



DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) Literature Review: How do Family Members and Informal Carers Understand Psychological Distress in Dementia? A Scoping Review; 2) Service-Related Project: An Audit of Gloucester Complex Psychological Intervention Team Service Delivery: What is Provided and to Whom?; 3) Main Research Project: Tracing the Landscape of Trauma in Dementia: A Reflexive Thematic Analysis of Psychological Distress from Family Member Perspectives.

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Research Portfolio Submitted in Part Fulfilment of the Requirements for the Degree of Doctorate in Clinical Psychology

Main Portfolio

Literature Review

How do Family Members and Informal Carers Understand
Psychological Distress in Dementia? A Scoping Review

Service-Related Project

An Audit of Gloucester Complex Psychological Intervention Team
Service Delivery: What is Provided and to Whom?

Main Research Project

Tracing the Landscape of Trauma in Dementia: A Reflexive Thematic
Analysis of Psychological Distress From Family Member Perspectives

Volume 1

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Doctorate in Clinical Psychology

University of Bath

Department of Psychology

June 2024

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Declaration of authorship

I am the author of this portfolio, and the work described therein was carried out by myself personally, with the exception of input from my supervisors with all projects and assistance from my research apprentice with the main research project and literature review.

Candidate's signature



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Abstracts

Literature Review: How do Family Members and Informal Carers Understand Psychological Distress in Dementia? A Scoping Review

Objective

The ways in which family members make sense of Behavioural and Psychological Symptoms of Dementia (BPSD) are important to understand given their important role in facilitating person-centred care of people with dementia, through information sharing. The scope of literature pertaining to family understandings of BPSD has not been previously explored, therefore the current review aimed to consolidate the available evidence.

Methods

Systematic electronic database searches (CINHAL, PsycINFO, PubMed) were conducted for studies which focused on investigating how family members understand behavioural and psychological symptoms of dementia. The quality of papers was assessed using the Mixed Methods Appraisal Tool.

Results

6645 articles were screened and 30 were identified as eligible. The elements featuring in carers' explanations and understandings of BPSD were grouped into six clusters: (1) high-level factors relevant to carers' understandings, including preferred language, beliefs about the person's ability to control their behaviour, divergence of perspectives between carers and professionals, and not knowing (2) 'dementia' as an explanation for BPSD, (3) life history and premorbid personality, (4) expressions of physical and psychological need, (5) interpersonal factors, and (6) environmental factors.

Conclusions

Findings highlight how family members and informal carers across settings make sense of BPSD and psychological distress in dementia by drawing upon multiple sources of information about the person, including their history and context. The findings support the value of including carer voices when seeking to support those with BPSD, whilst also leaving open important research questions regarding the generalisability of findings across cultural groups.

Keywords: dementia, informal carers, family members, behavioural and psychological symptoms, understanding

Key Points:

- Family member understandings of behavioural and psychological symptoms of dementia have important clinical applications.

- This is the first review to systematically identify and synthesise existing literature on family members' understandings of BPSD.
- Family members make sense of BPSD and psychological distress in dementia in varied ways, drawing on life history, premorbid personality, expressions of physical and psychological need, interpersonal factors and environmental factors.

Service-Related Project: An Audit of Gloucester Complex Psychological Intervention Team Service Delivery: What is Provided and to Whom?

Purpose

Recent NHS policy emphasises the importance of equitable access to psychological therapies for people with severe mental health problems in a community setting. The current study aimed to gain an understanding of who accesses direct psychological intervention from the Complex Psychological Interventions team in the Gloucester Recovery service, and what input is received.

Design

An audit was completed using routinely collected data on patient demographics, referral rates and appointments from the 2021-22 financial year.

Findings

Differences were highlighted in referrals to CPI, with those who are younger and female overrepresented in CPI caseload compared to Recovery as well as those with diagnoses of anxiety disorders, behavioural syndromes associated with physical factors, and personality disorders. Those from Black and 'Other' ethnic backgrounds were also underrepresented in CPI, despite overrepresentation in Recovery. 28% of service users on the Recovery caseload had received direct input from CPI in the previous five years and 6% had been discussed in reflective practice.

Originality

The study provides a detailed analysis of psychological therapy service provision within a particular secondary mental health service and potential disparities in access.

Implications

For results related to who accesses therapy, where comparable data is available, findings in Gloucester are in line with pre-existing research. These, and findings regarding what is offered by CPI provide a starting point for Gloucester Recovery team and CPI to explore further what might be driving such data. A need for streamlining data collection processes is also identified to improve completeness and therefore usefulness of data.

Key words: Secondary mental health care, recovery team, psychological interventions, audit, equality, access

Main Research Project: Tracing the Landscape of Trauma in Dementia: A Reflexive Thematic Analysis of Psychological Distress From Family Member Perspectives

Objective

People with dementia are at increased risk of delayed-onset post-traumatic stress disorder. However, the clinical manifestation of trauma-related symptomatology in dementia is poorly understood. This study drew upon retrospective accounts of relatives to explore the psychological experiences over time of people with dementia who have experienced trauma.

Methods

Sixteen semi-structured interviews were conducted with relatives of people with dementia who had experienced a traumatic event earlier in life. Transcripts were analysed using Reflexive Thematic Analysis.

Results

Two overarching themes were developed which characterised how participants made sense of their relatives' experience of trauma and dementia: "*I Might Feel Differently if I Didn't Know the Stories*", *Mental Health and Dementia are Inextricably Linked*. Within these ways of making sense was the theme *Varied Trajectories of Trauma*, with four subthemes: *The Fundamentality of Trauma*, *Dementia as a Magnifier of Trauma*, *Dementia Lightens the Load of Trauma* and *Unchanging Relationship With Trauma*.

Conclusion

Relatives describe multiple overlapping patterns by which earlier life trauma is implicated in the psychological experience of people preceding and through their dementia. These findings point to a multi-faceted relationship between lifetime traumatic events and subsequent psychological distress in dementia, highlighting the importance of trauma-informed dementia care.

Keywords: dementia, trauma, PTSD, family caregivers, neuropsychiatric symptoms, behavioural and psychological symptoms of dementia

Literature Review

How do Family Members and Informal Carers Understand Psychological Distress in Dementia? A Scoping Review

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The International Journal of Geriatric Psychiatry publishes research related to the causes, treatment and care of mental disorders affecting the elderly. It has previously published mixed methods scoping reviews and reviews related to distress in dementia. The word limit is 4500 words for review papers. The guidance on journal formatting requirements can be found here:

<https://onlinelibrary.wiley.com/page/journal/10991166/homepage/forauthors.html>

Up to 97% of individuals with dementia experience changes in mood and behaviour alongside more widely recognised cognitive changes (Steinberg et al., 2008). These changes are often collectively known as ‘Behavioural and Psychological Symptoms of Dementia’, or BPSD (Van Der Linde et al., 2016) and impact on functional ability (Warren, 2022) and quality of life for both people with dementia and their caregivers (Hurt et al., 2008). It is important to note the limitations of the term BPSD; conceptualisation as ‘symptoms’ of dementia can medicalise these experiences, which may lead to the underlying psychological causes, emotions or needs of these presentations being overlooked. In addition, it may create the perception that such experiences are inevitable parts of dementia (Markwell, 2016) and so must be accepted, when in actuality there are evidence-based ways to support people experiencing these changes. Alternative terminology such as Behaviour that Challenges has been proposed, which is more in line with a psychological, formulated-led approach to supporting individuals with such experiences (e.g., Stokes, 2017; James & Jackman, 2017), however research suggests this is also not the preferred language of caregivers (Wolverson et al., 2022) and does not encompass experiences which may not challenge those around the person. Therefore, acknowledging its limitations, and indeed the limitations of any all-encompassing phraseology, BPSD will be used through this paper to reflect its common usage in the literature, its general acceptability to people with dementia and their carers (Markwell, 2016) and with emphasis on the importance of understanding the personhood of the individual with dementia (Cunningham et al., 2019).

Family caregivers play a crucial role in the assessment and management of BPSD, especially in the early stages of dementia where home-based care is the preferred option (Clarkson et al., 2017). This is relevant given BPSD are well-recognised early signs in Frontotemporal Dementia (Liu et al., 2004), Alzheimer’s and vascular dementias (Taragano et al. 2009). Family members also act as an information bridge, sharing knowledge of the person with dementia with medical professionals (Wolff et al., 2011). They improve consistency in care and may notice changes in the person’s symptoms and functioning that others may not (Levine et al., 2010).

Family caregivers’ understandings of BPSD are also important to understand given the interaction between understandings and wellbeing, of both the family caregiver and the person with dementia. Levels of BPSD have a significant impact on caregiver burden (García-Martín et al., 2023), which then in turn impacts on levels of BPSD (Peterson et al., 2016), influencing quality of life in both of the dyad (Isik et al., 2019). Caregivers’ understandings of BPSD are important to consider in relation to this as knowledge of BPSD predicts carers’ perception of the positive aspects of caregiving (Hu et al., 2022). In addition, carers’ attribution of behaviour has been found to affect their emotional and behavioural reaction towards the person with dementia

(Singleton et al., 2017). Negative attributions can amplify BPSD, reduce quality of care (Kales et al., 2015) and increase carer burden (Tarrier et al., 2002), thus reinforcing the cycle of poorer quality of life for both the carer and person with dementia.

However, family reports of BPSD often differ from those of professionals, with inconsistencies noted in types of BPSD reported as well as their severity or clinical significance (Lukovitz et al., 1992; Stella et al., 2015). Reasons for these discrepancies are not always clear. Some may be expected due to practical factors, such as the amount of time spent with the person or the nature of their caring experiences meaning their perceptions are influenced by their own distress (Sink et al., 2006). In this case, family and professional reports of BPSD could be seen as complementary sources of information. However, if these discrepancies reflect fundamental differences in how BPSD is perceived and understood, they could lead to misunderstanding, particularly in relation to the pre-diagnostic stage of dementia where BPSD are common (Eikelboom et al., 2021), clinical priorities misaligned with the needs of the person, and a lack of collaboration between family members and professionals. Given the collaborative approach recommended by best practice dementia care models (James & Jackman, 2017), such variations are important to explore further.

Reviews of the literature on BPSD have predominantly focused on its management (e.g., Braun et al., 2018), its impact on carer wellbeing or burden (e.g., Feast et al., 2016), or the understandings of professionals (e.g., Jennings et al., 2018; Holst & Skär, 2017). The present review therefore aims to consolidate the available evidence pertaining to how family members and informal carers make sense of BPSD and psychological distress in dementia, providing an overview of how the area has been studied and the established findings, and discussing their implications for clinical practice and future research.

Method

Due to the paucity and the heterogeneity of research in this area, a scoping review was considered the most appropriate methodology (Munn et al., 2018). The process for selection of relevant literature and reporting of methodology and findings follows the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Scoping Review extension (PRISMA-ScR; Tricco et al., 2018; see Appendix A). The protocol for the review was pre-registered on PROSPERO (CRD42024546589).

Search Strategy

A literature search was conducted in Medline, PsycINFO and CINAHL in March 2024. Following initial pilot searches, the final search strategy was devised through research team discussion and support from a specialist subject librarian. Search terms included synonyms and index terms of key concepts: carers, family members, dementia, understanding and behavioural and psychological symptoms or distress. Boolean, truncation and proximity operators were also

used. Terms were applied to title, abstract and keywords. Full search terms can be found in Appendix B.

Inclusion and Exclusion Criteria

The inclusion criteria specified that the main aim of the paper, or a significant part of reported findings, relate to informal carers' or family members' understandings of, or perspectives on, distress or psychological symptoms of dementia. Articles were included whether they considered BPSD broadly or a specific symptom. The review was restricted to articles published in the English language and where full text was available. There was no limit on publication date or design of study.

This review excluded other review articles, articles assessing interventions, opinion or editorial pieces, non-peer reviewed articles, books and book reviews. Papers which were predominantly focused on caregiver wellbeing or burden, or where understanding of distress was not a main focus, were also excluded. Studies which reported the perspectives of formal carers or non-family members where these views were not represented or analysed separately from informal carers were also excluded.

Study Selection

References from literature searches were exported from EndNote software to the online software Covidence, which was used for study selection. During the first stage of screening, all duplicates were removed automatically by Covidence. At stage 1 of screening, the first author (G.C.) and second author (S.H.) independently screened titles and abstracts for inclusion using the inclusion and exclusion criteria. Disagreements were resolved by discussion between G.C. and S.H. or, where a unanimous decision was not reached, through discussion with A.V. At stage 2 of screening, all full-text records were screened by G.C. and A.V., with any disagreements resolved through discussion.

Data Extraction

Data extraction was conducted independently by G.C. and S.H., using a tool developed for the purpose of this review (Appendix C). Data were extracted pertaining to the aims, population, sample characteristics, methodology and key findings relevant to how carers understand psychological distress in dementia.

Quality Assessment

The Mixed Methods Assessment Tool (M-MAT; Pluye et al., 2009) was used to assess the quality of the included studies. This is a tool designed to be suitable to assess qualitative, quantitative and mixed methods studies, with raters assigning scores of "yes", "no" or "can't tell" to five questions. Two screening questions are applied for studies to be eligible for use and then raters select one of the five available versions of the M-MAT questions, dependent on

study design. Studies were assessed independently by G.C. and S.H., with any disagreements resolved in discussion with A.V.

Data Synthesis

All eligible studies were incorporated into a qualitative narrative synthesis, with a focus on developing a broad overview of how family perspectives on BPSD have been studied and summarising the main themes that emerge across the literature. This occurred through G.C. and S.H. making notes through screening and extraction on thoughts regarding key findings, which were then discussed between all three authors.

Results

Figure 1.1, a PRISMA Flow Diagram, shows the process of study selection. 8199 studies were identified through electronic database searches. Duplicates were identified by Covidence (n = 1532) and 22 were identified manually. The remaining 6645 studies were included in title and abstract screening and 6507 studies were excluded at this stage. Subsequently, the full texts of 128 studies were reviewed, 98 of which did not meet inclusion criteria. Thirty studies were identified for inclusion in the review. Full details of the included studies can be found in Table 1.1 and quality assessment results can be found in Appendix D.

Figure 1.1.

PRISMA Flow Diagram

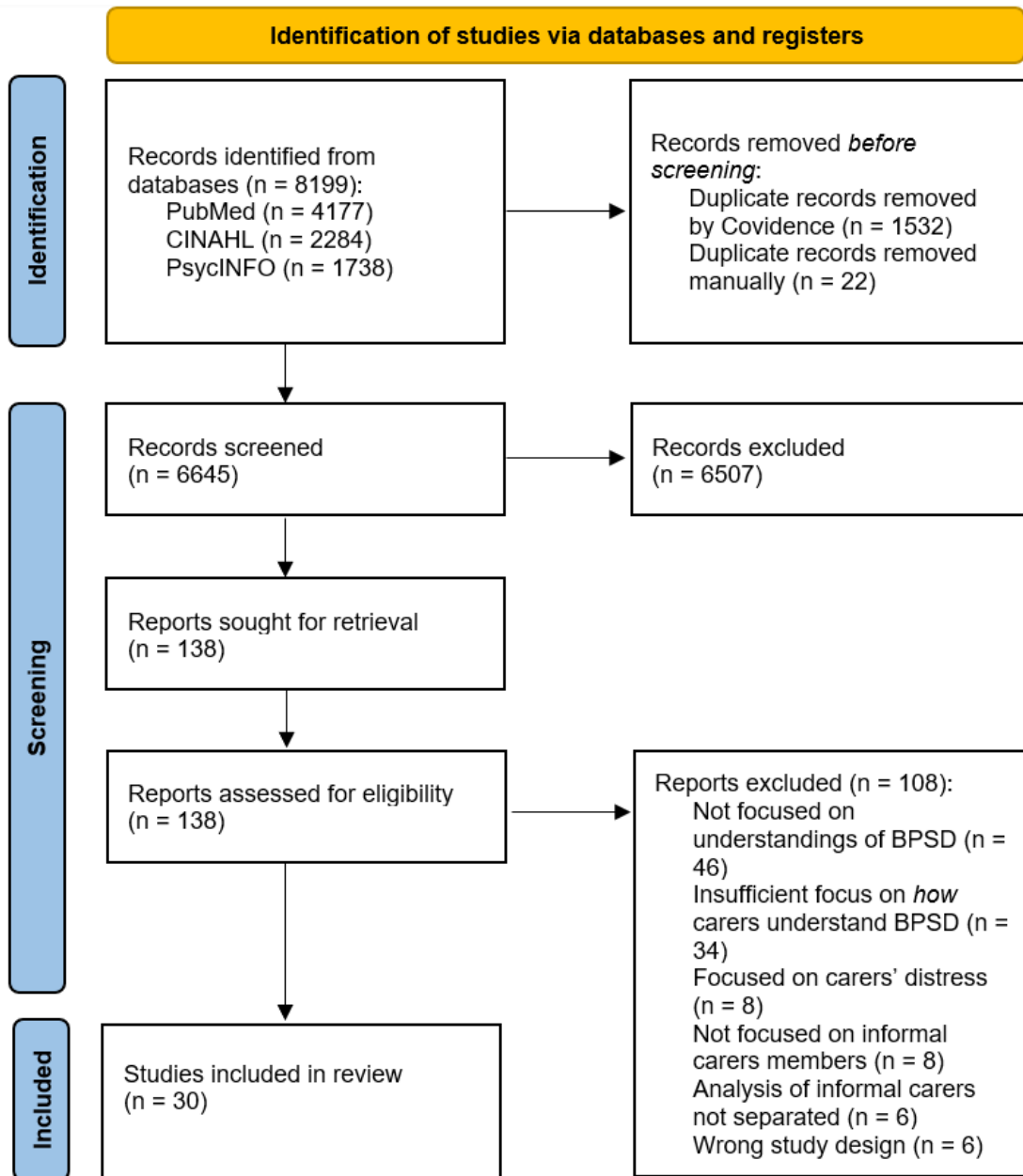


Table 1.1.*Summary of Included Papers*

Citation and Country	Main Focus and Aim	Sample	Methodology	Key Findings
Adekoya & Guse (2021) Canada	Main Focus: Wandering Aim: To understand the perceptions of past and current wandering behaviours and its relation to personality and values	8 participants: 3 sons, 2 daughters, 1 wife, 1 niece, 1 significant friend Type of Dementia: Mild to moderate, diagnosis not specified Setting: Residential	Qualitative Semi-structured interviews Interpretive description methodology	Participants used the term walking rather than wandering. Walking was not seen as aimless, and was instead seen as purposeful, improving socialisation and acting as a coping strategy while also having positive health benefits.
Band-Winterstein & Avieli (2019) Israel	Main Focus: Violence and Aggression Aim: To explore spouses' perceptions and the differences between the experiences of women with previously violent and not previously violent spouses	16 participants: all female, 8 experiencing lifelong violence, 8 experiencing dementia-related violence. Ages ranged from 63 to 84 years, mean age 72.25. Type of Dementia: Not specified Setting: Community	Qualitative Semi-structured interviews Interpretive phenomenological analysis	Participants experiencing lifelong violence noticed changes over time in shape and form, but they did not attribute the change to dementia and instead felt an overall worsening of relationship. Those experiencing dementia-related violence found the change sudden, drastic and unexpected but a diagnosis gave some relief and support.
Brittain et al. (2017) UK	Main Focus: Wandering	3 focus groups with 11 participants and 26 one-to-one interviews.	Qualitative Secondary analysis of interviews by revisiting	Wandering is often linked to meaningful locations people with dementia are attached to. Walking turns to wandering

	Aim: To understand when walking becomes wandering	Type of Dementia: Not specified Setting: Not specified	previously coded data relating to wandering – inductive approach using the constant comparative method and deviant case analysis	when it is perceived as dangerous.
Burley et al. (2021) Australia	Main Focus: BPSD Aim: To identify and compare the experiences, interpretation and approaches to BPSD and to obtain their views on terminology describing BPSD	20 participants: 14 female, 6 male, 13 partners, 5 daughter/sons, 1 carer, 1 friend Type of Dementia: Any subtype Setting: Not specified	Qualitative Semi-structured interviews Hybrid approach of thematic analysis that incorporated both deductive and inductive approaches	BPSD are understood as reactive or from cognitive deterioration. Memories of traumatic events manifest as difficult emotions. Carers focused on events consisting of multiple symptoms rather than describing individual behaviours or symptoms. Differences from perspectives of people with dementia.
Chen et al. (2017) USA	Main Focus: BPSD Aim: To clarify the relationship between expressed emotion and causal attributions among daughters caring for parents with dementia	77 participants: all daughters Type of Dementia: Not specified Setting: 63% lived residentially, 26% alone in the community, and 11% with their daughters	Quantitative Questionnaire data including CMAI and LEE Regression analysis examining the relationship between daughters' perceptions of controllability and expressed emotions	Overall perceptions of controllability were low. Daughters that felt parents had greater control over behaviours reported higher levels of expressed emotions. They were more emotionally reactive and had more negative attitudes about their parent's dementia.
Cohen-Mansfield et al. (2013) Israel	Main Focus: Delusions and Hallucinations	90 formal caregivers and 151 informal caregivers (43% daughters, 30% wives, 14%	Mixed methods Quantitative: Etiological Assessment of Psychotic	The type of caregiving relationship, its history, and level of emotional involvement can affect the views of informal

	Aim: To compare formal and informal caregivers' perceptions of delusions and hallucinations	sons, 9% husbands) to 151 persons aged 65 and older Type of Dementia: Any subtype Setting: Community, 49% lived with informal caregiver	Symptoms in Dementia (EAPSID) ratings from formal and informal carers Qualitative: Interpretive content analysis based on interviews	caregivers. Sometimes informal and formal caregiver's reports on events complement each other but other times different meanings are ascribed. Combining both reports creates better cohesion and clarity.
Duxbury et al. (2013) UK	Main Focus: Aggression Aim: To explore the views of nurses, and relatives regarding the causes of, and most effective ways of responding to aggressive behaviour	6 participants attended one focus group and 2 attended another: 3 male and 5 female. Relationships included spouse, partner, daughter, son-in-law, mother and niece. Type of Dementia: Not specified Setting: Residential	Qualitative Focus groups Content analysis	Internal, external and interpersonal factors identified. Aggression seen as 'poorly communicated need'. Participants tended to underplay dementia as a direct cause of aggressive behaviour, regarding it more as a mediating factor.
Fieldhouse et al. (2023) Netherlands	Main Focus: BPSD in FTD Aim: To understand caregiver perspectives on relevant target symptoms of the behavioural variant of FTD	20 participants: 15 female, 15 partners and 5 children People with dementia: mean age 64.8, 8 recently diagnosed/living at home, 5 progressed/in need of extra care, 3 institutionalized, 4 deceased 65% lived with relatives, 15% in a nursing home, and 20% were deceased.	Qualitative Semi-structured interviews Open and in vivo coding used on categorical, sub-categorical, dimension and concept levels.	Changes in personality and reduction in emotional connection attributed to FTD. Behavioural disturbances often led to conflict and distress for the caregiver. Sometimes the meanings behind these behaviours were misinterpreted.

