those that scored below 8 were downgraded to medium.

Deciding Criteria Points System:

1. *Rigorous Data Analysis (Yes, No, Somewhat):*

   Yes = 2 points. Somewhat = 1 point. No = 0 points

2. *Social Media Category (High, Medium, Low):*

   High = 2 points. Medium = 1 point. Low = 0 points

Total Points Breakdown:

1. *High Quality:*

   Total Points = 3 or 4. Studies that score high quality meet both criteria at high or medium levels (e.g., high rigor and high SM category) or a combination of one high and one medium.

2. *Medium Quality:*

   Total Points = 2. Studies that score medium quality typically meet one medium and one low criterion, or have a combination of somewhat rigorous data analysis with a medium or high SM category.

3. *Low Quality:*

   Total Points = 0 or 1. Studies that score low quality generally meet only one low criterion or fail both criteria (e.g., no rigorous data analysis and low SM category).

Any studies that scored less than 8 out of 10 on the CASP were downgraded to Medium quality even if they scored as High Quality on the deciding criteria.

Appendix 3: Characteristics of Included Studies Systematic Review

Table 3.1

Study Characteristics

Study	Aim(s)	Social Media	Design/Data Collection	Data analysis	Sample	Main Findings
Bailey, 2018	To explore how people with dementia discursively construct identity on an online forum	Online forum for people diagnosed with dementia	Analysis of all contributions to the online forum	Corpus-assisted discourse analysis	- Posters on the forum - Sample size not reported	Forum members use language to present dementia as key to their identity, to distance themselves from dementia and to create a collective group identity.
Brooks & Savitch, 2022	To explore the motivations and experiences of bloggers with dementia	Blogs sole-authored by people living with dementia	Semi-structured interviews with bloggers	Thematic analysis using the Framework approach	- n = 6 bloggers with dementia - Demographics: All participants were White British - Age at diagnosis: 58–63 years	Blogging provided a meaningful way for people with dementia to tell their stories. While bloggers faced practical challenges, they developed strategies to manage them. Motivations for blogging emerged at the personal, community and society level.

Study	Aim(s)	Social Media	Design/Data Collection	Data analysis	Sample	Main Findings
Castaño, 2020	To explore how people with early-onset dementia use metaphor in blogs	Blogs by individuals diagnosed with early-onset dementia	Analysis of blogs	Metaphor-identification procedure	- n = 10 bloggers diagnosed with early-onset dementia - Gender: Female n = 5, Male (n = 5	Metaphors framed dementia as a threat to autonomy and showed how PLWD fight this threat. Metaphors also conveyed a sense of diminished competence and illustrated how dementia can negatively impact relationships while fostering connection with other PLWD.
Castaño, 2023	To explore how and whether online first-person accounts of dementia reflect, challenge and reshape mainstream dementia discourse	Blogs by individuals diagnosed with early-onset dementia	Analysis of blogs by individuals diagnosed with early-onset dementia	Metaphor-identification procedure	- n = 10 bloggers diagnosed with early-onset dementia - Gender: Female n = 5, Male n = 5	Several different metaphors are used to portray dementia. Blogs challenge binary and simplistic narratives such as "tragedy" versus 'living well".

Study	Aim(s)	Social Media	Design/Data Collection	Data analysis	Sample	Main Findings
Frezza et al., 2022	To explore the negative emotions experienced by PLWD and consider how these can help PLWD live and make sense of dementia	Audio diaries shared on the "Dementia Diaries" online platform	Analysis of transcribed audio diaries	Combination of Discourse analysis and Grounded Theory Methodology	- n = 94 diarists with dementia - Gender: Female n = 43, Male n = 51	"Social neglect" was identified as triggering negative emotions. In relation to how individuals with dementia refer to negative emotions in terms of making sense of their illness, two discourses were identified: "Living with dementia" and "Empowerment".
Johnson et al., 2020	To investigate who posts in an online forum for people with dementia and to explore the types of social support being sought	Online forum for people living with dementia	Analysis of all original posts to an online discussion forum	Unspecified: "deductive and inductive qualitative coding"	- Sample size of posters not reported - Forum is for people with dementia but researchers found other groups posted on this site.	PLWD used the forum to "express negative emotions", vent, share fears related to disclosing their diagnosis and to express concern about "lack of support". PLWD seek social support for themselves and their caregivers and seek a range of informational support.

Study	Aim(s)	Social Media	Design/Data Collection	Data analysis	Sample	Main Findings
Kohl et al., 2024	To explore how PLWD use social media, examine differences in social media use amongst different age groups, and to investigate how individuals disclose their diagnosis or share information related to dementia on social media	Range including Facebook, Twitter, Instagram, LinkedIn, YouTube, TikTok	Mixed-methods study: Online survey (including open-ended questions) and semi-structured interviews conducted via phone or Zoom.	Mixed-methods. Qualitative methodology employs Content analysis	Survey sample: – n = 37 social media users with dementia – Age: 14 were under 65 years; 23 were aged 65 and older Interview sample: – n = 10 social media users with dementia - Gender: Female n = 7, Male n = 3 – Age: Mean = 65.3 years, range = 57–80	Three overarching categories emerged that capture reasons people with dementia disclose their diagnosis and/or post dementia-related information online. These were "(1) advocacy and awareness, (2) the dementia journey, and (3) peer support".

Study	Aim(s)	Social Media	Design/Data Collection	Data analysis	Sample	Main Findings
Rodriquez, 2013	To explore how people diagnosed with dementia construct community through illness narratives on an online forum	‘Patient Only’ thread on an online Alzheimer’s forum	Analysis of posts written on thread	Unspecified: "inductive qualitative analysis"	- n = 32 members of an online forum - Diagnosis: Users posted on a thread titled "For Patients Only". - Age: Majority indicated they were under 65; specific n not reported	A key theme was "You are Not Alone". Participants bonded over common experiences. Through these narratives they created a community and were able to "salvage a self".
Talbot et al., 2020	To explore how PLWD use Twitter and how they develop and share illness identities on the platform	Twitter	Analysis of tweets posted by PLWD	Thematic analysis	- n = 12 Twitter account holders with dementia - Age: Reported by 4 participants; range: 58–65 years - Gender: Male n = 8, Female n = 4 - Location: UK n = 6, US n = 5, Australia n = 1	Six themes emerged: “nothing about us without us; collective action; experts by experience; living with dementia not suffering from it; community; and stories of dementia".

