EXPLORING RELATIONSHIP CONTINUITY IN THE CONTEXT OF BEHAVIOURAL VARIANT FRONTOTEMPORAL DEMENTIA

By

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Thesis Overview

This thesis is submitted as partial fulfilment for the requirements of the degree of Doctor of Clinical Psychology at the University of Birmingham. It is comprised of three chapters: 1) a meta-ethnographic review paper, 2) an original, empirical research paper, and 3) two public dissemination documents summarising the first two chapters.

The first chapter, a qualitative meta-ethnography, examines the experiences of spouses of a partner with young-onset dementia. Using Noblitt and Hare's (1998) guidance for synthesising qualitative studies, seven themes were generated: 'A Complex and Evolving Emotional Journey', 'Grief and Loss', 'A Guilty Conscience', 'Stigmatised, Isolated and Alone', 'A Changed Relationship and Lost Companion', 'Lost Identity: Unexpected, Untimely and Unwanted Role Changes' and 'Striving to Cope'.

The second chapter is a qualitative exploration of how behavioural and personality change in the context of behavioural variant frontotemporal dementia can undermine the relationship between spouses. Using Braun and Clarke's (2022) Reflexive Thematic Analysis, six themes were generated: 'I'm never at ease': Disrupted Safety and Security, 'I can't talk to him anymore: Disrupted Communication and Connection, 'It's hard not to take it personally': The Emotional Toll, 'It's not the same anymore': Changing Appraisals of the Spouse and the Dyad, 'Why did you do that?': Trying to Understand, and 'You just learn to manage': Coping with Changes.

The third chapter includes two public dissemination documents providing a summary of chapters one and two. Written in the style of a press-release, they are suitable for dissemination to experts by experience, key stakeholders in the research, and a lay audience.

Dedication

I dedicate this thesis to Hendrix. Your eternally happy face and unconditional love were the light in my life. I miss you more than words can say. I hope you are running happy and free over the rainbow bridge. Until we meet again, my angel.

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To those who graciously offered their time to share their experiences with me, I extend my gratitude. Without you, this research would not be possible. It was a privilege to speak with you and I am extremely grateful that you entrusted me with your stories.

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CHAPTER ONE

THE SPOUSAL EXPERIENCE IN YOUNG-ONSET DEMENTIA: A META-ETHNOGRAPHY

Abstract

Aims: This meta-ethnography aimed to examine and integrate existing qualitative literature on spouses' experiences of having a partner with young-onset dementia, to develop a more comprehensive understanding of this experience.

Method: A search strategy was developed to conduct a systematic literature search to identify relevant papers. Ten papers were identified from academic journals. Directed by Noblit and Hare's (1988) seven-phase meta-ethnographic approach, the papers' findings were synthesised by comparing the key concepts between papers.

Results: The integration resulted in a primarily reciprocal translation, with areas of refutation identified within common concepts. Seven themes were identified: 'A Complex and Evolving Emotional Journey', 'Grief and Loss', 'A Guilty Conscience', 'Stigmatised, Isolated and Alone', 'A Changed Relationship and Lost Companion', 'Lost Identity: Unexpected, Untimely and Unwanted Role Changes', and 'Striving to Cope'.

Conclusions: This review highlights the complexity of the spousal experience in young-onset dementia. There was evidence that these spouses may be susceptible to role engulfment and find the identity of 'caregiver' incongruent with their identity at this phase of their life. There were also echoes of the concept of 'chronic sorrow' regarding the loss of an idealised future. This appears to be a particularly challenging loss for spouses to accept. The findings from this review highlight potential targets for support for spouses, particularly regarding complex loss and identity change. Additionally, the review

highlights the need for age-appropriate services for both the person with dementia and their spouse.

Introduction

Young-onset dementia (YOD) refers to dementia with symptom onset before the age of 65, and accounts for approximately 7.5% of total dementia cases in the United Kingdom (UK; Carter et al., 2022; Koopmans & Rosness, 2014). Although less prevalent than late-onset dementia (LOD), YOD presents some unique challenges. Alzheimer's disease, the most common YOD, is associated with more rapid, aggressive disease progression in younger adults compared to those with late-onset disease (Jeffries & Agrawal, 2009; Koedam et al., 2010; Stanley & Walker, 2014). Individuals with YOD are also more likely to experience changes in their communication abilities, personality characteristics, such as loss of empathy, and have increased behavioural disturbances, such as aggression and social disinhibition, relative to those with LOD (Draper & Withall, 2016; Ducharme & Dickerson, 2015).

Alongside symptom-specific challenges associated with YOD, the unexpected occurrence of dementia at this life-stage contributes to distinctive, age-related challenges for the individual and their loved ones (Fadil et al., 2009; Harris & Keady, 2004; van Vliet et al., 2010). Individuals living with YOD are generally in a more active life phase, typically amid their working life, have childcare responsibilities, and with ageing parents who require support (Withall, 2013). Their spouses, who are most likely to be the primary caregiver for the individual following diagnosis (Ducharme et al., 2016; Janssen et al., 2017), face new-found caregiving responsibilities alongside managing financial, household, and work responsibilities (Kelley et al., 2008).

Prior research focusing on the impact of caring for an individual with YOD highlights the complexity of the situation. Comparative studies have shown that, in comparison to their counterparts in LOD, carers in YOD feel less prepared for their caregiving role, experience higher levels of burden, report poorer quality of life, experience depressive symptomology to a greater degree, have lower levels of psychological wellbeing, report higher caring load, and find behavioural disturbances more difficult to cope with (Arai et al., 2007; Caspar & O'Rourke, 2009; Freyne et al., 1999; Hvidsten et al., 2020; Kimura et al., 2015; Kimura et al., 2021; van Vliet et al., 2010). Although dementia occurring at any age is likely to have a profound and disruptive impact on the individual and their spouse, dementia in younger age may also be more difficult to accept as it is so out of place of the expected (Millenaar et al., 2016; Tindall & Manthorpe, 1997).

The progressive nature of YOD means spouses also face a prolonged caregiving trajectory (Antoine & Pasquier, 2013). Concerns about their partners' increasing dependence and worrying about managing multiple responsibilities alongside caregiving have been cited as major concerns (Kaiser & Panegyres, 2007). Individuals with YOD are also cared for in the community more than twice as long as people with LOD, reflective of a lack of specialist, age-appropriate services for individuals and their families (Bakker et al., 2013; Rodda & Carter, 2016). In some instances, specialist YOD services have been de-commissioned placing additional burdens on spousal caregivers (Cations et al., 2017; Mayrhofer et al., 2018). This emphasises the importance of supporting spousal carers in their experience, so they remain able to provide care and retain their own wellbeing.

Arising from the 'Angela Project', a framework of what 'good' YOD services should look like, based on engagement with individuals with YOD and their caregivers, has been developed (Stamou et al., 2021). Although focussing primarily on diagnostic pathways and service-provision for the person with dementia, the availability and value of holistic care addressing the multiple facets of living with YOD for caregivers, was emphasised. Emerging evidence also indicates that healthcare professionals advise that caregivers should themselves be considered as a client within services, receiving their own reviews and support, owing to the significant psychosocial impact YOD has (Ducharme et al., 2014).

Although a recent meta-review identified over 500 studies reporting on non-pharmacological interventions for family carers in dementia (Cheng & Zhang, 2020), two recent reviews, focussing specifically on such interventions in YOD, emphasise the paucity of carer-focussed interventions specifically developed for this population (Cui et al., 2024; Kim et al., 2023), identifying only four and nine studies respectively. The authors highlight that interventions were limited to information provision or peer-support groups and may not address many of the emotional challenges family carers face, recommending that future studies develop and assess the effectiveness of interventions targeting the distinctive emotional challenges faced by YOD carers.

Rationale

Spouses of individuals with YOD experience a multitude of difficulties because of their situation, reflected in the number of poor psychosocial outcomes outlined here. Personal stories of experiences of dementia can provide important insights through which to develop specialised and innovative care and support (Bartlett & O'Connor, 2011). Consequently, it appears sensible to assess how spouses make sense of and respond to their experience to support the development of appropriate interventions.

Previous reviews exploring the experience of living with YOD have consisted of heterogenous samples, including spouses, children, siblings, and professionals, and have included both quantitative and qualitative literature (Cabote et al., 2015; Spreadbury & Kipps, 2019; Svanberg et al., 2011; van Vliet et al., 2010). These factors complicate the interpretation of their results regarding the lived experiences of spouses. Reviews that have focused solely on qualitative research have been limited in focus such as exploring the experience of use of services (Millenaar et al., 2016), preferences for support services (Bannon et al., 2021) and treatment preferences (Grunberg et al., 2021).

Meta-ethnography

Although several approaches to synthesising qualitative literature exist (Dixon-Woods et al., 2007), meta-ethnography moves beyond developing a summary or aggregation of existing literature (Noblit & Hare, 1988). The researcher re-interprets and compares the primary data, themes, and concepts identified by original studies, to create a whole that is greater than its parts alone (Noblit & Hare, 1988; Sattar et al., 2021). Meta-ethnography can increase the relevance of singular accounts, identify directions for future research efforts, and aid in intervention-development for complex issues (France et al., 2016; Levack, 2012; Ring et al., 2012). To the authors knowledge, there has been no meta-ethnographic review of the spousal experience in YOD. A meta-ethnographic review of the experience of individuals diagnosed with YOD is available (Greenwood & Smith, 2016), which the current review would complement.

Aim

This meta-ethnography aims to review the available literature exploring the experience of being the spouse of a partner with YOD. Through synthesising the existing qualitative research focused on the firsthand experiences of spouses of individuals with YOD, it is anticipated that new interpretations and a more comprehensive understanding of the experiences of spouses will be achieved, and this may inform targeted support and intervention(s) for this group.

Method

This synthesis followed the meta-ethnographic approach proposed by Noblit and Hare (1988) – a systematic, seven-phase process for synthesising qualitative research (Table 1). Their approach is an interpretative and analytical, rather than a descriptive and aggregative, analysis of the available literature.

Table 1

The Seven Phases of Meta-Ethnography (Noblit & Hare, 1988, pp. 26-29)

Phase	Process(es)
1) Getting Started	This phase involves identifying a subject of interest, where synthesising the available qualitative research can contribute valuable knowledge.
2) Deciding what is relevant to the initial interest	This phase involves deciding which studies are relevant and systematically locating them. Quality assessment of the included studies should also take place.
3) Reading the studies	This phase involves reading the included studies to become familiar with their key concepts. Study information and raw data is extracted from each study.
4) Determining how the studies are related	This phase requires the studies to be 'put together' and the relationships between them determined. Key concepts, phrases, metaphors, and ideas from each study are listed and juxtaposed to begin making initial assumptions about their relationship.
5) Translating the studies into one another	This phase involves examining the key concepts both within and across the studies.

Phase	Process(es)
6) Synthesising translations	Synthesising involves ‘making a whole into something more than the parts alone imply’. This may be achieved by examining commonalties and differences between the main concepts.
7) Expressing the synthesis	The synthesis should be presented in an appropriate form for the intended audience using intelligible language e.g., a written report.

Positionality of the Researcher

Meta-ethnographers increasingly recognise the importance of making the position of the researcher in relation to their synthesis explicit to the reader (Noblit, 2019). A statement of positionality supports readers to understand how the researcher has approached and influenced their review (Soundy, 2024), and may include “a description of the author’s identity as it relates to a research topic” (Savolainen et al., 2023). In this spirit, I am a mixed-heritage, heterosexual, female. I have never been married nor have I any personal experience of having a loved one with dementia, although have experience of having a close relative with a life-limiting health condition. As a trainee psychologist, I have received teaching on the biological, psychological, and social aspects of dementia and have worked in a dementia service, where I observed the devastating impact dementia can have on individuals and their loved ones. I have a professional interest in the psychological impact of physical health conditions. I hold a relatively ‘outsider’ position to the core aspects of this review but acknowledge the influence of my academic understandings and personal experiences on how I may have interpreted the study data.

In relation to my ontological and epistemological position, the critical-realist paradigm aligns with my beliefs regarding reality and knowledge. Aligned with this paradigmatic stance, I believe that there is an objective reality, but that attempts to explain this reality are subjectively influenced (Almashy, 2015; Taylor, 2018) i.e., I believe that YOD exists and spouses' experiences of this phenomenon exist, but I also recognise that my attempt to understand and explain this reality is undeniably influenced by my beliefs, knowledge, experiences, and values. As such, the interpretation of the studies included in this review, and my conclusions, are dependent on the influences described above. I do not claim that my interpretations are the 'truth', rather they are one such interpretation of a truth.

Phases 1-2: Systematic Literature Search

Following the identification of a subject of interest, as outlined in the introduction, a systematic literature search to identify relevant studies was conducted, outlined below.

Search Strategy

To identify potentially relevant studies, a search strategy informed by Shaw et al's (2004) guidance on searching for qualitative literature was implemented. The strategy included combining free-text terms centred on the key aspects of the aim of the review: what are the experiences of being the spouse of a partner with young-onset dementia? Free-text terms related to qualitative research were also included to further specify the search results (Shaw et al., 2004). Specific terms denoting relationships were included to ensure that papers returned were specific to the context of interest. The search terms and truncations (indicated by *) are displayed in Table 2.

Table 2

Database Search Terms

Key words	Search Terms
Qualitative investigations of experience	Qualitative OR perspective* OR view* OR experience* OR lived experience* OR feeling* OR interview*
Young-onset dementia	Young onset dementia OR early onset dementia OR early onset alzheimer* OR presenile dementia
Spouses	spous* OR partner* OR couple OR marri* OR relationship*

Databases searched included: PsycInfo, CINAHL, Web of Science, MedLine, Scopus, and Proquest. The search was conducted in August 2023 and focussed on research published in the last 20 years. Searches were exported to Mendeley Reference Manager to support an efficient and systematic screening process.

Inclusion and Exclusion Criteria

Duplicate results were removed prior to screening the titles and abstracts of the returned results. Papers were included or excluded from further review based on the criteria shown in Table 3.

Table 3

Inclusion/Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**	**Rationale**
Papers focusing on young-onset dementias (diagnosis below the age of 65)	Papers focusing on late-onset dementias (diagnosis 65+)	This synthesis focuses on young-onset dementia due to the unique challenges faced by this population
Papers focusing on spouses whose partner has young-onset dementia	Papers focusing on other relationship dyads e.g., parent-child, siblings, other familial connection, professional-care-recipient.	This synthesis aims to review the experience of spouses living with a partner who has young-onset dementia
Papers focused on any aspect of personal experience(s) living with YOD and using an established qualitative methodology	Quantitative papers e.g., focus on biological, epidemiological, psychiatric aspects of dementia. Papers using psychometric measures to explore aspects of the experience e.g., burden, quality of life, marital satisfaction, without any qualitative exploration of questionnaire responses.	The aim of this synthesis was to review qualitative accounts of spousal experiences of having a partner with young-onset dementia
Papers reporting primary data	Papers reporting secondary data e.g., literature reviews	Meta-ethnography requires the researcher to interpret first-order constructs and second-order constructs i.e., primary data, to engage in interpretative analysis
Papers published in peer-reviewed journals	Alternative publications e.g., student	Focus is on high-quality evidence.

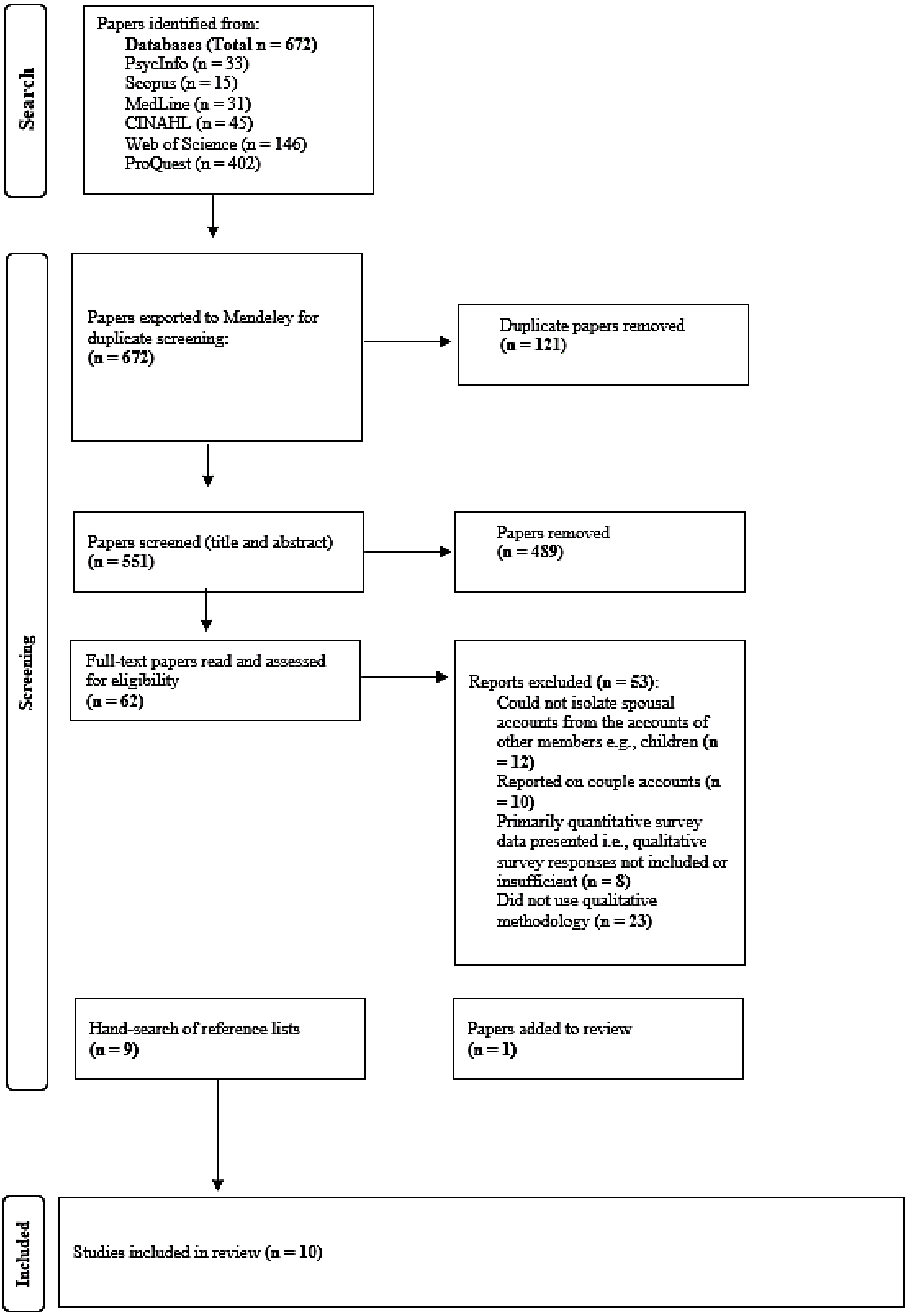
Inclusion Criteria	Exclusion Criteria	Rationale
	dissertations/theses, book chapters, newspaper articles, opinion papers	
Papers published in or accessible in the English language	Papers not published or accessible in the English language	The researcher is a mono-lingual, native English speaker and as such, the synthesis must be conducted in English. Furthermore, translation of qualitative research can result in losing the nuance of the original meanings expressed in the native language of the research

Screening Process

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart (Moher et al., 2009) is used to present the systematic approach to screening taken. Reference lists of included papers were also searched to identify any papers that the search may have missed. The total number of papers produced from the review, as well as the stages at which they were either included or excluded from the review, are shown in Figure 1.

Figure 1

PRISMA Flowchart Displaying Systematic Screening Process



Ten papers were included in the final synthesis, summarised chronologically in Table 4.

Table 4

Summary of Studies Included in the Final Synthesis

Title/Author/Year	**Study Aims**	**Participant Information**	**Data Collection/Analysis**	**Themes Reported**
Bakker et. al (2010) Needs in early onset dementia: a qualitative case from the NeedYD study	To explore the experiences of a caregiver of a patient with early onset dementia and the needs of patient and caregiver, to gain new insights into the complex experiences and evolving needs of the caregiver	Sample size: N=1 Gender ratio: Female Age: 55 Ethnicity: Not reported (NR) Diagnosis of spouse: Alzheimer's Disease (AD) Age of spouse at diagnosis: 56	Sampling method: randomly selected from a pool of 217 cases in a larger follow-up study on needs in young-onset dementia Data collection: semi-structured interview; audio-recorded and transcribed; focused on exploring the period prior to and after diagnosis, caring, transition in care and future perspectives Data analysis: **Inductive Content Analysis** (Elo & Kyngas, 2008)	**Three main themes** were reported: 1) Making Choices in the Care Situation - This included *five subthemes*: Decision-making Process, Diminishing Reciprocity, Changing Perspectives, Grieving and Adjusting to Change, Duality in the Caring Situation 2) Conditions for the Use of Care - This included *three subthemes:* Confirmation, Availability of Supportive Caregivers, Need for Continuity of Care 3) Involvement in Care - This included *two subthemes*: Letting Go, Trust and the Fit Between Services
Lockeridge & Simpson (2013) The experience of caring for a partner with young onset dementia: how younger carers cope.	To explore carers' experience of their relationship with their partner with young onset dementia and their coping strategies	Sample size: N=6 Gender ratio: 3M:3F Age: 52-70 (M=63) Ethnicity: White British Diagnosis of spouse: NR Age of spouse at diagnosis: (M=58)	Sampling method: Purposive Data collection: face-to-face semi-structured interviews lasting 50-90 minutes; the schedule focused on the carers' life with their partner with dementia; audio-recorded and transcribed Data analysis: **Interpretative Phenomenological Analysis** (Smith, 1996)	**Four 'interconnected' themes** were reported: 1) 'This is not happening: the use of denial as a coping strategy 2) 'Let's not have any more of this demeaning treatment: carers' perceptions of stigma 3) 'I've had to fight every inch': struggling to maintain control of events and emotions 4) 'What will become of me': adaption to loss

Title/Author/Year	Study Aims	Participant Information	Data Collection/Analysis	Themes Reported
Ducharme et. al (2013) The unique experience of spouses in early-onset dementia	To document the lived experience of spouse caregivers of young patients in order to inform the development of professional support tailored to their reality	Sample size: N=12 Gender ratio: 4M:8F Age: M=55 Ethnicity: NR Diagnosis of spouse: AD (N=9), Pick's Disease (N=1, Mixed AD + Dementia with Lewy bodies (DLB; N=1), Mixed AD + Vascular Dementia (VaD; N=1) Age of spouse at diagnosis: NR	Sampling method: Purposive Data collection: face-to-face semi-structured interviews lasting on average 90 minutes; focusing on the couple's trajectory since the appearance of the disease including main difficulties encountered and the evolution of relationships within the dyad and family; audio-taped and transcribed verbatim Data analysis: **Phenomenological principles** underlined **'thematic content analysis'.** Coding scheme developed based on method outlined by Miles & Huberman (2003)	**Six recurring themes** were reported: 1) Difficulty managing behavioural and psychological symptoms of partner 2) Long quest for diagnosis 3) Non-disclosure to others and denial of diagnosis 4) Grief for loss of spouse, married life and midlife projects 5) Difficulty juggling unexpected role and daily life responsibilities 6) Difficulty planning for future
Massimo et. al (2013) Caring for loved ones with frontotemporal degeneration: the lived experiences of spouses	To explore spouses perceived experiences of and responses to living with a person with FTD	Sample size: N=2 Gender ratio: Female Age: NR Ethnicity: NR Diagnosis of spouse: Frontotemporal dementia (FTD) Age of spouse at diagnosis: Mid 50s-early 60s	Sampling method: Purposive Data collection: face-to-face semi-structured interviews lasting 60 minutes; the aim of the conversation was to enable the caregivers to give an account of caring for their spouse; audio-recorded and transcribed verbatim	**Five themes** were reported: 1) Identity and role change 2) Isolation 3) Anger 4) Facing the future 5) Reframing