Type of Dementia: FTD

Setting: Residential and Community

Gilbert et al. (2021) Australia	Main Focus: Emotion Aim: To understand the emotional dimensions of caregiving for ethnic minority carers	93 participants: 50 female, 43 male Language spoken: Arabic - 17, Mandarin - 10, Cantonese - 10, Hokkien - 2, Hindi - 2, Tamil - 10, Greek - 14, Italian - 22. Type of Dementia: Any type Setting: Not specified	Qualitative Semi-structured interviews Descriptive coding used then a further thematic analysis, coded inductively	The onset of dementia led to negative changes in personality and emotions. Withdrawal from social contact was seen as a response to shame. The emotions carers perceived in people with dementia, and the meanings they attributed to those emotions, were fundamental to how carers defined their roles and responsibilities as caregivers.
Gilmore-Bykovskiy et al. (2020) USA	Main Focus: BPSD Aim: To identify terminology to describe NPS and to examine contextual factors	20 participants: 11 female, 9 male, 9 caring for spouse, 11 caring for parent/step-parent Ages ranged from 48 to 82 Type of Dementia: Not specified Setting: Not specified	Qualitative Semi-structured interviews Two phases of analysis: 1. a directed content and text analysis of terminology 2. a thematic analysis to form themes	Descriptions reflected specific events using nonspecific, and often broad, terms. Caregivers attempted to rationalise symptoms and use strategies to help with challenging situations. Caregivers were often able to recognise cyclic patterns to behaviours.
Hansen et al. (2019) USA	Main Focus: Aggression	13 participants: all African-American, 12 female, 1 male, 11 cared for a parent, 12 lived	Qualitative Semi-structured interviews	Aggression seen as due to the disease, not the person. It is difficult to not take it

	Aim: To explore how African-American caregivers describe their experiences, including their reactions and management strategies	with people with dementia, mean age - 65.5 years Type of Dementia: Not specified Setting: Community	Stress Process Model underpinned analysis using process coding, holistic coding and pattern coding	personally, particularly when linked to past relationships.
Harvath (1994) USA	Main Focus: BPSD Aim: To describe the perception, interpretation, and management of behaviour problems, and explore how these might mediate the negative consequences caregivers experience when managing these problems	10 participants: all female and Caucasian ranging in age from 51 to 80 years, 8 spouses and 2 daughters caring for their mothers. All people with dementia lived with caregiver and ranged in age from 67-86. Type of Dementia: Multi-infarct dementia, Alzheimer's disease, or mixed dementia. Setting: Community	Qualitative Semi-structured interviews Interactive process as comparisons were made across subjects and categories to explore management strategies. 3 participants completed validation interviews	Many behaviours were not attributed directly to the dementia but situational circumstances, underlying needs and emotions, historical events, certain mitigating circumstances and other unknown causes were recognised as contributing to behaviours. Caregivers who felt relatives could control their behaviours and acted deliberately experienced more stress and intervened in confrontational ways.
Herron & Wrathall (2018) Canada	Main Focus: Aggression Aim: To examine actions that are often perceived as aggressive and the role the environment plays	9 participants: 6 female, 3 male, 5 spouses, 1 daughter, 2 sons, 1 sister, aged from 32-86. Type of Dementia: Not specified Setting: Residential and Community	Qualitative Semi-structured interviews Constant comparison approach looking at the individual, interpersonal, local, macro-scale and temporal influences	Understood as a meaningful way to express feelings. The environment influences behaviours differently in each PLWD but intimate spaces such as bedrooms were often where incidents occur, perhaps feeling safe there.

Houston et al. (2011) USA	<p>Main Focus: Wandering</p> <p>Aim: To explore inconsistencies between ICs' and experts' use of the term wandering</p>	<p>128 participants, 92% female, 79% wives - Mean age 70</p> <p>Type of Dementia: Any mild dementia in veterans</p> <p>Setting: Community</p>	<p>Mixed methods Interviews with open and closed questions.</p> <p>Percentages of responses calculated across caregivers. Themes created from open-ended questions</p>	Caregivers predominantly used the term "lost" to describe scenarios rather than "wandering" which only 5% endorsed. Wandering was understood as aimless walking and was mostly used in hypothetical situations.
MacAndrew et al. (2017) Australia	<p>Main Focus: Wandering</p> <p>Aim: To explore the experience caring for a person with dementia who wanders and transgresses boundaries into out-of-bounds and potentially hazardous areas</p>	<p>12 participants: 3 spouses, 8 daughters, 1 sister</p> <p>Type of Dementia: Not specified</p> <p>Setting: Residential</p>	<p>Qualitative</p> <p>8 semi-structured interviews and 1 focus group</p> <p>Content analysis with an inductive approach through:</p> <ol style="list-style-type: none"> 1. Open coding 2. Collation 3. Concept development 4. Themes 5. Model development 	Caregivers used "intrusion," "invasion," or "wandering" to describe boundary transgression and thought it was needs-driven and occurred when spaces lost meaning or couldn't be navigated. Caregivers became worried when adverse outcomes were experienced.
Mackenzie et al. (1989) USA	<p>Main Focus: Depression</p> <p>Aim: To compare the occurrence of depression in patients from people with dementia and carer perspectives</p>	<p>Caregiver sample and demographics not reported</p> <p>46 people with dementia: 28 women, 18 men, mean age of 72.9 years</p> <p>Type of Dementia: Alzheimer's</p> <p>Setting: Not specified</p>	<p>Quantitative</p> <p>Structured interviews</p> <p>Kappa coefficient used to compare agreement between people with dementia and caregivers. Variables were compared by means of chi-square tests</p>	Using scores of people with dementia, 5 patients met depression criteria, but 18 met criteria when using caregiver's scores. There was disagreement in 19 cases, with 16 cases skewed towards depression by caregivers. Disagreement more likely in cases of mental health

				history and related to specific items.
Nijsten et al.(2023) Netherlands	Main Focus: Apathy Aim: To explore the experiences of persons with apathy, their family caregivers and professional caregivers in identifying and managing apathy in nursing homes	3 participants: 2 female, 1 male, ages ranged from 60-64 Type of Dementia: Not specified Setting: Residential	Qualitative Semi-structured interviews An inductive and descriptive approach taken	Apathy creates recognisable changes in person with dementia is likely the cause of their apathy. Apathy and a sad mood was thought to be a burden for the person with dementia. However, carers did not always find it easy to identify and understand signals of apathy.
Paton et al. (2004) UK	Main Focus: BPSD Aim: To explore how caregivers who find particular symptoms difficult, attribute these symptoms; To explore whether carers believe the behaviour is under the control of the person with dementia	205 participants: 70% female, 30% male, 75 spouses, 76 children, 19 relatives, 10 friends, 25 carers, age range 28– 93, mean = 63 205 people with AD: 72% women, 28% male, 90 lived with caregiver (44%), age range 55–98, mean 81 Type of Dementia: Alzheimer’s Setting: Residential and Community	Qualitative Semi-structured interviews Themes broken down into those related to AD and those unrelated (childhood factors/ pre-morbid personality)	Aggression was considered related to pre-morbid personality factors or frustration and apathy was associated with ageing, depression and medication. 25%, all relationship statuses, believed the person with dementia could control their behaviour across. Many recognised the role of negative experiences and past difficulties on behaviours including during childhood.
Polenick et al. (2018) USA	Main Focus: BPSD Aim: To consider family caregivers’ perspectives	26 participants: 21 female, 5 male, 25 white	Qualitative Focus groups	Some caregivers felt that people with dementia had some control over behaviours, some felt it was uncontrollable. Five

	of BPSD triggers, the causes of behaviours and the language used to describe them	Type of Dementia: Not specified Setting: Not specified	Content analysis was used to identify attribution categories. A procedure called rigorous and accelerated data reduction (RADaR) was applied	attribution categories were identified: neurobiological disease factors, physical symptoms, psychological reactions, shifting social roles and environment.
Qazi et al. (2010) UK	Main Focus: Anxiety Aim: To identify symptoms, risk factors and intervention strategies for anxiety	36 participants: 18 female, 8 male, 10 husbands, 13 wives, 2 daughters, 1 friend, mean age 78 Type of Dementia: Not specified Setting: Not specified	Qualitative Focus groups Long table approach used, transcriptions were cut up and comments arranged in groups of similar concepts, allowing themes to emerge	Carers noted anxiety in the person with dementia before diagnosis. Levels of anxiety increased as skills were lost. Not recognising family members or names induced high levels of anxiety. Environmental factors also invoked anxiety but these factors differed.
Rasmussen et al. (2019) Norway	Main Focus: BPSD in FTD Aim: To explore the family caregivers' experiences of the pre-diagnostic stage of FTD.	14 participants: 7 female, 7 male, 35.7% husbands, 21.4% wives, 7.1% friend, 7.1% siblings, 28.6% child Type of Dementia: FTD Setting: Residential and Community	Qualitative Semi-structured interviews Gadamerian hermeneutic tradition used for analysis	Person with dementia interpreted as gradually becoming distant with increase in silence and apathy. Understood as aging, stress or downturn in relationship. Carers felt person became a stranger.
Rognstad et al. (2020) Norway	Main Focus: BPSD Aim: To explore the challenges of family caregivers of people with	11 participants, 9 female, 2 male, 5 spouses, 4 daughters, 1 sister, 1 nephew, aged 46–78 years	Qualitative Semi-structured interviews Descriptive, explorative design using three contexts of	Caregivers found the gradual change in behaviour and personality such as withdrawal and aggression frightening and incomprehensible. Gradual withdrawal and social

dementia causing behavioural disturbances

7 people with FTD: 2 female, 5 male

interpretation: self-understanding, common sense and theoretical understanding using dignity theory

difficulties, Saw as loss of loved one.

Type of Dementia: FTD

Setting: Residential

Song et al. (2018)
Korea

Main Focus: BPSD

Aim: To identify what family caregivers may experience when managing BPSD focusing on interpersonal interactions

15 participants: 10 female, 5 male. 11 spouses, mean age = 66.7

Type of Dementia: Not specified

Setting: Not specified

Qualitative

Focus groups

Content analysis

Caregiver perceptions of BPSD triggers were associated with the person with dementia (realisation of their loss of power, failure to understand the situation, and inability to communicate) and factors related to family caregivers (lack of knowledge, lack of consideration and ignoring needs).

Tappen & Williams (1998)
USA

Main Focus: Expression of emotion

Aim: To explore family and caregiver perspectives on the expression of emotion by individuals in the middle and late stages of Alzheimer's disease

20 participants, 4 wives, 3 husbands, 4 sons and 9 daughters

Type of Dementia: Middle and late stages of Alzheimer's

Setting: Residential and Community

Qualitative

Semi-structured interviews

Results of staff and caregivers were compared for verification. Preliminary results were also shared with staff to further verify themes

Caregivers could confidently identify emotions but negative emotions were mentioned twice as much as positive ones. Families of day centre and residential clients different in opinion. The unpredictability of sudden shifts in mood posed difficulties especially when non-verbal cues were difficult to interpret.

Tyrrell et al. (2019)
Sweden

Main Focus: BPSD

14 participants: 11 female, 3 male, aged 64-85

Qualitative

Changes in behaviours and personality, often drastic, were

	Aim: To describe family members' experiences of living with persons with NPS related to dementia	Person with dementia: 3 female, 11 male, aged 68-86 Type of Dementia: Alzheimer's Disease, Vascular Dementia or combined diagnosis Setting: Community	Semi-structured interviews Content analysis, with both latent and manifest processes used cyclically	regarded negatively and made it difficult to understand the person. Changes to personalities were understood as involuntary.
Tyrrell et al. (2020) Sweden	Main Focus: BPSD in FTD Aim: To describe spouses' experiences of living with partners with NPS related to FTD	9 participants, 6 female, 3 male, 4 wives, 2 husbands, 1 partner, 1 daughter, 1 son Type of Dementia: FTD Setting: Community	Qualitative Semi-structured interviews Content analysis, with both latent and manifest processes used cyclically	Caregivers saw person with dementia as changed in personality, grieving the person that existed before diagnosis. These were seen as unpredictable and not inherent to the person.
Wang et al. (2015) Taiwan	Main Focus: BPSD Aim: To investigate and compare the needs underlying hoarding, aggressive behaviour, repetitive behaviour, altered eating behaviour and delusion as perceived by family caregivers	65 participants: 47 female, 18 male, 16 spouses, 24 daughters, 6 sons, 8 daughter in laws, 11 other relatives, age range 34 - 81, mean 54.17 Type of Dementia: Alzheimer's Setting: Not specified	Qualitative Semi-structured interviews Directed content analysis method used based on key codes identified prior to analysis using needs-driven dementia-compromised behaviour model	Difficult behaviours are used to communicate unmet needs including physical and psychological comfort, mental and material security, feelings of belonging, and self-control.
Wang et al. (2014) Taiwan	Main Focus: Delusions Aim: To understand the influences of earlier life	20 participants, 13 female, 7 male, 5 spouses, 9 daughters, 4 sons, 2 daughter in laws	Qualitative Semi-structured interviews	Delusions are often linked to negative experiences and routine responsibilities from earlier in life. The environment

experiences and the current environment on delusions, as well as the underlying needs of individuals with AD experiencing delusions.

Type of Dementia: Alzheimer's
Setting: Not specified

Directed content analysis

such as dim light and loud noises can affect delusions but are person specific. Also identified illness and discomfort. Delusions may allow people with dementia to express loneliness and a desire for relatives to visit.

Wang et al. (2012)
Taiwan

Main Focus: Hoarding behaviour

Aim: To examine the characteristics and underlying meaning of hoarding behaviour from the perspective of family caregivers.

12 participants, all female, 7 daughters, 4 daughters in law, 1 spouse, age range 47-78 years

Type of Dementia: Alzheimer's
Setting: Not specified

Qualitative
Semi-structured interviews

Directed content analysis with need-driven dementia-compromised behaviours used as an initial framework. Peer debriefing was conducted with a focus group of six participants

Influence of previous hoarding behaviour recognised. Carers see recurrence of past personal characteristics and habits. May be re-experiencing. Hoarding fills unmet psychological needs as it brings comfort and safety to people with dementia.

Wolverson et al. (2022)
UK

Main Focus: BPSD

Aim: To explore the views of family carers on the language used to describe changes in behaviour associated with dementia.

229 participants: 207 female, 22 male, average age 60 years

Type of Dementia: Not specified
Setting: Not specified

Mixed methods
Questionnaire exploring preferred terms for BPS

Analysed using Chi-square tests and thematic content analysis

Behavioural and Emotional Expressions of Need was the most preferable term. Participants preferred terms that were positive, person-centred and acknowledge the role of the caregiver.

Note: BPSD = Behavioural and Psychological Symptoms of Dementia; CMAI = Cohen-Mansfield Agitation Inventory; LEE = Level of Expressed Emotion questionnaire; FTD = Frontotemporal Dementia; NPS = Neuropsychiatric Symptoms; AD = Alzheimer Dementia

Study Characteristics

Papers were published between 1989 and 2023, with the majority published since 2018. Most were published in the USA (n=8) or the UK (n=5), with others in Taiwan (n=3), Australia (n=3), Canada, Israel, the Netherlands and Norway (n=2 for each) and Korea (n=1).

Study design was predominantly qualitative (n=25). Nineteen were interview studies, four used focus groups, one was a mixture of focus groups and interview and one was secondary analysis of previously conducted interviews. Three used mixed methods and two were quantitative descriptive studies. This predominant use of qualitative methods was expected, given the research question.

The included studies were conducted in community settings (n=7), residential settings (n=5) or both (n=6). Twelve studies did not specify setting. Almost half of the studies did not specify the type of dementia of the relatives of participants (n=13). Of those that did, four included any type, seven included only Alzheimer disease and four only included Frontotemporal dementia (FTD). A further two included a combination of diagnoses.

Twenty-nine of the 30 articles reported details on their sample of caregivers. 1301 caregivers were represented across all studies, 74% of whom were female (n=968). For studies which reported relationship type, samples included spouses (n=387), children or daughters-in-law (n=403), other relatives (n=44) and friends (n=14). Only six studies reported data on the sample of people with dementia, of whom there were 443. Four studies gave data on gender split of people with dementia; 181 females and 91 males.

Twelve of the 30 articles examined understandings of BPSD in broad terms. The remaining papers addressed expressions of emotion in dementia (n=2), wandering (n=4), violence and aggression (n=4), BPSD specific to FTD (n=2), delusions or hallucinations (n=2). Depression, apathy, anxiety and hoarding were the focus of one article each.

Quality Appraisal

The overall quality of the studies in the review was judged to be high, particularly for qualitative papers, and most papers could be rated as 'yes' or 'no' on each criterion, with 'yes', 'no' and 'can't tell' as the three options for all questions. However, for the three studies receiving 'Can't tell' ratings on the third question, which related to whether the findings were adequately derived from the data (Qualitative) or whether integrated data was adequately interpreted (Mixed Methods), this was due to a lack of detailed information about the analysis process. In addition, for both quantitative descriptive studies it was difficult to answer the second question regarding whether the sample was representative of the target population. One did not provide carer demographics (Mackenzie et al., 1989) and the other did not provide enough detail about the target population or approach to sampling (Chen et al., 2017).

Synthesis

The elements featuring in carers' explanations and understandings of BPSD were grouped into six clusters: (1) high-level factors relevant to carers' understandings, including preferred language, beliefs about the person's ability to control their behaviour, divergence of perspectives between carers and professionals, and not knowing (2) 'dementia' as an explanation for BPSD, (3) life history and premorbid personality, (4) expressions of physical and psychological need, (5) interpersonal factors, and (6) environmental factors.

High-Level Factors Relevant to Carers' Understandings

There are many ways in which carers seek to explain and understand BPSD broadly as well as specific behaviours. Studies most often identified multiple explanations, highlighting how carers draw on multiple sources of information. Indeed, Polenick et al. (2018) identified several categories of attributions and noted that 50% of carers provided attributions from two or more categories.

Sometimes carers could not develop explanations; some studies identified a lack of understanding of BPSD. For example, BPSD in FTD was seen as incomprehensible (Rognstad et al., 2020) and unpredictable (Tyrell et al., 2019). Song et al. (2018) and Tappen and Williams (1998) also identified that carers did not have knowledge about why BPSD occurred or were puzzled by this.

Questions of personal agency emerged frequently in carers' explanations of BPSD, with perceptions of controllability varying between studies. Polenick et al. (2018) highlighted how some carers considered BPSD as uncontrollable, while others saw it as partly controllable or deliberate. Chen et al. (2017) identified that daughters perceived their parents' BPSD as mostly uncontrollable, with those perceiving behaviour as controllable holding more negative attitudes towards their parents. Similar results were found by MacAndrew et al. (2017) in relation to wandering, Duxbury et al. (2013) for aggression and Tyrrell et al. (2019) for personality changes. Conversely, Harvath (1994) identified that some carers thought people with dementia could control their behaviour or were acting deliberately. Paton et al. (2004) also found that 25% of carers believed this.

Issues of language and terminology matter to carers and may imply certain explanations or perceptions of BPSD. Language has particularly been explored in relation to wandering: the preferred term for this appeared to be walking (Adekoya & Guse, 2021) or lost (Houston et al., 2011), although 'wandering' was used more often than 'boundary transgression' (MacAndrew et al., 2017). Brittain et al. (2017) found carers believe 'walking' becomes 'wandering' when it becomes dangerous. Tappen and Williams (1998) found that when describing the emotions of people with dementia, family of people in day centres most often used words such as sad, angry and worried, in contrast to those of nursing home residents, who talked more about frustration,

upset, sadness and fear, but less anger. Carers often described BPSD symptoms collectively rather than distinctly. Gilmore-Bykovski et al. (2020) and Burley et al. (2021) both found a broad overlap in descriptions.

While not the main focus of the review, studies that compared understandings between groups found differences. Burley et al. (2021) identified that carers and the person with dementia would provide conflicting explanations about the reason for BPSD. Similarly, Mackenzie et al. (1989) identified disagreement in understandings of depression between carers and people with dementia, in particular on specific areas such as loss of interest. Cohen-Mansfield et al. (2013) noted similar findings for perceptions on causes for delusions of formal and informal caregivers. However, different reports sometimes complemented each other to provide a more nuanced picture. Houston et al. (2011) found disparities between how clinicians and carers view wandering.