Study	**Aim(s)**	**Social Media**	**Design/Data Collection**	**Data analysis**	**Sample**	**Main Findings**
Talbot et al., 2021	To explore the reasons people with dementia use twitter and the challenges they face, with a focus on identity	Twitter	Series of three interviews with people with young-onset dementia who use Twitter. Semi-structured and ‘scroll-back’ method	Thematic analysis	- n = 11 people with young-onset dementia - Gender: Male n = 8, Female n = 3 - Age: Mean = 59.73 years; range = 48–66 years - Ethnicity: All White British - Location: All participants lived in the UK	Four themes emerged in relation to reasons for using Twitter and challenges encountered: "(1) re-establishing identity; (2) communicating and preserving identity; (3) redefining dementia identities; (4) threats to identity".
Talbot & Coulson, 2023	To explore the content of messages posted on a peer-support discussion forum for people with dementia	‘I have dementia’ sub-forum on the Dementia Talking Point online discussion forum	Analysis of forum posts	Reflexive thematic analysis	- n = 251 forum usernames - Diagnosis: Users posting on the “I have dementia” forum.	Posters used the forum to discuss their journey with dementia and for reciprocal peer support. They also posted about how they engage with creative activities and used the forum for "creative self-expression".

Study	Aim(s)	Social Media	Design/Data Collection	Data analysis	Sample	Main Findings
Talbot et al., 2025	To explore how people with dementia use social media to navigate identity	Platforms included Facebook, Twitter, online forums and blogs.	Semi-structured interviews	Reflexive thematic analysis	- n = 10 people with dementia - Location: UK n = 6, Canada n = 2, Republic of Ireland n = 1, Australia n = 1 - Gender: Male n = 7, Female n = 3	Four themes were generated that showed how PLWD uses dementia to navigate identity: "(1) Self-disclosing dementia; (2) Sustaining identity; (3) I'm more than my diagnosis; and (4) Platform identity affordances".

Appendix 4: CASP Ratings Questions 1-10

Table 4.1

Study Scores on CASP Questions 1-10

Study	Clear statement of aims	Methods appropriate	Research design appropriate	Theory clear, consistent, and coherent	Recruitment strategy appropriate	Data collection addresses the research issue	Researcher-participant relationship considered	Ethics considered	Rigorous data analysis	Clear statement of findings	Criteria met out of 10:
Bailey, 2018	Yes	Yes	Yes	Yes	Somewhat	Yes	Can't tell	Somewhat	Yes	Somewhat	6
Brooks & Savitch, 2022	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	9
Castaño, 2020	Yes	Yes	Yes	Yes	Somewhat	Yes	Can't tell	Yes	Yes	Yes	8
Castaño, 2023	Yes	Yes	Yes	Yes	Somewhat	Yes	Can't tell	Yes	Yes	Yes	8
Frezza et al., 2022	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Can't tell	Yes	8
Johnson et al, 2020	Yes	Yes	Somewhat	Somewhat	Yes	Yes	Somewhat	Yes	Somewhat	Yes	6
Kohl et al., 2024	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes	9
Talbot et al., 2020	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Yes	Yes	Yes	8

Study	Clear statement of aims	Methods appropriate	Research design appropriate	Theory clear, consistent, and coherent	Recruitment strategy appropriate	Data collection addresses the research issue	Researcher-participant relationship considered	Ethics considered	Rigorous data analysis	Clear statement of findings	Criteria met out of 10:
Talbot et al., 2021	Yes	Yes	Yes	Can't tell	Yes	Yes	Somewhat	Yes	Yes	Yes	8
Talbot & Coulson, 2023	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Talbot et al., 2025	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes	9
Rodriquez, 2013	Yes	Yes	Yes	Somewhat	Somewhat	Yes	Can't tell	Yes	Somewhat	Yes	6

Appendix 5: Quality Appraisal Deciding Criteria Scores

Table 5.1

Quality Rating Deciding Criteria

Study	Rigorous Data Analysis	Social Media Classification	Points	Quality
Kohl et al., 2024	Yes	High	2 + 2 = 4	High
Talbot et al., 2020	Yes	Medium	2 +1 = 3	High
Talbot et al., 2025	Yes	High	2+2 = 4	Yes
Talbot & Coulson, 2023	Yes	Medium	2 + 1 = 3	High
Bailey, 2018	Yes	Medium	2 + 1 = 3	High (later downgraded to medium due to CASP score)
Brooks & Savitch, 2022	Yes	Low	2 + 0 = 2	Medium
Castaño, 2020	Yes	Low	2 + 0 = 2	Medium
Castaño, 2023	Yes	Low	2 + 0 = 2	Medium
Rodriquez, 2013	Somewhat	Medium	1 + 1 = 2	Medium
Johnson et al, 2020	Somewhat	Medium	1 + 1 = 2	Medium
Talbot et al., 2021	Yes	Medium	2 + 1 = 2	Medium
Frezza et al., 2022	Can't tell	Low	0	Low

Appendix 6: Ethical Approval Letters

NHS
Health Research
Authority

London - Riverside Research Ethics Committee
2 Redman Place
Stratford
London
E20 1JQ

11 August 2023

Professor Aimee Spector
UCL Department of Clinical and Health Psychology
1-19 Torrington Place
London
WC1E 7HB

Dear Professor Spector

Study title:	**Being kind to ourselves: A feasibility randomised controlled trial of Compassion Focused Therapy (CFT) to improve depression and anxiety in Dementia**
REC reference:	**23/LO/0535**
IRAS project ID:	**327086**