Title/Author/Year	**Study Aims**	**Participant Information**	**Data Collection/Analysis**	**Themes Reported**
			Data analysis: **Interpretative phenomenological methods** (Benner, 1994)	
Bergman et. al (2016) The meaning of living close to a person with Alzheimer disease	To explore the lifeworld of spouses when their partners are diagnosed with early-onset AD	Sample size: N=10 Gender ratio: 5M:5F Age: 40-64 Ethnicity: NR Diagnosis of spouse: AD Age of spouse at diagnosis: NR	Sampling method: Purposive Data collection: face-to-face semi-structured interviews lasting between 60-95 minutes; the interview focused on what it was like to be a spouse in a relationship with a partner diagnosed with AD; audio-recorded and transcribed verbatim Data analysis: **Interpretative Phenomenological Reflection** (van Manen, 1997)	**Four main themes** were reported: 1) The experience of being restricted, 2) The experience of being evolved 3) The experience of being alone 4) The ambiguous experience of being together
Johannessen et. al (2017) Experiences and needs of spouses of persons with young-onset frontotemporal lobe dementia during the progression of the disease	To examine the spouses of yo-FLTD experiences and needs for assistance in daily life	Sample size: N=16 Gender ratio: 6M:10F Age: 51-69 (M=59.6) Ethnicity: NR Diagnosis of spouse: FTD Age of spouse at diagnosis: M=58	Sampling method: Purposive Data collection: face-to-face semi-structured interviews lasting between 31-79 minutes; the schedule focused on the experiences of spouses in regard to having a partner with young-onset FTD, how it had affected their life and relationships, and what support may have been helpful	**Three main themes** were reported: 1) Sneaking signs at the early stage of dementia - This included *two subthemes*: Incomprehensible early sings, lack of self-insight 2) Life turning upside down at the later stage of dementia - This included *three subthemes*: the torment, interference with work, vanishing social relations 3) Needs for assistance through all stages of dementia

Title/Author/Year	Study Aims	Participant Information	Data Collection/Analysis	Themes Reported
			Data analysis: **Grounded Theory** (Corbin & Strauss, 2008)	- This included *three subthemes*: relief of the diagnosis, support at home, the path to the nursing home
Pang & Lee (2019) Finding positives in caregiving: the unique experiences of Chinese spousal caregivers of persons with young-onset dementia	To explore the caregiving experience of spousal caregivers of persons with YOD and provide recommendations for future practice	Sample size: N=6 Gender ratio: 3M:3F Age: 61-73 (M=66.5) Ethnicity: Chinese Diagnosis of spouse: NR Age of spouse at diagnosis: M=58.3	Sampling method: Purposive Data collection: face-to-face semi-structured interviews lasting between 55-128 minutes; the interview schedule focused on the caregiving experience and difficulties and satisfactions encountered during the caregiving journey; audio-taped and transcribed verbatim Data analysis: **Qualitative Content Analysis** (Graneheim & Lundman, 2004)	**Three major categories** identified: 1) Coming to terms with an unexpected diagnosis 2) Multiple unanticipated and 'early' losses 3) Finding positives and meaning
Popok et. al (2022) One diagnosis, two perspectives: lived experiences of persons with young-onset dementia and their care-partners	To gain a better understanding of the unique experiences, psychosocial stressors and adaptive coping strategies of person with young-onset dementia and their spouses	Sample size: N=17 Gender ratio: 8M:9F Age: 54-69 (M=61.47) Ethnicity: White (N=16), Asian (N=1) Diagnosis of spouse: Atypical AD (N=3), Early onset AD (N=2), posterior cortical atrophy (N=2), progressive supranuclear palsy (N=2), primary progressive aphasia (N=2), FTD (N=1) Age of spouse at diagnosis: M=54.4	Sampling method: Purposive Data collection: open-ended interview inviting participants to share anything about their individual experience of being a spouse of a partner with young-onset dementia; interviews were conducted via Zoom; audio-taped and transcribed Data analysis: **Thematic Analysis** (Fereday & Muir-Cochrane, 2006)	A **total of 12 themes** were reported: **Seven themes were reported** related to **psychosocial stressors:** 1) Adjustment to partners' cognitive and behavioural changes 2) Navigating partner's disagreement, denial, or avoidance related to symptoms and care 3) Adjustment to increased responsibilities and loss of equal partnership 4) Exhaustion and burnout from caregiving 5) Loss of physical and emotional intimacy with partner 6) Lack of social support and loneliness

Title/Author/Year	Study Aims	Participant Information	Data Collection/Analysis	Themes Reported
				7) Loss of anticipated future and need to re-envision future **Five themes were reported** related to **adaptive coping strategies:** 1) Cultivate understanding of illness to reduce frustration and connect with partner 2) Identify resources for managing illness (for self and partner) 3) Focus on the present with gratitude and patience 4) Connect with social support and accept help 5) Practice self-care and patience to manage stressors
Thorsen & Johannessen (2023) How gender matters in demanding caring for a spouse with young-onset dementia. A narrative study	To examine narrated experiences of the meaning and content of demanding spousal caring for partners with young-onset frontotemporal dementia, concentrating on a female perspective	Sample size: N=16 Gender ratio: 6M:10F Age: 51-69 (M=59.6) Ethnicity: NR Diagnosis of spouse: FTD Age of spouse at diagnosis: M=58	Sampling method: Purposive Data collection: face-to-face semi-structured interviews lasting between 31-79 minutes; the schedule focused on the experiences of spouses in regard to having a partner with young-onset FTD, how it had affected their life and relationships, and what support may have been helpful Data analysis: **Narrative Qualitative Approach** (Wertz, 2011)	**Four gendered main themes** were reported: 1) Different caregiving periods 2) Distancing - experiencing a transformed spouse and relationship 3) Social isolation 4) Needing assistance and relief **Two detailed condensed narratives from a wife and husband** are also presented: 1) Wife's stories about long caring 2) Husband's stories about long caring

Title/Author/Year	**Study Aims**	**Participant Information**	**Data Collection/Analysis**	**Themes Reported**
Binford et. al (2023) Role identity transition: a conceptual framework for being the spouse of a person with early onset dementia	To understand the underlying psychosocial processes of being a spouse of a person with early-onset dementia	Sample size: N=15 Gender ratio: 5M:10F Age: 46-68 (M=57) Ethnicity: White (N=14), Asian (N=1) Diagnosis of spouse: AD (N=6), bvFTD (N=4), svPPA (N=3), corticobasal degeneration (N=1), progressive supranuclear palsy (N=1) Age of spouse at diagnosis: NR	Sampling method: Purposive Data collection: face-to-face semi-structured interviews lasting between 60-90 minutes; up to 3 interviews were conducted if new questions arose in subsequent interviews; the schedule focused primarily on what it was like having a spouse with early-onset dementia, what aspects of life had changed, what is means to be a spouse/caregiver, and how spouses' identities had changed Data analysis: **Grounded Theory** (Corbin & Strauss, 2015)	**Three primary concepts** were reported: 1) The Situation of Being the Spouse of a person with early-onset dementia 2) Moments of Significance 3) Conditions of the Situation - Changes in the Spouse and Interpersonal Dyad Changes **Two core concepts** highlighting the **consequences of the above concepts** were reported: 1) The process of role identity change 2) Stepwise Progression of Role Identity Change

Most studies took place in North America and Europe, including the United States of America (n=3), Norway (n=2), Sweden (n=1), the Netherlands (n=1), Canada (n=1), and the UK (n=1). One study took place in China (n=1). The studies reported on a total of 101 participants; the majority were female (n=61). Sample sizes ranged from one (Bakker et al., 2010) to 17 (Popok et al., 2022). In studies that reported the ethnicity of participants (n=4), the majority were "White" (n=36), two were "Asian", and six were Chinese. Although one study (Massimo et al., 2013) did not report the age of participants at the time of interview, the youngest reported participant was 40 (Bergman et al., 2016) and the oldest was 73 (Pang & Lee, 2019).

All studies used interviews to collect their data. The data were primarily analysed using forms of qualitative content analysis (n=3). Other analytic methods included Grounded Theory (n=2), IPA (n=1), Thematic Analysis (n=1), a 'narrative qualitative approach' (n=1), 'interpretative phenomenological methods' (n=1) and 'interpretative phenomenological reflection' (n=1).

Quality Appraisal of Included Studies

Noblit and Hare (1988) recognise quality assessment as integral to phase 2 of their approach. Quality appraisal enables readers to make judgements regarding how much confidence they may have in the reported findings and typically involves assessing the methodological rigour and trustworthiness of a study (Booth et al., 2021; Johnson et al., 2020) i.e., has the study been conducted in a sufficiently rigorous manner through which to be confident in the credibility of its' results?

Quality appraisal of qualitative research is highly contested (Long et al., 2020; Tod et al., 2021; Williams et al., 2020). Debates continue regarding the appropriateness of applying broad quality appraisal tools to studies employing a range of ontological and epistemological positions (Garside, 2014) and regarding whether reviewer subjectivity undermines the consistency of how such tools are applied (Boeije et al., 2011). Additionally, as assessment can only be based on the information reported, appraisal may not necessarily reflect the actual conduct of the study and may be better conceptualised as an assessment of reporting practices (Carroll et al., 2012). Nevertheless, quality appraisal remains advocated as good practice (Noyes et al., 2018).

The Critical Appraisal Skills Programme qualitative studies checklist (CASP; 2018) is the most widely adopted appraisal tool and is endorsed by Cochrane (Noyes et al., 2018). The checklist was developed for use in health and social care research and is suitable for use by novice researchers, and as such was deemed suitable for this review. A modified version of the checklist has been developed to assess how well authors “reflect on and clearly report their approach to inquiry” i.e., how their ontological and epistemological positions informed their approach to their research and subsequent conclusions (Long et al., 2020). The modified version adds the question: are the study’s theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent, and conceptually coherent?

The papers were assessed using the modified CASP checklist (Appendix A) and the following response options and colours were assigned dependent on whether the study met the criteria: ‘yes/green’ (all or most criteria met), ‘somewhat/amber’ (criteria partially met; both strengths and limitations evident), ‘no/red’ (criteria not met) or ‘can’t tell/blue’ (insufficient evidence to make an informed judgement). The addition of the ‘somewhat’ option better delineates between partially met criteria and reporting issues, which were assigned ‘can’t tell’ (Long et al., 2010). Somewhat was assigned when it was deemed that the authors had made “a reasonable attempt at fulfilling a particular quality domain” (Long et al., 2020).

Although it is recommended that quality appraisal should result in categorising studies as either ‘low’, ‘medium’, or ‘high’ quality (Noyes et al., 2018), the CASP tool does not provide a scoring system that supports this. Some authors suggest that reviewers may identify “deciding criteria” to establish relative study quality based on what is considered important based on the aims of their review (Franzel et al., 2013; Long et al., 2020). Such criteria may identify “fatal flaws” in the research through which to call into question their relevance and trustworthiness (Dixon-Woods et al., 2004).

One deciding criterion was consideration of the relative rigorousness of the included studies’ data analysis, as assessed by question nine of the modified CASP tool. Quality here would increase the contribution of this review and increase confidence that its’ recommendations are grounded in quality data. Studies deemed as insufficiently rigorous as to result in a ‘no’ answer on the CASP tool would be excluded. Examples of insufficient data analysis would include lack of transparency regarding the analytic process and providing no data through which to support the authors interpretations. Questions one and two of the CASP tool were also key deciding criteria. If these questions were not answered ‘yes’, then a study would be excluded on the basis that their findings would be unlikely to add relevant information and undermine the value of their contribution to the overall review. The quality appraisal process applied to the 10 papers is displayed in Table 5.

Table 5

Quality Appraisal of Included Papers (CASP, 2018; Long et al., 2020)

Study	Validity		Findings							Value		Overall Comments
	1. Was the are clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	5. Was the recruitment strategy appropriate to the aims of the research?	6. Was the data collected in a way that addressed the research issue?	7. Has the relationship between researcher and participants been adequately considered?	8. Have ethical issues been taken into consideration?	9. Was the data analysis sufficiently rigorous?	10. Is there a clear statement of findings?	11. How valuable is the research?	
Bakker et. al (2010)	Y	Y	SW	N	SW	Y	C	C	Y	Y	SW	**Strengths:** Clear aim and relevance; explicit explanation of data collection; interview guide helpfully presented; rich analysis with good presentation of quotes; acknowledgement that clinical experience of researchers influenced interview guide; good description of avenues for further research and clinical implications. **Weaknesses:** Random selection of single case from pool of 217 not justified or explained; poor reporting of ethical issues; single case study limits the value of the findings, no consideration of the impact of the researchers on the analysis.

Study	Validity		Findings							Value		Overall Comments
	1. Was the are clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	5. Was the recruitment strategy appropriate to the aims of the research?	6. Was the data collected in a way that addressed the research issue?	7. Has the relationship between researcher and participants been adequately considered?	8. Have ethical issues been taken into consideration?	9. Was the data analysis sufficiently rigorous?	10. Is there a clear statement of findings?	11. How valuable is the research?	
Lockeridge & Simpson (2013)	Y	Y	Y	N	Y	Y	SW	C	SW	SW	Y	**Strengths:** Clear aims and relevance; good description of recruitment strategy; data collection adequately described; quality assessment procedures presented; analysis linked to existing literature to contextualise interpretations; several clinical implications considered. **Weaknesses:** Poor reporting of the researchers' position and influence on the research, particularly given the application of IPA; poor reporting of ethical issues; description of data analysis process may have been improved; reflexivity is referenced but not described; presentation of analysis weighted to researcher narrative
Ducharme et. al (2013)	Y	Y	Y	N	Y	Y	C	Y	SW	Y	Y	**Strengths:** Clear aims and relevance; recruitment strategy thoroughly explained; good description of interview guide development; adequate description of data analysis procedure; good description of ethical procedures followed; good use of quotes to support researchers' interpretations **Weaknesses:** Discussion of data saturation incongruent with underlying approach; there was no mention of how the authors' position may have impacted the analysis.

Study	Validity		Findings							Value		Overall Comments
	1. Was the are clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	5. Was the recruitment strategy appropriate to the aims of the research?	6. Was the data collected in a way that addressed the research issue?	7. Has the relationship between researcher and participants been adequately considered?	8. Have ethical issues been taken into consideration?	9. Was the data analysis sufficiently rigorous?	10. Is there a clear statement of findings?	11. How valuable is the research?	
Massimo et. al (2013)	Y	Y	Y	N	Y	Y	C	C	SW	Y	SW	**Strengths:** Clear aims and justification of chosen approach; helpful presentation of interview guide; quotes used to support interpretations. **Weaknesses:** No justification for only recruiting 2 participants; brief description that "researchers' assumptions and pre-understandings are made as explicit as possible" but no description of these assumptions; poor reporting of ethical procedures followed; description of analysis is brief and could have been improved; small sample limits value of findings

Study	Validity		Findings							Value		Overall Comments
	1. Was the are clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	5. Was the recruitment strategy appropriate to the aims of the research?	6. Was the data collected in a way that addressed the research issue?	7. Has the relationship between researcher and participants been adequately considered?	8. Have ethical issues been taken into consideration?	9. Was the data analysis sufficiently rigorous?	10. Is there a clear statement of findings?	11. How valuable is the research?	
Bergman et. al (2016)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	**Strengths:** Very clear justification of approach taken; phenomenological framework explained; good explanation of ethical procedures; helpful presentation of interview guide; good explanation of researcher reflexivity; rich analysis with good use of illustrative quotes
Johannessen et. al (2017)	Y	Y	Y	N	Y	Y	C	SW	SW	Y	Y	**Strengths:** clear aims and relevance; recruitment strategy well described; helpful presentation of interview guide; clear description of derivation of themes; good consideration of clinical implications **Weaknesses:** Poor reporting of the relationship between researcher and participants; poor reporting of ethical procedures; provision of more participant quotes would have been useful

Study	Validity		Findings							Value		Overall Comments
	1. Was the are clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	5. Was the recruitment strategy appropriate to the aims of the research?	6. Was the data collected in a way that addressed the research issue?	7. Has the relationship between researcher and participants been adequately considered?	8. Have ethical issues been taken into consideration?	9. Was the data analysis sufficiently rigorous?	10. Is there a clear statement of findings?	11. How valuable is the research?	
Pang & Lee (2019)	Y	Y	Y	N	Y	Y	C	Y	SW	Y	Y	**Strengths:** clear justification to explore experiences in Chinese population; good explanation of ethical procedures; helpful inclusion of example interview questions; good description of analysis process; adequate reporting of how final themes were arrived at; good consideration of contribution to existing literature **Weaknesses:** further quotes could have been presented to support analytic narrative, no description of researcher influence on the analysis

Study	Validity		Findings							Value		Overall Comments
	1. Was the are clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Are the study’s theoretical underpinnings clear, consistent and conceptually coherent?	5. Was the recruitment strategy appropriate to the aims of the research?	6. Was the data collected in a way that addressed the research issue?	7. Has the relationship between researcher and participants been adequately considered?	8. Have ethical issues been taken into consideration?	9. Was the data analysis sufficiently rigorous?	10. Is there a clear statement of findings?	11. How valuable is the research?	
Popok et. al (2022)	Y	Y	Y	N	Y	Y	C	SW	Y	Y	Y	**Strengths:** clear aims and relevance; good description of recruitment strategy; good description of process of analysis; good use of illustrative quotes **Weaknesses:** use of participants from prior study and the implications of this not considered; researcher influence on the analysis not considered

Study	Validity		Findings							Value		Overall Comments
	1. Was the are clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	5. Was the recruitment strategy appropriate to the aims of the research?	6. Was the data collected in a way that addressed the research issue?	7. Has the relationship between researcher and participants been adequately considered?	8. Have ethical issues been taken into consideration?	9. Was the data analysis sufficiently rigorous?	10. Is there a clear statement of findings?	11. How valuable is the research?	
Thorsen & Johannessen (2023)	Y	Y	Y	N	SW	Y	C	C	Y	Y	Y	**Strengths:** clear description of aims and relevance; good justification for use of narrative approach; good reporting of analytic process; good use of quotes; clear and relevant implications considered **Weaknesses:** using interview data from prior paper not explained; relationship between researcher and participants not reported; poor reporting of ethical procedures

Study	**Validity**		**Findings**							**Value**		**Overall Comments**
	1. Was the are clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	5. Was the recruitment strategy appropriate to the aims of the research?	6. Was the data collected in a way that addressed the research issue?	7. Has the relationship between researcher and participants been adequately considered?	8. Have ethical issues been taken into consideration?	9. Was the data analysis sufficiently rigorous?	10. Is there a clear statement of findings?	11. How valuable is the research?	
Binford et. al (2023)	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	**Strengths:** clear aims and relevance: good justification for interview setting and modifications made to interview schedule; adequate reporting of ethical procedures; thorough description of analytic process and consideration of researcher influence on data analysis; good description of quality analysis assessment **Weaknesses:** consideration to the theoretical assumptions underpinning grounded theory not provided

None of the papers were excluded based on poor quality in the key domains outlined above. All papers satisfied answering 'yes' to questions one and two of the CASP tool. Five papers satisfied answering 'yes' to question nine, and five were answered as 'somewhat', with both strengths and limitations evident. These papers provided reasonable accounts of data analysis procedures, and used adequate data to support their interpretations, but may have been strengthened by further description of the researchers influence on the analysis and by providing more plentiful participant quotes. Given a fair portion of the studies reported using interpretative and phenomenological analyses, the role of researcher interpretation should have been acknowledged. Additional areas of weakness identified across the papers included poor reporting of ethical procedures and not reporting the underlying epistemological and ontological assumptions underlying the research. These issues may be related to poor reporting and as such, quality appraisal of these domains was difficult.

Phase 3: Data Extraction

This phase involves reading the included studies and extracting their raw data. Participant quotes and themes/subthemes/key concepts from each paper were entered into an 'initial extraction' grid (Appendix B). Data was extracted verbatim to avoid losing important data (Atkins et al., 2008). Study information (country, sample, data collection etc.) was also extracted to contextualise interpretations (Table 4; Feast et al., 2018).

Phase 4: Determining how the Studies are Related

To determine how the studies were related, common themes/concepts identified from individual studies were entered into an 'initial translations' grid (Coventry et al., 2015; Appendix C) and clustered together with descriptive labels based on re-occurring concepts.

Phase 5-6: Translating the Studies into One Another and Synthesising the Translations

The reviewer must now decide how the studies and their concepts relate to one another (France et al., 2019). Phase five has been likened to 'constant comparison' (Cahill et al., 2018) and may include summarising the themes and concepts identified from paper one, then moving on to summarise the themes and concepts from paper two, and so forth, noting areas of convergence or divergence between the studies (Sattar et al., 2021). An example of this process can be found in Appendix D. Returning to the study characteristics during this phase aids in developing a deeper understanding of the commonalities and differences between papers (Scott & Grant, 2018). A second translations grid was created to display this phase of the synthesis (Appendix E).

When synthesising the translations in phase six, studies are now viewed as a 'whole' (Cahill et al., 2018; Sattar et al., 2021; Toye et al., 2014). 'Translation' involves comparing key concepts from primary studies to develop new understandings. A 'concept' is defined as "a meaningful idea that develops by comparing particular instances… fundamentally, concepts must explain not just describe the data" (France et al., 2014). Noblit and Hare (1988) identify two types of translation: reciprocal translation identifies and explores commonalities and shared concepts across studies, whereas refutational translation identifies and explores differences and incongruities across studies. Reciprocal translation may include consideration of refutation within a common concept i.e., differing perspectives on the same concept (Campbell et al., 2011; Sattar et al., 2021; Urrieta & Noblit, 2018). Column one of the translations table developed in phase five (Appendix E) displays the new concepts which provided a more comprehensive understanding of the phenomenon.

Phase 7: Expressing the Synthesis

Researchers should summarise their findings, describe the strengths, limitations, and influence of the researchers' position on the conduct and interpretations made from the review, and provide recommendations and conclusions informed by the review (France et al., 2019). To satisfy these requirements, a position statement describing the researchers background and epistemological and ontological position is presented at the beginning of this section. The findings from this review are presented in the next section and a critical reflection on the strengths and limitations of the review follows in the discussion.

Results

Seven themes were established from the papers included in this review, summarised in Table 6.

Table 6

Final Themes Developed Through the Meta-Ethnographic Process

Themes
A Complex and Evolving Emotional Journey
Grief and Loss
A Guilty Conscience
Stigmatised, Isolated and Alone
A Changed Relationship and Lost Companion
Lost Identity: Unexpected, Untimely and Unwanted Role Changes
Striving to Cope

A Complex and Evolving Emotional Journey

A complex and evolving emotional journey for spouses was evident across the studies. Descriptors such as "horrible", "hell", "devastating", "a torment", "surrealistic" and "awful" (Bakker et al., 2010; Binford et al., 2023; Johannessen et al., 2017) signal the extremeness of their situation. As YOD entered and disrupted their lives, spouses' emotional reactions varied, prompted by significant moments.

Prior to diagnosis, some spouses experienced doubt and questioned their own perceptions of changes within their partner (Bakker et al., 2010; Johannessen et al., 2017). This was linked to the young age of their partner and healthcare professionals' lack of consideration for dementia to be a possible explanation. Frustration also occurred in the pre-diagnostic stage at their partners denial and unwillingness to seek help, and the consequences of this: "At that time, I did not know that he was ill. He did not want to see a doctor. I thought: If you are not ill, I will leave you... it could have ended in a divorce" (Bakker et al., 2010).

Diagnosis was associated with mixed emotions: for some, diagnosis bought a sense of relief (Bakker et al., 2010; Ducharme et al., 2013; Johannessen et al., 2017), where their initial doubts were disconfirmed, and they finally had answers to the incomprehensible changes experienced within their partners: "So it was actually a relief to get that diagnosis and come to know that it was not me who had been hysteric and seen things I should not have seen. It had all been real" (Johannessen et al., 2017). For others, diagnosis was "hard to fathom" (Binford et al., 2023), accompanied by feelings of shock and disbelief (Ducharme et al., 2013; Johannessen et al., 2017; Lockeridge & Simpson, 2013; Pang & Lee, 2019) at their partner having dementia at such a young age and the implications of this:

> "… it's horrible. You know, and it's horrible to have it happen so young. First, you know, is disbelief, like, 'how could this be happening? You know, really happening?' And then it's… 'shit, what do I do?' Yeah… and to do it so young… I mean, this was

> really our time. And I think, all those [coming] years without him… but, I try not to think about it." (Binford et al., 2023).

This is further illustrated by a wife in Pang and Lee (2019): "I can't believe that he is demented. He is in his 50's. He is still young. Why him?". This highlights the complexity of the experience, where YOD is both confusing and shocking with its arrival in this stage of life.

There was evidence that particular symptoms were very difficult to experience and evoked intensely negative emotional responses. Aggression, apathy, and lack of insight were met with anger, fear, resentment, and anxiety (Ducharme et al., 2013; Johannessen et al., 2017; Lockeridge & Simpson, 2013; Massimo et al., 2013; Thorsen & Johannessen, 2023). A spouse in Popok et al., (2022) described "walking on eggshells" in response to the unpredictable nature of her partners mood. As explained by Lockeridge and Simpson (2013), two female spouses found it particularly difficult to manage their partners physical aggression, with one wife reporting she had begun to imagine that her husband might one day murder her. Another wife in Thorsen and Johannessen (2023) reported getting "death threats" from her husband as he became increasingly aggressive. A wife in the study by Ducharme et al., (2013) also highlighted the emotional impact of her husband's aggression, indicating the shock of being exposed to such behaviour: "What upsets me a lot is his aggressiveness... I'd never been confronted with this sort of thing in my life. I have to say it's quite something because he's aggressive and it's totally out of nowhere".