‘Dementia’ as an Explanation for BPSD

Many studies identified how carers sought explanations for BPSD beyond or alongside dementia. Dementia was seen as a mediating factor, or an additional explanation for BPSD, in addition to other meaningful reasons which rationalised symptoms (Duxbury et al., 2013; Harvath, 1994; Gilmore-Bykovski et al., 2020). For example, Adekoya and Guse (2021) found carers most often saw a purposeful, meaningful reason for wandering. Similarly, Polenick et al. (2018) identify neurobiological disease factors as a carer attribution *alongside* other factors. Tappen and Williams (1998) found that family identified the reasons behind emotions, but saw the expression of the emotion as impacted by dementia.

Carers however did sometimes seem to revert to ‘dementia’ alone as an explanatory factor. Tyrell et al. (2019) found carers of people with FTD saw changes as not inherent to the person; ‘dementia’ as the explanatory factor therefore sometimes occurred when carers struggle to reconcile the person they knew with current behaviour. Hansen et al. (2019) identified that carers attribute aggressive behaviours to dementia, rather than anything to do with the person, which helps them to manage. Similarly, Paton et al. (2004) found different attributions for different BPSD; some were more likely to be attributed to dementia, such as apathy, whereas others, such as aggression, were seen as more understandable in relation to personal factors. Nijsten et al. (2023) found that carers saw dementia as a probable natural cause of apathy, which made it difficult to distinguish or recognise as a distinct entity needing attention. Other identified dementia-relevant factors included the aging process (Rasmussen et al., 2019) and loss of skills (Qazi et al., 2010), including specifically related to wandering (MacAndrew et al., 2017).

Life History and Premorbid Personality

Ten papers identified how carers viewed BPSD in light of premorbid personality or life history. This could be as a new manifestation of a longstanding personality trait. For instance, hoarding behaviours were specifically linked to past traits like frugality (Wang et al. 2012). More broadly, aggression, hallucinations and delusions were also seen as linked to past personality traits (Paton et al., 2004; Polenick et al., 2018).

BPSD was also understood to be predominantly a change in past personality since dementia, including where this was an early sign and particularly in FTD. Fieldhouse et al. (2023) found that in FTD carers identified changes to peoples' premorbid personality traits such as social skills, sensitivity and communicative behaviour early on in the course. Gilbert et al. (2021) also identified that changes to premorbid personality, such as altered demeanour and emotional state and withdrawal from socialising, were part of carers' understandings of emotions in dementia that helped them to recognise the disease. Apathy was identified through deviations from pre-dementia personality, highlighting the importance of life history in recognising symptoms (Nijsten et al., 2023). Several papers, both specifically on FTD and more broadly, highlighted how changes in behaviour and personality were seen as someone becoming a stranger, or as a loss of the person that needed to be grieved (Rasmussen et al., 2019; Rogstad et al., 2020; Tyrrell et al., 2019; Tyrell et al., 2020).

Carer perceptions are also influenced by the previous mental health history of the person with dementia. Qazi et al. (2010) identified that carers noted that anxiety present in dementia was often present before the diagnosis was made and might have been pre-existing in life. Mackenzie et al. (1989) found that carers of those with pre-existing difficulties were more likely to endorse symptoms such as loss of interest, irritability, tiredness and loss of pleasure than people without such history, where the symptoms are more likely to be accepted as part of the disease process. Prior hoarding behaviour was also seen as influencing current hoarding (Wang et al., 2012). Specific BPSD are also sometimes interpreted in light of past trauma. For instance, carers felt part of delusions were earlier life experiences playing out in the present, including traumatic events (Wang et al., 2014; Burley et al., 2021). Similarly, Paton et al. (2004) also identified past negative experiences, such as loss or childhood difficulties, were implicated by relatives.

Personal history of the person seemed to be relevant even if unrelated to mental health. BPSD were seen as linked to past experience in general (Wang et al., 2014; Harvath, 1994). Brittain et al. (2017) found that caregivers recognise wandering being linked to key locations that had meaning and attachment for the person, and MacAndrew et al. (2017) also linked wandering to re-enacting past life experience.

Expressions of Physical and Psychological Need

Many papers identified how carers recognise BPSD as expressions of needs. These included: (1) fundamental psychological needs, including emotional expression, (2) psychological needs arising from the challenge of having dementia, and (3) physical needs or health problems. Broadly, Wolverson (2022) discovered carers preferred terms such as behavioural and emotional expressions of needs, attributing changes to unmet needs.

Several papers identified carers' understanding of BPSD as a communication of different psychological needs (Song et al., 2018; Harvath, 1994), such as wandering to seek company or familiar objects (MacAndrew et al., 2017), and aggression, seen as a 'poorly communicated need' (Duxbury et al., 2013). Wang et al. (2015) found BPSD were interpreted as seeking comfort (aggression, delusions, eating differences), material security (hoarding) and mental security (repetitive behaviours, delusions, eating differences).

Aggression was seen as meaningful to express a range of feelings (Herron & Wrathall, 2018), including frustration (Duxbury et al., 2013). Paton et al. (2004) identified that carers saw possible reasons for aggression, hallucinations and delusions as frustration and sexual frustration. Similarly, Tappen and Williams (1998) identified worry about new people or places and separation from family members as causes for BPSD and Rasmussen et al. (2019) identified stress as a perceived cause. Adekoya and Guse (2021) found that carers saw wandering as a coping strategy. Conversely, Nijsten et al. (2023) found carers saw apathy as due to a loss of emotion.

Carers noted various emotional reactions to dementia, which they thought led to BPSD. This included negative emotions about the diagnosis (Tappen & Williams, 1998), a realisation of loss of power and lack of understanding (Song et al., 2018), fear, frustration and anger at a loss of control or independence (Polenick et al., 2018), coming to terms with the diagnosis (Qazi et al., 2010) and social withdrawal stemming from shame about symptoms (Gilbert et al., 2021).

Carers also identified physical or health problems as potential causes for BPSD in general (Polenick et al., 2018), as well as for anxiety (Qazi et al., 2010), aggression (Paton et al., 2004; Duxbury et al., 2013), and hallucinations and delusions (Paton et al., 2004).

Interpersonal Factors

Twelve papers identified interpersonal factors, both past and present, comprising carers' understandings of BPSD. Wolverson (2022) found carers preferred terminology for BPSD which recognised their role within it. Band-Winterstein & Avieli (2019) found that carers interpreted identified aggression differently depending on pre-existing relationship dynamics and past couplehood memories. Violence was not initially attributed to dementia if it had been a feature of the relationship before the dementia diagnosis. By contrast, if violence was new, it

was experienced as a change and a dementia diagnosis brought relief. Hansen et al. (2019) identified that when carers saw an overlap between previous relationship patterns and current ones, the associated difficulties were harder to manage and required them reminding themselves that “they’re not who they were then”. Similarly, Cohen-Mansfield et al. (2013) found that carers’ understandings of delusions were influenced by their past and present relationship with the person with dementia. Shifting social roles were also identified as a causal factor for BPSD by Polenick et al. (2018).

While most findings are focused on how carers appraise BPSD in light of earlier interpersonal patterns, two studies found that carers might interpret BPSD as reflecting changes in the relationship. For carers whose relative had FTD, earlier behavioural symptoms were seen as signs of loss of emotional connection or relationship, or increased dependency (Fieldhouse et al. 2023; Rasmussen et al., 2019).

Current interactions between the carer and person with dementia were also identified as in-the-moment triggers for BPSD. Several studies found that relatives recognised their role in the triggering or development of aggression (Duxbury et al., 2013; Herron & Wrathall, 2018) and delusions (Wang et al., 2014). Similarly, Song et al. (2018) found carer-related influences on BPSD, including lack of understanding or consideration, instilling fear in the person or ignoring their needs. Conversely, Qazi et al. (2020) identified social isolation as a trigger for BPSD, with Adekoya and Guse (2021) also highlighting the role of bids for connection.

Environmental Factors

Five papers identified environmental factors as key contributors to BPSD from the perspectives of carers. Herron and Wrathall (2018) identified how social, spatial and temporal dimensions of local environments were seen as interacting to influence BPSD. For instance, private spaces such as bedrooms were seen to increase prominence of BPSD as the person felt safe to express their feelings, as was a lack of wider support and adequate spaces for socialisation. A crowded residential unit environment was identified as a cause for aggression (Duxbury et al., 2013), as were environmental changes (Polenick et al., 2018). Noise and being in crowds were identified as exacerbating factors (Qazi et al., 2010). Sound and dim light were seen as related to delusions (Wang et al., 2014).

Discussion

This review aimed to consolidate evidence on how family members and informal carers make sense of BPSD and psychological distress in dementia. Systematic searches identified 30 relevant papers which were synthesised into a qualitative narrative. Findings illustrated how across both community and residential care settings, carers attempt to make sense of the behavioural and psychological changes they observe in the person with dementia. They do so by drawing upon multiple sources of information about the person, including their life experiences

and personality, neurocognitive abilities, interpersonal patterns past and present, and environment. In searching to explain the person's BPSD, they encounter questions about agency and control of behaviour and preference of language.

The findings point to the nuanced and complex nature of carer understandings of both BPSD generally and specific symptoms. Few studies found carers reverting to monocausal explanations for BPSD and very few identified carers not finding an understanding at all. Importantly, while dementia is seen as an explanatory factor for BPSD, it is most often considered alongside other reasons, rather than the sole cause. Carers consider the individual's history and context, seeing BPSD as indications of these factors and unmet need. Carers understanding such experiences in this way emphasises the previously mentioned limitations of the term BPSD and supports its re-conceptualisation to be more in line with this holistic understanding (Burley et al., 2021), both in clinical practice and in research. Indeed, overall carers' views seem more aligned with alternative and more psychological ways of framing these experiences, such as psychological distress and Behavioural and Emotional Expressions of Need (Wolverson, 2022).

The multi-faceted nature of the understandings of caregivers underlines the importance of professionals and researchers drawing on the wisdom of family (Wolff et al., 2011), as many of these personal and contextual understandings are only possible given knowledge of the person. It is also important to consider how carers are supported to develop nuanced and helpful understandings. This is particularly important given the potential distress associated with not having an understanding (Rognstad et al., 2020), or having a singular understanding, such as seeing controllability as high, for example, that leads to negative attitudes, higher burden and therefore potentially worsening BPSD (Kales et al., 2015). Education for caregivers on common explanatory factors could help with this (Warren, 2022; Polenick et al., 2018). It was not possible to gauge from the included studies how carers' understandings had or had not been shaped by their prior interaction with services, and further research is needed to guide clinicians towards the most helpful ways of facilitating beneficial understandings of BPSD.

While MMAT ratings revealed generally high methodological quality, the samples of caregivers across studies was homogenous, with White, highly educated female spouses or children of people with dementia over-represented. This means findings may not be generalisable to unrepresented populations. This is particularly important to consider given cross-cultural differences in general understandings of dementia (e.g., Calia et al., 2019), which may suggest that understandings of BPSD also differ. Future research should aim to gather perspectives on BPSD more representative of populations as a whole.

It is also important to acknowledge how family members and carers are not merely passive or objective observers of the person with dementia's experience; their own

psychological history is likely to shape their understandings of BPSD, which was not necessarily captured in the evidence considered within this review. As carers are in relationship with the person with dementia, they are therefore wrapped up in the very process they are making sense of, particularly given the way in which dementia impacts the whole system around the person. There are many ways in which the psychological histories of the carers are likely to shape the narratives they provide. A particularly pertinent example of this is the way in which a carers' attachment style, influenced by their childhood experiences, meets with the attachment style of their relative with dementia (Meisen, 2014) to influence relationships and interactions. Research indicates that carers perceive more symptoms in those with avoidant attachment (Monin et al., 2013), highlighting how these interactions are likely to shape relatives' understandings. Future research should aim to elucidate how carers' own positionality impacts the differing understandings of BPSD they develop.

A potential limitation of the review is its use of a flexible approach to synthesis, rather than adherence to a formal model. The chosen approach allowed flexibility, but also leaves more scope for the authors' own perspectives to influence the organisation and emphasis of the findings. In addition, the review had a tight focus on papers where understanding of BPSD was a main aim of the study or the main focus of result. Literature on understandings of dementia more generally, which may offer insights into understandings of BPSD, was not considered. Future research could explore how perceptions of BPSD interact with perceptions of dementia as a whole. In addition, studies did not always differentiate between carers' views on what they understand to be causal, maintaining and triggering factors for BPSD (Polenick et al., 2018). Future reviews could aim to elucidate the differences between these, given the differential impact.

Conclusion

The current review has added a novel contribution to the literature by systematically identifying and synthesising research pertaining to how family carers understand BPSD. Findings reveal that across settings, a complex interplay of factors influence carers' perceptions and attributions of BPSD. It is clear that elements related to the person are viewed as important, as well as more proximal factors such as direct effects of the disease process and the environment. A recognition of the multiple varied ways in which carers make sense of BPSD should be incorporated into future clinical practice and research.

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Service-Related Project

An Audit of Gloucester Complex Psychological Intervention Team Service Delivery: What is Provided and to Whom?

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Ensuring equitable access to mental health services across diverse populations, and the availability of evidence-based psychological interventions within these services, is now recognised as a critical issue in UK mental healthcare delivery. The significance of this issue is highlighted in key drivers in the current NHS context; both the NHS Long Term Plan (NHS England, 2019a) and the Community Mental Health Framework for Adults and Older Adults (NHS England, 2019b) explicitly highlight the importance of psychological therapies for treating severe mental health problems within community mental healthcare. Policy documents such as these, and the more recent Psychological Therapies for Severe Mental Health Problems Implementation Guidance (NHS England, 2022), also emphasise the importance of timely evidence-based psychological therapies being available to all. They suggest that there should be proactive work to meet local need and minimise any geographical or racial disparities in access.

Issues of equal access to psychological interventions are particularly important to consider within the current NHS framework of secondary mental health care. Psychological therapies are part of the National Institute Health and Care Excellence (NICE) guidelines for all of the mental health difficulties most frequently seen in secondary mental health care (e.g., for psychosis; NICE, 2014a; for bipolar disorder; NICE 2014b; for ‘borderline personality disorder’; NICE, 2009). However, typically, individuals under the care of a secondary mental health care team only gain access to psychological therapy through a referral from another professional in the mental health team, designated as their care coordinator. As such, this professional, who may be a mental health nurse, occupational therapist or social worker, can be conceptualised as someone serving as a ‘gatekeeper’ for psychological therapy (Fiddick et al., 2020). Therefore, whether or not someone receives psychological therapy is dependent upon how such decisions are made; often through interaction between practitioner, service user and system factors (Prytys et al., 2011).

There is a surprising paucity of literature addressing who is accessing psychological interventions in secondary care and what input they are receiving. The 2019 National Clinical Audit of Anxiety and Depression (NCAAD; Royal College of Psychiatrists, 2020) investigated the delivery of psychological therapies in secondary care adult mental health services for those with anxiety disorders and depression. It found that recording of demographic data was variable; age was recorded for 100% of adults, ethnicity for 95% and disability for 63%. They found that cognitive behavioural therapy (CBT) was most the commonly provided type of therapy and adults received 13 sessions of therapy on average. While the NCAAD was limited to those receiving treatment for anxiety and depression, it identified that Trusts should enable clinicians to accurately collect and record demographic data and consider barriers to accessing

therapy to ensure services are provided adequately. It was also acknowledged that it is currently unknown what proportion of people are offered psychological therapy.

Research focusing specifically on issue of access to psychological therapies for different groups of people again is lacking, however what there is identifies significant inequalities. Mercer et al. (2019) found that, when compared to the local population, there was an overrepresentation of people from White and White British backgrounds amongst patients in the secondary care mental health service and an underrepresentation from those from minoritised ethnic groups. However, this effect varied by diagnosis, with a greater proportion of people from Black and Black British background amongst service users with psychotic disorders. In general though, there is a sustained pattern of overrepresentation of White and White British people within psychological therapies caseloads. Similar inequalities have been found in data from primary care services; people from Black, Asian and Mixed ethnic groups were less likely to be referred, receive an assessment and be treated than those from White British groups (Harwood et al., 2021). A pattern of under-representation has also been found for those who are older, male, born outside of the UK, have religious beliefs, have a disability or those without qualifications (Sharland et al., 2023). In this context, a recent report from the NHS Race and Health Observatory suggested that more studies are needed that allow an assessment of any inequalities in community services (Kapedia et al., 2022).

Project Development and Consultation

The Gloucester Recovery team is one such community mental health team within the Gloucestershire Health and Care (GHC) NHS Foundation Trust. They provide support for people aged 18-65 who are experiencing severe and enduring mental health problems. Individuals under the care of the Gloucester Recovery Team are able to access psychological support through the Complex Psychological Intervention (CPI) team, who are a team of psychological practitioners within the Recovery team, including clinical psychologists, art psychotherapists and cognitive-behavioural psychotherapists. CPI work both directly with service users, through in-depth psychological intervention, but also indirectly to help provide service users with psychologically informed care, through offering training, consultation and reflective practice to Recovery team clinicians.

A previous project conducted with the Gloucester Recovery team (Morgan, 2023) investigated referral patterns and whether service users were offered evidence-based psychological interventions. This analysis revealed that many service users are repeatedly referred to the Recovery service. Following this project, feedback was gathered from professionals and service users, which included reflections that the demographics of the Recovery team caseload do not reflect the cultural diversity of Gloucester. Questions were also raised regarding how many service users are offered the opportunity to engage in psychological

therapy with the CPI team. This led to a suggestion that a future audit would be useful to address these questions around who is accessing psychological therapy. Data available from the Care Quality Commission (CQC) report in neighbouring team in Herefordshire identified that 35% of the Recovery caseload were accessing some form of psychological therapy (CQC, 2016), which provides a benchmark to compare to.

From this starting point, the aims and questions of this audit were developed further in consultation with key stakeholders, including CPI and Recovery team clinicians and managers, and five paid service users from the Gloucester Experts by Experience (EbE) panel. This involved an initial proposal being sent to professional stakeholders and the EbE panel and regular meetings with those interested to share ideas. It was clear from these meetings that there was a particular interest from the CPI clinical lead and other members in what input is offered by CPI. EbEs were interested in who accesses CPI input. EbEs also shared their experiences of difficulties accessing psychological interventions and highlighted the importance of receiving psychological interventions in a timely manner, and so an additional focus on when therapies are accessed was added. The broad aims of the project are therefore to gain more information about who receives input from CPI, and what input they receive and when. These aims will be addressed through the following research questions, devised in consultation with service professionals and EbEs:

1. What are the characteristics of service users referred to CPI, in terms of demographic data and psychiatric diagnoses?
2. How representative are the service users referred to CPI of the Recovery caseload as a whole, in terms of demographic and diagnostic characteristics?
3. How representative are the service users referred to CPI of the Gloucester population as a whole, in terms of demographic characteristics?
4. What input is provided to those referred to CPI and when?
5. What are the demographic characteristics of those discussed in reflective practice?

Method

A GHC Business Intelligence analyst generated a report of data from the RiO patient information system. This included information from those on the Recovery team caseload in the 2021-22 financial year. It also included data on who, of those, had been referred to the CPI in the preceding five years, as this was deemed to be when accurate data was available from. Data provided from RiO included age, first part of postcode, ethnicity, gender, carer status, International Classification of Diseases 10 (ICD-10) diagnosis codes, first referral date to Recovery and CPI, current episode referral date, Recovery and CPI discharge date, total contacts of different mediums and details of contacts with CPI clinicians. Data on those

discussed in reflective practice were extracted from CPI's separate spreadsheet and added to this dataset. Data were cleansed and coded manually using Microsoft Excel, with descriptive and inferential analysis performed using SPSS. The dataset consisted of 1010 service users' data overall.

Meetings with key stakeholders, including both CPI professionals and a panel of EbEs continued every 3 months throughout data collection and analysis, in order to ensure a focus on the needs and interests of these groups and also to help with interpretation of the emerging findings. Within these meetings, EbEs raised the issue of those with multiple diagnoses, and wondered whether this impacts referral rates to CPI, therefore this was added as a variable to explore within the first research question. EbEs raised several relevant questions which were unfortunately not feasible to explore within the scope of this project, but were noted by the CPI lead for future projects.

Ethical Considerations

The project was registered with the GHC NHS Foundation Trust Quality Improvement team (approval number 22-091; see Appendix E). No additional ethical approval was required given all data was routinely collected.

Results

Research Question 1: What are the characteristics of service users referred to CPI, in terms of demographic data and psychiatric diagnoses?

Research Question 2: How representative are the service users referred to CPI of the Recovery caseload as a whole, in terms of demographic and diagnostic characteristics?

Research Question 3: How representative are the service users referred to CPI of the Gloucester population as a whole, in terms of demographic characteristics?

Of the total of 1010 service users on the 2021-22 caseload, 723 (72%) had not been referred to CPI in the previous five years and 287 (28%) had at least one previous referral. Of those referred, 63% were referred only once, 31% were referred 2-3 times and 6% were referred 4-6 times.