Thank you for responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, ‘clinical trials’ are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:
https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at:
https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at
https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Brief_Project_Outline_V2.0_09.08.23]	V2.0	09 August 2023
Copies of materials calling attention of potential participants to the research [CFT_Poster_V2.0_09.08.23]	V2.0	09 August 2023
Covering letter on headed paper [Cover_letter_CFT_24.05.23]	V1.0	24 May 2023
GP/consultant information sheets or letters [GP Information Sheet CFT Study V2.0 09.08.23]	V2.0	09 August 2023
IRAS Application Form [IRAS_Form_25052023]		25 May 2023
Letter from funder [Outcome Feedback]		05 April 2022
Letter from funder [Confirmation of Dates]		21 June 2023
Letter from sponsor [Being kind to ourselves NELFT letter of sponsorship and indemnity 24.05.23]	V1.0	24 May 2023
Non-validated questionnaire [Client Service Receipt Inventory V2.0 09.08.23]	V2.0	09 August 2023
Other [Response to Ethics]	V1.0	09 August 2023
Other [Demographics]	V1.0	09 August 2023
Other [Collection of Measures Built onto REDCap]	V1.0	09 August 2023
Participant consent form [Professionals Qualitative Consent Form V2.0 09.08.23]	V2.0	09 August 2023
Participant consent form [Carer or Supporter Consent Form CFT Study V2.0 09.08.23]	V2.0	09 August 2023
Participant consent form [Carer or Supporter Qualitative Interview Consent Form V2.0 09.08.23]	V2.0	09 August 2023
Participant consent form [Participant Consent Form CFT Study V2.0 09.08.23]	V2.0	09 August 2023
Participant consent form [Participant Qualatitive Consent Form V2.0 09.08.23]	V2.0	09 August 2023
Participant information sheet (PIS) [Participant Information Sheet CFT Study V2, 09.08.23]	V2.0	09 August 2023
Participant information sheet (PIS) [Participant Information Sheet Qualitative Interview V2.0 09.08.23]	V2.0	09 August 2023
Participant information sheet (PIS) [Carer or Supporter Information Sheet for Qualitative Interview V2.0 09.08.23]	V2.0	09 August 2023
Participant information sheet (PIS) [Carer or Supporter Information Sheet CFT Study V2.0 09.08.23]	V2.0	09 August 2023
Participant information sheet (PIS) [Professionals Information Sheet Qualitative Interview V2.0 09.08.23]	V2.0	09 August 2023
Research protocol or project proposal [CFT_Protocol_V2.0_09.08.23]	V2.0	09 August 2023
Summary CV for Chief Investigator (CI) [CV_Chief_Investigator]	V1.0	24 May 2023
Summary CV for student [Ben Loe CV_CFT]	V1.0	24 May 2023
Summary CV for student [Shoshanna Freedman CV_CFT]	V1.0	24 May 2023
Summary CV for supervisor (student research) [Josh Stott CV]	V1.0	24 May 2023
Summary CV for supervisor (student research) [Aimee Spector	V1.0	24 May 2023

medium CV]		
Validated questionnaire [HADS_for_screening]	V1.0	24 May 2023
Validated questionnaire [Cornell Scale for Depression in Dementia]	V1.0	24 May 2023
Validated questionnaire [Rating Anxiety in Dementia]	V1.0	24 May 2023
Validated questionnaire [Quality of Caregiver patient relationship PWD]	V1.0	24 May 2023
Validated questionnaire [Quality of the Caregiver patient relationship_carer]	V1.0	24 May 2023
Validated questionnaire [Clinical Dementia Rating]	V1.0	24 May 2023
Validated questionnaire [Self-Compassion_ Scale]	V1.0	24 May 2023
Validated questionnaire [EQ_5D_5L]	V1.0	24 May 2023
Validated questionnaire [MOCA-Test]	V1.0	24 May 2023
Validated questionnaire [demqol-questionnaire]	V1.0	24 May 2023
Validated questionnaire [Zarit-Caregiver-Burden-Assessment]	V1.0	24 May 2023

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 327086 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

PP Kevin Ahmed, Approvals Manager

Dr Matthew Hyde
Chair

[redacted]

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Professor Aimee Spector
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1-19 Torrington Place
London
WC1E 7HBN/A

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

11 August 2023

Dear Professor Spector

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Being kind to ourselves: A feasibility randomised controlled trial of Compassion Focused Therapy (CFT) to improve depression and anxiety in Dementia**
IRAS project ID:	**327086**
REC reference:	**23/LO/0535**
Sponsor	**North East London NHS Foundation Trust**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **327086**. Please quote this on all correspondence.

Yours sincerely,
Barbara Cuddon

Approvals Specialist

Email: [redacted]

Copy to: *Miss Fiona Horton ,*

Appendix 7: Participant Information Sheet

INFORMATION SHEET FOR PARTICIPANTS – QUALITATIVE INTERVIEW

Study Title: Being kind to ourselves: A feasibility randomised controlled trial of Compassion Focused Therapy (CFT) to improve depression and anxiety in Dementia.

Introduction

We are grateful that you have chosen to take part in our feasibility study investigating the use of group Compassion Focused Therapy to enhance mood in dementia. To help us plan a future study we would like your opinion on how you found the research process and your experience of taking part in the study.

What will happen if I agree to the interview?

If you agree, you will be invited to take part in an interview which will take about 30-60 minutes and can take place face to face, over video call or on the telephone. We will audiotape and transcribe the interview. The information you provide will help us determine if running a large study evaluating the effects of group Compassion Focused Therapy is feasible.

What will I have to do?

You will be asked to sign a consent form to take part in the interview then attend the interview when requested.

What are the possible advantages and disadvantages of taking part?