There was evidence that the experience of being the spouse of a person with YOD became emotionally draining for many spouses, as they struggled to not only come to terms with the diagnosis and what that meant for them, their partner, their futures, and their relationship, but also managing the wider challenges posed by behavioural symptoms, their new-found caregiving role and oftentimes financial difficulties. This was highlighted by a participant in Massimo et al., (2013): "Most of the time I am sad because I hate the change. I hate that we are going through this and we have to change our entire lives and everything about them. Nothing is the same.". A spouse in Binford et al., (2023) further illustrates the depth of the devastation YOD had bought to their life: “It’s devastated our lives – my life… it’s horrible. Financially devastating, emotionally very painful… and [I’m] telling people my husband has dementia at 53…”.

Grief and Loss

As spouses were faced with a life-changing diagnosis at this life-stage, they began to grieve their future and feelings of sadness and helplessness emerged both for themselves and for their partners, illustrated by a participant in Bakker et al., (2010): "... when my husband was asleep, I was in the living room, crying and thinking, not knowing what the future might bring... I was only just 50 years old ... how devastating for him". A spouse in Lockeridge and Simpson (2013) described feeling “cheated” by dementia entering their life at this life stage. Another spouse in Bergman et al., (2016) expressed anger at the perceived loss of their wife, which was simultaneously experienced as devastating:

> “At night when she sleeps, I hug her, feeling her scent and I beg, beg her not to leave me. There is nothing I can do, she has in a way already abandoned me… When I think about it I get angry instead, life is so unfair.”

Spouses described a breadth of losses to grieve, illustrated by themes such as ‘grieving and adjusting to change’, ‘adaptation to loss’, ‘grief for loss of spouse, married life, and midlife projects’, ‘multiple unanticipated and early losses’, and ‘loss of anticipated future’ (Bakker et al., 2010; Ducharme et al., 2013; Lockeridge & Simpson, 2013; Pang & Lee, 2019; Popok et al., 2022). Spouses gradually began to grieve their partner, their prior relationship, their imagined future and their own work and independence: "I'm grieving the loss of my husband, of my lover... I know that he'll grow more and more dependent. I'm also grieving the loss of my work" (Ducharme et al., 2013).

For those spouses with younger children, they spoke about the loss their children also faced (Binford et al., 2023; Ducharme et al., 2013) and the difficulty of telling their children: "My children... it broke my heart.... what broke my heart... most was for my children to see their father like that. How was I going to tell them the truth... their father has what? Alzheimer's" (Ducharme et al., 2013). One of the participants in Johannessen et al., (2017) encapsulates the burden of grief felt: "It is an enormous burden. It is extremely sad… what sort of life is that? It is a constant grief. It is not a life for him either. Death would be a relief. It is hell."

A Guilty Conscience

A theme regarding guilt, prompted by a variety of situations, was evident in this synthesis (Bakker et al., 2010; Johannessen et al., 2017; Lockeridge & Simpson, 2013; Popok et al., 2022; Thorsen & Johannessen, 2023). Guilt was described when participants turned to consider their own needs, and for one spouse there was a sense of requiring validation from others to make decisions to take a holiday for respite: "Maybe I can talk to the psychologist who can alter my way of thinking. Maybe he can take away the guilt" (Bakker et al., 2010). This was described as ‘duality’ in the caring situation, where the spouse inherently knew that they needed to source outside support but grappled with guilt born from seeking this.

Considering their partner’s new limitations and needing to communicate this to their partner prompted guilt and some friction for some spouses (Lockeridge & Simpson, 2013; Popok et al., 2022). A sense of being the “bad guy” was felt by a spouse when needing to point out limitations for their partners’ own safety, perhaps because of the young age of their partner and feeling discomfort at a perceived removal of their autonomy:

> "It's difficult to point out to him that I think it's a change… I'm not sure if he sees it that way. I try to point it out, but I don't know if I'm doing more harm than good trying to be sort of open by talking about it." (Popok et al., 2022).

When making decisions regarding their partners’ journey to moving into a permanent residential care setting, there was evidence that these provoked feelings of guilt, despite knowledge that this was in the best interest of their spouse:

> "I got a guilty conscience and said 'I have to think about it' (...) I wept bitterly but thought, 'I have to do it!'. However I kept him at home for another month. I was not able to let him go. It was incredibly difficult for me." (Thorsen & Johannessen, 2023).

The decision to move their spouse into a care setting was complicated by spouses balancing their sense of obligation to their partner yet needing to continue work for financial reasons. A spouse expresses grappling with this decision:

> “The CPN did say I need to look at my priorities. Whether my priorities were [partner] or the business. And, I mean, I can't choose between the two. The business is what keeps a roof over our heads and pays for our food... so I have a job. But I have also taken on a lifelong commitment to my husband and as far as I'm concerned the two go hand in hand." (Lockeridge & Simpson, 2013).

Many spouses in this synthesis expressed disappointment and frustration at a lack of age-appropriate services for their partner (Bakker et al., 2010; Ducharme et al., 2013; Lockeridge & Simpson, 2013). In the subtheme, ‘the fit between needs and services’ in Bakker et al., 2010), the spouse found the poor fit between services and her husband’s needs to be distressing, as he was “among older people with dementia with fewer activities and he just walked around there, lost.” Furthermore, a spouse in Lockeridge and Simpson (2013) was “horrified” and “heartbroken” when they arrived at a day centre to be confronted by their husband covered in a pink crochet blanket, asleep amongst a group of elderly women. Thus, guilt may be afflicted where spouses feel they are placing their partner in an unsuitable and care-situation if they feel forced to accept inappropriate services out of necessity for theirs and their partners wellbeing.

There was however evidence that guilt was not a shared experience for all spouses. Thorsen and Johannessen (2023) identified gendered differences in the experience of guilt when deciding to apply for nursing care for their spouse. Male spouses in their study spoke to this decision as being one of necessity and approached the decision ‘rationally’, seeking care and respite much sooner than wives. One husband emphasised this: “…it was wonderful. A relief! Really! Not having responsibility for an ill person any longer. I was so ready for it; I had no problems when letting her go”. Female spouses however expressed significant guilt at this decision: “You know, I had an extremely guilty conscience. I thought I was mean, since he was not that ill: he was just not able to take care of himself”. One wife also suggested that men are more easily able to move out of the home: “You can’t just move out. I know that men do. A great many is my impression. *They* can move out, while we women have a conscience, you know!”.

Stigmatised, Isolated and Alone

Spouses described YOD as a stigmatising and isolating experience driven by lack of understanding from others and a desire to avoid social embarrassment for themselves and their partners (Ducharme et al., 2013; Johannessen et al., 2017; Lockeridge & Simpson, 2013; Pang & Lee, 2019; Popok et al., 2022; Thorsen & Johannessen, 2023).

This was highlighted by themes such as ‘stigma in YOD’, ‘social isolation’, vanishing social relations’, ‘lack of social support and loneliness’ and ‘non-disclosure to others’. Social and cultural perceptions of dementia being an ‘old age’ disease were commented on and spouses expressed embarrassment at their situation, often in response to their perception of their partners’ limitations which appeared to the outside world to be incongruent with their abilities as a younger person: "… it got a bit embarrassing when we went out. You didn't want to. I knew people were looking at us but we'd sit somewhere out of view because he got so that he couldn't use a knife and fork properly" (Lockeridge & Simpson, 2013).

For one spouse, there was a sense of initially striving to avoid disclosing their partner’s diagnosis of YOD, however as the disease progressed, they felt they had little choice but to make others aware: "We didn't tell a whole lot of people at first... now I tend to come out with it because it just shows more" (Ducharme et al., 2013). Self-enforced isolation appeared to follow as a means of protection from negative responses and attitudes, which may be counterproductive to the wellbeing of both spouses and their loved one as their social support system shrinks. Spouses described an increasing sense of loneliness as they gradually withdrew from their social networks and limited social engagement with peers to avoid embarrassment from perceived negative attitudes: "Nobody really want to know you when you've got dementia so it wasn't like we could go out and make friends" (Lockeridge & Simpson, 2013).

The additional roles, and responsibilities they take on as their partners inevitably require more care, left little time to connect with others (Popok et al., 2022; Thorsen & Johannessen, 2023). This indicates a duality of isolation for spouses in YOD, where isolation is not only due to unique, practical obstacles they face but also to protect the dyad from stigmatisation. One of the spouses in Pang and Lee (2019) powerfully illustrates the sense of stigma, embarrassment, and the resulting impact of withdrawing from others:

> We [my husband and I] felt that we were being stigmatised by others [friends and neighbours]. For example, one of our neighbours always asked him: 'who is she [wife]?' My husband replied: 'she is my mom'. Then he [the neighbour] laughed. I felt so embarrassed... it's a 'loss of face' to have a husband with dementia, especially when he is so young. I will not seek help from others because they will look down on me. I felt inferior to others".

A Changed Relationship and Lost Companion

In addition to the loss of their imagined future, the papers in this synthesis primarily painted a picture of a felt sense of loss of their expected life-partner (Bergman et al., 2016; Binford et al., 2023; Lockeridge & Simpson, 2013; Massimo et al., 2013; Pang & Lee, 2019; Popok et al., 2022; Thorsen & Johannessen, 2023). Spouses noticed their partner "drift away" (Thorsen & Johannessen, 2023) and reflected on how this was unexpected at this stage of life: "I have never imagined that I would 'lose' my wife at such a young age. I thought we would support each other for lifelong" (Pang & Lee, 2019).

As dementia progressed, some spouses referenced their partner as being irreparably changed and not the same person any longer. This gave rise to feelings of aloneness within their relationship. As described by a spouse in Massimo et al., (2013), losing the person they would normally share difficulties with was particularly difficult: "I never expected to be by myself... all these changes in our lives by myself... not having someone to talk to... not having someone to talk things over with. That is the hardest part". For a spouse in Binford et al., (2023), a sense of partnership that was previously felt was no longer YOD affected their partners' ability to engage jointly in life decisions: "It was definitely a partnership… so, yeah, I am alone. I'm doing everything alone. You know, it feels terrible. It's more responsibility."

Furthermore, some spouses began to experience the relationship dynamic very differently. Changes in personality and new challenging behaviours contributed to the affected partner being experienced as no longer a romantic, loving, and supportive partner for a husband in Binford et al., (2023): "… the marriage was over long before diagnosis… it was certainly when she was abusive to the children. Her behaviours towards the kids and me were a betrayal of our marriage. I no longer saw her as my wife."

There was also evidence that some spouses came to view their partner in a more child-like manner due to the amount of care and support they required and had thus begun to feel more like a parent than a spouse (Binford et al., 2023; Ducharme et al., 2013; Johannessen et al., 2017; Thorsen & Johannessen, 2023). As illustrated by a spouse in Ducharme et al., (2013) their caregiving impacted upon their ability to feel like a spouse: "What it means deep down is that he's no longer your spouse and you become like his mother or his guardian!". This was mirrored by wives in Thorsen and Johannessen (2023) who used the metaphor "like a child" to describe their spouse. The authors noted that husbands in their study did not use this phrase and postulated that for young female carers, their new caregiver role may be seen as an extension to a mothering role they were preparing to reduce as their children were now older. Experiencing their partner in this way appeared to contribute to a further loss of the relationship where a 'husband and wife' relationship was incongruent with the new perceptions spouses had developed, illustrated by a wife in Binford et al., (2023):

> “He was a partner to me … and a good spouse … I’m caregiver now and he’s not really there in his mind … he’s just gone … right now, I don’t visualize myself as a spouse, because he’s not there … I mean, I am totally just caring for him.”

Contrary to the dominant discourse described above, there was evidence that some spouses were able to retain a sense of connectedness with their spouse in adjusted ways and maintained a sense of being ‘husband and wife’ (Bergman et al., 2016; Pang & Lee, 2019; Popok et al., 2022). These studies referenced making conscious efforts to ‘be’ with their partner through date-nights, arranging shared activities and taking time alone together, where spouses could concentrate on the present moment with their partner outside of their caregiving role. Spending time together became a key priority to retain connection, as explained by a spouse in Popok et al., (2022): “You have to learn to love your wife in a new way. She’s not the same person. The old ways don’t work anymore, so what’s the new way? You know, and that became – what should I say – the journey”. In addition, a spouse in Bergman et al., (2016) commented that togetherness without words is still an important way to retain the husband-wife bond:

> “Every evening, we take a walk around the neighborhood […] this is our most important moment, when we just walk without talking so much. We walk together and go hand in hand in the dark; it is a nice touch. We don’t need so many words; we know each other”.

There were notably more partners with Alzheimer’s type dementia in these examples, which perhaps links to the challenge posed by dementias that contribute to more personality and behavioural, rather than functional changes, in the experience of the relationship.

Lost Identity: Unexpected, Untimely, Unwanted Role Changes

A theme present across the papers was a reference to resentment at a perceived change in role from spouse to a 'caregiver' and a felt sense of a lost identity (Bergman et al., 2016; Binford et al., 2023; Ducharme et al., 2013; Johannessen et al., 2017; Lockeridge & Simpson, 2013; Massimo et al., 2013; Popok et al., 2022; Thorsen & Johannessen, 2023). This was reflected in themes such as 'acquiring caregiver role prematurely and juggling it with others', 'identity and role change', 'additional obligations' and 'the process of role identity change'. Spouses described being "too bounded" to (Thorsen & Johannessen, 2023), "institutionalised" in (Lockeridge & Simpson, 2013) and "restricted" (Bergman et al., 2016) by their new 'caregiver' role. This new role was often met with resistance and the heavy responsibility overwhelmed spouses who, still in an active phase of life, still occupied roles as professionals within the workplace and parents of young families: "I don't feel at all like an expert, just overwhelmed. I don't feel young anymore, I feel like an old lady. Being a family caregiver isn't where I was at in my life... I'm the mother of a young child" (Ducharme et al., 2013). Where these roles are perhaps perceived as chosen, expected, and wanted, that of a caregiver appeared to be unexpected, untimely, and unwanted, and a barrier to holding on to other important roles. This influenced intense rejection of the title for this spouse:

> "All of a sudden I went from wife to caregiver. And that label was put on my chest that said 'caregiver now'. And then I accepted it for a little while and then I realised that 'I don't want to be your caregiver'. I really don't want to do that." (Massimo et al., 2013).

This unwelcomed and unfamiliar change in role was compounded by the burden spouses felt by assuming new roles which were stressful and unfamiliar to their previous roles within the relationship and a loss of shared responsibilities as a couple:

> "Our roles are changing... when you first get married, you talk about sharing responsibilities... you really get into different mode, and you have roles. I'm assuming both roles in many ways and eventually I am going to be the sole provider of the family and that weighs heavily... that's a big impact" (Binford et al., 2023).

Spouses were left with little time to take care of themselves and there was a sense of threat to the sense of self where being enforced into a role which was out of sync with their life-stage and “goes against the flow” (Ducharme et al., 2013). This contributed to spouses ‘losing’ parts of themselves:

> “… I didn’t sign up for this kind of thing. I’m uncomfortable with that. So, my whole role is changing, I guess not only in terms of a husband-wife relationship… but my whole kind of role view of myself is having to change … this is not who I think I am.” (Binford et al., 2023).

There was a sense of feeling consumed by their new ‘carer’ identity and participants made references to wanting to “let go” (Bakker et al., 2010) and “find themselves” (Thorsen & Johannessen, 2023) again. There was a yearning for “freedom” (Bergman et al., 2016), “moving on” and getting “a piece of my life back” (Bakker et al., 2010), although as described above, this was met with feelings of guilt and shame for wanting this: "What if I could get some time with myself? I am ashamed that I feel like this, but it is not as bad as it may sound. I just need to be alone for a little while..." (Bergman et al., 2016).

In contrast to the prominent and pervasive discourse described above, there was evidence in the study by Pang and Lee (2019) that assuming the identity of caregiver was seen as something that must be accepted and ultimately, a privilege. Although both husbands and wives in this study found assuming new and unfamiliar roles difficult, assuming the role of 'caregiver' did not appear to be rejected or as troublesome as with other spouses in this synthesis. The authors reference the influence of Chinese cultural values including 'interdependence and marital obligation', 'fatalism', and 'collectivism' as underpinning the ability of spouses to accept and adjust to this change in role. The authors report that spouses believed that they had to accept the losses that came with the diagnosis to accept and adjust to their caregiving role. To facilitate with this acceptance, religious and spiritual support, prayer, and reviewing positives of life pre-dementia were commented on as contributors to this acceptance. The caregiving role was thus seen by this spouse as meaningful and purposeful, rather than burdensome as seen in other studies in the synthesis:

> "To me, taking care of my wife is definitely meaningful because I can bring hope to her and build up her confidence to live with dementia... even my siblings appreciated what I have done to my wife. I'm confident to say that I have made the right decision [to take up the caregiving role]".

There was also some evidence in the study by Binford et al., (2023) that caregiving was viewed as integral to the spousal role, rather than an additional burden to bear. The notion of being a 'caregiver' was highlighted as having different connotations for a spouse in this study:

> "… maybe further down the road I can identify as caregiver, but I'm just the spouse doing what spouses do … that's what you do in a relationship … you take care of the other person, but to the point of being a caregiver? … that has other implications to me."

Striving to Cope

To cope with the changes within their partners, their relationships and their future, spouses enacted a range of coping strategies (Bakker et al., 2010; Bergman et al., 2016; Ducharme et al., 2013; Johannessen et al., 2017; Lockeridge & Simpson, 2013; Massimo et al., 2013; Pang & Lee, 2019; Popok et. al., 2022). Reframing and ‘changing perspectives’ about the changes within their partners as caused by disease and not intentional appeared to be helpful in allowing spouses to release some of the frustrations and disappointments they experienced (Bakker et al., 2010; Ducharme et al., 2013; Lockeridge & Simpson, 2013; Massimo et al., 2013; Pang & Lee, 2019). A spouse in Massimo et al., (2013) illustrates this: "I've learned that is the disease. I've got that. It's not him. I can almost picture the neurons not being able to, you know, connect". A spouse in Popok et al., (2022) expressed that cultivating this understanding is not without difficulty, and takes a conscious and consistent effort:

> “I’ve cultivated a lot of patience, a lot of forbearance, a lot of understanding, and I find myself falling short time and again, but I see myself consciously making the decision about how should I phrase this response to something she says, or instead of saying something critical, or didn’t you know that something, or don’t you remember that, or have you forgotten that, or something like that.”

For some spouses who encountered conflicts regarding their partners’ declining functional ability or behavioural disturbances, there was some evidence that they made efforts to adjust their expectations or own behaviours to cope (Bergman et al., 2016; Lockeridge & Simpson, 2013; Massimo et al., 2013; Popok et al., 2022), as illustrated by a spouse in Massimo et al., (2013): "I don't have as many expectations for him. If he does or doesn't do something. I don't make a big deal about it. You know, like a hall pass". Additionally, a spouse in Bergman et al., (2016) referred to striving to maintain “harmony” by being less critical of her partner: “I try to minimize the conflicts; there is no point. We want happiness and harmony in our relationship and in our lives. I must remember how important it is to not contradict or correct him when he is wrong.”

Discussion

This meta-ethnography examined the existing qualitative literature exploring the spousal experience in YOD. The synthesis suggested that spouses go through a complex, emotional journey marked by a series of significant losses. Diagnosis triggers a cascade of emotional experiences, and the beginning of a difficult grieving process of both present losses and the loss of an anticipated life-course and future. Spouses also appeared to go through a complex process of role change as they suddenly became a caregiver earlier than anticipated, often with resistance. Not all spouses followed this course, which will be discussed. Some spouses experienced feelings of guilt and shame related to their situation, prompted by stigma and judgements received from others, and when making difficult decisions regarding their spouses’ care arrangements. Overall, the spousal experience has been explored in more depth, and the findings provide potential avenues for targeted support, and where future research efforts may be focussed.

The Challenge of Premature Caregiving and Role Shift

Many spouses in this synthesis referenced a challenging, perceived shift in their identity from spouse to caregiver, highlighted as being unexpected and unwelcomed during this life-phase. Caregiver identity theory (CIT) proposes that the caregiving ‘career’ is born from existing relational connections such as the spousal relationship, with pre-existing rules and expectations for engagement (Montgomery et al., 2007; Montogomery & Kosloski, 2009; Montgomery & Kosloski, 2013). Changes and transitions in the caregiving context prompt an eventual shift in role identity to that of caregiver. As dementia progresses and the behaviours of the caregiver change to meet the needs of the care-recipient, caregivers' lives may become dominated by their role, as their previous identity as a spouse shrinks and that of a caregiver becomes more dominant by necessity.

Montgomery and Kosloski (2009) propose that distress occurs if caregiving is perceived as incongruent with one's current role identity. The findings from this synthesis suggest that for spouses caring for a partner with YOD, their younger age has a negative impact on this transition and spouses find the identity of caregiver incongruent with their identity at this phase of their life. For example, in the quote by a spouse in Ducharme et al., (2013), caregiving wasn't what they expected at this phase of life as they were still the mother of a young child.

Additionally, spouses in this synthesis expressed concerns regarding the amount of time their caregiving role took in their day-to-day lives. As members of the workforce, parents to young children and with active social lives, spouses found little time to give their full attention to these other valued roles and experiences. These findings align with broader research exploring the impact of the caregiver role in dementia, where consumption by caregiving is referred to as 'role engulfment' (Skaff & Pearlin, 1992). Role engulfment refers to the process of caregiving activities expanding "to a point where they have, in effect, restructured and largely taken over the life of the person providing care, displacing or reducing previous activities and involvements" (Skaff & Pearlin, 1992, p. 657). According to this model, role engulfment gradually diminishes the caregiver's sense of self, negatively impacting their self-esteem and wellbeing.

Echoes of loss of self were shown in this synthesis, where spouses often spoke to their caregiver identity having taken over their previous role identities and yearned for their independence and freedom to have time for themselves. Three key predictors for loss of self that have been identified include young age, being a spousal caregiver and being female (Skaff & Pearlin, 1992). It is perhaps unsurprising that this synthesis highlighted elements of loss of self and role engulfment, particularly given the female skew in the samples. It may be argued that younger spousal caregivers in dementia are more susceptible to role engulfment and loss of self on account of their young age. Older spouses may find incorporating caregiving into age-based expectations of their spousal role easier, as this may be perceived as ‘expected’ given their age and life phase.

Whilst many studies document negative aspects associated with spousal caregiving in dementia, positive outcomes have also been identified including feeling fulfilment and purpose, personal growth, feelings of accomplishment, and a way to express gratitude to a loved one (Beach et al., 2000; Duggleby et al., 2009; Haley et al., 2003; Harmell et al., 2011; Jiang et al., 2020). For the Chinese spouses in Pang and Lee (2019), caregiving was experienced as a meaningful and fulfilling role. Their cultural values significantly influenced how they adjusted to caregiving, echoing existing literature that suggests cultural expectations and norms have a significant influence on caregiving identity and how this is experienced (Dilworth-Anderson et al., 2002; Janevic & Connell, 2001; Lawton et al., 1992). Despite sharing the characteristic of younger age with spouses in the sample, these spouses were less perturbed by their new caregiver identity and did not find this role as burdensome.

Grieving an Anticipated Future

Grief and loss have been extensively explored in the context of dementia, with researchers highlighting the uniqueness of the caregiver experience in this context (Blandin & Pepin, 2017; Chan et al., 2013; Lindauer & Harvath, 2014; Noyes et al., 2010). Dementia grief has been conceptualised as a specific form of pre-death grief characterised by the ‘psychological’ death of the person with dementia, resulting in changes to the self, such as declining cognitive ability and altered personality characteristics (Blandin & Pepin, 2017; Lindauer & Havarth, 2014). Dementia grief is also exacerbated by ‘serial losses’, building in quantity and magnitude because of the progressive nature of deterioration (Blandin & Pepin, 2017; Chan et al. 2013; Large & Slinger, 2013; Santulli & Blandin, 2015).

The ‘dementia grief model’ proposes that dementia grief may be regarded as a process rather than a distinctive emotional state (Blandin & Pepin, 2017). In the initial phase of this process, caregivers may enter a ‘state of separation’, where serial losses experienced provoke the caregiver to become separated from the person with dementia as they were once known, from life as it was experienced previously and from an anticipated future. The ‘liminal state’ follows, where caregivers straddle the transition between their previous and emerging lives. Accepting and tolerating the difficult emotions that arise from these serial losses allows caregivers to enter the final ‘state of re-emergence’, where losses have been recognised and accepted. Clarity and resolution of losses enables caregivers to adapt to their new reality.