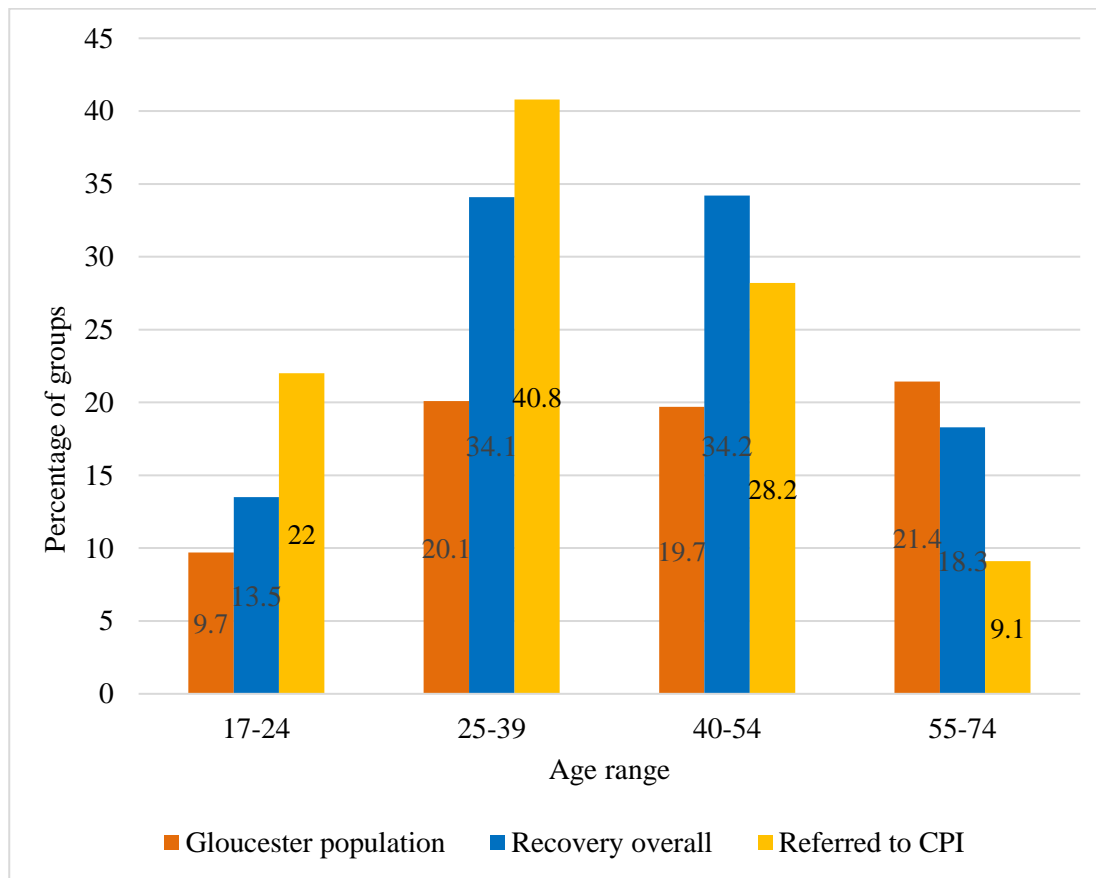
The Recovery caseload as a whole was 49.6% male and 50.3% female, which is comparable to the Gloucester population as a whole (49.5% male and 50.5% female) Data was missing for one person (0.1%). Of the 723 not referred, 402 were male (55.6%) and 320 were female (44.3%). Of those referred, 99 were male (34.5%) and 188 female (65.5%), meaning that female service users were more likely than male service users to be referred to CPI, $X^2(2, N=1010) = 37.29, p < .001$.

Service users who had been referred to CPI were significantly younger (median = 34 years, range = 17-64) than those not referred (median = 43 years, range = 17-74, $U = 75146, p =$

<.001. Figure 2.1 shows the proportion of people by age group for the Gloucester population, Recovery caseload as a whole, and those referred to CPI. For 17-24 year olds and 25-39 year olds, the percentage population of those referred to CPI exceeds the percentage of the Recovery caseload, which exceeds the Gloucester population. For 55-74 year olds, the pattern is reversed, whereby Recovery caseload and CPI referred see comparatively fewer than the Gloucester population.

Figure 2.1.

Percentage Age Ranges of Gloucester Population, Recovery Caseload and CPI Referred

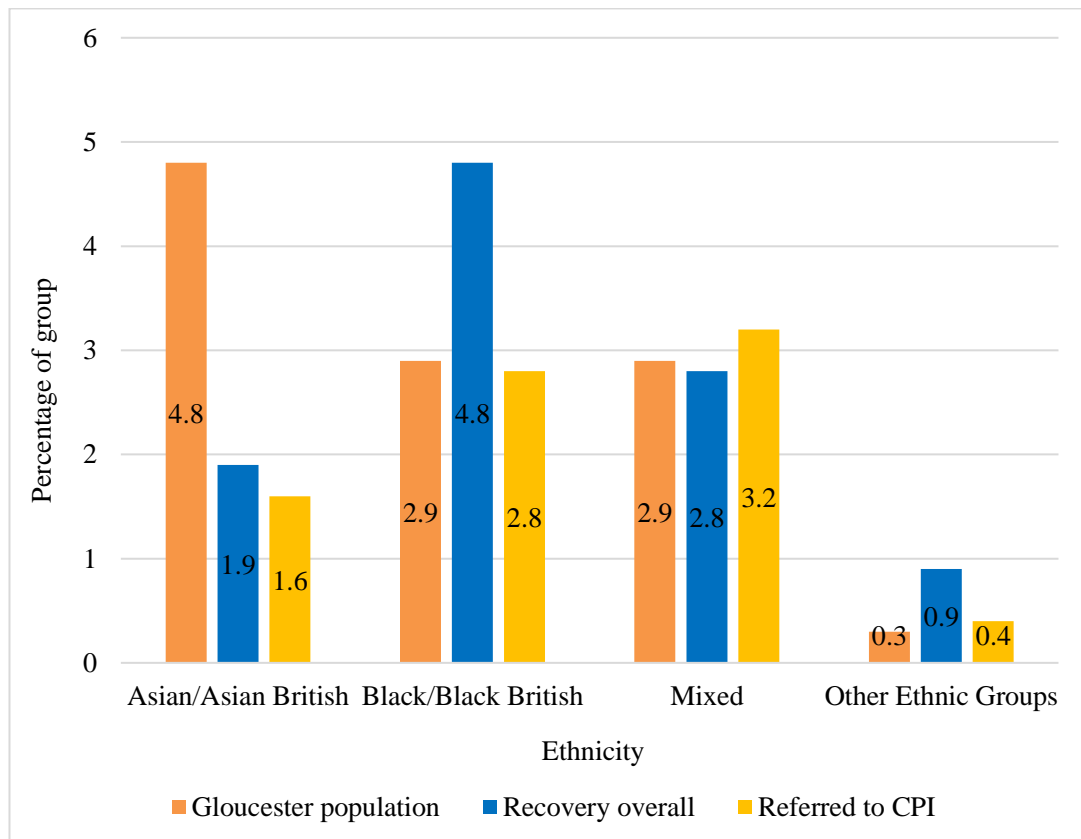


Ethnicity data were present for 85% of the Recovery caseload. The Gloucester population is 89.1% White, compared with 88.6% of the Recovery caseload and 92.1% of the CPI caseload. Figure 2.2 shows the percentage of people of different minority ethnicities in the Gloucester population, the Recovery caseload and the CPI caseload; the data are presented in this way as the high percentage of people of White ethnicities would have made the other data on the graph difficult to interpret. As shown in Figure 2.2, while almost 5% of the Gloucester population are from an Asian background, less than 2% of the Recovery and CPI caseloads are. Those from a Black background represent just under 3% of the Gloucester population; this increases for the Recovery caseload (4.8%) and drops back down for the CPI caseload (2.8%).

There was a similar pattern for those who have been categorised within ‘Other ethnic groups’. For those of Mixed ethnicity, the figures are fairly consistent across the 3 groups. However, when comparing across all four groups, no significant association was found between ethnicity and referral to CPI, $X^2(4, N=1010) = 4.679, p=.322$.

Figure 2.2.

Percentage Ethnicities of Gloucester Population, Recovery Caseload and CPI Referred



A total of 60 postcode prefixes were represented in the data. It was attempted to draw data about socioeconomic status using the first half of service users’ postcodes, however this was not available. Data on carer status categorised service users into either ‘no current or previous carers’, ‘no but has had previous carers’, or ‘yes’. 27.8% of those referred to CPI had current carers and 12.3% previous, compared with 19.1% of those not referred with current and 13.4% previous. Data on carer status was missing for 265 people (26.2% of the Recovery caseload).

Records provided service users’ diagnoses in the form of ICD-10 diagnostic codes (World Health Organisation, 1993). This data was missing for 199 people (19.7% of the Recovery caseload). For the purposes of analysis, codes were collapsed into the groups specified in ICD-10, i.e., any code between F01 and F09 coded into one group. The headings of these can be found in Table 2.1.

Service users who had been referred to CPI had been assigned significantly greater (median = 2, range = 0-5) than those not referred (median = 2, range = 0-6), $U = 81908$, $p = .002$. For example, only 26.1% of those assigned to only one diagnostic group were referred to CPI, however 40.0% of those with 4, 57.1% of those with 5 and 100% of those with 6 diagnostic groups were referred.

Service users who had been referred to CPI were significantly younger (median = 34 years, range) than those not referred (median = 43 years, range), $U = 75146$, $p < .001$.

Table 2.1.

ICD-10 Mental and Behavioural Disorder Codes

Codes	Description	Example diagnosis
F0 – F09	Organic, including symptomatic, mental disorders	Dementia
F10 – F19	Mental and behavioural disorders due to use of psychoactive substances	Dependence syndrome
F20 – F29	Schizophrenia, schizotypal and delusional disorders	Schizophrenia
F30 – F39	Mood (affective) disorders	Bipolar affective disorder
F40 – F49	Neurotic, stress-related and somatoform disorders	Social phobia
F50 – F59	Behavioural syndromes associated with physiological disturbances and physical factors	Anorexia nervosa
F60 – F69	Disorders of psychological development	Paranoid personality disorder
F70 – F79	Mental retardation	Mild mental retardation
F80 – F89	Disorders of psychological development	Expressive language disorder
F90 – F98	Behavioural and emotional disorders with onset usually occurring in childhood and adolescence	Tic disorder
F99	Unspecified mental disorders	Mental illness not otherwise specified

Table 2.2.

Frequency Of People Referred And Not Referred To CPI For Each Diagnostic Group And Chi Square Test Results

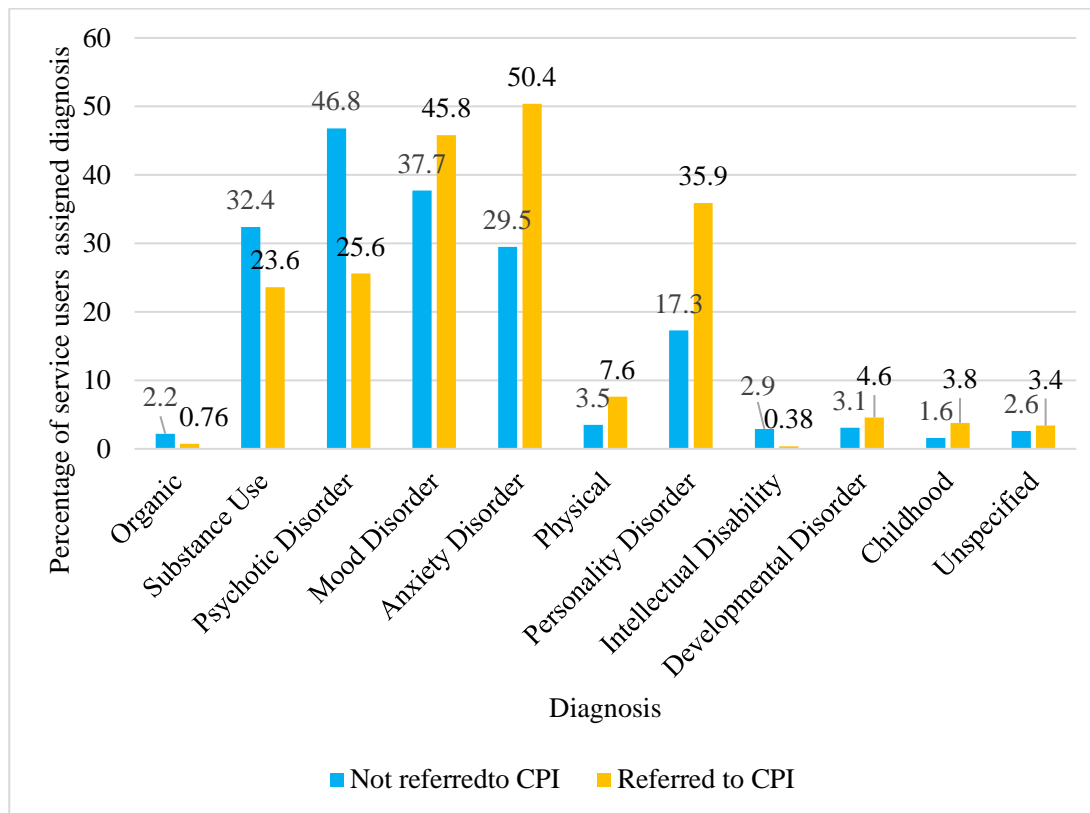
Diagnostic group	Number of people assigned these codes not referred to CPI	Number of people assigned these codes referred to CPI	X ² statistic (df = 1, N=811)	p value
F0 – F09	12	2	2.12	.146
F10 – F19	178	62	6.53	.011
F20 – F29	257	67	33.35	<.001*
F30 – F39	207	120	4.83	.028
F40 – F49	162	132	33.44	<.001*
F50 – F59	19	20	6.75	.009*
F60 – F69	95	94	34.23	<.001*
F70 – F79	16	1	5.54	.019
F80 – F89	17	12	1.13	.287
F90 – F98	9	10	3.68	.055
F99	14	9	0.50	.478

Note: * = significant difference

Table 2.2 shows the number of people referred and not referred within each diagnostic group and the results of chi-square tests of independence for each diagnostic group. As illustrated in Table 2.2, there was a significant association between whether or not someone was referred to CPI and whether they had been assigned a diagnostic code within the following groups: F20-F29, F40-F49, F50-F59 and F60-F69. Figure 2.3 illustrates the direction of these relationships; for psychotic disorders, people referred to CPI were less likely to have these diagnoses than those not referred. For anxiety disorders, behavioural syndromes associated with physical factors, and personality disorders, people referred to CPI were more likely to have these diagnoses than those not referred.

Figure 2.3.

Percentage Of People Assigned Each Diagnostic Group Who Have Been Referred And Not Referred To CPI



Research Question 4: What input is provided to those referred to CPI and when?

Overall, of the 287 people who had been referred to CPI in the previous 5 years, 63.4% had only been referred once, 20.9% twice, 10.5% 3 times, 4.5% 4 times and 0.7% 6 times. This amounted to 456 referrals in total.

There was a mean time of 99.5 weeks (around 22 months) between when people were referred to the Recovery team and their CPI referral. However, there was a median of 17 weeks (4 months) suggesting skewed data. This tended to be longer for men (*mdn* = 32 weeks) than for women (*mdn* = 15 weeks). Overall, 40.3% of people have less than 3 months between their Recovery referral and CPI referral, 57.1% have up to 6 months and 70.8% have less than a year.

The number of contacts per service user ranged from 0-69. Of those seen, the mean number of sessions was 8.10. The mean number of contacts was 7.10 for face-to-face sessions, 0.49 for telephone sessions and 0.51 for video sessions. Limited data were available regarding the specific nature of services provided during these contacts. However 12.3% of all contacts logged were by art psychotherapists and 28.8% were by cognitive-behavioural psychotherapists. There was an average of 24.2 weeks between referral and discharge of those seen.

Research Question 5: What input is provided to those discussed in reflective practice?

Of those on the Recovery caseload, 57 (6%) were discussed in reflective practice. 54% of these people were discussed once, 30% twice, 3% three times, 5% five times, 4% times and 4% six times. 74% (42) of those discussed had also been referred to CPI at some point in the previous 5 years, whereas 26% received input only through discussion in reflective practice.

Feedback

Professionals within the service and EbEs were invited to a feedback meeting to hear the findings of the study and offer their perspectives on these. All were interested to hear the findings as these were not data routinely available to them. A clinical psychologist in the team raised the point that non-referral to CPI or reflective practice did not necessarily mean the service user was not benefitting from the psychological knowledge of the team, as they also consulted with Recovery team professionals to influence psychologically informed care. This was linked to the changing role of the clinical psychologist in offering supervision and systemic influence over purely direct therapy. In addition, it was raised that the rates of referral could have been lower for those diagnosed with psychosis-related disorders as they may have previously received intervention from the early intervention in psychosis team and were receiving only medication management from the Recovery team. Professionals in CPI and Recovery were keen to look in more depth at the data to consider how to take this forward. They were keen to continue meetings with EbEs to maintain the focus on the issues important to them.

Discussion

The aim of the current study was to gain a detailed understanding about what input is provided by the Gloucester CPI team, when and who this input is provided to. Particular focus was given to those issues important to the professionals working within the service and EbEs with experience of accessing the service or similar offers. This is within the context of NHS drive to improve equitable access to psychological therapies.

The first three research questions related to the characteristics of service users referred to CPI and comparison to the Recovery caseload and Gloucester population. 28% of service users had been referred to CPI in the previous five years, slightly lower than the 35% receiving psychological therapies in neighbouring county Herefordshire (CQC, 2016). However, this is in the context of the CPI team having vacancies at the time of data collection. In terms of service user gender, the split was comparable between Recovery and the Gloucester population, however females were overrepresented in the CPI caseload. This was similar for those younger; CPI's caseload was predominantly those aged 25-39, with those aged 40-54 underrepresented in comparison to in Recovery. This reflects a similar trend as found in IAPT where those who were older and male were less likely to be referred for therapy (Sharland et al., 2023). Those

with carers were overrepresented in CPI compared to Recovery, however data were only present for 74% of service users.

Ethnicity data was present for 85% of service users. There was no significant difference found between those referred and not referred to CPI. However, the percentage of White service users was similar between the Gloucester population and Recovery caseload, but higher in the CPI caseload. People from an Asian background were underrepresented similarly in both Recovery and CPI compared to the Gloucester population. Those from a Mixed ethnicity background were similarly represented across the Gloucester, Recovery and CPI populations. Those from a Black background and those marked as from an 'Other' ethnic background were overrepresented in Recovery compared to the Gloucester population, however underrepresented in the CPI caseload. These are similar patterns to those found by Harwood et al. (2021) in IAPT and Mercer et al. (2019) in secondary care, particularly in relation to Black service user overrepresentation in mental health services generally, but underrepresentation in therapy services. This suggests that national patterns are also evident in Gloucester Recovery and CPI teams.

Differences between Recovery and CPI caseloads were also seen in terms of diagnoses. There was an overrepresentation in CPI of people who were assigned more than one diagnostic group, perhaps with a greater number of diagnoses indicating higher need for specialist intervention provided by CPI. People referred to CPI were less likely to have these diagnoses of psychotic disorders than those not referred. The pattern was reversed for those with anxiety, physical and personality disorders. It is unclear what is driving these differences and a lack of national data to compare to. There is the potential that service users less likely to be referred to CPI, those with substance use disorders, psychotic disorders and intellectual disabilities, have received psychological intervention elsewhere. This may particularly be the case for those with psychosis who have been under an early intervention in psychosis team previously. For instance, 46% of people referred into early intervention in psychosis teams receive CBT for psychosis (Royal College of Psychiatrists, 2022). Further research should be conducted to explore these differences, perhaps through interviewing Recovery professionals about what influences their decisions to refer, and their perceptions of the needs of people with different difficulties.

Research question four related to the input offered to those accessing CPI. 63% had been referred only once, 21% twice and the rest were referred three or more times, which amounted to 456 referrals. The average time between joining the Recovery caseload and referral to CPI was 22 months. This was skewed however by a few people with a significant gap, as the median time was 4 months, with 40% of people being referred in less than 3 months and 57% in less than 6 months. This was a longer gap for men than for women. While there is no

benchmark available to compare this to, this research question was a particular concern for EbEs, who shared concerns about difficulties accessing psychological therapies in a timely way once in the Recovery team. It will, therefore, be important for future research to investigate factors affecting the time in between Recovery and CPI referral and service user experience of this. Those who were seen in CPI had an average of eight sessions, which were mostly face-to-face, slightly lower than the average of 13 sessions found in the NCAAD (Royal College of Psychiatrists, 2020). Again, this was in the context of vacancies in the CPI team. Full data on the details of the specific input provided were difficult to easily access and would have required a full review of case notes. From data which could be easily extracted, it was evident that 12% of service users saw an art psychotherapist and 29% saw a CBT therapist. If further data on this would be helpful for CPI and Recovery to know, the process for collecting this data should be streamlined.

Research question five related to input received by those discussed in reflective practice. 6% of those on the Recovery caseload were discussed in reflective practice, 74% of whom had also been referred to CPI. It is difficult to draw firm conclusions from these data, however there is the potential that reflective practice input reduced referrals to CPI, given that 26% of those discussed were not referred. Further research is needed, however, to determine this as a causal link.

It is important to consider what might be driving some of these key findings, particularly differences in CPI referral rates related to gender, age, and ethnicity. Such issues are a key concern of the Psychological Therapies for Severe Mental Health Problems Implementation Guidance (NHS England, 2022) and are reflected in other similar studies across different areas. A full exploration of potential reasons is beyond the scope of the current paper, however Fiddick et al. (2020) identified a number of factors affecting practitioners' decisions about whether or not to refer, including beliefs about the usefulness of therapy for 'low risk' service users, whether or not service users asked, uncertainty about criteria for referral, external pressure and perceptions of service pressures. It would therefore be useful to see if these are also factors driving the decisions of professionals in the Gloucester Recovery team.

There is also a need to look more broadly at the issue of differences in access, especially considering similar patterns are found across both primary and secondary mental health care services. There are many wider social and environmental factors that may be influencing such inequalities. For example, clinicians in mental health services are often not representative of the local population's culture and identities (Wood & Patel, 2017), which is a potential barrier to access for marginalised groups. In addition, the notion that psychological intervention is the key to improving mental health is culturally specific; other forms of support may be valued by people. These are just two brief examples within a significant literature

relating to access to psychological therapies, however they are provided to illustrate the range of possible reasons driving the differences in referral rates seen, including both barriers and preferential differences. Further research would be needed to identify what specific factors are of influence in Gloucester CPI and Recovery.