There are no direct advantages for you in taking part, although you may enjoy the experience of talking about the impact of the Compassion Focused Therapy groups. By taking part, you will help to potentially shape an intervention, which will then be used as part of a trial and could be of benefit for future patients. It is very unlikely that any harm should come to you in this study.

How will we use information about you?

We will need to use information from you for this research project. This information will include your name, ethnicity, gender and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. At the end of the trial, all essential documentation will be archived securely by the study Sponsor for a minimum of 5 years from the declaration of end of trial.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- At www.hra.nhs.uk/information-about-patients/
- Our leaflet available from www.hra.nhs.uk/patientdataandresearch
- By asking one of the research team.
- By sending an email to NELFT Data Protection Officer, Robert Paley,
- [redacted]

What will happen to the results of the research?

The study will be registered on a public web-based database where the study design and results can be viewed. The results of the trial will also be published in a scientific journal and presented at conferences, but you will not be identified. Any quotations used from the interview will be anonymised in the final report or any publications. Once the study has ended, you and your carer / supporter can meet with a researcher to find out about the results; a written summary of the findings can also be requested.

Thanks for considering taking part in an interview with us.

Appendix 8: Participant Consent Form

UCL

CONSENT FORM FOR PARTICIPANT

Study Title: Being kind to ourselves: A feasibility randomised controlled trial of Compassion Focused Therapy (CFT) to improve depression and anxiety in Dementia.

Centre Number:

Please Initial Boxes: (researcher initials if verbal consent)

I confirm that I have read and understand the participant information sheet dated [date, version] for the above study, have had the opportunity to ask questions and have had these answered acceptably.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
I understand that if I lose capacity to consent, that I will be withdrawn from the study and no further data will be collected, however data collected up until that point will be retained for use in the study.	
I understand that sections of any of my medical notes and data collected during the study may be looked at by individuals involved in the study, where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my records	
I give permission for my GP to be informed of my participation in the study	
I understand that all information given by me or about me will be treated as confidential by the research team.	
I understand that I will be randomly assigned to either the Compassion Focused Therapy group or a ‘control’ group. I understand that if I am assigned to the control group, that I will not receive Compassion Focused Therapy.	
I consent to the audio recording of the intervention sessions for research purposes.	
I agree to take part in the above study.	

Name of participant **Date (DD/MMM/YYYY)** **Signature of participant**

Signature of researcher (verbal consent)

Name of researcher **Date (DD/MMM/YYYY)** **Signature of researcher**

Appendix 9: Semi-structured Interview Schedules

Compassion Focused Therapy for mood in dementia feasibility study

Interview schedule for Compassion Focused Therapy participants

Please follow this guide flexibly. The questions do not need to be asked in the exact order they are written below – the interviewer should respond to the interviewee and be guided by them. The questions in bold are the questions we will aim to ask. The bullet points that are below each question in italics are prompts. The prompts are not essential and do not need to be asked - they are here to steer the interviewer if helpful.

Introduction:

Hi [*insert name*] many thanks for taking the time to help with this interview today. Just to introduce myself [*insert name and role*].

As a reminder, this interview is being carried out to gather information about the experiences and opinions of participants in the Compassion Focused Therapy for mood in dementia project. We don't want this interview to feel like a test — there are no right or wrong answers in this interview and we're here to hear about your experience and your views, both positive and negative.

If at any time you want to stop the interview, have a break, or if you don't want to answer a question please let me know. Please also feel free to ask me to repeat a question or to rephrase it if it is unclear.

Can I ask you to confirm that you are happy to continue?

[Acceptability and feasibility: intervention]

If it's OK with you, I'm going to start by asking you some questions about your experience of the group Compassion Focused Therapy sessions. Then later on in the interview I'll ask questions about other parts of the project, such as questions about how you came to be involved with the project initially.

1. Overall, what did you think about the kinds of topics and activities that were covered in the Compassion Focused Therapy sessions?

If you would like to start by giving me your general thoughts please do or if you would prefer, I have some reminders of what was covered in the beginning, middle and end set of sessions that we can go through?

- *In the initial sessions, you were introduced to key concepts in Compassion Focused Therapy, such as what compassion and self-compassion involve; the brain's three systems: threat, drive and soothe [can show the three Circle model handout as an example]. You spent some time setting goals.*
    - *How did you feel about what was covered in these initial sessions?*
        - *Was there anything you liked?*
        - *Anything you disliked?*

    - *Did you feel you were able to engage in these initial sessions?*
        - *Did you feel you were able to understand the ideas that were covered?*
        - *Did you feel we were able to complete the tasks, such as goal setting?*
        - *If not, what got in the way?*

- *The middle set of sessions focused on learning techniques for self-compassion such as the safe place memory exercise to activate our soothing system, loving-kindness for the self where you generated kindness and compassion for yourself, a compassionate body scan which helped you notice different sensations in your body and writing a compassionate letter*
    - *How did you feel about what was covered in these sessions?*
        - *Was there anything you liked?*
        - *Anything you disliked?*
    - *Did you feel you were able to engage in these middle sessions?*
        - *For example, did you feel you were able to practise the techniques?*
        - *If not, what got in the way?*

- *The final set of sessions focused on learning to tolerate difficult feelings, such as anger, shame and fear; as well as giving and receiving compassion. and on maintaining benefits from the group longer-term, such as building your own compassionate kit bag to help you remember how to be compassionate to yourself and others.*
    - *How did you feel about what was covered in these sessions?*
        - *Was there anything you liked?*
        - *Anything you disliked?*
    - *Did you feel you were able to engage in these final sessions?*
        - *For example, did you feel you were able to learn to better tolerate difficult feelings?*
        - *If not, what got in the way?*

- *Each session had a compassionate or mindful Compassion Focused Therapy practice, such as soothing breathing and affectionate breathing, mindful attention exercise. How did you find these practices?*
    - *Anything that you liked about these?*
    - *Anything that you disliked about these?*
    - *Did you find you were able to participate?*
        - *If not, what got in the way?*

2. At the end of each session, the facilitators suggested a task to practise at home such as soothing breathing, the safe place memory exercise, and writing a compassionate postcard to yourself, what were your thoughts on the home practice tasks?