The accounts of the spouses in this synthesis were permeated with references to loss, both in the present and for the future. In the present, younger spouses referenced losing a partner with whom to share the responsibilities of mid-life, such as child-rearing and financial responsibilities. Spouses also referred to the loss of the relationship as it was once known and the loss of their independence and self-identity. The losses described in the dementia grief model are paralleled in late-onset dementia, but the loss of an imagined future may present as a particular issue for those dealing with YOD.

An attempt to capture this sense of loss of the imagined future is the concept of chronic sorrow. Originally developed to explain the distress of parents whose child is born with a disability (Olshansky, 1962), chronic sorrow has been applied to explain the experience of loss amongst dementia caregivers and in this context, relates to loss of an idealised reality and loss of potential of a valued person (Eakes et al., 1998; Lindgren et al., 1999; Mayer, 2001; Teel, 1991). Losing an anticipated life partner and imagined future were remarked on as particularly poignant losses for the young spouses in this synthesis, leading to feelings of anger and feeling "cheated" by dementia. Younger spouses may anticipate spending much more of their lives together as a couple and many spouses in this synthesis spoke to the loss of future opportunities for not only themselves but for the couple. This was further intensified by the adoption of a new caregiving role, which did not match with the envisaged future of later life retirement plans. Evidence from the spouses in this synthesis would therefore suggest that the tenets of the dementia grief model may not wholly encompass the experiences of younger spouses, whose present grief and loss may be further compounded by the loss of idealised potential and hopes for their future. Chronic sorrow regarding the loss of idealised potential and hopes for the future may hinder movement through the process of grief in YOD, and spouses may need targeted support to enable them to accept and process the loss of their anticipated future.

Practical Implications and Future Research

The results from this review suggest potential targets for support for spouses, particularly regarding complex loss and identity change. The difficult emotional experience identified in this synthesis supports the suggestion that services should treat spousal caregivers as service-users in their own rights (Ducharme et al., 2014), requiring clinicians to assess for and monitor changes in their emotional state throughout the caregiving journey. This suggestion may be incorporated into the ‘good practice’ guidance published by the Angela Project, which suggests that YOD services should be tailored to reflect the needs of people with YOD and their caregivers (Stamou et al., 2021). Additionally, the findings from this synthesis suggest that younger spouses may be highly susceptible to role engulfment. These findings complement the ‘Young Onset Dementia Pathway’ recommendation for the provision of respite support for caregivers (Young Onset Dementia Network, 2023). This provision may offer some protection from role engulfment amongst young spouses, enabling them to maintain aspects of their identity outside that of a caregiver.

Furthermore, some spouses expressed feeling guilty for turning to consider their needs for relief and respite from their caregiving duties, whether in temporary or more permanent arrangements. The concept of guilt regarding the decision-making process in transferring a loved one with dementia to a care setting has been explored in older adults (Teng et al., 2020). In this context, it is hypothesised that guilt and shame may be heightened by spouses perceiving the placement of their young partner in a care setting to be a cruel act, particularly if care settings are perceived to be ill-equipped to provide age-appropriate care for their loved one. Although further research exploring these hypotheses may be useful, and there is currently little evidence for what intervention may help in reducing this conflict that caregivers may feel (Lord et al., 2015), a sensible suggestion may be the provision of compassion-focused interventions aimed at reducing guilt and shame. Emerging evidence suggests that CFT-informed interventions for dementia caregivers can support in increasing self-compassion and reducing guilt and shame (Gallego-Alberto et al., 2019; Grant & Judge, 2022; Murfield et al., 2022).

This review has also highlighted where future research efforts may be focussed. Qualitative exploration of specific aspects of the experience may include exploring guilt and shame related to decision-making and the specific impact of grief related to the loss of an anticipated future. Additionally, longitudinal research following spouses through their journey may provide further insights ‘in the moment’. As this synthesis highlighted the evolving nature of the emotional experience for spouses, marked by key points in the journey, a longitudinal approach would allow for spouses to speak to their emotional experiences closer to these key moments, rather than relying on their memory.

A valuable area for future research would be to explore how some spouses manage the challenges associated with YOD more effectively than others. Some of the spouses in this synthesis reported managing changes in their partner by learning to love their partner in new ways (Bergman et al., 2016) and coping with the transition to ‘caregiver’ by reframing the meaning of this (Pang & Lee, 2019). This could provide a basis for the development of support and interventions.

Spouses also described a lack of social support and increasing isolation from their support networks. Isolation may be exacerbated by the fact that carers in YOD rarely have access to respite care (Stamou et al., 2021) which would enable them to retain their social lives. Carers have reported that generic dementia support groups are inaccessible due to lack of childcare and experience “indignity” and “otherness” when signposted to attend such groups with much older attendees (Cations et al., 2017), which may exacerbate the already felt sense of isolation in their experience. This review supports ongoing recommendations for the provision of tailored, accessible support groups for carers in YOD (Cations et al., 2017; Stamou et al., 2021).

Strengths and Limitations

A strength of this review is its identification of the paucity of published, qualitative research focusing exclusively on the spousal experience in YOD. Given that comparative research has demonstrated several poor outcomes in this population compared to their counterparts in LOD, including higher levels of psychological distress, poorer quality of life, and higher levels of burden, this is disappointing. Qualitative research has much to offer in offering insights as to why these outcomes are reported. More plentiful exploration of the spousal experience in YOD may extend, or refute the interpretations made from this review.

A further strength is its consideration of refutational information. Producing solely reciprocal translations has been criticised for producing simplistic, re-categorisation of existing concepts (Finfgeld-Connett, 2014). Considering refutational information aids in developing a deeper understanding of a particular issue (Booth et al., 2013). This synthesis was primarily reciprocal in nature however, reporting on refutational information identified within key concepts has contributed to some of the recommendations made.

This review excluded research that had not been subject to peer review i.e., ‘grey literature’ and as such constitutes a publication bias. Using grey literature presents several challenges, including how quality assessment may be applied to sources of information of varying presentation and scope. Nonetheless, this synthesis may have been made more inclusive through the inclusion of grey literature (Adams et al., 2017).

Meta-ethnography is a highly interpretative method (Campbell et al., 2011). It is important to acknowledge that this synthesis is influenced by the author’s own values, beliefs, experiences, and knowledge (see ‘positionality of researcher’ above) and thus, my interpretations came from a relatively ‘outsider’ perspective of this phenomenon. Additionally, meta-ethnography involves several layers of interpretation i.e., the participants' interpretation, the primary authors' interpretation, and the researcher's interpretation. In acknowledging this, direct participant quotes were presented throughout the analytic narrative to provide a credible base for the interpretations and the analysis was shared in research supervision to check the validity and coherence of the interpretations made.

This review identified several limitations in the included studies, including the Euro and US-centric bias in the current evidence-base. Only one study (Pang & Lee, 2019) was conducted in a non-Western country. This limits the transferability of the findings from this review to other cultural and social contexts. In the UK, YOD is more prevalent in ethnic minority groups with 6% of this group receiving a diagnosis of YOD compared to 2% of the broader UK population (Arblaster, 2021). It is therefore imperative that future research in this area purposefully broadens its scope. Given that this synthesis highlighted cultural differences in how caregiving in this context is perceived, exploration of the experiences of spousal caregivers from different geographical, cultural, and social contexts may contribute significant depth to our understanding of the spousal experience in YOD.

Two of the studies were based on the account of only one or two spouses (Bakker et al., 2010; Massimo et al., 2013). Two papers also reported on the same participant interviews (Johannessen et al., 2017; Thorsen & Johannessen, 2023). Although taking different foci and analysed using different methods, this creates bias in the available literature.

Many of the included papers did not report on the ethical procedures followed or the researchers influence on the data analysis, which limited making judgements of quality. Whilst it is acknowledged that qualitative researchers are bound by journal word-limits, this nevertheless limited the depth of quality analysis.

Additionally, suspicions of ‘cherry-picking’ in some of the included papers arose due to results sections presented in a primarily ‘documentary-style’. Documentary-style analyses are typically structured as author commentaries with data (quotes) selected that endorse the commentary, with little to no variation presented (Morse, 2010). Although this review identified refutational experiences across some of the included studies, there appeared to be little variation between participants noted within most studies, contrasting with what was found through this interpretative synthesis. It may be that researchers presented the most ‘dominant’ narrative in keeping with their initial assumptions and may not have given voice to ‘deviant’ narratives which are vitally important to developing understanding of complex, human experiences. Some of the included studies would have been improved by the inclusion of more plentiful and richer participant quotes, which may have highlighted important perspectives and complexities through which to understand the experience of this population more fully. Two papers provided online supplementary material (Binford et al., 2023; Popok et al., 2022) that significantly added depth and credibility to their findings.

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CHAPTER TWO

EXPLORING RELATIONSHIP CONTINUITY IN THE CONTEXT OF BEHAVIOURAL VARIANT FRONTOTEMPORAL DEMENTIA

Abstract

Introduction: There is evidence that suggests that the symptoms of behavioural variant frontotemporal dementia (bvFTD) can place significant strain on the spousal relationship. However, the processes through which these symptoms cause challenges in the relationship remains unclear. The aim of this study was to explore how challenging interpersonal behaviours and personality change undermine the spousal relationship in bvFTD. The framework and ideas of relationship continuity were used to guide the collection and interpretation of the data.

Method: Purposive sampling was used to recruit ten spouses of individuals with bvFTD. These spouses were interviewed regarding their experience of behaviour and personality change in their partner, how they interpreted these changes, and how these changes affected their relationship. Interview data was analysed used Braun and Clarke's (2021) Reflexive Thematic Analysis.

Results: Six themes were generated which provide an insight into how relationships are affected in this context: 'Disrupted Safety and Security', 'Disrupted Connection and Communication', 'The Emotional Toll', 'Changing Appraisals of the Spouse and Dyad', 'Trying to Understand', and 'Coping with Changes'.

Conclusions: The findings from this study highlight several emotional and relational processes which affect spouses' experience of the relationship with their partner in the context of bvFTD. The study findings provide the basis for the development and trialling

of interventions which may support spouses with their emotional wellbeing and adjustment to navigating their relationships within this difficult context.

Introduction

Frontotemporal dementias (FTD) are characterised by focal neural loss and atrophy in the frontal and anterior temporal lobes of the brain. The most common FTD syndrome is behavioural variant frontotemporal dementia (bvFTD; Ahmed et al., 2021). bvFTD is the second most common young-onset dementia, with an average age of onset between 45-64 years old (Bang et al., 2015). Of the 16,000 people in the United Kingdom with a diagnosis of FTD, approximately 50% have bvFTD (Alzheimer's Society, 2018).

Characteristics of bvFTD

The brain regions affected in bvFTD are primarily responsible for emotional control, behaviour, and social cognition (Ahmed et al., 2021; Kurz et al., 2014). As such, bvFTD is distinguishable by profound and progressive deterioration in social and emotional functioning and altered personality and temperament. Amongst the diagnostic criteria for bvFTD (Rascovksy et al., 2011) are behavioural disinhibition, apathy or inertia, and loss of empathy or sympathy:

- Behavioural disinhibition is considered a 'hallmark' feature of bvFTD, and aids in differential diagnosis from other dementias (Rankin et al., 2008). Symptoms include verbal and physical aggression, making offensive comments, and impulsive spending (Rascovksy et al., 2011).
- Apathy and inertia are associated with loss of motivation and decreased initiation, often the initial symptom observed (Mendez et al., 2008). Symptoms include a loss of interest in work, hobbies, and personal relationships (Rascovksy et al., 2011).
- Loss of empathy, the inability to read or imagine the emotional experiences of others, is commonly cited at initial presentation due to apparent indifference directed towards loved ones (Le Ber et. al, 2006). bvFTD causes emotional

blunting and impaired emotion recognition and regulation (Goodkind et al., 2015; Hua et al., 2018; Lee et al., 2014; Otero & Levenson, 2017) which may present as apparent indifference for other people's feelings, ambivalence to significant events, and appearing 'cold' or distant (Rascovksy et al., 2011).

Despite its relatively low prevalence, these hallmark symptoms make it a particularly devastating condition for individuals and their loved ones due to their relational impact (Warren et al., 2013).

Psychosocial Impact of bvFTD

Despite improvements in understanding the pathology and genetics of bvFTD, gaps remain in understanding its psychosocial impact (Hodges & Piguet, 2018). bvFTD has a profound impact on the social and emotional skills required for successful social relationships, further compounded by bvFTD-associated anosognosia and anosodiaphoria, which renders individuals both unaware of their symptoms and lacking emotional insight into, or concern about, the impact of their disorder on themselves and others (Mendez & Shapira, 2011). The current evidence-base demonstrates that bvFTD poses a significant challenge to interpersonal relationships, particularly within spousal relationships. In comparison to other FTD syndromes and Alzheimer's disease, divorce, and infidelity (by the person living with bvFTD) is more frequent in couples where a spouse has bvFTD (Takeda et al., 2019). Marital satisfaction is also lower amongst bvFTD couples compared to their counterparts with Alzheimer's disease (Ascher et al., 2010).

Relationship Continuity Framework

To conceptualise how symptoms of dementia impact the spousal relationship, the framework of relationship continuity has been developed (Chesla et al., 1994; Kaplan, 2001; Riley et al., 2013; Riley, 2019; Walters et al., 2010). Relationship continuity encapsulates five domains (Table 1) denoting whether the post-dementia relationship is experienced as a continuation of the relationship pre-dementia, despite the inevitable changes that occur (continuity) or, as radically different to the pre-dementia relationship (discontinuity; Riley et al., 2013).

Table 1

The Five Domains of Relationship Continuity (Riley et al., 2013; Riley, 2019)

Domain	Continuity	Discontinuity
Relationship Redefined	The relationship continues to be viewed as a marriage	The relationship is experienced as completely changed or reflective of another dynamic e.g., parent and child, carer and care-recipient
Same/Different Person	The person is viewed as fundamentally the same, despite the inevitable changes wrought by dementia	The person is viewed as radically different in an essential way
Same/Different Feelings	Feelings of love and affection remain	These feelings have been replaced with other feelings e.g., anger, resentment, protectiveness
Couplehood	A sense of belonging to a partnership and experiencing life together remains felt and established patterns of communication and time spent together continue	Spouses view themselves in an individualistic way
Loss	Feelings of loss are more limited or absent for those who perceive continuity in the relationship	Feelings of loss or grief for the person and relationship as they were pre-dementia are felt

It is important to note the interrelation between domains, for example, feelings of resentment will likely influence the perception of the relationship as a joint and loving 'partnership' (Riley, 2019). Additionally, continuity may become more difficult to maintain as the disease progresses, for example, feelings of loss may be more pronounced in the latter stages of the disease (Walters et al., 2010).

Using Relationship Continuity to Understand the Impact of Challenging Interpersonal Behaviours on the Relationship

Several studies (for review; see Riley, 2019) highlight an association between discontinuity and challenging interpersonal behaviours (CIB), such as aggression, disinhibition, and apathy, in dementia and acquired brain injury (ABI). Continuity, as measured by the Birmingham Relationship Continuity Measure (Riley et al., 2013), has been significantly negatively correlated with items measuring symptoms such as apathy, disinhibition, agitation, and verbal aggression (Lewis & Riley, 2021; Poveda et al., 2017; Riley et al., 2018). When comparing a wider range of dementia symptoms, Lewis and Riley (2021) found no such correlation with cognitive changes or mood (depression) changes, indicating that continuity is more negatively affected by CIBs than by changes to mood and cognitive abilities. The authors postulate that these changes are perhaps less central to the identity of the person, and thus do not have such an impact on continuity as do CIBs.

Qualitative investigations have explored this association. The shock caused and extremity of the perceived difference between the pre-dementia person and now may make it difficult to hold onto the sense that this is the same person and relationship (Lewis & Riley, 2021). In the context of ABI, experiencing discontinuity has been linked to the perception of the person as being viewed as a 'stranger' (Bodley-Scott & Riley, 2015; Villa

& Riley, 2017), which makes it difficult to hold feelings of love and affection. In the absence of continuity, a new identity is formed, and this may be constructed in terms of the dominant features of their interactions i.e., the CIBs. The person may be deemed as 'horrible' or 'nasty' (Bodley-Scott & Riley, 2015), thus undermining continuity.

Emotional reactions to CIBs such as aggression have been demonstrated to cause fear, hurt, and anger, particularly where the intentionality and controllability of such behaviours is uncertain (Bodley-Scott & Riley, 2015). It may be that it is very difficult to switch off these feelings in favour of positive feelings, or they may overshadow previously held positive feelings. In ABI, participants have described the challenge of resolving feelings of hurt and resentment, to maintain the loving feelings held in the relationship pre-injury (Bodley-Scott & Riley, 2015; Villa & Riley, 2017). Also, aggressive behaviours may make it very difficult to even like the person (Bodley-Scott & Riley, 2015).

Discontinuity has also been linked with reduced levels of expressed warmth, empathy, reciprocity, and affection by the person with ABI (Bodley-Scott & Riley, 2015; Villa & Riley, 2017; Yasmin & Riley, 2021). Without overt verbal or physical expressions of positive affect towards spouses, it may be difficult to maintain positive feelings where this is not reciprocated (Yasmin & Riley, 2021). Perceived emotional indifference has also been linked to the perception of changed identity in research exploring relationship difficulties in dementia (Boylstein & Hayes, 2012). Furthermore, an absence of pro-social behaviours, such as conversing, sharing humour, and initiating time spent together, may damage the bonds that maintain the relationship and sense of couplehood. The absence of prosocial behaviours may reduce the amount of enjoyment that spouses gain from spending time with their partner and pose a block to the sense of being in a loving partnership, as was experienced pre-injury (Bodley-Scott & Riley, 2015; Yasmin & Riley, 2021).

Discontinuity has been implicitly referred to in qualitative research exploring the experience of spousal carers in bvFTD. These studies have referred to the loss of the husband-wife relationship, loss of the person as they were once known and, growing of feelings of anger, frustration, and resentment in response to difficult interpersonal interactions (Massimo et al., 2013; Oyebode et al., 2013; Rasmussen et al., 2019; Thorsen & Johannessen, 2021; Thorsen & Johannessen, 2023).

Aims

The literature suggests that bvFTD places significant strain on the spousal relationship, leading to dissatisfaction and breakdown (Ascher et al., 2010; Takeda et al., 2019). The processes whereby the CIBs that characterise bvFTD undermine the relationship remains poorly understood. In relation to dementia more generally, and to ABI, the concept of relationship continuity has been used to suggest some possible processes of this impact and may offer some understanding of the impact that CIBs have on the relationship in bvFTD. Hypotheses include a stark difference between the prior personality of the spouse and incompatibility between positive, loving feelings and the experience of intensely negative emotional responses towards an aggressive or apathetic spouse (Lewis & Riley, 2021).

The aim of this study was to explore how challenging interpersonal behaviours and personality change undermine the spousal relationship in bvFTD. The framework and ideas of relationship continuity were used to guide the collection and interpretation of the data. It was considered important, however, that this should not have been done to the exclusion of exploring alternative possibilities.

Method

Ethics

Ethical and sponsorship approval was granted from the University of Birmingham Research Governance team (Appendix A). Further approval was granted by the Health Research Authority, through review by the South Yorkshire Research Ethics Committee (Appendix B). Local approval was obtained from two NHS mental health Trusts' Research and Development committees.

Participants and Recruitment

Inclusion/Exclusion Criteria

Spouses of individuals with a diagnosis of bvFTD were eligible to participate. As diagnosis is frequently protracted following symptom onset, with an average delay in diagnosis of between five and six years (van Vliet et. al, 2013), the length of the relationships prior to participation should have been at least five years. Spouses should have been able to identify at least one challenging interpersonal behavioural or personality change on which to base their experience of the changes that had occurred within their relationship. Table 2 displays the full inclusion criteria.

Table 2

Participant Inclusion/Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Spouse of participant has a diagnosis of bvFTD	Non-English speakers
Relationship length is 5+ years	Spouse of participant has a primary diagnosis of other frontotemporal dementia sub-types (e.g. progressive non-fluent aphasia), other forms of dementia (e.g. dementia with Lewy bodies), or other

	neurodegenerative disease (e.g. Huntington's disease)
Spouse aged 30-95	Relationship dyads of a non-romantic type (e.g., parent-child, sibling, other familial connection, friends
Spouse can identify *at least* one behaviour/personality change characteristic of bvFTD	
Diagnosis to have been received *at least* 6 months prior to interview	
Living with partner at time of participation	

Recruitment Procedure

Using purposive sampling, recruitment took place between July 2023-March 2024. Due to the rarity of bvFTD, several recruitment sources were utilised. Clinicians in two local NHS mental health Trusts were asked to identify and provide potential participants with the participant information sheet (Appendix C) and a ‘consent to contact’ form (Appendix D). Additionally, advertising posters (Appendix E) were displayed in appropriate clinical areas for potential participants to self-select.

‘Join Dementia Research’ (JDR), an online platform run by the National Institute for Health and Care Research (NIHR), was also utilised. A lay summary accompanied the study advert (Appendix F). Volunteers could either self-select and await contact by the researcher, or the researcher could contact potential participants whose profiles matched the inclusion criteria.

A study ‘thread’ was also established on the Alzheimer’s Society ‘Talking Point’ forum (Appendix G). Potential participants were asked to contact the researcher by email or telephone if they were interested in participating.

Sample Description

Practical, methodological, and theoretical considerations informed the pragmatic approach taken to estimating the targeted sample size range (Braun & Clarke, 2019; Sim et al., 2018). In line with the theoretical orientation of this study, the positivist notion of achieving ‘data saturation’ was rejected, as theoretically, new insights and interpretations may continuously be generated through engaging in a reflexive and recursive approach to data analysis (Braun & Clarke, 2019). A minimum of six qualitative interviews has been suggested to produce enough diversity to identify broad patterns of meaning (Braun et al., 2016). The lower limit for recruitment was therefore six participants, with an upper limit of 15 identified as both a practicable number of interviews for a doctoral-level thesis (Braun & Clarke, 2021) and to allow for deep and thorough engagement with the data (Sim et al., 2018).

Thirteen potential participants were identified. Three did not participate: one did not meet the inclusion criteria and two declined for personal reasons. Eight wives and two husbands were recruited (Table 3). All participants were heterosexual and married. One participant was recruited via the NHS, four through JDR, and five through the Alzheimer’s Society. Pseudonyms and age ranges have been used throughout the paper to maintain anonymity.

Table 3

Participant Demographic Information

Pseudonym	Sex	Age category	Ethnicity	Relationship length	Time since spouses' diagnosis
Alice	F	Early 70s	White British	35 years	12 months
Beth	F	Early 50s	White British	20 years	9 months
Claire	F	Early 60s	White British	45 years	8 months
Dawn	F	Early 60s	White British	27 years	16 years
Eve	F	Early 70s	White British	55 years	21 months
Frances	F	Early 70s	White British	57 years	4 years
Gina	F	Late 60s	White British	8 years	10 months
Harry	M	Early 60s	White British	45 years	2 years
Isabelle	F	Early 60s	White British	26 years	7 years
James	M	Early 60s	White British	45 years	14 months

Interview Procedure

An initial telephone call was arranged to provide further information, answer questions, verify eligibility (Appendix H) and assess willingness to participate. During this call, ethical rights were emphasised (e.g., right to withdraw, confidentiality procedures; British Psychological Society [BPS], 2021). In line with the BPS Code of Human Research Ethics (2021), all participants were required to provide written, informed consent prior to participation (Appendix I).

Semi-structured interviews provide an opportunity to obtain insight into peoples' experiences, perceptions, and meanings (Braun et al., 2016). Semi-structured interviews were utilised to collect information pertinent to answering the research question(s), as well as allowing flexibility for unexpected and potentially interesting topics to be explored. The interview schedule (Appendix J) contained open-ended questions focussing on a) behavioural and personality changes, b) emotions, cognitions and responses, c) how these changes had impacted the relationship and d) the interpretation, perception and understanding of these changes. The schedule included questions informed by the concept relationship continuity.

Nine interviews were conducted via Microsoft Teams and one at a participants' home. Synchronous online interviews were offered to make the study more accessible (Walton, 2021). Interviews lasted between 66 to 110 minutes (M=85 minutes). Interviews were audio-recorded using an encrypted Dictaphone.

Paradigmatic Position Statement

A critical realist ontological paradigm (Maxwell, 2012) underpinned this study. Accordingly, I acknowledged that 'reality' exists regarding the experiences, perceptions, and meanings participants described, and did not seek to 'prove' nor 'disprove' the existence of such realities. I acknowledged that access to this reality is not directly observable and relies on indirect evidence of such i.e., verbal expressions (Maxwell, 2012; Willis, 2023). Consequently, I appraised language as a tool participants used to communicate meaning and as reflective of their perception of their realities, rather than a tool through which to construct meaning (Hall, 1997). The aim was to provide an account of what individuals say about their experiences rather than to offer an account of hidden meanings that participants themselves may be unaware of. Adhering to a contextualist epistemology, I appraised knowledge to be context-contingent (Madill et al., 2000), viewing knowledge yielded from this study as co-produced between myself and the research participants, shaped by my own values, practices, and interpretation.