It is likely difficult in the current NHS context of pressures, including significant waiting lists, to dedicate time and resource to consider how access to services is increased. Indeed, while clinical psychologists are trained to research such issues, time and funding provided to complete such work is limited (Smith & Thew, 2017). This speaks to a wider issue. However, clinicians can maintain curiosity and raise important discussions about such issues. When resource is available, such as through trainee clinical psychologist doctoral projects, projects investigating increasing access are important to prioritise, given the aims of recent NHS policy guidance.

Strengths and Limitations

The current study was able to gain access, using business intelligence, to a large amount of data which is routinely recorded, which may not have been practically possible if data had to be manually extracted. While this means that broad patterns across caseloads were able to be identified, it also means that a level of detail is lost and more questions are raised regarding the reasons for these patterns. Future projects in the service should aim to elucidate this, perhaps through gaining views from those served by Recovery and CPI, and those working in the service, regarding the reasons for the patterns. In addition, focus could be given to how to routinely and easily collect more information.

An important limitation of the current study is the substantial amount of missing data. This was up to 26% for some variables such as whether someone had a carer. Findings can only be based upon the data that is present, therefore may not be representative of the caseloads as a whole. It is also important to consider whether gaps in data are random, or whether there is a risk of bias in where data is and is not collected. This demonstrates an area for development for the Recovery and CPI teams in terms of ensuring service user data are as complete as possible, particularly in order to maximise the utility of data used in future studies. It also highlights the importance of administrative support for mental health services, particularly in being able to know whether the service is providing equal access; if the data are not present, it is not possible to draw such conclusions.

A particular strength of the current study was the inclusion of EbE throughout the project. This enabled the project team and CPI to maintain a focus on how the audit was relevant to service users and its potential clinical implications. While several questions raised were outside the scope of the current study, these were documented as ideas for future service improvement projects by the CPI lead, who was keen to continue these meetings into the future.

In addition, this study provides a snapshot of what is provided by CPI based on data easily available, however as raised in the feedback, non-referral to CPI does not necessarily indicate a service user is not receiving psychologically informed care or has not received psychological intervention previously. Part of the role of CPI is to influence Recovery team care, through reflective practice and formulation meetings with practitioners, to improve psychologically informed care of all service users. This is in line with the changing role of the clinical psychologist (British Psychological Society, 2007). While some aspects of this input are notoriously difficult to measure, in particular how reflective practice and consultation influences care, future research could aim to investigate the full CPI offering and service user experience of this. For instance, several self-report instruments assessing the impact of reflective practice on practitioners' work are available (Ooi et al., 2020).

Conclusion

These quantitative findings regarding who accesses CPI input and what input is provided provide a useful starting point the Recovery and CPI teams to consider what these data mean for their services. Future research could investigate further, perhaps qualitatively, what occurs clinically to drive such data. The findings also provide a comparison point for any future studies. Importantly, findings also point towards the need to consider how data collection can be streamlined for clinicians, in order to ensure that data driving service decisions are as complete and as accurate as possible.

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Main Research Project

Tracing the Landscape of Trauma in Dementia: A Reflexive Thematic Analysis of Psychological Distress From Family Member Perspectives

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Psychology & Health publishes research related to the study and application of psychological approaches to health and illness. Its topic of focus includes psychosocial factors in the aetiology of illness and it has previously published qualitative papers related to dementia. There is no word limit, however a typical paper is around 8000 words. The guidance on journal formatting requirements can be found here:

<https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=gph20>

Approximately 97% of individuals with dementia experiences changes in mood or behaviour alongside more well-known cognitive changes (Steinberg et al., 2008). These changes, observed throughout the progression of dementia (Van Der Linde et al., 2016), are commonly labelled as ‘Behavioural and Psychological Symptoms of Dementia’ (BPSD). Changes in mood and behaviour often occur five to ten years before the onset of cognitive decline in dementia, potentially indicating prodromal signs (Ismail et al., 2018) or possible risk factors (Stella et al., 2014). BPSD significantly diminish quality of life for both individuals with dementia and their caregivers (Hurt et al., 2008). Such changes lead to decreased functional ability (Warren, 2022), premature residential home placement (Cunningham et al., 2019) and a higher cost of care (García-Alberca et al., 2019). Therefore, they are a significant research and clinical priority in dementia care.

Recent research has started to explore how other psychological conditions, such as post-traumatic stress disorder (PTSD) might intersect with these BPSD. Despite a growing literature on the topic, the relationship between dementia and PTSD remains poorly understood. In a systematic review of 25 studies, Desmarais and colleagues (2020) identified a bi-directional relationship between PTSD and dementia. They conclude that experiencing trauma earlier in life increases dementia risk and, conversely, developing dementia increases the risk of delayed-onset PTSD, where cognitive deficits precipitate the development or recurrence of PTSD symptoms following earlier trauma. This shared risk has also been reflected in a meta-analysis (Günak et al., 2020). However, both papers note that the exact mechanism linking these conditions remains unclear.

Martinez-Clavera et al. (2017) and Ritchie et al. (2019) have hypothesised various biological and psychosocial mechanisms which might underlie the link between PTSD and dementia. Whilst these mechanisms have some theoretical support, empirical evidence regarding how dementia develops and presents in individuals with trauma history is lacking. Preliminary evidence suggests PTSD presents differently in people with dementia compared with people without (van Dongen, 2022). However, much of the previous research has been case studies focused on veteran populations with diagnoses of PTSD, neglecting the consideration of non-combat traumas and overlooking expressions of trauma-related distress that fall outside of PTSD diagnostic criteria. This is potentially problematic given that around 70% of the older adult population are estimated to have experienced a traumatic event of any type (Reynolds et al., 2016), and considering that distress resulting from trauma and adverse childhood experiences confer transdiagnostic mental health risk (Sahle et al., 2022). Therefore, further research is needed to elucidate how trauma-related distress presents in those with

dementia, moving beyond diagnostic categories and accounting for the varied and dynamic challenges involving in living with dementia.

Understanding the relationship between trauma and dementia, and its clinical manifestations, holds significant implications. Psychological distress in dementia is often labelled as BPSD regardless of its origin, meaning that symptoms of post-trauma stress disorder in dementia could be regarded as BPSD (Ritchie et al., 2022). Indeed, recent research suggests that those who have experienced a previous trauma experience a higher rate of BPSD (Cations et al., 2024). While guidelines recommend treating depression and anxiety in dementia (National Institute for Health and Care Excellence, 2018), there remains a lack of guidance on identifying and managing trauma-related distress. This gap can lead to overlooking distress stemming from past trauma (Bruneau et al., 2020), potentially resulting in inappropriate treatments such as using antipsychotics, rather than environmental supports, for trauma-related flashbacks misinterpreted as hallucinations (Bruneau et al., 2020). Although it is recommended to routinely inquire about trauma history during dementia assessments (Hutchinson et al., 2021; Martinez-Clavera et al., 2017), this practice is seldom adopted (Cook et al., 2003). Trauma-informed care remains largely absent in dementia services (Cations et al., 2020). Several factors likely contribute to this issue, including concerns about asking patients and their families, a lack of care provider awareness, and insufficient understanding of how trauma affects dementia clinically and over time (Couzner et al., 2022). Detailed insights into trauma-related distress within dementia could enable more targeted clinical support.

Much of the available data on PTSD and dementia come from quantitative observational studies or case studies. Qualitative descriptions of symptom trajectories and how they are impacted by trauma, akin to those mapped for how Down's syndrome impacted dementia over time (Deb et al., 2007), could provide a complementary approach to illuminating how trauma-related distress manifests throughout dementia progression. This understanding could improve understanding of clinical presentations and therefore facilitate appropriate care. In particular, family member and informal carer (henceforth referred to as relative) perspectives of this would be particularly valuable. Relatives have unique insights into the histories of their loved ones with dementia, input significantly into care planning, and provide a significant proportion of care, especially in the early stages of dementia (Clarkson et al., 2017). The current study aims to explore qualitatively relative perspectives on the psychological experiences over time of people with dementia who have experienced trauma, with a particular focus on how traumatic experiences are implicated in the behavioural and psychological manifestations of dementia.

Methodology

This study has been reported in line with the Consolidated criteria for Reporting Qualitative Research (COREQ) guidelines (Tong et al., 2007; see Appendix F).

Design

A qualitative design using semi-structured interviews was used for this study, in order to gather a rich and meaningful insight into participants' perspectives of their family member's experiences.

Participants

Participants were eligible to take part in the study if they met the following criteria: being a family member or informal carer of a person with advanced dementia (defined as requiring constant care), who had a history of trauma; having known the person for at least 15 years prior to dementia diagnosis with regular contact of at least four times a year; willingness to share information about the person's life and feeling comfortable that the person would agree to this.

Sixteen individuals took part in the study. The demographic details of participants and their relatives with dementia can be found in Table 3.1. Eleven of the 16 participants were female and all described themselves as White British or Caucasian. The mean age of participants was 63.6 (range of 41-81). Nine participants were children of the person with dementia, six were partners or spouses and one was a close friend. For relatives with dementia, the split between males and females and those living and deceased was equal. The most commonly reported diagnosis was Alzheimer disease, but the sample also included those whose relatives had diagnoses of vascular, mixed, frontotemporal and Lewy Body dementia. Traumatic experiences of the relatives with dementia varied greatly, encompassing single incidents, repeated and prolonged trauma exposure, as well as complex trauma with an interpersonal element. These included experiencing and witnessing traumatic losses of family or possessions, conflict-related trauma, medical trauma, separation from family or displacement, childhood or domestic abuse and natural disaster. Most had experienced more than one traumatic event.

Table 3.1.*Participant Demographics*

Participant					Person with dementia					
Pseudonym	Gender	Age	Ethnicity (self-described)	Relationship to person with dementia	Living or deceased	Gender	Age or (age at death)	Ethnicity (as described by relative)	Type of dementia	Age at diagnosis
Adeline	Female	41	White British	Daughter	Living	Female	73	White British	Vascular	69
Beatrice	Female	58	White	Daughter	Living	Female	84	White	Alzheimer's	81
Callie	Female	76	White	Wife	Deceased	Male	(78)	White	Vascular	
Deborah	Female	63	Caucasian	Daughter	Deceased	Female	(93)	Caucasian	Lewy Body	
Evelyn	Female	65	White British	Daughter	Living	Female	94	White British	Alzheimer's	87
Florence	Female	69	White British	Partner	Deceased	Male	(72)	Black British	Lewy Body	
Gloria	Female	81	White British	Wife	Living	Male	80	White British	Alzheimer's	75
Herbert	Male	69	White British	Son	Deceased	Male	(87)	White British	Probable Alzheimer's	
Isaac	Male	63	White British	Son	Deceased	Male	(81)	White British	Alzheimer's	
Jasper	Male	55	White British	Son	Living	Female	81	White British	Alzheimer's	73
Kate	Female	62	White British	Daughter	Living	Female	89	White British	Alzheimer's	83
Liliana	Female	64	White British	Wife	Deceased	Male	(76)	White British	Mixed	
Max	Male	50	White British	Fiancé	Living	Female	49	White British	Frontotemporal	48
Nathan	Male	79	White British	Best friend and carer near end	Deceased	Male	(72)	White British	Lewy Body	
Olive	Female	47	Caucasian British	Daughter	Living	Female	79	Caucasian	Mixed	74
Prue	Female	76	White British	Wife	Deceased	Male	(76)	White	Alzheimer's which developed into Lewy Body	

Materials

Interview Schedule and Information Sheet. A semi-structured interview schedule and information sheet (Appendices G and H) were devised by G.C. and A.V. in collaboration with three people with personal experience of caring for relatives with dementia. One person also had a background in qualitative research. Across four meetings, people with personal experience raised important considerations around clearly defining trauma on the information sheet and wording of questions to best elicit key information, particularly around trauma, from the interview schedule.

The semi-structured interview schedule provided open-ended questions and prompts on four main sections: 1) the person's psychological presentation pre-dementia; 2) early signs of dementia; 3) how these developed through dementia and 4) how the trauma they experienced manifested in dementia.

Timeline and Questionnaires. Prior to the interview, participants were also given a demographic questionnaire asking for basic details about themselves and their relative with dementia. This also included the Neuropsychiatric Inventory (Cummings, 2020) to prompt participants' thoughts about psychological symptoms of dementia prior to interview. At the suggestion of PPI, participants were also provided with an optional blank timeline to complete with details of their relative's life and dementia prior to the interview. This was to assist with reminding themselves of the key events in preparation for discussing them.

Recruitment

Participants were recruited through volunteer sampling from a combination of social media advertisement and the research volunteer databases held by the Research Institute for the Care of Older People in Bath and Join Dementia Research. After expressing an interest, potential participants were sent an information sheet via email and offered a phone call to discuss the process and any concerns. Those who agreed to proceed were emailed a demographic questionnaire and a consent form to complete prior to meeting.

Procedure

Ethical approval was obtained from the University of Bath Psychology Research Ethics Committee (23-076; appendix I). PPI input was sought in relation to this in the project development stage. In particular, PPI were consulted on issues around consent and sensitively gaining trauma-related information. Practicalities of the interview and accessibility considerations were also discussed with PPI. Suggestions included providing options for where the interviews took place, providing the interview schedule in advance and offering the interview over two sessions, all of which were implemented.

Following completion of the demographic questionnaire and consent form, interviews were arranged at the participant's convenience. Two participants chose to complete the interviews in their own homes and the remaining 14 interviews were conducted online via Microsoft Teams. The researcher was not known to participants prior to interviews, besides the pre-interview phone call or emails, however they were aware of her professional background and context of the research. Interviews took place between September and October 2023 and lasted for an average of 1 hour 17 minutes (range of 57 minutes to 1 hour 48 minutes). All interviews were conducted by G.C. and were audio- or video-recorded using a Dictaphone and Microsoft Teams if completed online. The transcription function on Microsoft Teams was also used to create initial transcripts. Notes were taken throughout each interview and following to capture reflections. On completion of the interview, participants were debriefed and offered a £20 voucher for their participation. All participants who consented remained in the study until completion. Data collection was completed following 16 interviews for pragmatic reasons of time and resource. Data saturation was not used as it is inconsistent with the assumptions of RTA (Clarke & Braun, 2021).

Data Analysis

Paradigm and Theoretical Framework. A contextualist ontological stance and a critical-realist epistemological stance were adopted for the study. This is because it was assumed that there is a knowable reality of participants, and their relatives with dementia, that exists independently of the researcher's ideas about it. However, this reality is seen as also inherently subjective and influenced by context and socially available meanings.

Reflexive Thematic Analysis. The method of reflexive thematic analysis (RTA) was used to analyse the data (Braun & Clarke, 2019). RTA was chosen due to its theoretical flexibility and its aim of understanding the experience of participants and identifying patterns across the dataset (Braun & Clarke, 2020). RTA is underpinned by the assumption that meaning is generated through the interpretative process, which is influenced by the researcher's perspective, rather than merely extracted from the data (Braun & Clarke, 2023), fitting with the critical realist lens.

Transcripts generated by Microsoft Teams were checked and edited by a research apprentice (S.H.). The first author (G.C.) listened to each of the recordings whilst simultaneously reading through the transcripts to check accuracy and for familiarisation. NVivo 14 was used to facilitate coding, however theme generation was done on paper (see Appendix J for an example of grouping codes by hand on paper). The RTA was conducted iteratively using the six-stage process specified by Braun and Clarke (2006). Table 3.2 provides a summary of how RTA was applied throughout. Coding was conducted at a semantic and latent level and was inductive, as far as possible given G.C. had some pre-existing knowledge of the area.

Reflexivity. Interviews were conducted and coded by the first author (G.C.), who identifies as a White British female and is in her twenties. At the time of data collection and analysis, G.C. was a Trainee Clinical Psychologist, who had undertaken training in working with older adults and people with dementia as part of the academic component of her doctoral studies. G.C. had clinical experience of working with older adults, but little experience of working with people with dementia and their families. She had some personal family experience of dementia which drove her interest in the research. G.C. kept a reflexive journal throughout the course of interviewing and coding, in order to notice and reflect upon the influence of her own experiences and assumptions on her interpretation of the data. In particular, G.C. noticed her professional background driving a pull towards noticing psychological links between past and present in the data. The data were frequently revisited throughout the analysis process. This was also discussed with other members of the research team, which included A.V. and J.M. A.V. is a White male Clinical Psychologist whose research focuses on cognition and mental health, using predominantly quantitative methods. J.M. is a White female Clinical Psychologist who had expertise in qualitative research methods, but less in dementia. During analysis, the research team met to discuss the process regularly, both as a group and each separately with G.C. Further detail regarding this process can be found in Table 3.2.

Table 3.2.

Application of Reflexive Thematic Analysis

Analysis Stage	Description of the aim of each analysis stage	Application of analysis stage, reflexivity and epistemological/ontological stance
1. Familiarisation	Immersion in and becoming familiar with the content of the data.	G.C. listened to each interview recording once while reading through the transcript. She then read through each transcript twice, recording her initial thoughts. G.C. noticed a pull to spend more time and attention on transcripts she initially felt were richer, so purposefully attempted to pay equal attention to each.
2. Generating Initial Codes	The production of initial codes that identify important features of the data that may be relevant to answering the research question.	The entire dataset was coded by G.C. inductively, with a critical-realist perspective. She considered what assumptions were underlying what participants said. Initially, G.C. felt a responsibility to do justice to every part of participants' stories, which meant initial coding was finely grained. Therefore, similar codes were collated and refined and each dataset was revisited with refined codes.

3. Searching for Themes	The synthesis and analysis of codes to generate candidate themes.	G.C. read through all the codes and grouped them where there was shared meaning or appeared to be themes. G.C. noticed that, counter to her assumptions prior to interviews, participants often used people's life histories to make sense of their behaviour. Ideas were discussed briefly in meetings with A.V. and in depth in two meetings with J.M. Data extracts relevant to the themes were reviewed in meetings between G.C. and J.M. Separate meetings were felt appropriate as the research team recognised that the knowledge created would differ depending on who was present in discussions. Thematic maps were developed to explore relationships between themes and the boundaries of each theme.
4. Reviewing Themes	The refinement of candidate themes through checking the fit with the story of the data.	Stage 3 of the analytic process was repeated, and initial themes were refined; some initial themes were combined, separated or discarded. Meetings at this point involved G.C., J.M. and A.V.
5. Defining and Naming Themes	The development of a detailed analysis, definition and name of each theme to capture its 'story'.	The final name and definition of each theme was developed through discussion within the research team; this was an iterative process.
6. Producing the Report	The writing up of the analysis, weaving together the analytic narrative and data extracts.	Data extracts were chosen to illustrate key aspects of each theme and the final report was produced.

Trustworthiness. To increase credibility, G.C. developed an early familiarity with the culture of the population through discussions with A.V., who works clinically in this area. Participants were given opportunities to refuse to participate and so were genuinely willing to offer data freely (Shenton, 2004); indeed many expressed they did not want the voucher incentive or asked for it to be donated to a dementia charity. Interview responses were also triangulated with NPI responses, with some interview prompt questions building iteratively on responses from the NPI. Peer debriefing and reflexive journalling assisted with confirmability (Ahmed, 2024).

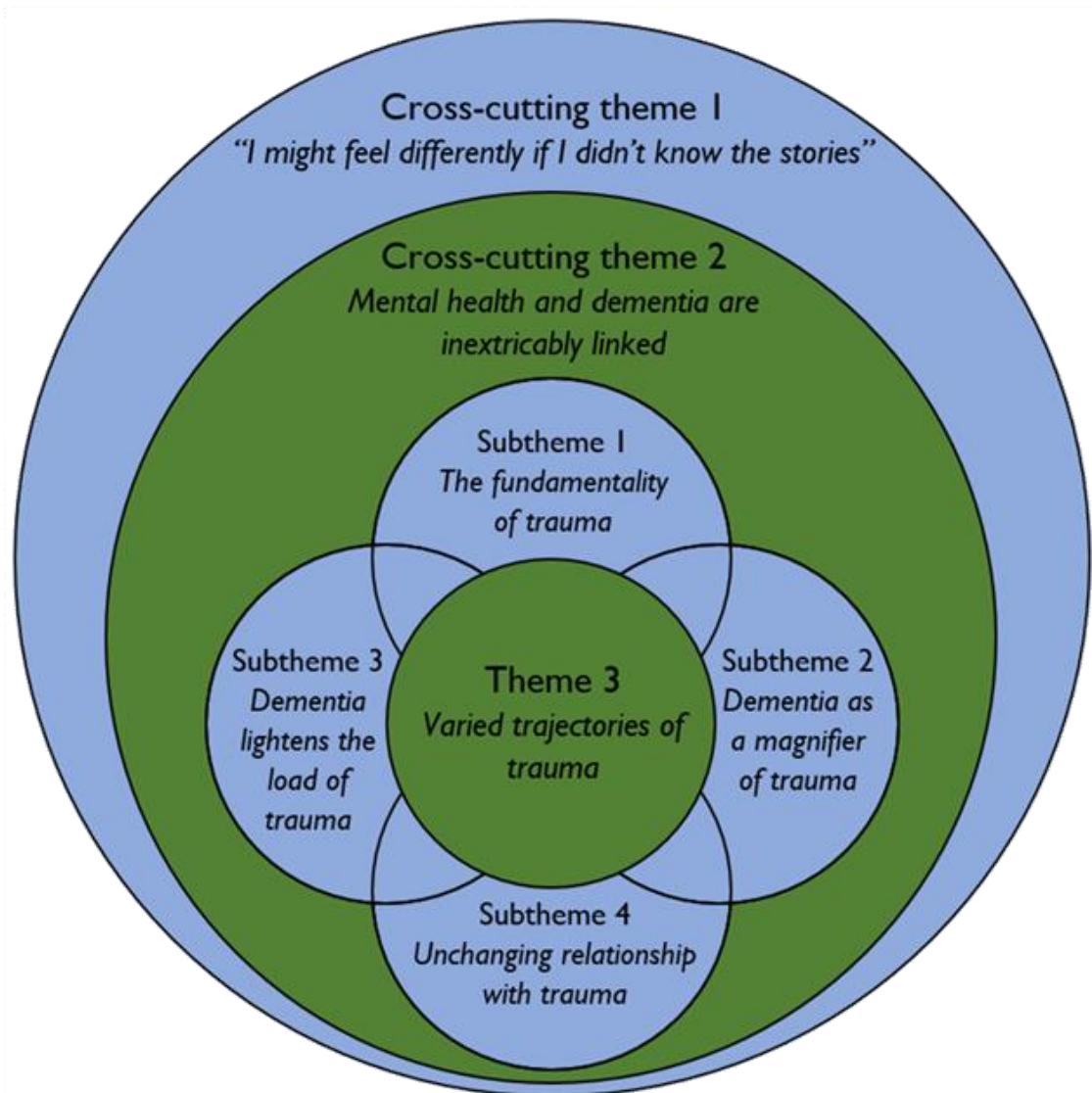
Results

Two cross-cutting themes, as well as one theme with four subthemes were constructed from the data. The relationships between themes are depicted in the thematic map in (Figure 3.1). The two cross-cutting themes focus on *how* participants spoke about their relative's

psychological distress over time in dementia. These seemed to shape their narratives of the main theme, *Varied Trajectories of Trauma*, and its subthemes, hence their cross-cutting nature and their depiction as outer concentric circles. The overlapping nature of the subtheme circles in the thematic map illustrates how people’s experiences did not always only fit into one subtheme; different elements of experience, or different traumas, could have fallen into one or more patterns or trajectories.