    - *How did you get on with practising these tasks at home?*
        - *Did you manage to practise the tasks at home?*

            - *Did you feel you understood what you were being asked to do?*
            - *Were some tasks easier or harder than others?*
                - *If so, why?*
            - *Was there anything that helped you practise these tasks at home?*
            - *Did you get help from others?*
        - *Was there anything that got in the way of your practising these tasks at home?*

3. What are your thoughts about Compassion Focused Therapy being delivered in a group (as opposed to one on one)?

- *How did you find engaging with the activities in a group setting?*

4. What are your thoughts on your group facilitators [insert name and show photograph if possible]?

- *Did the facilitators help you to engage in the sessions?*
- *Anything you liked about the facilitators?*
- *Anything they could have done better?*

5. The Compassion Focused Therapy sessions took place over a period of [insert number for specific group e.g. 12/15 weeks] What did you think about the number of sessions?

- *Do you think it was the right amount?*
- *Would longer or shorter have been better?*
- *Were you able to attend the whole twelve weeks?*
    - *Did anything get in the way?*

6. Each session was one hour. What did you think about the length of the sessions?

- *Do you think it was the right amount?*
- *Would longer/shorter would have been better?*

7. You attended these sessions [insert either in person or virtually], is that right? I would like to ask you some questions about the experience attending these sessions [insert either in person or virtually]

7A. If attended face to face: What was your experience like attending sessions face to face?

- *How was travelling to and from the sessions?*
    - *Able to secure transport?*
    - *Able to afford transport*
    - *Able to set aside the time?*
    - *Any help needed from e.g. friend or family member to travel to sessions?*

- *What were your thoughts about the space where you went for the sessions (show photograph of the space)?*
    - *Did you feel it was fit for purpose?*
        - *Did you feel comfortable in this space?*
        - *Did you feel you were able to engage with the Compassion Focused Therapy activities?*
            - *Were you able to hear OK?*
            - *Were you able to see OK?*

6B: If attended virtually: What was your experience like attending sessions virtually?

- *How was it engaging in the sessions virtually?*
    - *Able to access the sessions?*
    - *Able to participate in the sessions?*
    - *Able to participate in the activities?*
    - *Did you have appropriate resources, such as a computer, tablet or smartphone?*
    - *Did you have access to an internet connection?*
    - *Did you have an appropriate (private) space at home to access the sessions?*
    - *Did you find that you had the digital skills to log on and participate?*
        - *Did anyone help you?*
    - *Were you able to hear OK?*
    - *Were you able to see OK?*

[Perceived impact of the intervention and potential mechanisms of change]

8. Do you think the Compassion Focused Therapy sessions have impacted you in any way?

9. What do you think has led to these changes?

- *What would you say is the main benefit (if any) you gained from engaging with Compassion Focused Therapy*
    - *What do you think led to this?*

- *Do you think engaging with Compassion Focused Therapy has had any negative impacts?*
    - *What do you think led to this?*

- *Have you noticed any changes in your mood, positive or negative?*
    - *Changes in your emotions, such as feeling low or anxious?*
    - *If yes, what do you think led to these changes?*

- *Have you noticed any changes in your behaviour?*
    - *If yes, what do you think led to these changes?*

- *Have you noticed any changes in your relationship with others and how you interact with others?*
    - *Changes in how you respond to key people in your life?*
    - *Changes in how you respond to people you see less often?*
    - *Changes in how you interact with acquaintances or strangers?*
    - *If yes, what do you think led to these changes?*
    -
- *Have you noticed any changes in how you feel about yourself and how you treat yourself?*
    - *How you feel about your symptoms of dementia?*
    - *How you respond when you feel impacted by dementia?*
    - *If yes, what do you think led to these changes?*
- *Have you noticed any changes in your symptoms of dementia?*
    - *For example, any changes in key things you were struggling with?*
    - *What do you think led to these changes?*
- *How does this compare to the impact of support you were receiving already?*
    - *Did the Compassion Focused Therapy sessions provide you with anything different?*

10. Is there anything you were hoping that would change that hasn't?

11. Do you think the Compassion Focused Therapy sessions could be improved in any way?

12. Do you think you will be able to keep gaining benefit from these sessions longer-term?

- *If yes, why is this?*

13. Overall, do you think this experience could be improved in any way?

- *Could it be made more dementia-friendly?*

[Acceptability and feasibility: trial procedures]

[Recruitment]

14. Could you tell me a bit about how you came to be involved in this project?

- *Who first discussed the study with you?*
    - *What did you think about this discussion?*

15. What were your first impressions of the study when you were first heard about it?

- *What made you interested in joining the study?*
- *Was there anything that was off-putting or made you hesitate about joining the study?*

- *Were you aware it was possible that you might be allocated to a group receiving Compassion Focused Therapy and that you might be allocated to a group not receiving the Compassion Focused Therapy sessions?*
    - *What were your thoughts on this?*

[**Baseline and follow-up assessments**]

You may remember at the start and at the end of the project that you met with a researcher to answer a range of questions.

The researcher you met with was called [insert name] and this is a photo of them. They spoke to you [insert details of e.g. online, in X location, did caregiver come with?]

They asked you questions to collect demographic information such as your age and ethnicity and ethnicity. They also asked you questions about a range of areas such as your mood, quality of life, how you feel about yourself and how you treat yourself and questions about your relationship with your carer/supportive other. You were asked to complete tasks such as drawing a clock face and recalling names of animals. A lot of questions were asked so don't worry if you can't remember specific questions you were asked, we're interested in your overall experience and thoughts on these meetings.

Would it be helpful for me to repeat some of the questions asked as a reminder?

If yes, read some of the 'assessment reminder prompts' at the end of this guide.