Interpretations were offered in terms of suggesting patterns in the data, relating the account to previous research, and my sense-making. Engaging in reflexivity throughout the research process made my role in this visible and provides the reader with insight to my relationship to the material (Madill et al., 2000; Tebes, 2005).

Data Analysis

In line with the aims and theoretical and paradigmatic assumptions of this study, Reflexive Thematic Analysis (RTA) was chosen. RTA is a six-phase, theoretically flexible method for identifying, analysing, and interpreting patterns across a qualitative dataset (Braun & Clarke, 2022). RTA deems researcher subjectivity and reflexivity as integral to knowledge production and so; in utilising this approach, participants' experiences could be analysed in a manner respectful of their subjectivity whilst accounting for the influence of my reflexive interpretations. Extracts from my reflexive journal (Appendix K) provide insight into my reflections during the analysis stage.

When considering which analytic method was best suited to address the aims of this study, Interpretative Phenomenological Analysis (IPA; Smith et al., 2022) was also considered as a potential approach due to its focus on personal experience(s). However, RTA was deemed preferable as a non-theoretical approach it allowed the opportunity to use prior research and ideas about the impact of personality and behavioural changes on the relationship, to shape both data collection and interpretation. The flexibility of RTA allows for the use of existing theory which can support the insights gained from the analysis, and as such was the preferred method as IPA does not allow for this.

Phase One: Familiarisation

To gain "deep and intimate knowledge" of the dataset (Braun & Clarke, 2022, pp. 42), I began by 'actively listening' to each audio-recording and then transcribed the interviews verbatim. Manual transcription was chosen as this facilitates familiarisation through repeated pausing and re-playing recordings to check for accuracy (Byrne, 2022). Following this, I read and re-read the transcripts and began to critically engage with them through an "inquiring and interpretative" lens (Braun & Clarke, 2022, pp. 44). This enabled me to begin making connections between the dataset and my research questions. Questions supporting this process can be found in Table 4. This phase was supplemented by 'notetaking'. An illustrative excerpt from my reflexive journal can be found in Appendix K.

Table 4

Critical Engagement Questions

Critical Engagement Questions
How is this person making sense of what they are discussing?
What is this person trying to communicate by telling me this part of their story?
Why might they be making sense of things in this way ('common-sense', social norms, assumptions)?
How would I feel if I was in that situation (is this different from or similar to the participant and why?)
Why might I be reacting to the data in this way?
What ideas does my interpretation rely on?
What are they *not* saying?
What assumptions about relationships are being made?

Phase Two: Coding

To adhere to the theoretical orientation of this study and retain closeness to the dataset, a pragmatic decision was made to code by hand, facilitated by digital means. Duplicate copies of each transcript were created in Microsoft Word and the 'comment' function was used to attach code-labels to relevant segments of data (Appendix L). Code-labels identify analytically interesting ideas, concepts and meanings of relevance the research question (Braun & Clarke, 2022). I considered using qualitative data analysis software (QDAS), however, QDAS has been critiqued for limiting analytic depth and aligning with paradigmatic assumptions that suggest knowledge is waiting to be 'discovered' (pure realism), rather than influenced by researcher subjectivity and interpretation (Braun & Clarke, 2022).

A predominately inductive approach to coding was adopted to emphasise the expressed meanings and perspectives of participants. An element of deductive coding was utilised to ensure that codes were relevant to the research question and reflected the reflexive orientation of this research. When coding deductively, the concept of relationship continuity provided a lens through which to make sense of and interpret the data. Reflecting the paradigmatic assumptions of this research, codes were both semantic and latent, coding both explicit meaning as expressed by participants and conceptual codes which involved my interpretation of how the meaning expressed was relevant to the research question. Codes were then transferred to individual sheets in Microsoft Excel (Appendix M).

Codes for each participant were collapsed into one Excel sheet and the number of codes were refined and reduced by combining similar codes with each other. Data extracts for each code label were transferred into a separate Excel sheet (Appendix N). Notes were made in the reflexive journal (Appendix K) about developing ideas about potential patterns in the data.

Phase Three: Generating Initial Themes

This phase moves to considering the larger patterns of meaning within the dataset i.e., themes, "a pattern of shared meaning organised around a central concept" (Braun &

Clarke, 2022, pp. 77). Developing initial themes involves clustering related codes to explore meaningful ideas relevant to the research question. Codes were printed out and physically clustered together, with code clusters tagged with a word(s) identifying the broad pattern of meaning within each cluster (Appendix O).

Phase Four: Developing and Reviewing Themes

This phase involves checking the validity of the initial themes to ensure that they are not too 'fragmented' i.e., are they reflective of a central organising concept, the diversity within the dataset and distinct with clear boundaries (Braun & Clarke, 2022). Questions that guided this process can be found in Table 5.

Table 5

Questions Supporting Theme Review

Theme Review Questions
Is this theme viable – does it have a central organising concept that I can clearly articulate?
Does this theme have clear boundaries – what is the focus of this theme; what does this theme include and not include?
Is there enough data to evidence this theme – are there multiple articulations of the core idea?
Is this theme coherent – does it make sense?
Is this theme important – does it offer a relevant and useful information that addresses my research question(s)?

At this stage, candidate themes were shared in research supervision to reflect on theme coherence, relevance, and boundaries. This resulted in some subthemes being moved into themes which better represented their underlying concept.

Phase Five: Refining, Defining and Naming Themes

This phase involves developing theme definitions which illustrate the themes' central organising concept (Braun & Clarke, 2022). These can be found in Table 6 in the succeeding results section. A decision was made to preface theme names with vivid, explanatory quotes to allow participants' voices to shine through in the analytic story and provide a clear indication of its central organising concept.

Phase Six: Writing the Report

The final phase involves producing a written report documenting the process of analysis as well as presenting a narrative of the interpretation (Braun & Clarke, 2022). Illustrative and compelling data extracts were selected from across data items to provide evidence of patterning across the dataset and to evidence my interpretations (Braun & Clarke, 2022). A thematic map was also created to indicate the 'story' of the analysis (Figure 1).

Quality and Reflexivity

Credibility of this account was bolstered by several means. To demonstrate 'commitment and rigour' (Yardley, 2000), I attended qualitative research support groups to develop my understanding knowledge of RTA. I also read published RTAs to gain insights into the 'real-world' application of this method, which enabled me to immerse myself in the application of the method and reflect on my own practices. I present plentiful participant quotes throughout the succeeding section to highlight the bases for my interpretations and arguments hereafter. I strove to provide a balance of participant quotes with my analytic narrative, reflecting the reflexive nature of the analysis.

To demonstrate 'transparency and coherence' (Yardley, 2000), I provided a thorough and thoughtful account of my analytical approach, supported by prose and images documenting the analytic journey. I attended regular research supervision which supported in developing my insights and interpretations of the data. I also shared a draft of my account of the findings with my supervisors who offered their reflections and guidance on the coherence and presentation of the themes.

To illustrate the active role of the researcher and how reflexivity shaped the analytic process (Braun & Clarke, 2022), first-person language has been used in this section. I kept a reflexive journal and excerpts from this are presented in Appendix K to illustrate my analytic decision-making, thought processes and interpretations. Reflexivity also requires the researcher to reflect on their insider and outsider positions when conducting research (Le Gallais, 2008) and consider their personal interest in the research topic (Terry et al., 2017). Outsider positions I hold include not being married and not having experienced a loved one with a neurodegenerative disease. As such, I was able to approach the analysis from a position of open curiosity. Additionally, I am from a different ethnic and cultural background to the participants included in this study. I did however come to this research from a position of personal interest in how physical health conditions affect individuals and their loved ones. I also came to this research with my own personal values and assumptions regarding relationships and had imagined how I may have responded to a loved one with this form of dementia.

Results

Six themes illustrating how ten spouses experienced their partners behaviour and personality changes in the context of bvFTD, and how this affected their relationships, were identified. The final themes, subthemes, and their central organising concepts are summarised below in Table 6.

Table 6

Theme Summary Table

Theme	Subtheme(s)	Central Organising Concept
'I'm never at ease': Disrupted Safety and Security		Participants made implicit and explicit references to anticipatory anxiety and fear when spending time with their partner or in social situations. This affected their relationships as participants felt unable to relax with and enjoy time with their partner.
'I can't talk to him anymore: Disrupted Communication and Connection	A) 'You can't get through the fog to speak to him': The Importance of Perspective-Taking B) 'There's no reaction whatsoever': The Importance of Empathy	This theme is centred around how loss of empathy and blunted emotional responsiveness caused difficulties communicating and connecting with their partner. This affected their relationships as conflict resolution became very difficult.
'It's hard not to take it personally': The Emotional Toll	A) 'What did I do wrong?': Felt sense of Rejection B) 'I Resent Him': Felt sense of Resentment C) 'It's really difficult to turn those feelings off': Difficulty Accessing Positive Feelings D) 'Don't be so bloody selfish': Guilt at Negative Feelings	Evident across participants accounts were primarily strong and pervasive negative emotional responses to the difficult interpersonal and behavioural characteristics of their partners. This affected their relationships as hurt and offence caused hindered access to positive feelings. Additionally, some participants described the emotional impact of having negative emotional responses towards their partner.
'It's not the same anymore': Changing Appraisals of the Spouse and the Dyad	A) 'It's like living with a stranger': A Different Person B) 'We don't have a husband-and-wife	This theme captures how the starkness of the symptoms of bvFTD influenced complex changing appraisals of the affected

Theme	Subtheme(s)	Central Organising Concept
	relationship: A Different Dynamic C) Together but not 'together': Loss of Emotional Connection D) 'I know she loves me in there': The Power of Love E) 'Is it unmasked': Exposed/Changed Personality	partner and the dyad, both post- and pre-dementia.
'Why did you do that?': Trying to Understand	A) 'That is deliberate': Perceptions of Intention and Control B) 'It's the disease': Perceptions of Dementia as the Cause	This theme is centred around differing perceptions of and attempts to understand the cause and controllability of challenging interpersonal behaviours and interactions between the couple.
'You just learn to manage': Coping with Changes	A) 'I have stepped back': Emotional Detachment B) 'I've got to do my best for her': The Role of the Protector	Evident across the interviews were attempts to cope with the situation participants found themselves in, with there appearing to be a gender split between male and female participants.

'I'm never at ease: Disrupted Safety and Security

A pattern evident across participants' accounts was a reduced capacity to feel safe, secure, and relaxed with their partner. Interviews were permeated with implicit and explicit references to how physical violence, verbal aggression, disinhibition, and a volatile temperament, led to feelings of fear and/or anticipatory anxiety. For some participants, this was one of the most difficult changes they experienced in their partner as it disrupted the ability to feel at ease within their relationship. Several metaphors illustrated the anxiety of living with an unpredictable partner including "walking on eggshells" (Beth), being "on edge” (Isabelle) and a sense that their partner could “turn on a six-pence” (Eve). Beth highlights this:

> It's very scary […] we just don't know which Matthew's coming through the door now. When I say which Matthew it's, is it nice Matthew today? Is it nasty Matthew? Is it angry Matthew? […] We just don't know what's going to walk through the door […] your guard is always up so, you know, if if nasty Matthew’s going to walk through the door, you're on edge, how am I going to tackle this? How are we going to sort this out? […] you do sort of have that expectation of what's coming through the door? How am I going to deal with this? (Beth)

Participants who had been physically assaulted described being fearful of their partner, evident through descriptions of self-monitoring such as avoiding “saying things in the wrong tone” (Isabelle), further illustrated by Eve:

> I would think about what I would say, and I would be very aware of what would trigger him to be aggressive, or to push me out of the way […] he’d be very forceful in, you know, that pushing me out the way […] it makes you frightened, yeah, yeah it does [long pause] and I do resent being afraid in my own home. (Eve)

Alice describes becoming less close to her husband, Jim, due to this anxiety:

> …most of the time I was waiting for what was gonna happen next, (you’re on edge) uh huh, therefore it doesn't become, ah, it doesn't become a close relationship it, it just becomes wary of what's coming next yeah… (Alice)

As partners became objects of uncertainty, participants described social engagement with their partner as no longer enjoyable or relaxing as they anticipated negative evaluation or strong reactions from others. Phrases such as “on the lookout” (Dawn), “constantly on the watch” (Frances), and “on guard all the time” (Harry), highlighted the difficulty in being relaxed in the company of their partner. Some participants gave examples of instances where their partner making disinhibited, socially inappropriate and/or offensive comments in public caused fear, illustrated by Dawn:

> …there is no filter with Roger, if he thinks he wants to say something, no matter how inappropriate or outlandish, then he will say it […] that was one of the issues with the neighbour […] he called them some racist names was the bit that just, um, triggered a reaction from them […] that was one of the ones that was a wee bit scary because this young chap legged it across the road and managed to get Roger by the throat, so to stand in between them to do the, 'woah woah, this is what's going on here, there's this mental health problems' […] but in that moment, when you can see it all going, getting out of hand, yeah, you don't know how it's going to end up so there's fear in there […] you don't know how someone else might react to him […] some people might feel so affronted that they just feel they need to tackle him directly… (Dawn)

Participants ultimately felt unable to relax with and enjoy time with their partner, as they found themselves distracted by anxieties of potentially difficult situations, highlighted by James:

> …the thing that she does when we're out is that she stares at people until she gets a reaction from them […] it's quite an aggressive stare like there's gonna be trouble […] I find that I'm constantly scanning around discreetly to see if she's got someone looking back at her wondering what's going on cus then I feel like I've gotta pick up on it […] so yeah it's very difficult to relax unless I'm around the people that I know and even then sometimes it's difficult to relax cus I know they're sort of putting up with her to an extent. (James)

These participants articulate how some of the overt symptoms of bvFTD undermine their ability to enjoy their relationships and feel relaxed in the company of their partner.

‘I can’t talk to him anymore: Disrupted Communication and Connection

This theme centred around barriers to communicating with and connecting as a couple. Two subthemes were identified: a) ‘You can’t get through the fog to speak to him’: The Importance of Perspective-Taking, and b) ‘There’s no reaction whatsoever’: The Importance of Empathy.

‘You can’t get through the fog to speak to him’: The Importance of Perspective-Taking

A perceived inability of their partner to perspective-take affected communication between spouses. Participants described finding conversations with their partner very difficult, as highlighted by Claire: “It’s hard […] I try to explain things, but it goes in it doesn’t even rattle around and it’s like that’s a waste of two minutes…”.

Participants primarily reflected on the inability of their partner to perspective-take affecting open, mutual, and effective dialogue, illustrated by Beth:

> … when previously Matthew would like to have, you know, you see something on the news that you debate but it was always a case of, even if we didn't agree, we would accept each other's points of view (hmm) whereas now, he will not, it's his view, he's right, even if he's wrong, and you know, that's it don't- doors closed, so he won't even discuss anything now… (Beth)

This also influenced the ability to resolve conflicts or share feelings. Participants repeatedly referenced physically distancing themselves from their partners or suppressing emotional expression, as they felt rational and respectful conversation wasn’t possible, as expressed by Isabelle:

> I've bitten my tongue because most of the time it doesn't get me anywhere, I'm not one for arguing and stuff but I can't have an argument with him, it won't work [long pause] um, it's all very personal to him but it's not, I'm just trying to explain how I'm feeling but it's all I'm having a go at him […] I've given up trying to even talk to him now cus it's just not worth it… (Isabelle)

The significance of feeling unable to communicate with a partner was highlighted by Gina. Gina's first husband had become quadriplegic following an accident and was cared for at home by Gina until he died. She later re-married Craig, and drew comparisons between her marriages, particularly her experiences of being a long-term spousal caregiver:

> I was married to [ex-husband] […] and for 11 of these years he was disabled from here (gestures to neck) and I had no problems with [ex-husband] but there was nothing wrong with his brain, he was dead from the neck down but there was nothing wrong with-you could hold a conversation […] we (Gina and Craig) don't talk now because it's too difficult, we pass information but we don't actually have a conversation now, and I suppose that's one of the things I miss, sitting talking to somebody who is a normal human being. (Gina)

'There's no reaction whatsoever': The Importance of Empathy

All participants referred to their spouse losing empathy which was described as "startling" by Eve. This was particularly problematic within the relationship as participants linked this to their spouse having a reduced capacity to acknowledge and respond to upset they may have caused, as highlighted by James: "… she's got no understanding of the fact or that the consequences of the things she does affect people or upset them […] which is hurtful…".

Participants perceived their spouse as unresponsive and emotionally blunted. Dawn reflected on the response of her husband, Roger, when she discovered he had gotten into severe debt in the early stages of bvFTD, and was deceitful about this:

> … for me as a husband and wife there would have been a conversation to be had there, about what have you been doing, where's all this money […] the fact that he just didn't engage with that […] there's important things that need attention and where emotions should maybe run a bit high […] that failure to acknowledge that I might feel upset about it and his inability to acknowledge that I've found that quite stressful… (Dawn)

Participants also commented on how a lack of emotional expression and recognition affected the relationship and the ability of their spouse to support them, as described by Beth: "… if he understood just a little bit of his emotions were having such an impact on somebody else's emotions […] we could take that forward and perhaps hold each other's hands through it…".

'It's hard not to take it personally': The Emotional Toll

This theme captures emotional responses participants experienced in relation to the changes in their partners' interpersonal characteristics and behaviours. Pervasive, negative emotional responses often hindered access to positive feelings towards their partner. Additionally, some participants described the emotional impact of having negative emotional responses towards their partner. Four subthemes were identified: a) 'What did I do wrong?': Felt Sense of Rejection, b) 'I resent him': Felt sense of Resentment, c) 'It's really difficult to turn those feelings off': Difficulty Accessing Positive Feelings, and d) 'Don't be so bloody selfish': Guilt at Negative Feelings.

'What did I do wrong?': Felt Sense of Rejection

Participants referred to feeling rejected by their partner due to a perceived apathy and disinterest in their relationship, withdrawing from expressing affection, and perceived rejection of their care. Beth explains the emotional impact of her husband, Matthew's, withdrawal:

> Matthew doesn't spend a lot of time with us, in the early days when he sort of started um, withdrawing into himself, then it-it-it was sad, it was hurtful, it was, well, 'what did I do wrong?', you know, 'why don't you want to spend time with me?' […] he will do things like, for example, Christmas work party, and everybody was taking their spouses but he wouldn't, he didn't take me, and I said 'Matthew, don't you think you should take me?' 'Why would I want to take you?', so just little things like that, and I feel well it's up to you then, so it's-he doesn't want to-to be engaged with me. (Beth)

Claire, Isabelle, and James spoke about feeling rejected when their partner showed disinterest towards their sexual relationship. Claire illustrates the impact of this:

> I think the physical side of the relationship as well is really hard to come to terms with, it just stops (yeah) and that is (short pause) I dunno, bit of a shock really I suppose, but it is what it is isn't it […] it's quite hard that one of us doesn't miss it so […] he's not been very touchy feely sort of thing […] I find that really hard. (Claire)

Participants responded to rejection with dejection and sadness and, questioned why their partner no longer wanted to engage with them. Isabelle explains how feeling rejected led to her withdrawing her own efforts to engage with her partner, Paul:

> … I am a very loving, touchy-feely kind of person and I miss that, um [long pause] yeah I do miss that side of things, it was never perfect but it was there, whereas this has taken that away completely […] it's actually making the effort of spending time with

> someone and then-when there's only so many times you can make the effort and then told 'no' well, you don't want to bother do you. (Isabelle)

'I resent him': Felt sense of Resentment

Another key emotional response evident was participants' resentment towards their partner for their perceived unkind, disrespectful, and unpleasant treatment of them. Participants found it difficult not to feel affronted, as illustrated by Eve:

> … he'd asked me to remind him to do a little job […] so when he came back in later on, he said um, 'what did you ask me to do', I said, 'well you asked me to remind me about that little job', and um, he stood to attention, clicked his heels, and gave me a Hitler salute, and said (inaudible) 'Mussolini', and you could tell he was really angry with me, and I was really upset, I was really upset, because it's not the kind of person I am […] and I said […] 'if it happens again, I will walk away from you' […] 'I am not going to be treated like that, I don't deserve it, and I'm not having it' […] I don't know whether you think that sounds trite, but […] I really, really felt insulted, and really insulted I mean, when he did that […]. (Eve)

The perceived restriction imposed on them by their spouses in the form of "spoiling" relationships (Frances) or restricting their engagement with loved ones because of their difficult behaviours, also fostered resentment, as explained by Frances:

> … you're having to manage his behaviour then, it's just constantly repetitive, stupid jokes and being rude to people and you know, all of that sort of thing, which is not interesting is it, it's just tedious and um yeah, doesn't lead to good social relationships which for me, are absolutely key […] key to my survival, I can't manage without people so, you know, the fact that he's seemingly to me, spoiling a lot of my

> relationships, I mean other people say that's not true, again my friends are very loyal and good friends but, you know, he does, it's there as a wedge really I think. (Frances)

Where spending time with family was restricted or impacted by the spouse's behaviour, some participants found this a further source of resentment as Isabelle explains:

> …obviously when the grandchildren are there, and I know he struggles with having them here and that again I resent him for […] I would love to have them a lot more but because he won't tolerate them, and it's not fair on them to have them there, cus they don't wanna be in that atmosphere. (Isabelle)

Participants also described resentment at feeling restricted in their freedom due to their partners difficult interpersonal and behavioural characteristics. This is illustrated by Dawn:

> I've certainly described how we live sometimes almost like coercive control, where there is a person you are with, is limiting the people you see, the things that you do, the places you go, to an extent where your world becomes quite small um, and it's-it is unhealthy I think, on this side of the relationship, that sometimes feels like a really uncomfortable place to be. (Dawn)

As described in the first theme, resentment was also felt by Eve, when she described how afraid she felt in her home, and for being the victim of verbal aggression. Eve speaks to the impact of resentful feelings:

> … it's difficult, because it's hard not to feel resentful […] I suppose it's only human nature really […] you wish for what you like […] what makes life better […] I do find the fact I can't be open and honest with Anthony about everything because A he doesn't understand, B he doesn't accept it, C he's got no sense of humour, so he doesn't find fun in anything and C, I tend to think sometimes 'oh it's all down to me', so it just

> makes having a relationship really difficult, because I am very resentful towards him. (Eve)

'It's really difficult to turn those feelings off': Difficulty Accessing Positive Feelings

Most participants referred to having trouble accessing positive feelings towards their partner. For Isabelle, her husband Paul could be "quite nasty" to her verbally and she described how this affected her: "… he would go off and do something really horrible and come back and expect me to accept like as though nothing's happened and it's really difficult to turn those feelings off…".

When participants were hurt by their partner, this also impacted participants' ability to feel positively towards their partner, as illustrated by Beth: "I'm less close to Matthew simply because he's hurt us so many times […] but emotionally, I don't think I'm there at all […] I just can't be there…". Difficult emotional responses and sometimes actively disliking their partner also impacted participants feeling able to be affectionate, as highlighted by Gina:

> When I said to you I felt sorry for him that day we were out […] I felt sorry for him trapped in that body, I sometimes feel like I could give you a cuddle but I just couldn't, I think it might be because I don't like him. (Gina)

Shifts in the relationship dynamic also affected the ability of participants to feel loving towards their partner, described by Frances:

> I mean we don't have a close loving relationship […] he would perhaps say he does, but I don't […] I find that hard actually now I think about it, I find it hard to be as loving as perhaps he'd want me to be… (Frances)

'Don't be so bloody selfish': Guilt at Negative Feelings

When some participants experienced negative emotions towards their partner as a result of their challenging behaviour or perceived ill-treatment, they described feeling that they shouldn’t feel frustrated, upset, or disappointed. Claire became upset when reflecting on her feelings towards her husband, David, when he was behaving in challenging ways: “It's been really hard not to get really I suppose cross with him you know and it's not his fault […] and you shouldn't get cross with him”.

Similarly, James became upset when discussing his anger towards his wife, Nicola:

> …sometimes it’ll make me feel the anger because it’s like, you know, it’s frustration […] and then guilt comes out because you feel bloody angry about the fact that you’ve been angry about it, you know what I mean, it’s a very mixed emotion, that it’s not Nicola and to calm down and like ‘don’t be so bloody selfish’, you know what I mean, that’s when the selfishness and the guilt feeling kind of kicks in (becomes tearful)… (James)

Participants expressed that it was hard to hold in mind that the changes in their partner and subsequent difficulties they faced as a couple were a result of dementia. Eve commented that it was difficult to be “rational” about her feelings:

> I thought ‘I don’t deserve that’ (verbal abuse) you know, and then I thought to myself, it’s because he doesn’t know, it’s his condition, it’s not him talking, so when I’m rational about it, it’s alright, but sometimes I’m not rational. (Eve)

Some participants also described feeling guilty for having changed feelings towards their partner, as illustrated by Isabelle:

> I: Yeah I feel guilty for feeling the way I feel and that kind of impacts on my own feelings as well […]
>
> Int: Why do you think you feel guilty for those feelings?