Figure 3.1.

Thematic Map



Cross-Cutting Theme 1 – “I Might Feel Differently if I Didn’t Know the Stories”

Across the data, participants had ways of making sense of behaviour of their relative that might have been seen by others as confusing or difficult to understand. Behaviour was interpreted through two main lenses: 1) in light of their relative’s current emotional experience,

and 2) in light of past events and the person's life history, including trauma. Both ways of understanding behaviour seemed to help the relatives. These two ways of understanding were sometimes implicit in how participants spoke about the person and their behaviours. However, they were also spoken about explicitly by some of the participants. Understandings went beyond dementia; it was rare that participants saw their relatives' presentation as purely a consequence of their dementia, and even rarer that they had no way of making sense of it at all. This is counter to the dominant way of making sense of such experiences, as 'behavioural and psychological symptoms' of dementia. For many, these interpretations seemed to come naturally, as accepted stories they had already internalised. However, for some this increased understanding appeared to occur over the course of the interview.

When participants made sense of their relative in relation to their current emotional experience, this seemed to be as a result of them taking the perspective of the person. This helped them to see their presentation, which could be experienced as challenging, as understandable, valid and making sense. For example, Beatrice said:

If you go to the world of the person with dementia what she's doing is completely normal, you know [...] who are these people who are coming in here with an injection holding me down, you know, causing pain? [...] I think it makes sense in the context of what she's going through

Relatives understanding in this way seemed to happen even in conditions where it might have been presumed that behaviour would be difficult to make sense of. For instance, participants reframed times when their relative's perception of the world diverged from consensus reality, or instances of aggression, as meaningful responses rather than mere symptoms. This attitude was encapsulated in a statement by Deborah, when describing her mother's hallucinations: "it was a false fright but it was true to her".

When relatives' presentations in dementia were made sense of in relation to their life history, this was often linked to a past trauma that shaped who they were pre-morbidly and who they became in dementia. This framework helped explain both behaviours of distress and positive adaptations. For instance, specific emotional experiences in dementia, such as anxiety, were made sense of by relatives in relation to a past trauma. However, the sense-making also happened in ways that suggested the person had drawn some positive and adaptive attitudes and beliefs from their experiences that helped them in life, including sometimes when they later developed dementia.

Many participants also indicated that it was helpful to them to be able to make sense of their relative in this way, speaking about the understanding as a gift. Florence said: "I'm blessed because I only saw and I also understood what that was [...] I might feel differently if I didn't know the stories and I didn't know what had happened to him". This understanding for some

was described as impacting how they, and carers, approached and treated their relative: “It's one of the reasons why I never treated her as though she had anything other than sort of her wits about her most of the time” (Deborah).

Cross-Cutting Theme 2 – Mental Health and Dementia are Inextricably Linked

This theme encompasses two main ideas; 1) the intertwining of mental health and dementia within participants’ narratives, and 2) participants’ lack of clarity about which to attribute presentation to. Firstly, across the data, participants’ discussion of their relatives’ experience of dementia was interwoven with their discussion of their relatives’ psychological experience. Secondly was how, when participants did distinguish between mental health and dementia, it was often to reflect on a lack of clarity about which to attribute their relative’s presentation to. This was particularly the case when mental health difficulties were a feature of the person’s life pre-morbidly.

In relation to the interweaving of mental health and dementia, participants did not usually make a distinction between parts of their relatives’ presentation they attributed to dementia, versus those attributed to mental health. Relatives’ mental health, including personality, behavioural and emotional changes, were spoken about in the same vein as cognitive changes. They were viewed as part of dementia rather than separate symptoms or ‘mental health’ related, as they might be clinically.

Emotional and behavioural changes were often identified as part of the lead up to or one of the first, or very early, signs that something was wrong for their relative. This may only have been identified when looking back. In Isaac’s words, “That stands out to me now, it didn't at the time”. For some, emotional changes were spoken about in a way that indicated these were some of the hardest or most defining parts of dementia as they saw it; Beatrice distinguished “contented” from “uncontented” dementia, indicating that the latter was less desirable.

When delineations in narrative between mental health and dementia did occur, it was most often to reflect on how there was a lack of clarity about which of these concepts to attribute their relative’s presentation to. This was particularly the case when describing the lead up to dementia, or if the person had prior psychological difficulties. For instance, Jasper spoke about the time prior to his relative diagnosed:

We weren't sure if she was bipolar [...] because she would talk to you normally and then she would just flip [...] and then seconds later she'll be fine again and you'll be like this is rather strange

The other way in which delineation did occur was when participants spoke about the emotional impact of the cognitive changes in dementia. The trajectories of all of the aforementioned emotional and psychological changes were varied, with some experiences

worsening over the course of dementia and some lifting, as described further in relation to trauma in the next theme.

Theme 3 – Varied Trajectories of Trauma

The previous cross-cutting themes highlight participants' holistic understandings; relatives do not compartmentalise their relatives' behaviours purely as symptoms of dementia but integrate them with their relative's broad psychological and emotional context, over time. This holistic understanding, and integration of mental health and dementia, extends to how participants perceive and trace their relatives' trauma across their life trajectories. Participants identified various ways in which trauma influenced and shaped their relative, manifesting in their behaviours and emotional responses prior to and proceeding into dementia. This recognition unfolds across four subthemes. In each, trajectories could have been explicitly identified by the participant or could have been noticed by the researcher as a feature across time. Participants also attributed reasons for the variations in these trajectories. This will be discussed further in the relevant subthemes, however the variation is summarised by Liliana when reflecting on her husband's experience with two different traumas. She felt the first trauma was less present in dementia, because of a time she recalled decades ago when "I think he'd done a conscious processing [...] it meant that [husband's name] could release that". The second trauma, she suspected that "maybe he was carrying his mom and his brother so that with his dementia [...] that came back a little bit more". Liliana highlights here how different traumas, or aspects of a person's trauma, are seen to follow varied trajectories into dementia, which are attributed to differing processing.

Subtheme 1 – The Fundamentality of Trauma

For many participants, trauma's trajectory across their relative's life was fundamental in two ways. Firstly, it was often described that there was something fundamental and exceptional about the *one* specific trauma that impacted the person the most. Secondly, participants described the trauma having a fundamental impact on the person carrying through their life into dementia. This perceived fundamental impact did not seem to depend on 1) how the trauma manifested in dementia (it could have shown in positive or negative ways, or not at all), or 2) how the person was seen to have processed the trauma pre-dementia.

Participants often highlighted one specific traumatic event that profoundly impacted their relative's life. This event was viewed as singular and exceptional, with a profound and lasting effect compared to other traumas. Other traumas were often highlighted as an aside later on in interviews, or as secondary, with a more transient or less profound impact than others. The unparalleled or exceptional nature of the trauma and its impact across the trajectory of life and dementia was described by participants as foundational. It was something that the rest of life stemmed from; life and the person were described as being different before and after. Trauma

might have “shaped their whole personality from the get go” (Olive). Some felt the impact was so significant that they wondered if this had contributed causally to their relative developing dementia.

For some participants whose relative had experienced multiple traumas, the most profoundly impacting event identified was often interpersonal in nature, for example a difficult divorce or betrayal, or abuse. Olive highlights this when comparing her mother’s experience of a medical trauma to traumatic childhood experiences. The traumatic childhood experiences were what she felt had characterised her mother’s mental health throughout life and then was noticed as a change in dementia:

There's nothing more traumatic than being declared you know dying [...] but because it was an isolated incident [...] I think there's probably actually nothing more traumatic than an unhappy childhood actually you know genuinely so even though it's like you know it sounds like the biggest most traumatic event I don't think it was

The second point relates to the longitudinal impact of these singularly exceptional events, across the relative’s life and into dementia. This impact was sometimes identified by its permeating negative influence across life and into dementia, with participants using words such as ‘scarring’, ‘life shattering’ or ‘ingrained’. For instance:

Adeline: Yeah I think you know even though [...] she's forgetting more and more kind of people and faces and but like that [the trauma] is always the (.) the thing that is always (.) there [...] that you know it's always gonna be there erm [...] it's really really ingrained

However, the fundamental impact was sometimes identified by the *absence* of the trauma in the person’s dementia presentation. Some participants spoke about knowing the trauma had fundamentally impacted because it was the *one thing* the person never spoke about and continued not to into dementia. For instance, Nathan explained: “the one area was this, it's the fact that they would never he would never talk about it (.) it makes me think it was a lot more important in his life or it weighed very heavily on him”.

The participants’ perception of the trauma as fundamentally impactful seemed to be consistent across the data however the relative seemed to cope with and process the trauma. For example, Deborah described: “She didn't collapse for very long on any occasion when things went wrong... equally they obviously had a very (.) deep significance for how she viewed life”. For some, the fundamentality was related to a lack of processing, for example Evelyn said of her mother: “I don’t think she ever really recovered from it”.

However, for others, the fundamentality of the impact and its continuation into dementia were seen as positive and were attributed to the sense they had made of it. For example, Callie linked her husband’s lack of distress in dementia to an aspect of his personality

that she felt had been developed by the trauma: “Maybe he was the quiet (.) grateful person for want of a better word maybe did harp back to his childhood that like he was alive he did have food and anything after that wasn’t terribly important”. Similarly, Herbert felt his dad’s earlier experiences had made him more “resilient” and “determined” to cope with his later dementia, highlighting the ongoing nature of positive personality traits developed from trauma.

Even when participants could not pinpoint exact ways in which the trauma may have manifested in dementia, there was often a sense from relatives that its impact was fundamental enough to still be felt or present, as encapsulated by Adeline: “even if she didn’t mention it I’m pretty sure that it was it was there”.

Subtheme 2 – Dementia as a Magnifier for Trauma

This theme encapsulates the several ways in which participants felt their relative’s dementia magnified the trauma, or the impact of it. This could have been through dementia bringing the trauma to the surface or intensifying its impact, particularly in the early stages and through its links with mental health. Participants described these changes happening in several ways: 1) increased focus on the trauma, 2) heightened emotional responses to talk of the trauma, or 3) specific but more implicit behavioural or emotional manifestations of links to the trauma, such as increased anxiety, paranoia or hallucinations, which were possible only due to participants’ personalised knowledge of the person. Dementia appeared to be able to magnify past traumas in this way no matter how the trauma was present pre-dementia.

Firstly, participants described their relative speaking more about the trauma since dementia, sometimes when it had not been recounted much before. Dementia was understood as having “brought it out” (Isaac). This was often understood by participants as the person “regressing” (Isaac) or “reliving” (a word used by Gloria, Isaac and Olive). For example, Olive explained:

She would phone me constantly and her best friend all the time and say ‘[dad’s name] [...] left me for somebody else I’ve just found out he’s had an affair’ so yeah she did relive that when she got dementia [...] just it came back again and again and again she kept reliving it, it was clear that it was just stuck she’d never got over that

This fixated nature of talking about the trauma was echoed by other participants. Participants observed that their relatives, who had previously not discussed these traumas extensively, began to frequently recall and dwell on these memories once dementia began. Beatrice noted her mother “went into this sort of repetitive mode”, while Deborah described it as “having conversations with the past”.

As well as increased frequency, increased emotion related to discussion of the trauma was also identified by participants as the person reliving the trauma. For example, Jasper described the times his mother became upset in dementia as being exclusive to being reminded

by others about the trauma:

The one time I do notice a lot more emotion [...] after they've gone I get the backlash because obviously it's stirred a few memories of what's gone on and she gets quite aggressive then and she gets quite upset [...] so there's a trigger there

In addition to a direct difference in how the trauma was spoken about or revisited, participants also highlighted specific ways in which the trauma seemed to manifest more covertly in dementia in the person's experiences, feelings or behaviours. These presentations were often understood in this way due to the participants' knowledge of their relatives history and may otherwise have been difficult to make sense of. For example, moving things was being linked to possessions being taken previously; new beliefs about people of certain nationalities were linked to the trauma; new anxiety around roads were linked to a road traffic accident; and an increased desire to keep people close was linked to previous loss. These were understood as because of "what happened to her" and "for the person I know she is is really alien", highlighting the contrast and intensification of these experiences since dementia. This is illustrated in Olive describing how her mother's fear of weather and electricity, stemming from a traumatic event in childhood, intensified. This intensification of feeling was also accompanied by qualitative changes in how her mother responded to triggers:

Olive: And she is absolutely petrified and she won't listen to the news because she is frightened that she will hear a weather forecast that there's going to be thunder and lightning (.) when she was when we were at home well even in her last sheltered accommodation she used to put tea towels and towels up over the mirrors and anything shiny because she thought that lightning would come through and be attracted to the shiny surfaces (.) and she was frightened of being struck by lightning and that stayed with her and you know if there's a rumble of thunder she's absolutely petrified [...] I mean when we were kids she didn't cover up mirrors and things like that (.) but certainly as she's got older and the dementia's progressed it's got worse (.) and you can see her panicking see the panic on her face if anyone mentions you know that bad weather's coming she says you know 'I hope there's not going to be any thunder and lightning'

Heightened anxiety was also linked by participants to what they called hallucinations and paranoia in dementia. Participants attributed such experiences to feeling of unsafety or loss, which stemmed from previous trauma, again highlighting how their knowledge of the person's history enabled them to see beyond the classic conceptualisation of 'symptoms'. For instance, Florence linked her partner's hallucinations of people coming after him in his later dementia and feeling threatened to his childhood experiences where a similar event and feelings had happened:

Florence: My instinct is he was reliving old traumas

Interviewer: Mmm what made you think that?

Florence: The words he used ‘they’re coming for me they’re gonna hit me they’re gonna hit me they’re gonna kill me they’re coming for me they’re gonna get you as well’ he generally thought people were coming after him and he told me about (.) how much they were ill-treated when they were young and in (partner’s country of origin) and it was normal to beat kids [...] and I just I just just knowing him”

For many however, the magnification of their relatives’ lives seemed to be particularly apparent in the early trajectory of dementia, in the time leading up to diagnosis and early stages. For example, Adeline described how in the early stage of dementia her mother was: “literally [...] reliving every single negative experience in her life”. This was linked by some to early changes in mental health. Adeline spoke of how her mother focused on her trauma in times of mental health exacerbation pre-dementia, and then again in the period leading up to her dementia. This was magnified in frequency in her dementia, being seen by Adeline as arising more in mood-congruent situations:

When she's becoming anxious or if she's not you know if she's (.) a bit not happy with her surroundings or situation she will start she will revert to talking about the past and that you will eventually come on to that

This pattern seemed to hold regardless of how prominent a part of the person’s experience the trauma was before dementia. Jasper, for example linked the trauma to repressed emotion pre-dementia and a lack of emotion being shown, whereas Gloria described how before: “You know it sort of happened and he got [...] over that sort of thing [...] mmm perhaps he hasn’t”.

Subtheme 3 – Dementia Lightens the Load of Trauma

This theme captures the several ways across the data in which participants described a sense of lessening of the emotional weight of trauma that happened with dementia and the range of impacts that this had. This was different to the converse to the intensification or increase described in *Dementia as a Magnifier of Trauma*, although less frequently described. This lightening of the burden seemed to happen in three main ways: 1) a reduction in distress associated with the trauma, often linked to reduced avoidance of trauma-related triggers, 2) an opening up to expression of emotions related to the trauma and 3) cognitive impairment making it harder to hold the traumatic memory in mind, possibly interrupting processes such as rumination. All were linked to emotional changes happening more generally for the person.

In relation to the first, participants spoke about the trauma being spoken about less, “impacting” or “impinging” less, or their relative gaining “some relief”. There may have been a

reduction in distress or worry. For some participants, the reduced impact came about through reduced avoidance of cues related to the traumatic event. For example, Florence's partner's trauma caused him to avoid and fear horses throughout his life, which seemed to reduce in dementia. Similarly, Evelyn's mother had experienced a trauma just before her birthday:

Evelyn: She would never let us have presents before (.) Christmas and birthdays [...] she doesn't talk about that now (.) yeah she doesn't seem to worry about it we can even go and celebrate Christmas early with her without her worrying about it

Interviewer: Yeah (.) okay (.) mmm

Evelyn: She seems to not worry about it anymore ((pause))

Importantly, the lightening of the load of trauma did not necessarily always relate to a reduction in presence of talking about the trauma; instead for some, dementia facilitated a newfound ability to express emotions associated with past traumas after a lifetime of avoidance and related mental health difficulties. For instance, Olive described how her mother would "cry more easily now", whereas she felt that before her trauma had caused her to be "avoidant". Max described how his fiancé had seemed to begin processing her trauma just preceding the onset of dementia, but that this opening up continued and was interlinked with her experience of mental health changing into dementia:

Max: She's definitely lighter as I describe her she just doesn't seem to have that weight on her shoulder anymore do you know what I mean?

Interviewer: ((overlapping)) Mmm

Max: Not that she always carried that weight it wasn't that she's always gone round you know like (.) saggy but you know it massively affected her you know materially she was an anxious person

The shift in burden could also have been attributed to the impact of cognitive impairment. Some participants described that their relative's distress now was often more related to physical needs or more present concerns than "complicated" matters, or that they had lost the ability to "explore or understand it". For instance, Olive described how she felt her mother's ability to hold her trauma in mind had reduced, which had reduced the depression she had experienced through her life:

If you're dwelling on something you have to hold it in your in your brain don't you?
And she can't hold things anymore in her memory or her brain so [...] I presume that the feelings that are associated with that memory have diminished

The reduced presence of the trauma in the relative's life could have several differing impacts for both the person with dementia and their relative. Importantly, the relative's loss of a shared traumatic memory could be experienced as a loss for the person who shared in that

experience. Liliana spoke about her husband no longer talking about the loss of their son: “not so much grieving for [son’s name] as grieving for the fact that I didn't have [husband’s name] with me because he (.) had lost that concept”. Conversely, participants identified the reduced presence of the impact of the trauma in the person’s life bringing something positive, such as increased interpersonal connection or easier access to other memories. For Kate, this was moments of connection with her mother following her being unhappy throughout life, which she attributed to the trauma. For Evelyn, this was her mother being able to access happy memories, which previously had been overshadowed by the traumatic memory: “But definitely she seems to remember the happier times with him now more than she did before she had the dementia”.

Subtheme 4 – Unchanging Relationship with Trauma

This theme explores how, contrary to the more common experience of dementia intensifying or relieving one’s distress associated with trauma, some participants noticed a consistency in how individuals continued to relate to their past traumas. This could be either a consistency in their talk about the trauma or their emotional expression related to it. The unchanging relationship could either be attributed to a processing, a lack of processing, or the impact of other life events around the trauma.

Participants sometimes recognised a continued silence in relation to the trauma, both before and since dementia. This consistency was also highlighted in relation to the emotional expression around trauma. Either the person seemed to always be emotionally impacted, or they maintained an emotional detachment over their life trajectory. For example, Beatrice said:

I've never remembered a time where she's cried about any of these events, so she does talk she does talk about them with empathy and not in anyway as a matter of fact [...] but all almost just sort of recounting things that have happened but without that sort of deep emotional attachment. I've never never seen her cry about it

The stability in the relationship with the trauma over time was attributed to varying and different post-trauma reactions: 1) openness about the trauma and processing it, 2) other life events and a sense of ‘resetting’, 3) or avoidance and lack of resolution of trauma. In relation to the first, for example, Florence said “I can't think of any other flashbacks... because he talked about it so openly I suppose”, suggesting that a lack of resurgence of the trauma in dementia was due to his openness facilitating effective processing. In relation to the second, Herbert described how his father met his wife within his traumatic experience, and so: “it's a little bit like life started in [year] in a sense... you know sort of press the restart button. Conversely, others described the opposite response of “tucking away” leading to this unchanging. Nathan discussed his close friend who continued to not discuss the trauma throughout life and into dementia:

You know if we'd have had a (.) a continual wailing and gnashing of teeth then ((pause)) that sort of gets it out the system [...] I mean you know you have a physical, you can physically see the thing being (.) explained and worked through but no this is this is (.) a stick it in a hole

Here, Nathan speculates that avoidance prevents emotional processing and resolution of the trauma, one of the several responses that is seen to result in a persistent and unchanged relationship through the life trajectory into dementia.