16. Could you tell me a bit about your experience of these meetings?

- *How comfortable did you feel in these meetings?*
    - *Were you able to engage in the way you wanted?*
    - *Were there any questions that you did not feel comfortable answering?*
- *Did you feel you were able to answer the questions accurately?*
- *What did you think about the length of the meeting?*
- *Did you attend this meeting virtually or face to face?*
    - *Did this affect your experience?*
- *Could these meetings be improved to be more dementia-friendly?*

To end: I have asked you all the questions I wanted to ask you, is there anything you would like to say or any other issue I haven't mentioned that you would like to discuss?

Thank you very much for your help.

Compassion Focused Therapy for mood in dementia feasibility study
Interview schedule for control group participants

Please follow this guide flexibly. The questions do not need to be asked in the exact order they are written below – the interviewer should respond to the interviewee and be guided by them. The questions in bold are the questions we will aim to ask. The bullet points that are below each question in italics are prompts. The prompts are not essential and do not need to be asked - they are here to steer the interviewer if helpful.

Introduction:

Hi [*insert name*] many thanks for taking the time to help with this interview today. Just to introduce myself [*insert name and role*].

As a reminder, this interview is being carried out to gather information about the experiences and opinions of participants in the Compassion Focused Therapy for mood in dementia project. We don't want this interview to feel like a test — there are no right or wrong answers in this interview and we're here to hear about your experience and your views, both positive and negative.

If at any time you want to stop the interview, have a break, or if you don't want to answer a question please let me know. Please also feel free to ask me to repeat a question or to rephrase it if it is unclear.

Can I ask you to confirm that you are happy to continue?

[Acceptability and feasibility: trial procedures]

[Recruitment]

1. Could you tell me a bit about how you came to be involved in this project?

- *Who first discussed the study with you?*
    - *What did you think about this discussion?*

2. What were your first impressions of the study when you were contacted about it?

- *What made you interested in joining the study?*
- *Was there anything that was off-putting or made you hesitate about joining the study?*

3. What were your thoughts when you learnt that you might be allocated to a group receiving Compassion Focused Therapy sessions and that you might be allocated to a group not receiving the Compassion Focused Therapy sessions?

- *How did you feel about this?*
    - *Did this affect your desire to take part?*

- *Did you understand the reason for this set-up?*

4. How did you respond when you were learnt that you were allocated to the group who would not be receiving the Compassion Focused Therapy sessions?

- *How did you feel about this?*

- *What are your thoughts on how this was communicated to you?*
  - *Could this have been explained more clearly?*
  - *Could this have been explained more sensitively?*

[**Baseline and follow-up assessments**]

You may remember at the start and end of the project that you met with a researcher to answer a range of questions about your mood, quality of life, thinking, feelings towards yourself [and your relationship with your carer/supportive other].

The researcher you met with was called [insert name] and this is a photo of them. They spoke to you [insert details of e.g. online, in X location, did caregiver come with?].

They asked you questions to collect demographic information such as your age and ethnicity and ethnicity. They also asked you questions about a range of areas such as your mood, quality of life, how you feel about yourself and how you treat yourself and questions about your relationship with your carer/supportive other. You were asked to complete tasks such as drawing a clock face and recalling names of animals. A lot of questions were asked so don't worry if you can't remember specific questions you were asked, we're interested in your overall experience and thoughts on these meetings.

Would it be helpful for me to repeat some of the questions asked as a reminder?

If yes, read some of the 'assessment reminder prompts' at the end of this guide.

5. Could you tell me a bit about your experience of these meetings?

- *How comfortable did you feel in these meetings?*
  - *Were you able to engage in the way you wanted?*
  - *Were there any questions that you did not feel comfortable answering?*

- *Did you feel you were able to answer the questions accurately?*
- *What did you think about the length of the meeting?*
- *Did you attend this meeting virtually or face to face?*
  - *Did this affect your experience?*
- *Could these meetings be improved to be more dementia-friendly?*

[Acceptability of and perceived impact of Treatment as Usual (TAU)

We're interested in hearing more generally about your experience of being in the control group and a bit more about how you manage living with dementia and about how you manage your mood – for example, if you receive any formal support from services.

6. How have you found being in the control group and not receiving the Compassion Focused Therapy sessions?

- *Is this something you have thought about the last few weeks?*
- *Do you think it has affected you in any way?*

7. Would you take part in this type of project again?

- *If yes, why?*
- *If no, why not?*

8. Do you access or receive any support to help you manage living with dementia?

- *Do you receive any formal support from services?*
    - *Are you prescribed medication?*
    - *Do you receive regular support from professionals?*
        - *Social care professionals?*
        - *Health care professionals?*
    - *Do you attend any day groups?*
- *What about informal support, such as support from friends or family?*

9. Do you access or receive any support to help you manage or cope with your symptoms of anxiety or low mood?

- *Do you receive any formal support from services?*
    - *Are you prescribed medication?*
    - *Do you receive regular support from professionals?*
        - *Social care professionals?*
        - *Health care professionals?*
    - *Do you attend any day groups?*
- *What about informal support, such as support from friends or family?*

10. How do you feel about the current support that is on offer to you to help you manage living with dementia?

- *Do you think it meets your needs?*
- *Is there anything you feel that is missing from what is on offer at the moment?*
- *Is there anything that gets in the way of you accessing support?*

11. How do you feel about the current support that is on offer to you to help you manage or cope with symptoms of anxiety and low mood?

- *Do you think it meets your needs?*
- *Is there anything you feel that is missing from what is on offer at the moment?*
- *Is there anything that gets in the way of you accessing support?*

To end: I have asked you all the questions I wanted to ask you, is there anything you would like to say or any other issue I haven't mentioned that you would like to discuss?

Thank you very much for your help.