I: (long pause) I feel guilty for the way I feel because I know it's not his fault (long pause) but I can't help feeling the way I feel and I suppose I need to find a way of acknowledging those feelings, that those feelings are right, and it is normal to feel like that, but it's actually processing those feelings… (Isabelle)

'It's not the same anymore': Changing Appraisals of the Spouse and Dyad

This theme focuses on how, for most participants, their perception of their partner, the relationship and their dynamic had shifted because of the behavioural and personality changes exhibited by their partner. Five subthemes were generated: a) 'It's like living with a stranger': A Different Person, highlights how partners were perceived as a fundamentally changed and different person, b) 'We don't have a husband-and-wife relationship': A Different Dynamic, discusses how changes within their partner became incongruent with participants perceiving the relationship as a marriage, c) Together but not 'together': Loss of Emotional Connection, discusses how the relationship became one of distance rather than closeness, d) 'I know she loves me in there': The Power of Love, discusses the non-dominant narrative of three participants who retained the view of their partners as fundamentally the same person at their core being and e) 'Is it unmasked?': Exposed/Changed Personality, which offers an interesting perspective from two spouses regarding the 'true' nature of their spouse.

'It's like living with a stranger': A Different Person

Most participants no longer viewed their partner as being the same person. Frances referred to her husband, Tom, as having a "complete reversal of personality", Gina felt her husband, Craig, "doesn't exist anymore" and Beth referred to living with her husband, Matthew, as like "living with a stranger". They described their partners as having many positive qualities prior to bvFTD, such as being caring, engaging, empathic, loving, and polite, qualities perceived as no longer present. These participants now described their partners in negative terms and often referred to them as selfish and self-centred. Isabelle illustrates the gravity of the experience: "… this person's changed and it's not the same [long pause] it's like I've got a different person now [long pause] he's just, he's not the same person […] completely different person…" (Isabelle).

As a result to the perceived changes in their partners personality, these participants expressed feeling that the partner they once knew was lost, as Frances illustrates:

> … I've lost a companion, you know, we've been married for 53 years […] so I suppose the thing I find most difficult about the whole thing […] is that fact that you're just left alone and, you know, you've lost your mate, that person is gone, but not gone. (Frances)

'We don't have a husband-and-wife relationship: A Different Dynamic

Most female participants referenced their married relationship as no longer existing. Changes in their partner, such as a loss of empathy, perceived disinterest and behaving in abhorrent ways towards them in some cases, had altered their perception of being in a reciprocal and mutually beneficial relationship, leading to feeling as an individual rather than a couple, as expressed by Dawn:

> … it would be difficult to describe what we have as a marriage, I think we occupy the same house, I care for him, we make things work, but it would not be anybody's idea of a marriage in any conventional sense […] I think the relationship I have with Roger is I have no expectation of him ever looking out for me […] but absolutely every day, he gets what he needs in terms of, kind of, support and care […] that is how it is […] but I think our relationship is fundamentally different […] it isn't a reciprocated thing. (Dawn)

Where participants expectations were disappointed through lack of care, respect, and reciprocity from their partner, this challenged their ability to perceive their relationship as a marriage, as described by Dawn:

> …if something should go wrong in life […] you expect to have somebody that can maybe pick up the slack a bit and can help you through it and when, you know, that's not there, those really difficult life experiences seem all the more difficult because you're just sort of toughing it out on your own really […] and that's sad, you expect that if you've got-you're married and you've got a partner, they are there through thick and thin, that's not how it works, that's not been my experience of how it works… (Dawn)

Additionally, some participants used infantilising language such as "like a wee boy" (Gina), "a naughty toddler" (Isabelle) and "like a three-year-old" (Claire) to describe their partner. This was linked to the perception of their partner as behaving in ways more reflective of a child, such as being impatient (Isabelle), having "tantrums" (Gina) and needing to be monitored (Frances), as illustrated by Beth:

> …there's a little bit of mothering, perhaps Matthew's behaving more like a child so, 'come on Matthew' you know 'you mustn't do this' and grabbing his arm so, 'come on Matthew', we're gonna go and-and try and distract him, so there's almost that mother-mothering sort of behaviour around him um, you feel as if you have to support him more […] you gotta watch him all the time and just make sure that he's understanding so yeah, it-it's like having a toddler around the house. (Beth)

Participants expressed that they felt they were primarily closely monitoring their partners behaviour. This shift in engagement led participants to reference feeling more like a mother or carer, and excluded the experience of being in a partnership, illustrated by Frances:

> I mean, he's constantly blowing kisses to you and that sort of thing […] I just, I find it a bit creepy […] I mean, you don't do that with your mother or your carer […] I mean, you can't be in all of those roles, that's the problem, there's a divide in the roles that- you can't be a wife, a carer, a mother, um, a gatekeeper, security guard […] all the things you have to be, personal assistant […] I mean, I suppose I am still the wife, but I'm not, cus I'm all those other things really, being a wife is a bit of it probably what got me into this, and the rest got added on really. (Frances)

Together but not 'together': Loss of Emotional Connection

Most participants made references to feeling emotionally disconnected from their partner. Partners were experienced as "cold" (Alice), "absent" (Beth), and "like a mechanical toy" (Gina). Frances described this loss of connection as "somebody to do nothing with syndrome", indicating the disconnect between herself and Tom. Isabelle concludes: "… the emotional connection isn't there […] that emotional contact isn't there…". Over time, relationships became superficial and based in practical matters as illustrated by Dawn:

> …he tends to have quite a literal response […] not particularly an emotional response […] I think over the years […] it is what I expect now and so, my reaction to it is that you just kind of deal with factual stuff and then move on with life. (Dawn)

Participants expressed feeling lonely as a result, highlighted by Isabelle: "I'm not on my own but I'm alone if that makes sense […] it was like there was something missing". Participants also found their spouses to be emotionally unresponsive, making it difficult to share feelings with their partner. Alice describes a particularly muted response to her birthday from husband Jim:

> Very distant yes, no empathy, no feeling, recently I said to-'oh Jim, today was my birthday', 'oh, was it', you know […] any of the things that a person would want to share a feeling with, not there, not there. (Alice)

'I know she loves me in there': The Power of Love

There was some evidence that not all participants' experiences fit with the dominant narrative regarding the perception of their partner as a stranger and their relationship as no longer a marriage. For Harry, James and Claire, their descriptions were complex and paradoxical at times. Although they struggled with the differences in their partners, they viewed their partners as inherently the same person at their core. Although they shared some of the same emotional experiences as the other participants, they were able to maintain a sense of being in a marriage. A key differentiating feature for these participants were their partners', admittedly sporadic, expressions of love and gratefulness. This appeared to be a powerful factor shaping their ability to maintain the sense of their partners being the same person and as being husband and wife. Harry illustrates this:

> Int: Does Sarah still feel like the same person despite […] the being aggressive and all those things do you still view her as the same person?
>
> H: Um, I would say yes because-yes she is the same person, because she has moments where she might say something like 'thank you for looking after me' […] and you know that the way she said it, and the in the context in which she says it, you know she really means that, so yeah, you get little moments um, you know, and literally they are little moments […] so yeah, if you can get a period where it's nice, you know, you get moments that make it worth it. (Harry)

This was also shared by James when discussing his feelings towards his wife, Nicola:

> …I know in there she loves me, cus sometimes she'll tell me she loves me and that's like a ray of sunshine, so I feel we're still strongly husband and wife with feelings for each other […] the dynamic has definitely changed because we now have the difficult side […] I know she loves me in there. (James)

For Claire, her husband, David, made verbal expressions of his love for her and she was able to view him as the same person, despite the differences in his presentation:

> … you think, well he's still the same person that I, you know, married, he's still the same person I love […] you have to sort of remind yourself every now and again that he might be hiding somewhere inside but he is still him, he's just different, I still love him, but he is different. (Claire)

The complexity of this situation is illustrated by James. Although he acknowledges that his wife has changed, he also acknowledges that he has shared his life with Nicola and knows that the person presenting to him is not the 'true' Nicola:

> … I see her as the person I married and the person I love um, she's definitely not the same person […] and it's living off the memories of all the fantastic times that we've had and remembering that […] I still love her regardless of what's going on […] I'm not being funny I mean, you can't just 'oh, I'm very sorry, you're not the person you used to be, you're ill, I don't wanna know anymore' you can't just throw, you know, forty-five years of love away. (James)

'Is it unmasked': Exposed/Changed Personality

Two participants considered whether their partner had changed because of dementia or whether the changes caused by dementia in the form of affected inhibition, had in fact 'unmasked' a hidden personality of their partner. Alice stated that "there are areas within [Jim] that are coming out, but probably were always there, but none of us ever saw them”. She grappled with an idea that her relationship with Jim may have been “complete make believe”, and questioned whether the person she had spent her life with was not who she thought they were:

> …well part of you said, ‘was he always like that’, but managed to hide it for, you know, thirty six years, or has the change been so great that, you know, the Jim that was there has just disappeared, has just gone, I don't know which […] I say, well he maybe not a nice, gentle man, maybe he was always a damaged person, I don't know the answer […] is it unmasked and it was always there or, has it literally changed Jim in terms of how he views himself, how he has seen his life um, and certainly the partnership that we thought we had, was not there, and possibly has not been there for a while, it does make you question… (Alice)

Dawn also referred to there being a question mark about the ‘true’ nature of her husband, Roger, and whether dementia had exposed the “unfiltered”, suppressed personality of Roger:

> I would say that probably, there is probably an underlying racism that is a part of him that wasn’t there, that wasn’t as noticeable before, as he was able to think and filter out inappropriate responses, as it’s progressed, his ability to do that is compromised um, and therefore […] he is more overtly racist than he ever used to be and maybe yeah, maybe his dementia is that you see more of what’s hidden, because he’s less able to conceal the things that wouldn’t be acceptable, maybe that’s-I have no clue […] if you thought about it too much you might, I dunno, that might take me in, in a quit- a different direction I suppose (mm) cus if truly that’s how he is, no, we don’t have a huge amount in common if that’s the case […] is some of this really him and the dementia actually means you see more of the raw him, the unfiltered him um (short

> pause) yeah, I think the lines are really blurred (mm), it would be really difficult to say this is Roger and this is what the illness has done… (Dawn)

‘Why did you do that?’: Trying to Understand

A pattern evident across the interviews was participants attempts to make sense of why their partner behaved in challenging ways. Two subthemes were identified that highlight this: a) ‘That is deliberate’: Perceptions of Intention and Control, and b) ‘It’s the disease’: Perceptions of Dementia as the Cause.

‘That is deliberate’: Perceptions of Intention and Control

There was evidence that in some instances, participants perceived their partner to have understanding, control, and intentionality of their behaviours, especially where partners were deemed to behave in particularly abhorrent ways i.e., cheating, physical violence, making deeply personal, unpleasant verbal comments. For Alice, she deemed her husband, Jim, to have an “extreme need to hurt” through describing his infidelity with other women:

> … I actually vomited that time and I said ‘why did you do that’, and the answer was och, I’d upset him, so it was a deliberate attempt to hurt […] because those things, where he has this need to describe to me in graphic detail the woman he was with, he does that to hurt me, but in terms of his throw away lines or his, uh, disinhibition, in terms of a not really caring how I would react to lies for instance, things like that-they are two different things […] the other ones were you could actually ride above that and sort of, you know, not quite throw it away, but not be affected by it, but the ones where it was deliberate, no […] it is deliberate, I mean, he knows himself and he's told me at the time, you know, he knows he's done it, and he did do it to hurt me. (Alice)

Some spouses described feeling that their partner made conscious choices to offend or anger their partner as highlighted by Dawn:

> … there are times where I am sure he is tormenting somebody […] in fact he will occasionally do it with me, if I've upset him, he'll talk about the things he thinks I will react to, so he'll talk about politics, he'll talk about um (short pause) things that are to do with people's ethnicity or um, refugees, all of that kind of stuff […] I have quite a view about the rights and wrongs of society, he will go for that as a way of trying to provoke a reaction, that takes some thought and flies against that's to do with a lack of filter, so I do find it quite complicated sometimes. (Dawn)

Gina also felt that her husband, Craig, made conscious choices to behave in difficult ways:

> G: …sometimes I think he is making a fool of me sometimes […] if he doesn't want to do something, he gets so slow, or he can't remember, and to me that shows cognitive function, he doesn't want to do it and therefore he's going out of his way to be awkward […]
>
> Int: Do you feel there's a um an intentionality in how he behaves then
>
> G: Yep, I do, I really do, somebody said he plays me for a fool. (Gina)

The sense of control and choice over behaviour was also highlighted by Beth when she spoke about her husband, Matthew's, violence towards her:

> … it is anger, his anger, and the fact that he says he can't control it, but sometimes I think he can, cause if I pick up my phone and say, 'look I'm going to record you', he tones it down a little bit, he doesn't stop, but he tones it down […] so I just wonder yes he's got a bit of control, cause the minute I pulled my phone and say I'm gonna record him, he just backs down it, it just comes down several notches… (Beth)

'It's the disease': Perceptions of Dementia as the Cause

When trying to make sense of why their partner behaved in challenging ways, some of the participants perceived dementia as causing their partners to behave in a difficult way, and appeared to use their knowledge and memories of their partner prior to dementia to understand the behaviour and personality changes they experienced. These participants appeared to separate the pre-morbid person from the dementia person. For Harry, despite experiencing physical violence from his wife, Sarah, he used his knowledge of Sarah's pre-morbid personality to make sense of why she behaved in unpleasant ways and would not have treated him this way previously:

> …I just went with it's the disease, you know, it's whatever is going on in her brain is causing her to be like this […] this person who's in my face giving me a load of shit is not my loving wife who, you know, we've had so many good years. (Harry)

Claire further speaks to the perception of dementia being the cause for her husband David's socially disinhibited behaviours, which caused her to feel immense embarrassment in public, by reminding herself that it wasn't David's "fault":

> I think you have to, yeah, you have to remember that it's the condition it's not him and you have to really focus on I think, seeing the positives and about, you know, seeing the best of things and realising and reminding yourself that it's not his fault […] it isn't him […] he doesn't mean to do the things that he does (tearful) […] it's not his fault (Claire).

When discussing the changes in Nicola and the difficulties that caused between them, James spoke about taking the time to reflect and coming to an understanding that it was Nicola's "condition" that caused her difficult behaviours:

> … at first I really, really, really struggled with it because it just wasn’t her […] but then I’ve realised it’s not her and it’s her condition […] sometimes you feel like it’s gotta be personal cus she’s just doing it all the time to wind me up and I know she’s not […] I know it’s not, I know damn well it’s not that she’s doing it to wind me up […] I think it’s understanding more now it’s the condition and the brain and it’s not her… (James).

‘You just learn to manage’: Coping with Changes

There was evidence that there were varying ways of coping with the changes in their partners, which appeared to differ between female and male participants. Two subthemes were identified: a) ‘I have stepped back’: Emotional Detachment and b) ‘I’ve got to do my best for her’: The Role of the Protector.

‘I have stepped back’: Emotional Detachment

Some participants spent much time trying to manage their difficult feelings towards their spouse and their situation. Beth describes needing to act in “self-preservation” to manage her difficult emotions and described emotionally “stepping back” as a way to protect herself from further hurt:

> I’m making sure he’s fed, he’s clean, and everything basic but emotionally, I have stepped back, just to protect myself […] the reason for that is there’s been so much hurt, so much anger, so much pain […] you sort of become hard in some ways just to sort of protect your own emotions […] I've become a little bit more um, self-centred […] I would say it's kind of changed me in in some ways. (Beth)

Alice further speaks to stepping back emotionally from her husband, Jim, as a means of self-preservation:

> I don’t have any personal investment towards him anymore […] do you know something, it's almost like it's self-preservation that I've moved away from Jim, because

> the changes mean he’s not-the relationship is not what it was, probably it is probably self-preservation, you move back (hmm) to keep yourself as I was because you do think-wonder ‘have I changed’ (yeah), I asked somebody ‘is dementia catching’ because you do wonder sometimes if it's catching […] yeah I'm-I'm certainly aware of my sense of self keeping myself back now. (Alice)

Isabelle also expressed a sense of needing to detach from her emotions as a means to cope:

> I: … it’s my self-preservation thing really, that was the way-that was my, I don’t know how to put it really [pause] sort of, my own saving I think in some ways, um, because the way I dealt with it […] it was like work mode kicked in […]
>
> Int: Do you think that was, that was conscious the turning into work mode or?
>
> I: Yeah, from day one my work head kicked in, definitely, I’ve not dealt with it emotionally [mm] um, I think I’ve just tried to put those feelings away, but obviously those feelings are there and certain situations does make them kind of bubble over sometimes. (Isabelle)

Dawn also referred to emotionally detaching from her husband and “focusing on the practical bits of life”, as further evidence of the emotional detachment turned to in order to cope with her situation.

‘I’ve got to do my best for her’: The Role of the Protector

For Harry and James, there was a felt sense that both men coped with the changes in their wives by leaning into their perceived duty to protect and support their wives. This appeared influential in their ability to tolerate the changes in their wives. Harry spoke about placing his wife’s needs above his own:

> I would let her like take her frustrations out and like, she could basically scratch me, bite me, kick me, hit me, whatever she wanted to […] to a degree I was getting used to being berated, and being scratched and, you know, being belittled, and I was getting used to that and I was like sort of trying to process that as trying help Sarah in any way, and I didn't want her being taken away from me… (Harry)

This motivation was shared by James: "…you've got to protect her and you've gotta take care of her and do the best that you can". Both men also referenced trying their best for their partner and having a strong desire to make their lives as fulfilling as possible as expressed by Harry:

> …unfortunately I'm totally loyal and um so that's I won't let Sarah go and that's it I'm totally committed to her and that's it lots of people probably think I'm nuts and I'm trying to do the best I can… (Harry)

The men also appeared to try to empathise with their wives which appeared to mitigate against some of the challenges they experienced. This is illustrated by James:

> … the feeling wise, if you wanna try and analyse it, is the feeling of love and protection still, and empathy and wanting to look after her […] I think also, when times get really hard, I sort of try and put the shoe on the other foot if you like, if it had been me she'd have done exactly the same and probably more, and that makes me, you know, understand that I've got to do my best for her. (James)

For most of the female participants, although expressions of empathy were sometimes made, caring for and remaining with their partner appeared to be motivated by either a moral duty (Alice, Gina), social or financial circumstances (Alice, Beth, Gina, Isabelle), or wanting to maintain a semblance of family life for their children (Dawn). This was described as feeling “trapped” by Isabelle and is further illustrated by Alice, whose husband Jim had been physically violent towards her:

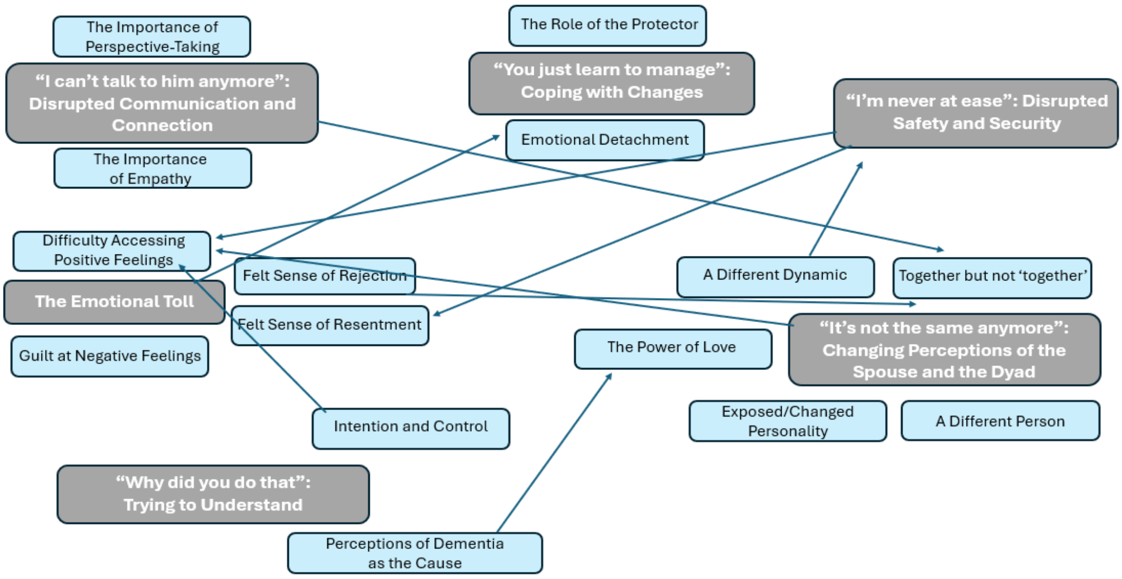
> Int: What stopped you leaving Alice?
>
> A: … if I'd left him, he’d have been dead within days […] if it had been for myself, I would have gone but I knew I couldn't […] I mean, you cannot leave somebody who is physically incapable as well as having a degenerative disease, because they're not going to snap out of it, but if I could have, I would have. (Alice)

Discussion

This study aimed to explore how challenging interpersonal behaviours and personality change undermine the spousal relationship in the context of bvFTD. The analysis of semi-structured interviews, conducted with ten spouses whose partner had a diagnosis of bvFTD, resulted in five themes which provided insight into the contributing factors and processes through which relationships may be undermined. Figure 1 displays a thematic map, demonstrating proposed connections between themes.

Figure 1

Thematic Map



Everyday Interactions, Sense-Making, and Attempts to Cope

Participants reflected on a variety of challenging interpersonal behaviours that impacted their everyday interactions with their partner. Overt behaviour such as physical and verbal aggression, disinhibition, and unpredictability, brought understandable fears and anxieties to the everyday experience of the relationship for most participants. Resulting vigilance and self-monitoring, to avoid or reduce the possibility of distressing interactions, resulted in quality time together being severely disrupted, as participants felt unable to relax with and enjoy their partner's company.

Challenging interpersonal behaviours had further emotional impacts. Participants experienced hurt, anger, and resentment for being treated in ways perceived to be unjust and unacceptable, heightened by their partners' apparent lack of care or remorsefulness. A lack of expressed affection, empathy, and interest also contributed to participants feeling rejected and frustrated.

Participants also struggled with a loss of effective communication with their partner and found that loss of empathy contributed to a lack of emotional awareness and responsiveness, making conflict resolution following emotional injuries caused by their partners very difficult.

Some participants tried to cope by emotionally distancing and disengaging from their partner to protect themselves from further emotional turmoil. Some participants avoided engaging with their partner unless necessary and physically distanced themselves from distressing and frustrating encounters.

In attempting to make sense of their partner's behaviours and ways of interacting, some participants queried the controllability and intentionality of their partner to behave or speak in objectionable ways. Some appraised their partner's behaviour to be motivated by purposeful and/or malicious intent to cause emotional injury or to manipulate situations. Some participants also believed their partner had control over their behaviours, rather than believing them to be caused by the symptoms of dementia. An interesting but unexpected finding concerned a minority of participants who considered whether the changes in their partner were not manifestations of dementia but rather an exposure of a suppressed, unpleasant personality that the symptoms of dementia (i.e., disinhibition or 'lack of filter') meant their partner was no longer able to hide. This finding is complex but highlights that the extremity of changes in some cases may lead spouses to question the pre-dementia person and relationship when attempting to make sense of these changes.

Contrary to the majority, three participants (Claire, Harry, and James) utilised their knowledge of the pre-dementia person and relationship to make sense of the changes in their partner. These participants were successful in separating their partner from their unpleasant behaviours and personality traits and understood them as a manifestation of dementia. This led to more empathic responses, more tolerance of the difficulties experienced. and these participants continued to engage in valued activities together. A potential, impactful factor in their ability to separate their partner from the behaviours exhibited was their partners' continued expressions of love and gratefulness.

Potential Gender Differences in Identified Themes

Although the two male participants did endorse the earlier themes (including a disrupted sense of safety and security, disrupted communication and connection, and the emotional toll), there did appeared to be a gender difference in the theme 'Why did you do that?': Trying to Understand'. The men appeared to make sense of the changes in their wives through a symptom-based lens i.e., that their wives behaved in challenging ways because of dementia. This appeared influential in their ability to appraise their wives as inherently the same person, and their relationship as still one of husband and wife. Additionally, the male participants appeared to have a more empathetic response to their wives' perceived mistreatment of them, whereas female participants appeared to take things more personally and have a stronger and lasting negative emotional response. The implication of these potential differences will be discussed in future research implications below.