Discussion

This qualitative study endeavoured to add to the limited understanding of how trauma history influences dementia presentation. It aimed to do so by exploring relatives' perspectives on the psychological experiences of time of people with dementia who have experienced trauma, with particular focus on how the trauma is implicated in the experience. Participants viewed their relatives' presentations, even those that might seem to others difficult to understand, as making sense in their current context and considering their life stories including trauma. They also frame dementia as inextricably linked with psychological experience, which shapes the varied trajectories of trauma they discuss.

Importantly, the study identified multiple possible manifestations of a person's trauma across their life into dementia. There were differences in trajectories followed between individuals, but also within individuals; a person's experience could have been characterised by more than one of the trajectories across different traumas, or even different aspects of the same trauma. Trauma was often exceptional in having a fundamental impact through life which continued into dementia, regardless of how it was processed. Its impact may have been magnified in dementia, through a new or increased focus or revisiting, or links to specific behaviours. Conversely, its previous emotional burden may have been lightened, through a reduction in distress or, avoidance, or through its interaction with changes in cognition and emotion. Finally, though less frequently described, the person's relationship with the trauma could have been unchanged by dementia, again regardless of how it was perceived to have been processed previously. Overall, the findings highlight the multi-faceted and varied relationship between lifetime traumatic events and subsequent psychological distress in dementia. This is an important addition to previous studies which have quantitatively established bidirectional relationships between PTSD and dementia (e.g., Desmarais et al., 2020). The nuanced descriptions of experiences illustrated within the findings highlight clinically important variation that may not have been detected in previous quantitative research based on group differences.

The rich descriptions of how trauma-related distress can manifest in dementia could be used to contribute to the gap identified by Bruneau et al. (2020) in guidelines for managing

trauma-related distress in dementia. Importantly, the themes characterising participants' experiences cut across diagnostic categories; it is not clear that participants' relatives would have met criteria for a PTSD diagnosis, even if trauma continued or begun to have impact in their lives in dementia. The ambiguity between mental health and dementia is in contrast with the current dominant biomedical discourse, which situates 'behavioural and psychological symptoms of dementia' and 'neuropsychiatric symptoms' as something separate from cognitive changes. This finding calls into question whether existing diagnostic categories offer the most clinically relevant way of defining and measuring mental health in dementia. Indeed, findings of multiple varied trajectories underline the importance of an individualised formulation-based and life history informed approach to managing distress. Experiences in dementia, traditionally seen through the 'BPSD' lens, such as seeing things others cannot, specific worries and fixated speech have all been understood by relatives in relation to life history including trauma.

Findings also highlight how trauma-related distress is not inevitable in dementia, even if a feature of life pre-morbidly. The overlap in trajectories, and the finding that trauma-related distress can reduce in dementia, adds a caveat for clinicians drawing on life history to not assume a direct correspondence between trauma history and current psychological experience in dementia, and to maintain an open curiosity in this regard when formulating. Research into the underlying mechanisms of the highlighted reduction in distress could elucidate modes of intervention, new or existing, which have the same effect.

Findings also highlight how relatives hold a wealth of wisdom regarding the life and trauma history of a person with dementia and its importance in understanding distress in dementia. This was experienced as a gift which helped them. Importantly, relatives, when supported through the interview, appeared comfortable and keen to discuss their relatives' stories. Such knowledge could also be helpful in a similar way for formal carers. Indeed, Craftman et al. (2019) found that knowing a person's life story allowed nursing assistants to adapt their care to best support trauma survivors, improving quality of care. This understanding also helped with empathy and patience, which is important given the links found between high cognitive empathy and lower caregiver burden (Jütten et al., 2019). This is a particularly important consideration in the current NHS and social care climate where burnout and burden are key issues. Overall, the findings highlight the value of a collaborative approach to person-centred care.

It is important to acknowledge relevant factors impacting the positionality of the participants which therefore may have shaped their narratives and meaning-making, and consequently the themes derived from the data. Family members and carers are not merely passive or objective observers of the person with dementia's story, as they are in relationship with the person and are therefore wrapped up in the very process they were making sense of in

the interviews, particularly given the ripples of impact of both trauma and dementia. For some, they themselves also experienced the same traumatic event as their loved one, and so their own understanding of this is likely to have influenced their narrative.

There are many ways in which the psychological histories of the carers are likely to shape the narratives they provide. A particularly pertinent example is the way in which a carers' attachment style, influenced by their childhood experiences, meets with the attachment style of their relative with dementia (Meisen, 2014) to influence relationships and interactions. Research indicates that those with dementia who have anxious attachment styles report more psychological symptoms, and carers perceived more symptoms in those with avoidant attachment (Monin et al., 2013), highlighting how these interactions are likely to shape both experiences of people with dementia and their relatives' narratives regarding these experiences.

Participants' narratives and sense-making are also likely to be influenced by their relationship to the person with dementia and whether the person with dementia is still living or is deceased. The majority of participants were either children or spouses of the person with dementia; the differing roles, attachment styles and emotional experiences associated with these different relationships are likely to have shaped narratives. In addition, some of the people with dementia spoken about were living and some had died, and the time since death differed. Given the sense- and meaning-making process that occurs following bereavement of a family member (Rolbiecki et al., 2023), these differing viewpoints are likely to have shaped participants' narratives. *How* these differing perspectives shape the narratives remains a question for future research.

For the purposes of the study, carers of the person with dementia were the ones to decide whether their loved ones' experiences fitted with the definition of trauma provided. This allowed for a more holistic view of how adverse and traumatic experiences present in dementia, compared to the narrower focus on single-event traumas or PTSD more commonly described in the literature. It is important to acknowledge too that dementia itself can be conceptualised as a trauma, and indeed an existential threat to both the person with dementia and the carer (Cheston et al., 2015). Dementia's existential threat can compromise one's identity and ability to find meaning and purpose in life, which is likely to shape both the way the person with dementia relates to previous trauma, and how their relatives make sense of their past and present experiences. Indeed, some of the presentations described in participants' accounts, such as clinging to past traumas, may be ways in which people with dementia aim to protect themselves from the emotional impact of the condition (Cheston & Christopher, 2019).

While there were strengths to this study, particularly in its novel approach to exploring this research area, there are also areas for future research to address. The positioning of participants' accounts varied in many ways, including in terms of their relationship to the person

with dementia, the dementia diagnosis of the person and their trauma experience. However, the majority of both participants and their relatives were from White ethnic backgrounds and were born in the UK, therefore the voices of ethnically or geographically minoritised families were not represented. Given evidence of cross-cultural variations in representations and understandings of dementia (e.g., Calia et al., 2019), future research should aim to add additional perspectives to this area.

In addition, the study relied on retrospective self-report by interested family members, which is vulnerable to self-selection and hindsight bias. This allowed a feasible way to capture a rich picture of participants' meaning-making process. In addition, the focus on the perspectives of relatives has important clinical applicability. Best practice models of dementia care, such as the Newcastle Model, use information gained from family members (James & Jackman, 2017). Additionally, a significant proportion of care for those with dementia is provided by family members, and this is preferred in the early stages (Clarkson et al., 2017). However, to further understanding of the underlying neurocognitive mechanisms of trauma and dementia links would benefit from larger scale longitudinal data, and this study offers considerations for the design of such a study. Furthermore, had time allowed, it would have been best practice to implement member checking, to enhance credibility of the study (Shenton, 2004) and ensure themes encapsulated participants' meanings. Future research should aim to investigate whether the themes as they are described fit with the lived experiences of people with dementia and their relatives.

Conclusion

The study has contributed to a predominantly quantitative literature by offering a rich and nuanced account of how trauma manifests in the trajectories of distress of people with dementia. It highlights the multiple overlapping patterns by which earlier life trauma is implicated in these experiences, shaped by the holistic understandings of relatives. These varying patterns illustrate the multi-finality of trauma-related distress in dementia. The findings emphasise the importance of truly trauma-informed formulation-led dementia care and a holistic approach to understanding distress in dementia, both in clinical practice and in future research.

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Executive Summary

The two presented papers reporting the literature review and main research project focus on psychological distress in dementia, in particular how it manifests and is understood. Together, these underline the importance of person-centred, holistic, individualised and nuanced understandings of this area. The paper presenting the service-related project differs in theme, focusing on psychological therapy service provision within a secondary mental health service and potential disparities in access.

Literature Review

Understanding how family members interpret, understand and make sense of Behavioural and Psychological Symptoms of Dementia (BPSD) is crucial, due to their significant role in facilitating person-centred care for their loved ones. Family understandings are also important to understand given the potential mismatch with professional understandings, which could lead to misaligned clinical priorities and a lack of collaboration, reducing quality of care for the person with dementia. Despite this, the breadth of literature on family member understandings of BPSD has not been comprehensively reviewed. This scoping review aimed to consolidate existing evidence in this area.

A systematic search of electronic databases (CINAHL, PsycINFO and PubMed) was conducted to identify studies focused on understanding how family members make sense of BPSD. The quality of identified studies was assessed using the Mixed Methods Appraisal Tool. From the 6645 articles screened, 30 were deemed eligible for inclusion. The elements central to the understanding of carers' explanations and understandings of BPSD were grouped into six clusters: (1) higher level factors, including preferred language, beliefs about controllability, divergence of perspectives and a lack of understanding; (2) dementia as an explanation; (3) life history and premorbid personality; (4) expressions of physical and psychological need; (5) interpersonal factors and (6) environmental factors. The review highlights that family members and informal carers have multiple understandings of BPSD, drawing on various sources of information. These sources pertain to the life history, personality and context of the person with dementia. Recognising the complexity of these interpretations provides important implications and directions for clinical practice and research, including drawing on the multi-faceted understandings of carers and supporting them to develop the most helpful ways of making sense, to improve quality of life for them and their loved ones with dementia.

Service-Related Project

Aligned with recent NHS directives promoting equitable access to psychological therapies for severe mental health problems in community settings, this audit aimed to understand the representativeness of demographics of individuals accessing direct psychological interventions from the Complex Psychological Interventions (CPI) team within Gloucester's

Recovery service. CPI and the Recovery team function as most secondary mental healthcare teams, in that referrals for psychological intervention are made by other professionals, creating the potential for disparities. The study also sought to characterise the nature of the services provided. The aims and direction of the project were steered by CPI and Recovery team professionals and Experts by Experience.

The audit used routinely collected data from the 2011-22 financial year, drawn from patient information systems. This included patient demographics, referral patterns and appointment offer within the CPI service. Results indicated that 28% of Recovery team service users had been referred to CPI in the previous five years. Those who were female and younger were overrepresented in CPI compared to the Recovery team and Gloucester populations. Ethnicity data was available for 85% of service users. This indicated an overrepresentation of people from White ethnic backgrounds in CPI, and an underrepresentation of people from Black and 'Other' ethnic backgrounds. Those with diagnoses of anxiety disorders, behavioural syndromes associated with physical factors, and personality disorders were also overrepresented. 6% of service users had been discussed in reflective practice.

These results corroborate existing literature on disparities in access to psychological therapies, as well as amount of data missing from clinical records. Results add to the literature by providing insight into CPI service delivery. Findings serve as a foundation for secondary mental healthcare teams to explore further what might be driving service accessibility and delivery outcomes. They also highlight the importance of streamlining data collection processes so that full data are available to investigate these issues further.

Main Research Project

People with dementia face an elevated risk of delayed-onset post-traumatic stress disorder, yet research focused on understanding the clinical manifestation of trauma-related distress in this population remains limited. This is important to explore considering the potential overlap in trauma-related distress and what are termed 'behavioural and psychological symptoms of dementia'. There is the potential for this lack of clarity in understanding to lead to misattribution of presentations and inappropriate treatments. The aim of this study, therefore, was to explore the psychological experiences over time of people with dementia who have experienced trauma, from the knowledgeable perspectives of their loved ones.

Data were gathered through 16 semi-structured interviews with relatives of individuals diagnosed with dementia who had experienced traumatic events earlier in life. Interviews were analysed using Reflexive Thematic Analysis through a critical-realist lens. Two cross-cutting themes were developed which characterised how participants made sense of their relatives' experiences: "*I Might Feel Differently if I Didn't Know the Stories*" which highlighted how participants saw presentations as understandable in the person's context, and *Mental Health and*

Dementia are Inextricably Linked, which encapsulated how participants saw the two concepts as intertwined. Within these cross-cutting themes was the theme *Varied Trajectories of Trauma* which encompassed the multiple and overlapping ways in which earlier life trauma was experienced over life into dementia. The subthemes within this highlighted *The Fundamentality of Trauma*, how dementia could be a *Magnifier of Trauma* or *Lighten the Load* of trauma, or how the person maintained an *Unchanging Relationship with Trauma*.

The study elucidates the multiple overlapping patterns by which relatives use their knowing of the person with dementia to see past traumas as being implicated in the psychological experience of people preceding and through their dementia. These are seen as understandable within the context and a result of the intrinsic links between mental health and dementia. Findings emphasise the importance of truly trauma-informed, holistically viewed, individualised and collaboratively devised dementia care, and provide new directions for research in this area.

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Appendices

Appendix A: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	10
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	7
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	11-12
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	12
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	12
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	12-13
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	12
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	96-99
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	13
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	13
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	13
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	13
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	13

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	14
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	15-26
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	101
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	15-26
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	27-31
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	31-32
Limitations	20	Discuss the limitations of the scoping review process.	32
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	33
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	N/A

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473. doi: 10.7326/M18-0850.

Appendix B: Scoping Review Search Strategy

MEDLINE (PubMed)

- Automatically explodes MeSH terms
- Filtering for only English language publications
- Searching in Title or Abstract (as also covers keywords automatically)
- Doesn't allow proximity operators when truncation symbols are being used, so no proximity operator to cut down as least amount of hits

Carers	Of people with dementia	Understanding	Of BPSD
Carer*	Dementia*	Understand	Distress
Caregiver*	Alzheimer*	Understanding	Psychological
Care giver*		Attitude*	Behav*
Family*		Knowledge	Neuropsychiatric*
Families		Belief*	BPSD
Familial		View	Aggressi*
Relative*		Views	Agitat*
Loved one*		Viewpoint*	Mood
Spous*		View point*	Delusion*
		Perspective*	Depress*
			Paranoi*
			Sleep
			Apathy
			Anxi*
			Non-cognitive
			Non cognitive
			Noncognitive
MeSH – caregivers, family (includes different family members including spouse)	MeSH – dementia, Alzheimer disease	MeSH – attitude, knowledge	MeSH – Psychological distress, behavioral symptoms, aggression, affect, anxiety, apathy, depression, paranoid disorders (Behavioural symptoms covers aggression, psychomotor agitation, wandering, delusions, depression, problem behaviour, paranoid behavior)

(((((("Caregivers"[Mesh]) OR "Family"[Mesh]) OR (carer*[Title/Abstract] OR caregiver*[Title/Abstract] OR care giver*[Title/Abstract] OR family*[Title/Abstract] OR families[Title/Abstract] OR familial[Title/Abstract] OR relative*[Title/Abstract] OR loved one*[Title/Abstract] OR spous*[Title/Abstract]))) AND ((dementia*[Title/Abstract] OR alzheimer*[Title/Abstract]) OR (("Dementia"[Mesh]) OR "Alzheimer Disease"[Mesh]))) AND ((understand[Title/Abstract] OR understanding[Title/Abstract] OR attitude*[Title/Abstract] OR knowledge[Title/Abstract] OR belief*[Title/Abstract] OR view[Title/Abstract] OR views[Title/Abstract] OR viewpoint*[Title/Abstract] OR view point*[Title/Abstract] OR

perspective*[Title/Abstract]) OR (("Attitude"[Mesh] OR "Knowledge"[Mesh])) AND
 (((((((("Psychological Distress"[Mesh] OR "Behavioral Symptoms"[Mesh]) AND
 "Aggression"[Mesh]) AND "Affect"[Mesh]) AND "Anxiety"[Mesh]) AND "Apathy"[Mesh])
 OR "Depression"[Mesh] OR "Paranoid Disorders"[Mesh]) OR (distress[Title/Abstract] OR
 psychological[Title/Abstract] OR behav*[Title/Abstract] OR neuropsychiatric*[Title/Abstract]
 OR BPSD[Title/Abstract] OR aggressi*[Title/Abstract] OR agitat*[Title/Abstract] OR
 mood[Title/Abstract] OR delusion*[Title/Abstract] OR depress*[Title/Abstract] OR
 parano*[Title/Abstract] OR sleep[Title/Abstract] OR apathy[Title/Abstract] OR
 anxi*[Title/Abstract] OR non-cognitive[Title/Abstract] OR non cognitive[Title/Abstract] OR
 noncognitive[Title/Abstract])) Filters: English

PsycINFO (APA PsycNET)

- Filtering for only English language publications
- Searching in Keywords or Abstract (as keywords also covers title)

Carers (within 5 words of understanding)	Of people with dementia	Understanding (within 5 words of carers)	Of BPSD
Carer*	Dementia*	Understand	Distress
Caregiver*	Alzheimer*	Understanding	Psychological
Care giver*		Attitude*	Behav*
Family*		Knowledge	Neuropsychiatric*
Families		Belief*	BPSD
Familial		View	Aggressi*
Relative*		Views	Agitat*
Loved one*		Viewpoint*	Mood
Spous*		View point*	Delusion*
		Perspective*	Depress*
			Paranoi*
			Sleep
			Apathy
			Anxi*
			Non-cognitive
			Non cognitive
			Noncognitive
Index Term – Family Members (+), Caregivers	Index Term – Dementia (+), Alzheimer’s Disease	Index Term – Health Knowledge, Declarative Knowledge, Caregiver Attitudes, Attitudes	Index Term – Aggressive Behavior, Agitation, Distress, Anxiety, Apathy, Major Depression (+), Depression (Emotion), Paranoia, Sleep, Psychiatric Symptoms (+)

((((((title: (dementia*)) OR ((title: (alzheimer*)))) OR ((abstract: (dementia*)) OR ((abstract: (alzheimer*)))) OR (((IndexTermsFilt: ("Alzheimer's Disease")) OR ((IndexTermsFilt: ("Dementia")) OR ((IndexTermsFilt: ("AIDS Dementia Complex")) OR ((IndexTermsFilt: ("Alzheimer's Disease")) OR ((IndexTermsFilt: ("Dementia With Lewy Bodies")) OR ((IndexTermsFilt: ("Frontotemporal Lobar Degeneration")) OR ((IndexTermsFilt: ("Presenile Dementia")) OR ((IndexTermsFilt: ("Pseudodementia")) OR ((IndexTermsFilt: ("Senile Dementia")) OR ((IndexTermsFilt: ("Vascular Dementia")))))))) OR (((title: (distress)) OR (title: (psychological)) OR (title: (behav*)) OR (title: (neuropsychiatric*)) OR (title: (BPSD)) OR (title: (aggressi*)) OR (title:

(agitat*) OR (title: (mood)) OR (title: (delusion*)) OR (title: (depress*)) OR (title: (paranoi*)) OR (title: (sleep)) OR (title: (apathy)) OR (title: (anxi*)) OR (title: (non-cognitive)) OR (title: ("non cognitive")) OR (title: (noncognitive)) OR ((abstract: (distress)) OR (abstract: (psychological)) OR (abstract: (behav*)) OR (abstract: (neuropsychiatric*)) OR (abstract: (BPSD)) OR (abstract: (aggressi*)) OR (abstract: (agitat*)) OR (abstract: (mood)) OR (abstract: (delusion*)) OR (abstract: (depress*)) OR (abstract: (paranoi*)) OR (abstract: (sleep)) OR (abstract: (apathy)) OR (abstract: (anxi*)) OR (abstract: (non-cognitive)) OR (abstract: ("non cognitive")) OR (abstract: (noncognitive)))) AND (((title: (dementia*)) OR (title: (alzheimer*))) OR ((abstract: (dementia*)) OR (abstract: (alzheimer*)))) OR (((IndexTermsFilt: ("Alzheimer's Disease")) OR (IndexTermsFilt: ("Dementia")) OR (IndexTermsFilt: ("AIDS Dementia Complex")) OR (IndexTermsFilt: ("Alzheimer's Disease")) OR (IndexTermsFilt: ("Dementia With Lewy Bodies")) OR (IndexTermsFilt: ("Frontotemporal Lobar Degeneration")) OR (IndexTermsFilt: ("Presenile Dementia")) OR (IndexTermsFilt: ("Pseudodementia")) OR (IndexTermsFilt: ("Senile Dementia")) OR (IndexTermsFilt: ("Vascular Dementia")))) AND (((title: (carer*)) OR (title: (caregiver*)) OR (title: ("care giver*")) OR (title: (family*)) OR (title: (families)) OR (title: (familial)) OR (title: (relative*)) OR (title: ("loved one*")) OR (title: (spous*))) NEAR/5 ((title: (understand)) OR (title: (understanding)) OR (title: (attitude*)) OR (title: (knowledge)) OR (title: (belief*)) OR (title: (view)) OR (title: (views)) OR (title: (viewpoint*)) OR (title: ("view point*")) OR (title: (perspective*)) OR ((abstract: (carer*)) OR (abstract: (caregiver*)) OR (abstract: ("care giver*")) OR (abstract: (family*)) OR (abstract: (families)) OR (abstract: (familial)) OR (abstract: (relative*)) OR (abstract: ("loved one*")) OR (abstract: (spous*))) NEAR/5 ((abstract: (understand)) OR (abstract: (understanding)) OR (abstract: (attitude*)) OR (abstract: (knowledge)) OR (abstract: (belief*)) OR (abstract: (view)) OR (abstract: (views)) OR (abstract: (viewpoint*)) OR (abstract: ("view point*")) OR (abstract: (perspective*)))) OR (((IndexTermsFilt: ("Caregivers")) OR (IndexTermsFilt: ("Family Members")) OR (IndexTermsFilt: ("Adopted Children")) OR (IndexTermsFilt: ("Adult Offspring")) OR (IndexTermsFilt: ("Ancestors")) OR (IndexTermsFilt: ("Biological Family")) OR (IndexTermsFilt: ("Cousins")) OR (IndexTermsFilt: ("Daughters")) OR (IndexTermsFilt: ("Foster Children")) OR (IndexTermsFilt: ("Grandchildren")) OR (IndexTermsFilt: ("Grandparents")) OR (IndexTermsFilt: ("Inlaws")) OR (IndexTermsFilt: ("Only Children")) OR (IndexTermsFilt: ("Orphans")) OR (IndexTermsFilt: ("Parents")) OR (IndexTermsFilt: ("Siblings")) OR (IndexTermsFilt: ("Sons")) OR (IndexTermsFilt: ("Spouses")) OR (IndexTermsFilt: ("Stepchildren")))) AND ((IndexTermsFilt: ("Declarative Knowledge")) OR (IndexTermsFilt: ("Health Knowledge")) OR (IndexTermsFilt: ("Attitudes")) OR (IndexTermsFilt: ("Caregiver Attitudes"))))