ADDITIONAL QUESTIONS/PROMPTS (for both interview schedules)

Assessment reminder prompts (nb these are examples of baseline and follow-up assessment questions and not an extensive list – we have provided a long list of examples below, you do not need to read all of these, read however many feels appropriate to remind the participant)

*You were asked **demographic questions**, such as your age, registered sex at birth and ethnic group.*

*You were asked **questions about your preferences if you were invited to attend a Compassion Focused therapy group,** such as whether you would prefer to attend a face-to-face group or online.*

*You were asked about your **participation in other activities**, such as dementia support groups.*

*You were asked questions about **symptoms of depression** (for example, whether you have been feeling sad or irritable, have you been feeling restless, have you lost interest in your normal activities,, have you lost your appetite, have you had low energy)*

*You were also asked questions about **symptoms of anxiety** (for example, you were asked questions about your level of worry about certain things such as your worry about physical health, your memory and your finances. You were also asked whether you have been feeling nervous or on edge and whether you have had trouble sleeping and you were asked questions about physical symptoms of anxiety, such as shortness of breath, heart palpitations and sweating).*

*You were also asked questions about your **quality of life** (for example, you were asked about your feelings, memory and everyday life. You were also asked about whether you have any problems with your mobility, with self-care or performing usual activities and if you have pain or discomfort)*

*You were also asked to complete a range of tasks to **assess your memory and attention** (for example, you were asked to draw a clock, you were asked to remember the names of animals and you were asked for the date, month and year).*

*You were asked some questions about h**ow you feel about yourself and how you treat yourself** e.g. when you go through a hard time, whether you give yourself the care you need?*

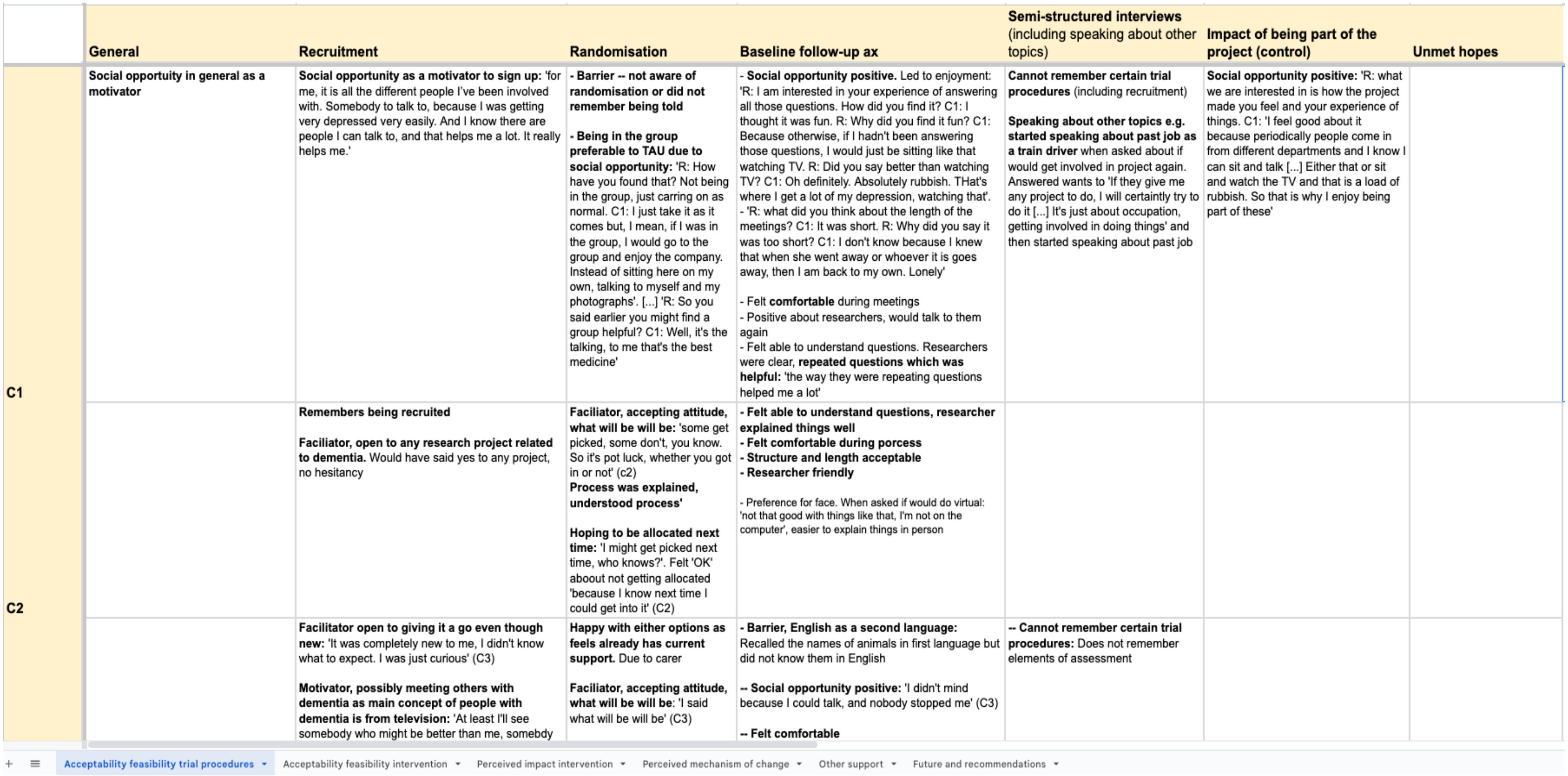
*And you were asked some questions about **your relationship with your carer/supportive other** (such as do you spend time together in an enjoyable way?)*