Impact on the Relationship

The findings from this study highlight several ways in which challenging interpersonal behaviours and personality changes may undermine the relationship in the context of bvFTD.

Continuity of Feelings

The narratives of participants indicate that continuity of feelings is difficult to maintain when faced with such challenging interpersonal behaviours. Participants described difficulty in switching off their natural, emotional responses to such objectionable behaviours and found it difficult to maintain or experience positive feelings towards their partner. This finding aligns with Bodley-Scott and Riley (2015) who found that spouses of individuals who had experienced a traumatic brain injury (TBI) similarly found it difficult to switch off negative feelings in favour of more positive feelings such as love and intimacy. It is reasonable to consider that the deeply personal, offensive, and frightening nature of the changes in some circumstances make it very difficult to retain continuity of feelings, despite a logical appreciation that bvFTD is a contributory factor. Eve highlights this, describing finding it very difficult to be "rational" about her feelings when her husband, Anthony, was verbally abusive to her.

Furthermore, it appears that it is difficult to maintain positive feelings in the absence of demonstrative, positive relationship-focussed behaviours (apparent disinterest and lack of emotional warmth) indicating to the spouse that they are valued, desired, and loved. Broader research in both dementia and brain injury has previously linked apathy, lack of emotional warmth, and apparent indifference with discontinuity (Bodley-Scott & Riley, 2015; Poveda et. al, 2017; Villa & Riley, 2017; Yasmin & Riley, 2021). For those participants that did receive positive feedback from their partner (e.g., gratitude, expressions of love), it was easier to maintain positive, loving feelings towards them.

In some cases, the queried 'unmasking' of the true self may lead to discontinuity between the 'actual' pre-dementia self and the 'pretend' self that participants enjoyed a positive relationship with. In this case, spouses may lose connection with the feelings they had with the pretend self because they appraise that this person was never real. Several participants also indicated that their feelings changed prior to a confirmed diagnosis of bvFTD. This indicates that emotional injury caused prior to diagnosis may also threaten continuity of feelings.

Continuity of the Identity of the Person

There was evidence that indicates continuity of the identity of the other person is difficult to maintain in the face of such marked and dramatic behavioural and personality change. Most participants' narratives indicated perceptions of their partner as dramatically different to the person as known pre-dementia; previously valued, positive qualities in their partner were deemed to no longer exist, instead replaced with undesirable and unpleasant traits. This finding supports previous hypotheses that when faced with such stark behavioural or personality changes, retaining a sense of continuity of the pre-dementia person is challenging (Lewis & Riley, 2019). However, some participants managed these changes by separating the person from the behaviours and retained a sense that their partner was inherently the same person.

One hypothesis for why such discontinuity may be more likely to occur in bvFTD is the absence of other ‘markers’ which serve as a reminder of degenerative illness. Whilst spouses of individuals with other forms of dementia, such as Alzheimer’s disease, may be able to appraise these changes as related to cognitive decline in the presence of other difficulties their partner displays, it may be that the absence of other functional and cognitive limitations in bvFTD make it more difficult to hold on to dementia as an explanation and understanding of these changes. This idea is supported by the findings of Lewis and Riley (2019), who found that discontinuity is more likely to be experienced in response to challenging interpersonal behaviours, in comparison to changes in cognition, mood, and communication. Interpersonal behaviour may therefore be viewed as more central to our identity in a way that cognitive or physical impairments are not.

This idea is supported by Strohminger and Nichols’ (2014) ‘essential moral self hypothesis’ which proposes that morality is core to a person’s identity. To test their hypothesis, members of the public were presented a fictional scenario regarding a person receiving a ‘brain transplant’ and asked to consider whether they were still the same person post-surgery in the case of a) agnosia, b) apathy, c) amnesia, and d) change to morality. Individuals were more likely to view the individual as a ‘different person’ if they experienced changes in their morality in comparison to the other cognitive deficits. The authors conclude that “moral traits are considered more important to personal identity than any other part of the mind” (Strohminger & Nicholls, 2014, pp. 168). These authors also found that changes to morality, mediated by perceived identity change, significantly impacts relationship deterioration (Strohminger & Nicholls, 2015). These findings highlight that perceptions of a change in morality in bvFTD (e.g., antisocial behaviour, reduced empathy) may contribute to the person being perceived as no longer being the same, as well as how this perception may threaten relationships.

Continuity of the Identity of the Relationship and Couplehood

Most participants reflected on how a lack of expressed care, empathy, gratitude, and affection from their partner was particularly difficult and contributed to a loss of togetherness and connectedness. This suggests that a lack of positive relationship-centred behaviours from the person with dementia makes it difficult to maintain a sense of being together in a relationship dealing with the challenges of dementia. Perceptions of a lack of control or care about the impact of their behaviours may also contribute to a feeling that spouses are alone in dealing with the situation.

In addition, the absence of positive interactions that bond and cement the relationship also appear to have a detrimental impact on continuity of the relationship dynamic. Experiencing little enjoyment from time together and the absence of quality time spent as a couple may diminish positive feelings towards the relationship as time spent together is by necessity rather than desire. Furthermore, feeling more like a parent in their vigilance to, and felt need to manage, disinhibited and unpredictable behaviour, also appears to undermine the relationship for spouses, as this role was perceived as incongruent with feeling like a spouse.

How Useful was the Relationship Continuity Framework in Understanding Relationships and Coping of Spouses in bvFTD?

As explained in the introduction to this paper, the framework of relationship continuity presents a theory through which to understand whether relationships following a diagnosis of dementia are experienced as a continuation of the relationship prior to dementia, despite the inevitable changes that occur, or, as radically different to the relationship as experienced prior to dementia. The framework provided a useful way of contextualising and understanding the narratives of participants when they reflected on how the symptoms of bvFTD had caused significant challenges in the spousal relationship, as discussed above, and echoes of the framework were certainly evident in the themes discussed in ‘Changing Appraisals of the Spouse and Dyad’.

However, the results from this study indicate aspects of the experience that the original framework may not include when attempting to understand how relationships are affected in bvFTD. The severity of the changes in behaviour and personality in bvFTD led to a small number of participants not only experiencing discontinuity in the same/different person domain (i.e., viewing their partner as a different person post-dementia) but even led them to question the validity or ‘true’ personality of their partner prior to being diagnosed with bvFTD. This suggests that the original relationship continuity framework is predicated on the assumption that spouses will appraise the changes in their partner to be the result of changes in the brain caused by dementia. However, this finding suggests that there may be other factors, i.e., whether changes in the affected spouse are understood as truly a ‘change’ or a revelation of the ‘real’ person, that contribute to the experience of discontinuity which the original framework does not account for. This is a particularly interesting finding that requires further research, which will be discussed in the research implications section below.

The results of this study also suggest that the language of ‘continuity’ and ‘discontinuity’ may be suggestive of a dichotomy rather than as being two ends of a spectrum of experience(s). Whilst the framework does not intend for continuity and discontinuity to be viewed as rigid and opposing opposites (Riley 2019), the interviews conducted as part of this study suggest that the language of the framework may be indeed suggest such a rigidity and may not account for the complexity of the experience of relationship change in bvFTD. This was particularly evident when analysing the interviews of Claire, Harry, and James, and attempting to utilise the framework to understand their experiences. For example, although these participants expressed the experience of continuity of feelings e.g., still having loving feelings for their partner, and viewed the relationship as a marriage still, they also expressed experiencing discontinuity with other feelings of protectiveness and frustration being experienced as well as loving feelings, rather than instead of. Additionally, these participants expressed that their partner was not the person they once knew, whilst simultaneously holding the view that they remained the same person at their core. These participants used complex and apparently opposing terminology when explaining their experience which, when using the framework in its original form, made it difficult to consider whether these individuals fell into the continuity or discontinuity side of the spectrum in these domains. The results from this study suggest that the language used in the original framework may imply that only continuity or discontinuity may be experienced, despite that not being the intent of the framework. The terminology of the framework was therefore, in some cases, difficult to apply in this context.

Additionally, whilst the framework suggests that spouses experiencing discontinuity in the ‘couplehood’ domain, i.e., seeing the self in an individualistic way and feeling as though they are facing the situation alone post-dementia, is potentially a negative change in the relationship, the results of this study suggest that in this context (bvFTD), viewing the self as an individual can actually be a way of coping and managing difficult feelings, as seen in the ‘I have stepped back’: Emotional Detachment subtheme.

The implications of this finding for future research in relationship continuity will be discussed below.

Strengths and Limitations

A strength of this study is its exploration of an under-researched area of the psychosocial impact of bvFTD. Although previous research has identified correlations between symptoms associated with bvFTD (specifically, challenging interpersonal behaviours and the loss of positive interpersonal behaviours) and the experience of discontinuity (Lewis & Riley, 2021; Poveda et al., 2017; Riley et al., 2018), this study provides insights into the processes that may contribute to the experience of discontinuity in the presence of such symptoms.

The limitations of this study provide considerations for future research in this area. Homogeneity within the sample regarding sexual orientation, cultural, and ethnic background limits the transferability of the findings. All participants in the sample were heterosexual and white British, so it cannot be assumed that the findings are applicable to those from different cultural and ethnic backgrounds.

Recruitment was challenging and time constraints prevented further recruitment. A larger sample may have afforded the opportunity for further insights to be gained, particularly given some of the differences between participants. Additionally, the self-selection of participants may have skewed the findings as self-selecting participants may have stronger opinions or particularly negative experiences in comparison to non-self-selecting participants.

This research aimed to explore how behavioural and personality changes may undermine spousal relationships, and the choice of RTA allowed for pre-existing ideas from the concept of relationship continuity to be incorporated. Whilst RTA was deemed the most appropriate method, an interpretative phenomenological analysis (IPA) may have taken this research in unanticipated directions, by focusing on personal, lived experience and meaning making, to shed further light on the unique experience of spouses in bvFTD. However, RTA provided flexibility to allow for the exploration of other possibilities unrelated to continuity that may have impacted the relationship.

Clinical and Research Implications

Research Implications

Based on the findings from this exploratory study, there are several lines of enquiry that future researchers may explore further to continue in developing our understanding of how relationships between spouses are affected by bvFTD.

As the results from this study suggest potential gender differences in how relationships between spouses may be affected in bvFTD, future research should focus here. Two particular areas that warrant further investigation include husbands' coping and husbands' interpretation of changes in bvFTD. Are male spouses more likely to perceive the changes in bvFTD to be the result of dementia, and if so, why is this more likely? Furthermore, husbands appeared to cope with the changes in their wives by empathising, putting themselves in their partner's shoes, and leaning into their perceived role to protect their wives. Further research may explore this finding further. Do men and women cope differently with managing the challenges in interpersonal interactions/changes in the relationship in bvFTD? It is important to note that the relationships in this study were heteronormative. It would be useful to explore this phenomenon in non-heteronormative relationships as further insights in the apparent gender differences in the experience may be gained.

The finding that some participants queried the ‘true’ nature of their spouse is important to explore further as this was only endorsed by a small percent of participants but may be an appraisal that significantly undermines relationships in bvFTD. Is this one of the processes that affects the experience of continuity in bvFTD if spouses begin to question the pre-dementia life they shared together due to starkness of changes?

bvFTD can lead to a broad spectrum of observed behaviours and challenging interpersonal interactions, and as such, there were varying descriptions of how bvFTD had affected the spouse of participants in this study. Whilst there were shared experiences despite the broad presentations described, there were some possible differences. It appeared that bvFTD-related presentations that were more ‘extreme’, such as overt physical violence towards the spouse, racism, and infidelity, were more present in those that considered whether their partners were in fact not the person they thought they were and bvFTD had ‘unmasked’ their ‘true’ personality. In contrast, participants whose spouses presented with ‘less extreme’ presentations, such as social disinhibition, did not endorse this. Future research may look to explore relationship continuity based on presentation in bvFTD. Are there particular behaviours or extremities of behaviour and/or personality changes in bvFTD that undermine relationships/cause more significant difficulties within the relationship?

Heterogeneity within the sample also provides some avenues for future research. Two participants (Dawn and Gina) were widowed from their first marriages, with Gina querying if her emotional responses may not have been as negative had she and her husband had a longer history and a more established, stable foundation as a couple. These women had remarried with the hope of another chance at a loving, supportive and happy marriage which had been impeded by their husbands’ diagnosis of bvFTD. Beth, the only participant with dependent children living at home, spoke about the hatred she had towards her husband for the effect his behaviours had on their children. Future research may therefore explore if there are particular factors (e.g., prior relationship history, shorter relationship length, having young children at home), that increase negative emotional responses, such as resentment, and/or the likelihood of experiencing discontinuity in relationships affected by bvFTD?

The finding that some participants appeared to actively emotionally detach from their partner in order to cope with the emotional impact of their experience, highlights another interesting area to explore further. In these cases, it may considered that participants actively attempted to invoke discontinuity by disengaging from their partner as a means of protecting themselves from further emotional hurt and to manage the emotional impact of disappointment and rejection. This would appear to be a different experience than those who may subtly find themselves in a position of feeling emotionally disconnected and experiencing discontinuity. This may be viewed as pro-active versus reactive discontinuity e.g., – do some people actively try to experience discontinuity to cope with the changes in bvFTD i.e., do some individuals actively attempt to re-define their view of the relationship to manage difficult emotions; do some individuals actively attempt to view themselves as an individual to manage disappointment/rejection?

Finally, whilst this study did not ask participants about the pre-dementia relationship in detail, some participants recalled their ‘fantastic memories’ of their partner and relationships, which appeared influential in their tolerance of difficult behaviours and interactions, and also the experiencing of their partner as ultimately the same person This suggests that perhaps the experience of the relationship prior to dementia may be influential in the experience of continuity and discontinuity in this context. Future research may explore whether a positive pre-dementia relationship influences the tolerance of difficult behaviours and/or experience of continuity within the relationship.

Clinical Implications

A complex and sensitive finding from this research concerns the descriptions of 'abusive' behaviours (physical violence and verbal aggression) perpetuated to some participants. The behaviour of one person to another, whom they are personally connected (e.g., spouses), is defined as 'domestic abuse', if the behaviours consist of violent/threatening behaviour, and/or psychological, or other abuse (Domestic Abuse Act, 2021). Whilst this paper recognises the occurrence of such behaviours in the context of a neurodegenerative disease, the emotional impact described by spouses in this study may be considered to parallel the experiences of victims of domestic abuse. Beth reported that mental health and social services did not support her with her concerns regarding living with a violent partner as this was deemed a "mental health problem". Services should proactively safeguard spouses' physical and psychological wellbeing and consider whether it is suitable for spouses to remain co-habiting with their partner if their wellbeing is compromised. Services entering dialogues primarily involving psychoeducation on the role of bvFTD in such behaviours, may inadvertently invalidate the concerns of spouses who express such anxieties.

While pharmacological interventions demonstrate some effectiveness in symptom reduction in bvFTD, no curative treatment exists (Gambogi et al., 2021; Tsai & Boxer, 2016). Non-pharmacological interventions may therefore pose useful in the managing the relational impact of this disease. Patients with bvFTD show little concern regarding their diagnosis or its impact on others (Mendez & Shapira, 2011). This has important implications, as involving the person with bvFTD in interventions aimed at modifying/decreasing relationship-damaging behaviour(s) perhaps has little chance of being effective. However, interventions may be adapted to support patients to increase/engage in positive, pro-relationship behaviours. For example, given the significant value three participants gained from their partner's expressions of love and gratitude, may other individuals with bvFTD be supported to express similar sentiments? Whilst these sentiments may be felt by the person with bvFTD, the issue may lie with difficulties in spontaneously, or otherwise, expressing these sentiments.

Short-term, education-based interventions aimed at increasing caregiver understanding of the cause of challenging behaviours in bvFTD have been found ineffective in addressing their emotional impact (Diehl et al., 2003) and may risk trivialising or invalidating the experience of spouses. Although brief education about behaviours may be ineffective, supporting spouses to make better sense of the behaviours through using their knowledge of the other person is another option for intervention. For the three participants who were able to separate the person from the behaviour, their ability to respond more empathically to the behaviours, using their knowledge and understanding of the person, supported them in managing their emotional impact. Externalising and depersonalising problems are techniques from narrative therapy (White, 2007) which may support spouses to consider that their partner does not deliberately mean to cause hurt or offense. A narrative approach could involve supporting spouses to develop more balanced perceptions of difficult behaviour and disappointing or frustrating interactions, and future research may explore this.

Although there is evidence that brief, educational interventions are ineffective in managing the emotional impact of symptoms of bvFTD, the delivery of these interventions post-diagnosis may be delivered at a point by which damage to the relationship may have already occurred. One of the damaging aspects of the behaviours noted by participants was the confusion and emotional injury they generated pre-diagnosis, emphasising the need for earlier, or at least earlier potential, diagnosis. Misdiagnosis prior to eventual diagnosis of bvFTD is common given the overlap between symptoms of primary psychiatric disorders (PPD) (Lanata & Miller, 2016). A broader clinical implication that this study supports is that efforts to educate primary care clinicians on the differentiating factors between PPD and bvFTD (Ducharme et al., 2020; Pressman et al., 2021) and the core, clinical features of bvFTD (Rascovksy et al., 2011), may enable them to consider bvFTD earlier in the process of differential diagnosis. This knowledge may support clinicians to consider and share with couples the possibility of bvFTD earlier in clinical encounters. This may provide some buffer against the damage caused by the symptoms noted in this study, as spouses may be able to earlier appraise these as a potential symptom of dementia.

As guilt in response to negative feelings towards the spouse was highlighted as a theme, it is important for clinicians working with couples where a diagnosis of bvFTD has affected half of the dyad to be attuned to expressions of guilt from the unaffected spouse. Identifying and working with guilt may be helpful in reducing distress that may be felt in response to the experience of ‘negative’ emotional responses. Clinicians may also seek to normalise and validate the experience of ‘negative’ emotional responses in efforts to acknowledge the challenging situation spouses find themselves in.

Conclusions

Marriage is an intimate relationship with the propensity to be threatened by interpersonal challenges arising from a neurodegenerative disease. This study highlights how behavioural and personality changes characteristic in bvFTD, particularly disinhibition, apathy, and loss of empathy, can undermine spousal relationships. The findings suggest some of the processes involved in how these changes impact the relationship and indicate that it is not simply the presence of these changes, but the interpretation of, and emotional response to such changes, that can undermine the relationship. The results from this study also highlight several directions for future research in this area, that could add further to the initial insights gained from this study. Such research would facilitate the development of supportive interventions for couples affected by bvFTD. Furthermore, these findings provide some basis for developing and trialling novel interventions, to support spouses with their emotional wellbeing and adjustment to navigating their relationships within this difficult context. It is important to note that retaining continuity may not be appropriate, nor indeed wanted, in some circumstances, particularly where spouses have been victims of significant emotional or physical abuses.

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CHAPTER THREE

PRESS RELEASES

Out of Sync: Spouses' Struggles with Young-onset Dementia

Researchers from the Centre for Applied Psychology at the University of Birmingham have undertaken a meta-ethnography exploring the experience(s) of spouses whose partner is diagnosed with Young-Onset Dementia (YOD). Reviewing the current qualitative literature brought together a range of spousal accounts highlighting some of the unique challenges faced by this population.

The review integrated the findings from 10 qualitative papers exploring different aspects of the spousal experience. The papers were primarily conducted in North America and Europe. Participants were the spouse of individuals who had received a diagnosis of YOD, which refers to dementia with a symptom onset before the age of 65. A range of qualitative data analysis methods were used to analyse interview data, to provide an insight into the experience from the perspective of spouses.

The integration of the individual results from each paper highlighted that spouses go through a complex, and evolving, emotional process from pre- to post-diagnosis. The arrival of dementia at this phase in life was often shocking and unbelievable. Spouses gradually began to grieve the loss of their partner and their relationship dynamic as it once was, whilst also having to grieve the loss of their anticipated future. Spouses also faced a shift in their role to caregiver at an unexpected phase of their lives, which was a source of frustration and upset. This new role was consuming and a challenge to manage alongside other key mid-life role.

The review also highlighted that these spouses often felt stigmatised and alone in their experience due to a lack of public understanding of the condition, and the unavailability of age-specific support services. In addition, some spouses also felt guilt when considering their own needs and for seeking outside support for their partner. Spouses employed a range of coping strategies to manage their situation.

Some areas of variance were noted during the integration. Although the spouses in the only non-Western paper struggled with taking on new and unfamiliar familial roles (e.g., male spouses taking on more ‘domestic’ household responsibilities when their wives functional abilities deteriorated), these spouses did not experience their new caregiving role as a negative. In fact, caregiving was perceived to be a meaningful and necessary role to hold. The research team note the influence of differing cultural values in the appraisal of and adaptation to the caregiver role. Furthermore, male spouses did not appear to experience the same guilt that female spouses described when making the decision to seek respite and relief from their caregiving.

The researchers conclude that, although some of the experiences spouses have in YOD may mirror those in late-onset dementia, there are some unique difficulties that these spouses face, namely the challenge of premature caregiving and the process of grieving an imagined and valued future. Future research directions identified include exploring the experience of guilt in this population, and the importance of expanding current research efforts to include the exploration of the experience across a range of sociocultural and geographical contexts, to improve our understanding of this devastating disease.

Rhea Asfaw, lead researcher, offered the following statement: “This review shines the light on the need for tailored provision of care and support for spouses caring for their partner with YOD. It is important that services are provided to meet the complex emotional needs of these spouses, and interventions are developed and/or adapted to meet their needs accordingly. The results from this review suggest that the needs of spouses in this context may extend beyond peer support and information provision. The dissolution of specialist YOD services is concerning as, outlined by this review, the provision of adequate, age-appropriate respite and residential services, may provide an important buffer against the role engulfment spouses experience in this context".

A Stranger at Home: Behaviour and Personality Change in Dementia Puts Significant Strain on Relationships

According to new research from the University of Birmingham, behavioural and personality changes arising from a rare form of dementia can put relationships under significant strain.

Researchers from the Centre for Applied Psychology have explored the impact of symptoms of behavioural variant frontotemporal dementia (bvFTD) on the spousal relationship. bvFTD causes individuals to experience significant changes to how they behave and interact with others. Most notably, individuals will experience significant changes in their social and emotional skills, such as making inappropriate comments to others, showing aggression, and being unable to read and respond to the emotions of others. Amongst this, individuals are unaware of their condition however, their memory and self-care skills are unaffected.

This study focussed on how these symptoms can threaten the spousal relationship, and how spouses may respond to these changes. Ten spouses whose partner had a diagnosis of bvFTD were interviewed about their experiences. The interviews focussed on asking spouses about the changes in their partner, what their emotional responses to these changes was, how they made sense of these changes, and how these changes affected their relationships.

The results highlighted that spouses can become fearful of and anxious when spending time with their partner, which impacted their ability to feel relaxed in their company. Spouses also struggled to feel positively towards their partner as they experienced strong, negative emotional responses to their partners behaviour, particularly in extreme circumstances such as aggression, violence, and an unpredictable temperament. Communication became strained between couples as spouses found their partners to be unresponsive to their emotional state. The significant and incomprehensible change in their partner led most spouses to view them as a fundamentally different person, which made it difficult for spouses to retain their previously held feelings towards their partner. Spouses struggled to feel as though they were in a husband-wife relationship as their partners no longer showed affection or care towards them.

In contrast, some spouses were able to maintain positive feelings towards their partner despite experiencing these difficulties. These spouses spoke about the importance of the expression of love and their perceived need to protect their partner as being valuable drivers in their ability to cope with their situation and the changes in their partner. These spouses also held in mind the influence of dementia on their partners behaviour, whereas the spouses that struggled most, often questioned whether their partner meant to cause them hurt and whether they were in control of their behaviour.

Lead researcher, Rhea Asfaw, explains the implications of the findings from this study: “Despite its rarity, bvFTD is a particularly devastating condition in that it has the potential to seriously damage relationships. This research has provided important insights into the experience of spouses in this difficult and unusual context. It was clear that having positive and meaningful interactions with their partner was severely compromised, thus contributing to a loss of connection between couples. It is important that research continues to explore the potential for targeted interventions for these spouses, in order to support them in adjusting to these difficult changes in their partners."