CINAHL (Embase)

- Filtering for only English language publications
- Searching in Title or Abstract (can't do keywords)

Carers (within 5 words of understanding)	Of people with dementia	Understanding (within 5 words of carers)	Of BPSD
Carer*	Dementia*	Understand	Distress
Caregiver*	Alzheimer*	Understanding	Psychological
Care giver*		Attitude*	Behav*
Family*		Knowledge	Neuropsychiatric*
Families		Belief*	BPSD
Familial		View	Aggressi*
Relative*		Views	Agitat*

Loved one* Spous*		Viewpoint* View point* Perspective*	Mood Delusion* Depress* Paranoi* Sleep Apathy Anxi* Non-cognitive Non cognitive Noncognitive
Subject Heading – Caregivers, Family (exploded)	Subject Heading – Dementia (exploded), Alzheimer’s Disease	Subject Heading – Attitude, Caregiver Attitudes, Knowledge (exploded)	Subject Heading – Psychological Distress, Affect, Aggression, Anxiety, Apathy, Behavioral Changes, Behavioral Symptoms (exploded – includes aggression, agitation, delusions, sleep disorders), depression (exploded), paranoid disorders

S20 AND S24 AND S31 (Expanders - Apply equivalent subjects

Narrow by Language: - English

Search modes - Boolean/Phrase)

S31 - TI ((carer* OR caregiver* OR "care giver*" OR family* OR families OR familial OR relative* OR "loved one*" OR spous*) N5 ((understand OR understanding OR attitude* OR knowledge OR belief* OR view OR views OR viewpoint* OR "view point*" OR perspective*)) OR AB ((carer* OR caregiver* OR "care giver*" OR family* OR families OR familial OR relative* OR "loved one*" OR spous*) N5 ((understand OR understanding OR attitude* OR knowledge OR belief* OR view OR views OR viewpoint* OR "view point*" OR perspective*)) OR (((MH "Caregivers") OR (MH "Family+")) AND ((MH "Attitude") OR (MH "Caregiver Attitudes") OR (MH "Knowledge+"))))

S24 - ((MH "Psychological Distress") OR (MH "Affect") OR (MH "Aggression") OR (MH "Anxiety") OR (MH "Apathy") OR (MH "Behavioral Changes") OR (MH "Behavioral Symptoms+") OR (MH "Depression+") OR (MH "Paranoid Disorders")) OR TI (distress OR psychological OR behav* OR neuropsychiatric* OR BPSD OR aggressi* OR agitat* OR mood OR delusion* OR depress* OR paranoi* OR sleep OR apathy OR anx* OR non-cognitive OR "non cognitive" OR noncognitive) OR AB (distress OR psychological OR behav* OR neuropsychiatric* OR BPSD OR aggressi* OR agitat* OR mood OR delusion* OR depress* OR paranoi* OR sleep OR apathy OR anx* OR non-cognitive OR "non cognitive" OR noncognitive)

S20 - ((MH "Dementia+") OR (MH "Alzheimer's Disease")) OR TI (dementia* OR alzheimer*) OR AB (dementia* OR alzheimer*)

Appendix C: Scoping Review Data Extraction Template

Authors		
Year		
Country		
Research parameters	Research questions/Aim	
	Theoretical approach	
	How were the data collected? (Method, by whom, setting, when)	
Population and sample selection	Population	
	Recruitment	
	Sample	
	Inclusion criteria	
	Exclusion criteria	
Methods of analysis and outcomes	Method and process of analysis	
	Key relevant findings	
Discussion	Limitations identified by author	
	Evidence gaps and or recommendations for future research	
	Author's conclusion	
	Source of funding	

Appendix D: Quality Assessment Results

Citation	Study Design: Qualitative				
	Q1. Appropriate approach	Q2. Adequate methods	Q3. Findings adequately derived	Q4. Substantiated interpretation	Q5. Coherence
Adekoya & Guse (2021)	Yes	Yes	Yes	Yes	Yes
Band-Winterstein & Avieli (2019)	Yes	Yes	Yes	Yes	Yes
Brittain et al. (2017)	Yes	Yes	Can't tell	Yes	Yes
Burley et al. (2021)	Yes	Yes	Yes	Yes	Yes
Duxbury et al. (2013)	Yes	Yes	Yes	Yes	Yes
Fieldhouse et al., (2023)	Yes	Yes	Yes	Yes	Yes
Gilbert et al. (2021)	Yes	Can't tell	Yes	Yes	Yes
Gilmore-Bykovskiy et al. (2020)	Yes	Yes	Yes	Yes	Yes
Hansen et al. (2019)	Yes	Yes	Yes	Yes	Yes
Harvath (1994)	Yes	Yes	Yes	Yes	Yes
Herron & Wrathall (2018)	Yes	Yes	Yes	Yes	Yes
MacAndrew et al. (2017)	Yes	Yes	Yes	Yes	Yes
Nijsten et al. (2023)	Yes	Yes	Yes	Yes	Yes
Paton et al. (2004)	Yes	Yes	Yes	Yes	Yes
Polenick et al. (2018)	Yes	Yes	Yes	Yes	Yes
Qazi et al. (2010)	Yes	Yes	Can't tell	Yes	Yes
Rasmussen et al. (2019)	Yes	Yes	Yes	Yes	Yes
Rognstad et al. (2020)	Yes	Yes	Yes	Yes	Yes
Song et al. (2018)	Yes	Yes	Yes	Yes	Yes
Tappen & Williams (1998)	Yes	Yes	Yes	Yes	Yes
Tyrell et al. (2019)	Yes	Yes	Yes	Yes	Yes
Tyrell et al. (2020)	Yes	Yes	Yes	Yes	Yes
Wang et al. (2015)	Yes	Yes	Yes	Yes	Yes
Wang et al. (2012)	Yes	Yes	Yes	Yes	Yes
Wang et al. (2014)	Yes	Yes	Yes	Yes	Yes
	Study Design: Quantitative Descriptive				
	Q1: Sampling strategy	Q2: Representative sample	Q3: Appropriate measures	Q4: Risk of nonresponse bias	Q5: Appropriate analysis
Chen et al. (2017)	Yes	Can't tell	Yes	Yes	Yes
Mackenzie et al. (1989)	Yes	Can't tell	Yes	Yes	Yes
	Study Design: Mixed methods				
	Q1: Adequate design rationale	Q2: Component integration	Q3: Adequate interpretation	Q4: Divergences	Q5: Both quality criteria
Cohen-Mansfield et al. (2013)	Yes	Yes	Yes	Yes	Yes
Houston et al. (2011)	Can't tell	Yes	Can't tell	Can't tell	Can't tell
Wolverson et al. (2022)	Yes	Yes	Yes	Yes	Yes

Appendix E: Audit Approval Email

Hi Georgia,

Thank you for your email. I presented the 2022-23 Clinical Audit Programme to the Improving Care Group last week and no concerns were raised, therefore we now have a 'final' clinical audit programme. The audit reference numbers are as follows:

22-091 Audit of Gloucester Complex Psychological Intervention Input (Dr Hannah Steer and Georgia Chambers)

Apologies for the delay with regards to the sign off. I hope the audits are progressing well. If you have any further questions or require any advice please do let me know.

Kind regards,

Hanna Tunbridge

Clinical Audit Manager
Gloucestershire Health and Care NHS Foundation Trust

Mobile: [REDACTED] **Email:** hanna.tunbridge@ghc.nhs.uk **Website:** www.ghc.nhs.uk

working together | always improving | respectful and kind | making a difference

Appendix F: Consolidated criteria for Reporting Qualitative Research (COREQ) guidelines

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	64
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	65
Occupation	3	What was their occupation at the time of the study?	65
Gender	4	Was the researcher male or female?	65
Experience and training	5	What experience or training did the researcher have?	65
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	64
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	64
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	65
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	64
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	63
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	63
Sample size	12	How many participants were in the study?	61
Non-participation	13	How many people refused to participate or dropped out? Reasons?	64
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	64
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	64
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	62
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	63
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	64
Field notes	20	Were field notes made during and/or after the interview or focus group?	64
Duration	21	What was the duration of the interviews or focus group?	64
Data saturation	22	Was data saturation discussed?	64
Transcripts returned	23	Were transcripts returned to participants for comment and/or	79

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	64
Description of the coding tree	25	Did authors provide a description of the coding tree?	66-67
Derivation of themes	26	Were themes identified in advance or derived from the data?	64-65
Software	27	What software, if applicable, was used to manage the data?	64
Participant checking	28	Did participants provide feedback on the findings?	79
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	67-77
Data and findings consistent	30	Was there consistency between the data presented and the findings?	67-77
Clarity of major themes	31	Were major themes clearly presented in the findings?	67-77
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	67-77

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix G: Main Research Project Interview Schedule

Read each key question verbatim, then follow up with optional prompts as necessary.

1. Opening:
 - Inquire about pre-interview questionnaires & clarifying any responses as necessary
 - Address participant questions about the interview process
 - Remind participant that some material may be difficult to discuss and that they are free to discontinue at any point or to skip any questions they would rather not discuss.
2. **“How would you describe your [husband/mother/brother/etc.] as you knew him/her, before he/she developed dementia?”** *Query to develop a broad sense for premorbid personality in middle adulthood, values, and interpersonal patterns.*
Optional prompts:
 - “What was [the person] like? / From your perspective, what were [the person’s] defining characteristics?”
 - “Do you have any stories that sum up what the person was like?”
 - “What was important to [him or her]?”
 - “How did [he or she] get on with other people?”
3. **“Looking back, what do you think were the first signs that your loved one might have been developing dementia or some other problem, even if you didn’t recognise it at the time?”** *Establish earliest signs, including changes in emotions/mood or exacerbation of pre-existing psychiatric symptoms. Follow-up as necessary:*
 - If participant is uncertain: “What type of problems led to the person being assessed for dementia?” *Then follow-up to query for earlier or more subtle changes in emotions/mood, cognition, or function in higher-order ADLs.*
 - *If participant cannot recall, or if the referral was first prompted by an external party – e.g. concerns raised by a professional during the course of other medical care:* “Was there a moment when you first noticed something might have been wrong or different for your loved one?”
 - *If pre-morbid mental health concerns were mentioned in questionnaires but not raised in participant response, query for changes to mental health in the years prior to suspected dementia.*
4. *Following from previous question, establish a sequence of the most prominent changes to behaviour, emotions, and cognition. The objective of this question is to capture the broad narrative as recalled by the participant, rather than to reconstruct a precise timeline. “As time passed, what other changes did you notice in [the person’s] mood, thinking, and behaviour?” Follow-up as necessary to establish the participant’s recollection of the symptom trajectory:*
 - *If the participant makes no reference to the sequence of changes:* “You mentioned [briefly recap changes]... which of those did you notice first?... and what did you notice next?” *Offer prompts to continue the narrative, but do not repeat the query if they indicate that they are uncertain (e.g. due to multiple problems emerging in close succession or with insidious onset) or appear frustrated.*
 - *If the narrative omits mood/affect, thinking/cognition, or behaviour:* “What about changes in [the person’s] [mood and emotions or behaviour or memory and thinking]?”
 - *If not implied in earlier responses, follow up on the evolution of mental health symptoms mentioned in No.3:* “You mentioned [mental health symptoms/issues]. Have you noticed changes to those [symptoms/issues] as [the person’s] dementia progressed?”

- *If the narrative does not mention symptoms or changes having improved or evolved: “Sometimes a person with dementia might have difficulties at one time that subsequently get better as the disease progresses. For example, the person might go through a period in which they are prone to becoming agitated but then appear to become calmer later on. Do you recall whether any of the difficulties you mentioned have stopped or changed into something different over time?” OR (if only one improvement/discontinuation was mentioned): “You mentioned that [change that had subsequently resolved or evolved into something else]. Were there other issues that seemed to stop or change into something different over time?”*
5. **“In the timeline, you identified difficult or traumatic events that the person has experienced. For all of us, what we think, feel and do might be affected by events that have happened in the past. Looking back on it, how do you think these events might have shaped how [the person] is thinking, feeling and behaving now that they have dementia?”**
- *If re-experiencing symptoms are not mentioned: “When people have experienced traumatic events, sometimes they later have flashbacks or feel they are reliving it. Have you seen any indication that this might be happening for your loved one?” (If yes, then elicit details and example, establish timeline, and query possible associated event)*
 - *If avoidance symptoms are not mentioned: “Often, people who have experienced traumatic events try to avoid things that remind them of the event. Reminders of the event could include certain types of places, pictures and sounds, smells, or certain topics of conversation. Have you noticed situations where this might be the case for [the person]?” (If yes, then elicit details and examples, establish timeline, and query possible associated event)*
 - *If potential hypervigilance symptoms are not mentioned: “Experiencing a traumatic event can cause a person to feel on edge and extra-alert for danger, sometimes years after the event. Have you noticed [the person] having this sort of difficulty?” (If yes, elicit detail/examples and establish timeline. Connection to an event may be unclear.)*
 - *If not addressed earlier: “Are there times that the person seems upset or distressed and it has been hard to understand why?” If yes, elicit further detail and examples.*
6. **“We’ve now finished most of the questions I had for today. I’m wondering what it has been like to talk about [the person] and [his/her] difficulties?”**
- a. *Use standard active listening prompts to allow the participant to describe their experience.*
 - b. *If no indication of distress: “Some people find that it feels good to share their experiences, while other people might find it more difficult. I’ve prepared a handout for you with some information on supports that could be helpful for someone in your position, which I will send out after we finish talking.” (Introduce debrief according to script)*
 - c. *If participant shares that it has been upsetting: Ascertain whether there is immediate risk to the participant. In the unlikely event of serious and imminent risk, seek the participant’s consent to contact the relevant emergency service. If not, discuss possible informal supports (e.g. friends or family) and encourage the participant to reach out. Select the most appropriate source of support (e.g. helpline) from the debrief sheet and provide the contact information verbally, with written details to follow via post. Tell participant that a debrief is available and ask if they would prefer to discuss it today or to arrange a short follow-up call. Inform research supervisor immediately.*

Appendix H: Main Research Project Information Sheet

University of Bath
Department of Psychology
Georgia Chambers, Clinical Psychologist in Training



INFORMATION SHEET

A qualitative exploration of loved ones' accounts of the trajectory of psychological distress in dementia for people who have experienced trauma

Thank you for your interest in the project. Please find below some more information about taking part. If you have any questions about the below or wish to arrange a brief phone or online Teams call to discuss more about the project, please contact the researcher on gnc21@bath.ac.uk.

Who am I and what is the study?

My name is Georgia Chambers and I am studying for my doctorate in Clinical Psychology at the University of Bath. As part of my doctorate, I am conducting this study into the links between dementia and trauma. I am doing this in collaboration with my supervisor, Dr. Ashley Vanstone, who is a Clinical Psychologist who works with people with dementia and their loved ones and carers. We are interested in finding out more about how dementia symptoms develop over time for people who have experienced a traumatic event in their life.

Can I take part?

We are looking to speak to people who have, or have had, a loved one or family member who:

- Has or had a diagnosis of dementia
- Has or had experienced a traumatic event in their life (a stressful event or situation that was very threatening, or horrific)
- Has or had advanced dementia requiring 24 hour care
- They have or had known for at least 15 years with regular contact with them (at least 6 times per year)

We would also ask that you are comfortable sharing information about your perceptions of the timeline of the person's dementia, and feel happy that they would be okay with you sharing this. We will not be asking for specifics, e.g., names, locations or exact details of traumatic experience.

What would I be asked to do?

If you wish to take part, you will be offered a pre-interview call to talk through what taking part might involve and to allow you to think this through. Following this, you will be sent a questionnaire to complete, asking some questions about your loved one's dementia. This will also include a blank timeline for you to prepare for the interview if you think this would help. You will also be sent an interview schedule, so you know what will be asked in the interview beforehand if you wish to. The pre-interview questionnaire and timeline task should take no longer than around half an hour. Following this, we will arrange a time that is convenient for you to be interviewed. This can take place in person, at your home, or at the University of Bath, if you live within 1.5 hours, or online over a Microsoft Teams video call if you live further away or would prefer this. The interview should take around an hour in total; you can decide whether you would like to do this in one or two parts. Although the interviews should take around an hour, you will not be stopped from speaking if you wish to continue sharing up to an hour and a half. This will involve me asking some questions about your perceptions of how your loved one's dementia symptoms developed over time. You will not have to answer any questions that you do not want to and you will only need to disclose information that is comfortable for you, and that you think your loved one would be happy with you sharing. We can take a break during the interview if you would like to, and you have the right to end the interview at any point. I will check at the end of the interview whether you are still happy for all the answers you have given to be included in the analysis and if there is anything you are not happy with being analysed, this will not be included in the transcripts. After completing the interview, you will receive a £20 voucher of your choice (that can be sent online) to thank you for taking part.

Do I have to take part?

You do not have to take part in this research. Taking part is voluntary, which means you can choose whether or not you want to. If you take part, you are allowed to stop the interview at any time without giving a reason why. If you stop the interview, your data will not be included in the analysis and any audio recording obtained up to that point will be deleted. If you wish to withdraw from the study once your interview has taken place, you will be required to contact us to request to withdraw your data. You will be able to remove your data within a week of taking part (after this point it will have been anonymised).

What would be the benefits or disadvantages of taking part?

Some people find it therapeutic to talk about their experiences and their loved ones. In addition, the research, and your participation in this, should advance knowledge in this area, which is currently limited. This may help healthcare providers to improve the support they offer to people with dementia who have experienced trauma.

You may find that the interview causes you to be upset if this is a difficult topic for you. If you find the discussion difficult, you are able to take a break or stop the interview at any time. In addition, if the interviewer feels that the interview is causing you distress, the interview will be stopped. You will also be provided with a debrief sheet following the interview including details of any services which may be useful if you have found the interview to bring up anything distressing.

What will happen to the information I provide?

The interview will be recorded on Microsoft Teams, on a password-protected account. It will also be recorded on a Dictaphone for backup, which will be stored in a locked cabinet. This will be transcribed by the researcher within a month, removing any names or identifiable information mentioned, and then the recordings will be deleted. Transcripts, as well as your consent form and questionnaire will be scanned in and stored in a password-protected computer, on the secure university network. This will be accessed only by the researcher and the research supervisor. Your consent form with your name on and your other study documents will be stored separately so you cannot be identified.

What will happen to the results of this research?

What you tell me will inform our project on how dementia presents and develops for people who have experienced trauma. I may use extracts from what you have told me in my thesis, however these would not identify you or your loved one and any specific details that would be identifiable will be removed. The findings of the research may also be published in research journals or used in presentations. If you would like to be sent a summary of the findings, we can arrange for this.

What do I do if I would like to take part or have any more questions?

If you have any questions about taking part, you can contact me, Georgia Chambers, by emailing gnc21@bath.ac.uk. We can have a brief phone or online Teams call to discuss more about what taking part might be like. You are also able to view the interview questions and pre-interview questionnaire prior to the interview, if this helps you decide whether or not to take part. If you have decided you would like to take part, please email me and we can arrange a time that is convenient for you.

You can also speak to the supervisor of the project, Dr. Ashley Vanstone, by emailing adv30@bath.ac.uk. If you have any concerns related to your participation in this study, please direct them to the Chair of the Department of Psychology Research Ethics Committee, by emailing psychology-ethics@bath.ac.uk.

Appendix I: Main Research Project Ethical Approval



21 August 2023

Dear Georgia,

Re: Amendment request

Project ref: 23-076 A qualitative exploration of loved ones' accounts of the trajectory of psychological distress in dementia for people who have experienced trauma (date: 21/08/2023)

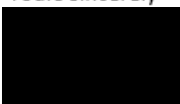
Thank you for submitting the above amendment request. This letter is to confirm that we have considered the information provided and can confirm that the amendment has been approved.

Document name	Version & Date
REACH Application Form for an Amendment 20.08	V1 20/08/2023
Amended ethics form 20.08.23 with documents	V1 20/08/2023

Please proceed with the necessary arrangements within your research team so that this amendment can be implemented. The documents above will supersede any previously submitted documentation for this project.

Should you require any further information, or any further amendments please contact research-ethics@bath.ac.uk.

Yours sincerely



Fran Baber
Research Ethics Officer
Research Governance and Compliance Team
Vice-Chancellor's Office
University of Bath
research-ethics@bath.ac.uk

Appendix J: Example of Part of Reflexive Thematic Analysis Process