Appendix 10: Excerpt from Final Indexing Framework and Framework Matrix

Final Indexing Framework Excerpt

Code	Notes
1. Acceptability and Feasibility of Trial Procedures	
1.0 General trial procedures	
Social opportunity in general as a motivator	E.g. appreciated meeting people at different stages, distraction being alone, chance to speak regardless of what task is.
Barrier to trial procedures general – concern about taking time of carer	E.g. carer joins to help and participant is concerned that the process is time-consuming for them
1.1 Recruitment	
Barrier – uncertainty / not knowing what to expect	
Barrier – concern about group format	Including feeling nervous about being in a group, unsure about sharing with others, not knowing what other group members would be like
Barrier – discomfort re dementia	Don’t want to discuss dementia, difficulty accepting diagnosis
Barrier – cynical/sceptical to start	
Barrier – concern that talking about difficulties might make things worse	
Facilitator – remembers being recruited	
Facilitator – willing acceptance of process	
Facilitator – motivation: social opportunity	
Facilitator – open to giving it a go	
Facilitator – open to any research project related to dementia	Generally interested as related to dementia
Facilitator – wanting to get involved in dementia-related research.	Motivators include wanting to help others, wanting to find out more info themselves
Facilitator – wanting to connect with others with dementia	
1.2 Randomisation	
Barrier – unclear understanding / didn’t remember element	Either said was not told or not aware or did not remember being told about randomisation or was told but does not completely understand

Framework Matrix Excerpt



	General	**Recruitment**	**Randomisation**	**Baseline follow-up ax**	**Semi-structured interviews** (including speaking about other topics)	**Impact of being part of the project (control)**	**Unmet hopes**
C1	**Social opportuity in general as a motivator**	**Social opportunity as a motivator to sign up:** 'for me, it is all the different people I've been involved with. Somebody to talk to, because I was getting very depressed very easily. And I know there are people I can talk to, and that helps me a lot. It really helps me.'	**- Barrier -- not aware of randomisation or did not remember being told** **- Being in the group preferable to TAU due to social opportunity:** 'R: How have you found that? Not being in the group, just carring on as normal. C1: I just take it as it comes but, I mean, if I was in the group, I would go to the group and enjoy the company. Instead of sitting here on my own, talking to myself and my photographs'. [...] 'R: So you said earlier you might find a group helpful? C1: Well, it's the talking, to me that's the best medicine'	- **Social opportunity positive.** Led to enjoyment: 'R: I am interested in your experience of answering all those questions. How did you find it? C1: I thought it was fun. R: Why did you find it fun? C1: Because otherwise, if I hadn't been answering those questions, I would just be sitting like that watching TV. R: Did you say better than watching TV? C1: Oh definitely. Absolutely rubbish. THat's where I get a lot of my depression, watching that'. - 'R: what did you think about the length of the meetings? C1: It was short. R: Why did you say it was too short? C1: I don't know because I knew that when she went away or whoever it is goes away, then I am back to my own. Lonely' - Felt **comfortable** during meetings - Positive about researchers, would talk to them again - Felt able to understand questions. Researchers were clear, **repeated questions which was helpful:** 'the way they were repeating questions helped me a lot'	**Cannot remember certain trial procedures** (including recruitment) **Speaking about other topics e.g. started speaking about past job as a train driver** when asked about if would get involved in project again. Answered wants to 'If they give me any project to do, I will certaintly try to do it [...] It's just about occupation, getting involved in doing things' and then started speaking about past job	**Social opportunity positive:** 'R: what we are interested in is how the project made you feel and your experience of things. C1: 'I feel good about it because periodically people come in from different departments and I know I can sit and talk [...] Either that or sit and watch the TV and that is a load of rubbish. So that is why I enjoy being part of these'	
C2		**Remembers being recruited** **Faciliator, open to any research project related to dementia.** Would have said yes to any project, no hesitancy	**Faciliator, accepting attitude, what will be will be:** 'some get picked, some don't, you know. So it's pot luck, whether you got in or not' (c2) **Process was explained, understood process'** **Hoping to be allocated next time:** 'I might get picked next time, who knows?'. Felt 'OK' aboout not getting allocated 'because I know next time I could get into it' (C2)	**- Felt able to understand questions, researcher explained things well** **- Felt comfortable during porcess** **- Structure and length acceptable** **- Researcher friendly** - Preference for face. When asked if would do virtual: 'not that good with things like that, I'm not on the computer', easier to explain things in person			
		Facilitator open to giving it a go even though new: 'It was completely new to me, I didn't know what to expect. I was just curious' (C3) **Motivator, possibly meeting others with dementia as main concept of people with dementia is from television:** 'At least I'll see somebody who might be better than me, somebdy	**Happy with either options as feels already has current support.** Due to carer **Faciliator, accepting attitude, what will be will be**: 'I said what will be will be' (C3)	**- Barrier, English as a second language:** Recalled the names of animals in first language but did not know them in English **-- Social opportunity positive:** 'I didn't mind because I could talk, and nobody stopped me' (C3) **-- Felt comfortable**	**-- Cannot remember certain trial procedures:** Does not remember elements of assessment		

Appendix 11: Joint Project Outline of Roles

This thesis formed part of a larger project which was already up and running at the time my thesis partner, Ben Loe (BL), and I joined. Ethical approval had been granted, and participant recruitment was underway prior to our involvement.

The original plan was for BL to focus on the quantitative outcomes of the feasibility RCT, while I would lead on the qualitative component, which included interviews with PLWD (both treatment and control groups), carers, and professionals. Accordingly, I led the initial planning for the qualitative interviews for all groups. This included drafting the initial interview schedules and chairing a meeting with the Patient and Public Involvement (PPI) group to obtain feedback and make revisions.

I conducted the first round of interviews following the completion of the initial intervention groups, working alongside the project's research assistant (Mel Melville). These interviews included participants with dementia, their carers, and group facilitators.

However, BL was later informed that he would not be able to proceed with his quantitative thesis due to an embargo on data access until the overall project concluded. As a result, he joined me on the qualitative component of the study.

We subsequently revised our roles. We shared responsibility for conducting the remaining interviews, and then divided the analysis and write-up. I focused on the interviews with participants with dementia (both intervention and control groups), while BL took the lead on analysing interviews with professionals and carers.

In addition, we co-facilitated a CFT group together as part of the broader project