APPENDICES FOR CHAPTER ONE: LITERATURE REVIEW

Appendix A. Modified CASP Checklist

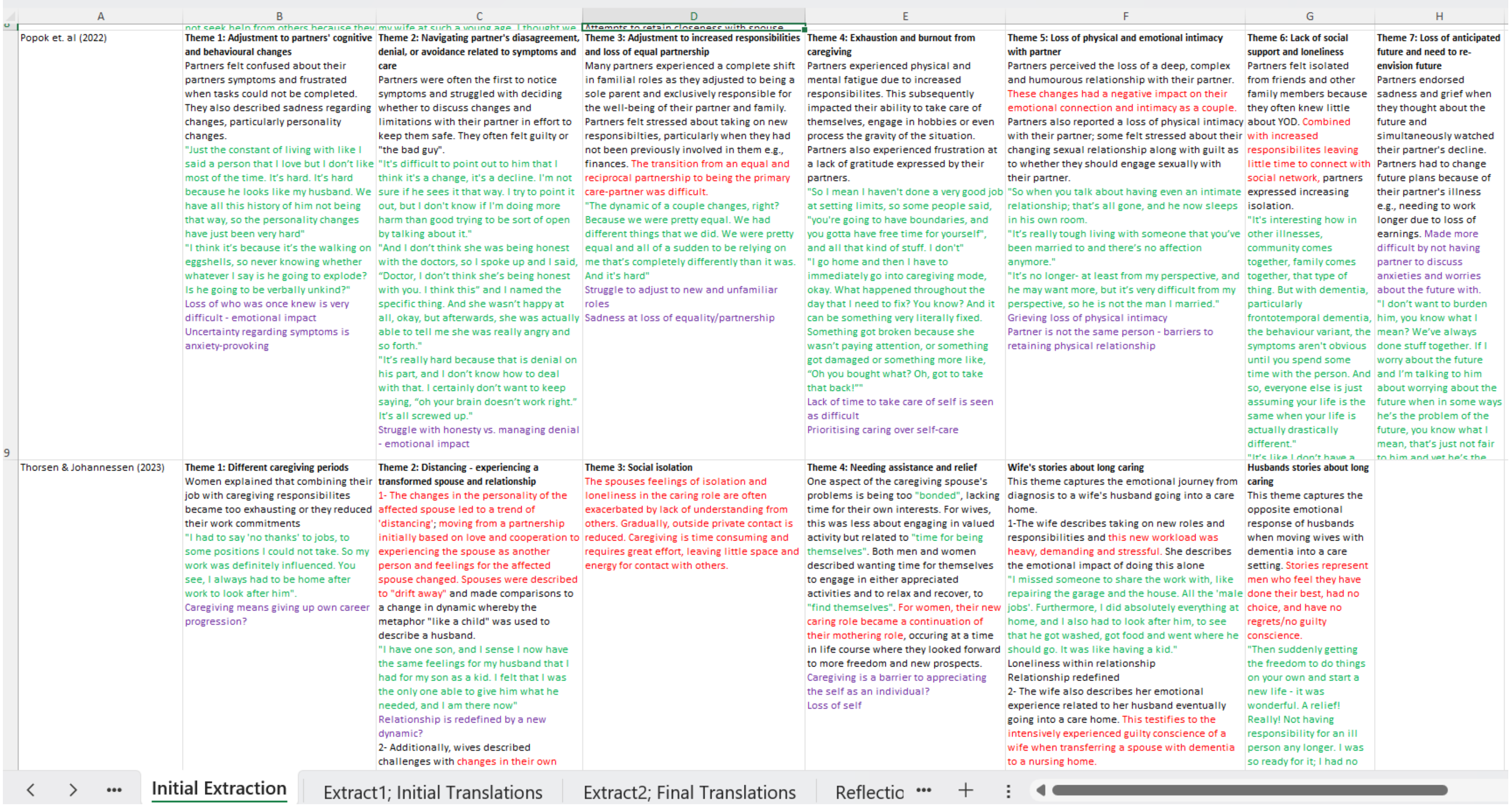
CASP Checklist Item	Indicators of Quality
1. Was there a clear statement of the aims of the research?	• What was the goal of the research • Why it was thought important • Its relevance
2. Is a qualitative methodology appropriate?	• If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants • Is qualitative research the right methodology for addressing the research goal
3. Was the research design appropriate to address the aims of the research?	• If the researcher has justified the research design (e.g., have they discussed how they decided which method to use)
4. Are the study's theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent, and conceptually coherent?	• To what extent is the paradigm that guides the research project congruent with the methods and methodology, and the way these have been described? • To what extent is there evidence of problematic assumptions about the chosen method of data analysis? I.e., assuming techniques or concepts from other methods (e.g. use of data saturation, originating in grounded theory) apply to chosen method (e.g. Braun and Clarke's reflexive thematic analysis) without discussion or justification. • To what extent is there evidence of conceptual clashes or confusion in the paper? E.g., claiming a constructionist approach but then treating participants' accounts as a transparent reporting of their experience and behaviour.

5. Was the recruitment strategy appropriate to the aims of the research?	• If the researcher has explained how the participants were selected • If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study • If there are any discussions around recruitment (e.g., why some people chose not to take part)
6. Was the data collected in a way that addressed the research issue?	• If the setting for the data collection was justified • If it is clear how data were collected (e.g., focus group, semi-structured interview etc.) • If the researcher has justified the methods chosen • If the researcher has made the methods explicit (e.g., for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) • If methods were modified during the study. If so, has the researcher explained how and why • If the form of data is clear (e.g., tape recordings, video material, notes etc.) • If the researcher has discussed saturation of data
7. Has the relationship between researcher and participants been adequately considered?	• If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location • How the researcher responded to events during the study and whether they considered the implications of any changes in the research design
8. Have ethical issues been taken into consideration?	• If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained • If the researcher has discussed issues raised by the study (e.g., issues around informed consent or

	confidentiality or how they have handled the effects of the study on the participants during and after the study) • If approval has been sought from the ethics committee
9. Was the data analysis sufficiently rigorous?	• If there is an in-depth description of the analysis process • If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data • Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process • If sufficient data are presented to support the findings • To what extent contradictory data are taken into account • Whether the researcher critically examined their own role, potential bias and influence during data analysis and selection of data for presentation
10. Is there a clear statement of findings?	• If the findings are explicit • If there is adequate discussion of the evidence both for and against the researcher’s arguments • If the researcher has discussed the credibility of their findings (e.g., triangulation, respondent validation, more than one analyst) • If the findings are discussed in relation to the original research question
11. How valuable is the research?	• If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature) • If they identify new areas where research is necessary

	• If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

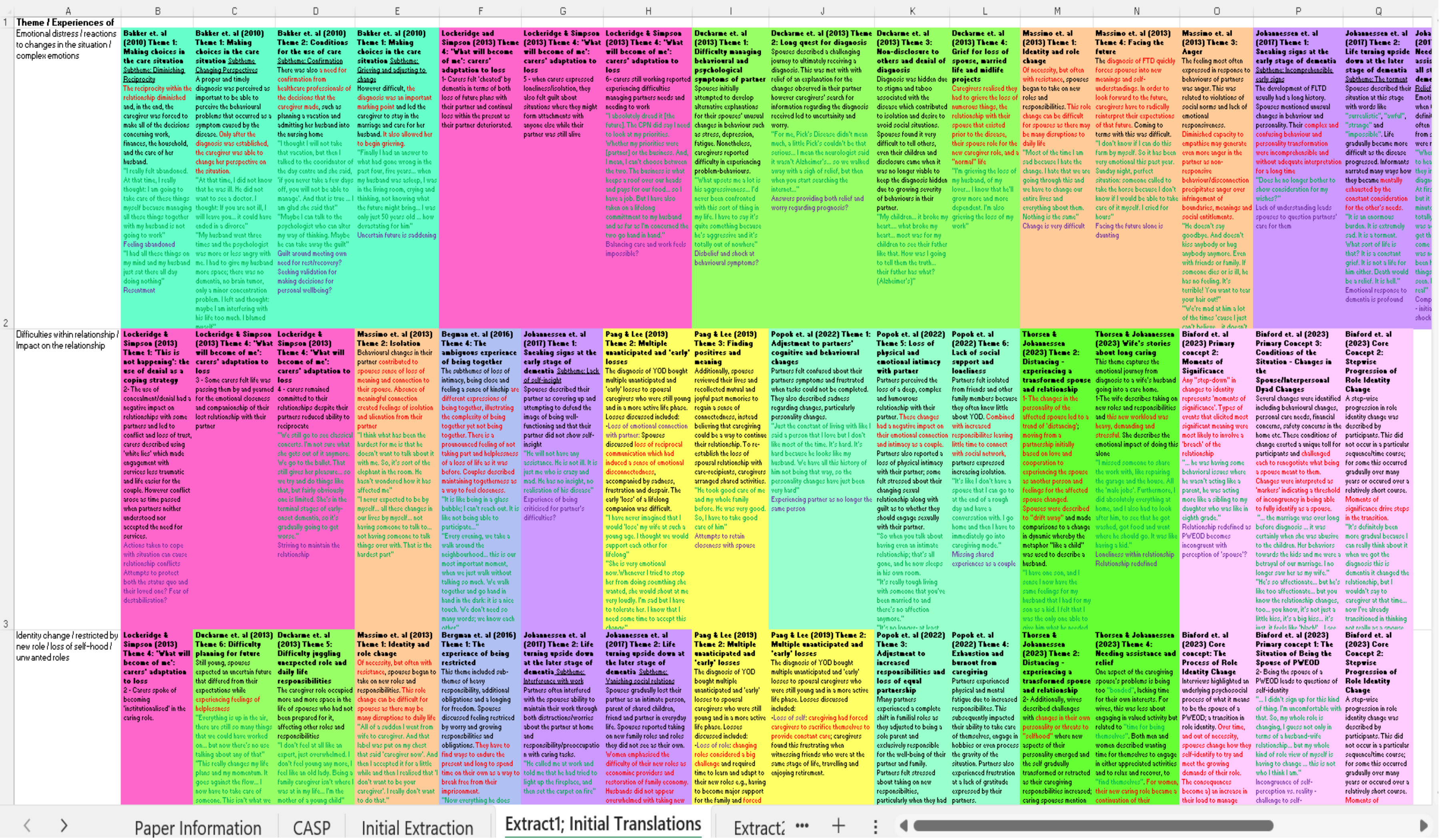
Appendix B. Initial Extraction Grid



	A	B	C	D	E	F	G	H
8		not seek help from others because they	my wife at such a young age. I thought we	Attempts to retain closeness with spouse				
9	Popok et. al (2022)	**Theme 1: Adjustment to partners' cognitive and behavioural changes** Partners felt confused about their partners symptoms and frustrated when tasks could not be completed. They also described sadness regarding changes, particularly personality changes. "Just the constant of living with like I said a person that I love but I don't like most of the time. It's hard. It's hard because he looks like my husband. We have all this history of him not being that way, so the personality changes have just been very hard" "I think it's because it's the walking on eggshells, so never knowing whether whatever I say is he going to explode? Is he going to be verbally unkind?" Loss of who was once knew is very difficult - emotional impact Uncertainty regarding symptoms is anxiety-provoking	**Theme 2: Navigating partner's diasagreement, denial, or avoidance related to symptoms and care** Partners were often the first to notice symptoms and struggled with deciding whether to discuss changes and limitations with their partner in effort to keep them safe. They often felt guilty or "the bad guy". "It's difficult to point out to him that I think it's a change, it's a decline. I'm not sure if he sees it that way. I try to point it out, but I don't know if I'm doing more harm than good trying to be sort of open by talking about it." "And I don't think she was being honest with the doctors, so I spoke up and I said, "Doctor, I don't think she's being honest with you. I think this" and I named the specific thing. And she wasn't happy at all, okay, but afterwards, she was actually able to tell me she was really angry and so forth." "It's really hard because that is denial on his part, and I don't know how to deal with that. I certainly don't want to keep saying, "oh your brain doesn't work right." It's all screwed up." Struggle with honesty vs. managing denial - emotional impact	**Theme 3: Adjustment to increased responsibilities and loss of equal partnership** Many partners experienced a complete shift in familial roles as they adjusted to being a sole parent and exclusively responsible for the well-being of their partner and family. Partners felt stressed about taking on new responsibilties, particularly when they had not been previously involved in them e.g., finances. The transition from an equal and reciprocal partnership to being the primary care-partner was difficult. "The dynamic of a couple changes, right? Because we were pretty equal. We had different things that we did. We were pretty equal and all of a sudden to be relying on me that's completely differently than it was. And it's hard" Struggle to adjust to new and unfamiliar roles Sadness at loss of equality/partnership	**Theme 4: Exhaustion and burnout from caregiving** Partners experienced physical and mental fatigue due to increased responsibilites. This subsequently impacted their ability to take care of themselves, engage in hobbies or even process the gravity of the situation. Partners also experienced frustration at a lack of gratitude expressed by their partners. "So I mean I haven't done a very good job at setting limits, so some people said, "you're going to have boundaries, and you gotta have free time for yourself", and all that kind of stuff. I don't" "I go home and then I have to immediately go into caregiving mode, okay. What happened throughout the day that I need to fix? You know? And it can be something very literally fixed. Something got broken because she wasn't paying attention, or something got damaged or something more like, "Oh you bought what? Oh, got to take that back!"" Lack of time to take care of self is seen as difficult Prioritising caring over self-care	**Theme 5: Loss of physical and emotional intimacy with partner** Partners perceived the loss of a deep, complex and humourous relationship with their partner. These changes had a negative impact on their emotional connection and intimacy as a couple. Partners also reported a loss of physical intimacy with their partner; some felt stressed about their changing sexual relationship along with guilt as to whether they should engage sexually with their partner. "So when you talk about having even an intimate relationship; that's all gone, and he now sleeps in his own room. "It's really tough living with someone that you've been married to and there's no affection anymore." "It's no longer- at least from my perspective, and he may want more, but it's very difficult from my perspective, so he is not the man I married." Grieving loss of physical intimacy Partner is not the same person - barriers to retaining physical relationship	**Theme 6: Lack of social support and loneliness** Partners felt isolated from friends and other family members because they often knew little about YOD. Combined with increased responsibilites leaving little time to connect with social network, partners expressed increasing isolation. "It's interesting how in other illnesses, community comes together, family comes together, that type of thing. But with dementia, particularly frontotemporal dementia, the behaviour variant, the symptoms aren't obvious until you spend some time with the person. And so, everyone else is just assuming your life is the same when your life is actually drastically different." "It's like I don't have a	**Theme 7: Loss of anticipated future and need to re-envision future** Partners endorsed sadness and grief when they thought about the future and simultaneously watched their partner's decline. Partners had to change future plans because of their partner's illness e.g., needing to work longer due to loss of earnings. Made more difficult by not having partner to discuss anxieties and worries about the future with. "I don't want to burden him, you know what I mean? We've always done stuff together. If I worry about the future and I'm talking to him about worrying about the future when in some ways he's the problem of the future, you know what I mean, that's just not fair to him and yet he's the
	Thorsen & Johannessen (2023)	**Theme 1: Different caregiving periods** Women explained that combining their job with caregiving responsibilites became too exhausting or they reduced their work commitments "I had to say 'no thanks' to jobs, to some positions I could not take. So my work was definitely influenced. You see, I always had to be home after work to look after him". Caregiving means giving up own career progression?	**Theme 2: Distancing - experiencing a transformed spouse and relationship** 1- The changes in the personality of the affected spouse led to a trend of 'distancing'; moving from a partnership initially based on love and cooperation to experiencing the spouse as another person and feelings for the affected spouse changed. Spouses were described to "drift away" and made comparisons to a change in dynamic whereby the metaphor "like a child" was used to describe a husband. "I have one son, and I sense I now have the same feelings for my husband that I had for my son as a kid. I felt that I was the only one able to give him what he needed, and I am there now" Relationship is redefined by a new dynamic? 2- Additionally, wives described challenges with changes in their own	**Theme 3: Social isolation** The spouses feelings of isolation and loneliness in the caring role are often exacerbated by lack of understanding from others. Gradually, outside private contact is reduced. Caregiving is time consuming and requires great effort, leaving little space and energy for contact with others.	**Theme 4: Needing assistance and relief** One aspect of the caregiving spouse's problems is being too "bonded", lacking time for their own interests. For wives, this was less about engaging in valued activity but related to "time for being themselves". Both men and women described wanting time for themselves to engage in either appreciated activities and to relax and recover, to "find themselves". For women, their new caring role became a continuation of their mothering role, occuring at a time in life course where they looked forward to more freedom and new prospects. Caregiving is a barrier to appreciating the self as an individual? Loss of self	**Wife's stories about long caring** This theme captures the emotional journey from diagnosis to a wife's husband going into a care home. 1-The wife describes taking on new roles and responsibilities and this new workload was heavy, demanding and stressful. She describes the emotional impact of doing this alone "I missed someone to share the work with, like repairing the garage and the house. All the 'male jobs'. Furthermore, I did absolutely everything at home, and I also had to look after him, to see that he got washed, got food and went where he should go. It was like having a kid." Loneliness within relationship Relationship redefined 2- The wife also describes her emotional experience related to her husband eventually going into a care home. This testifies to the intensively experienced guilty conscience of a wife when transferring a spouse with dementia to a nursing home.	**Husbands stories about long caring** This theme captures the opposite emotional response of husbands when moving wives with dementia into a care setting. Stories represent men who feel they have done their best, had no choice, and have no regrets/no guilty conscience. "Then suddenly getting the freedom to do things on your own and start a new life - it was wonderful. A relief! Really! Not having responsibility for an ill person any longer. I was so ready for it; I had no	

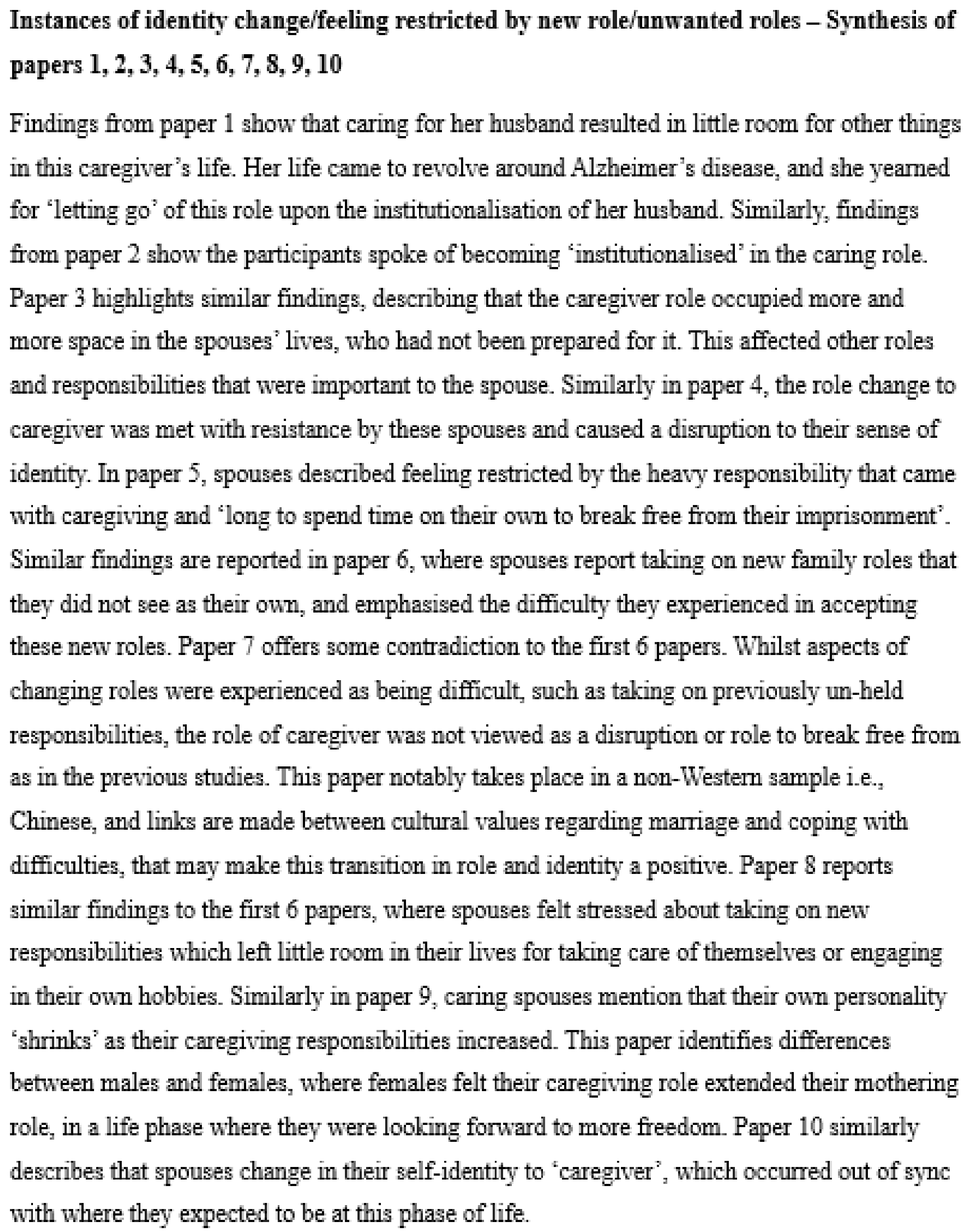
Red = author's interpretations; Green = direct participant quotes; Purple = researcher interpretations

Appendix C. Initial Translations Grid



	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q
1	**Theme / Experiences of**																
2	Emotional distress / reactions to changes in the situation / complex emotions	**Bakker et. al (2010) Theme 1: Making choices in the care situation** Subtheme: Diminishing Reciprocity The reciprocity within the relationship diminished and, in the end, the caregiver was forced to make all of the decisions concerning work, finances, the household, and the care of her husband. "I really felt abandoned. At that time, I really thought: I am going to take care of these things myself because managing all these things together with my husband is not going to work" Feeling abandoned "I had all these things on my mind and my husband just sat there all day doing nothing" Resentment	**Bakker et. al (2010) Theme 1: Making choices in the care situation** Subtheme: Changing Perspectives A proper and timely diagnosis was perceived as important to be able to perceive the behavioural problems that occurred as a symptom caused by the disease. Only after the diagnosis was established, the caregiver was able to change her perspective on the situation. "At that time, I did not know that he was ill. He did not want to see a doctor. I thought: If you are not ill, I will leave you... it could have ended in a divorce" "My husband went three times and the psychologist was more or less angry with me. I had to give my husband more space; there was no dementia, no brain tumor, only a minor concentration problem. I left and thought: maybe I am interfering with his life too much. I blamed myself"	**Bakker et. al (2010) Theme 2: Conditions for the use of care** Subtheme: Confirmation There was also a need for confirmation from healthcare professionals of the decisions that the caregiver made, such as planning a vacation and admitting her husband into the nursing home "I thought I will not take that vacation, but then I talked to the cooridnator of the day centre and she said, 'if you never take a few days off, you will not be able to manage'. And that is true ... I am glad she said that" "Maybe I can talk to the psychologist who can alter my way of thinking. Maybe he can take away the guilt" Guilt around meeting own need for rest/recovery? Seeking validation for making decisions for personal wellbeing?	**Bakker et. al (2010) Theme 1: Making choices in the care situation** Subtheme: Grieving and adjusting to change However difficult, the diagnosis was an important marking point and led the caregiver to stay in the marriage and care for her husband. It also allowed her to begin grieving. "Finally I had an answer to what had gone wrong in the past four, five years... when my husband was asleep, I was in the living room, crying and thinking, not knowing what the future might bring... I was only just 50 years old ... how devastating for him" Uncertain future is saddening	**Lockeridge and Simpson (2013) Theme 4: 'What will become of me': carers' adaptation to loss** 1- Carers felt 'cheated' by dementia in terms of both loss of future plans with their partner and continual loss within the present as their partner deteriorated.	**Lockeridge & Simpson (2013) Theme 4: 'What will become of me': carers' adaptation to loss** 5 - when carers expressed loneliness/isolation, they also felt guilt about situations where they might form attachments with anyone else while their partner was still alive	**Lockeridge & Simpson (2013) Theme 4: 'What will become of me': carers' adaptation to loss** 6- carers still working reported experiencing difficulties managing partners needs and needing to work "I absolutely dread it [the future]. The CPN did say I need to look at my priorities. Whether my priorities were [partner] or the business. And, I mean, I can't choose between the two. The business is what keeps a roof over our heads and pays for our food... so I have a job. But I have also taken on a lifelong committment to my husband and as far as I'm concerned the two go hand in hand." Balancing care and work feels impossible?	**Ducharme et. al (2013) Theme 1: Difficulty managing behavioural and psychological symptoms of partner** Spouses initially attempted to develop alternative explanations for their spouses' unusual changes in behaviour such as stress, depression, fatigue. Nonetheless, caregivers reported difficulty in experiencing problem-behaviours. "What upsets me a lot is his aggressiveness... I'd never been confronted with this sort of thing in my life. I have to say it's quite something because he's aggressive and it's totally out of nowhere" Disbelief and shock at behavioural symptoms?	**Ducharme et. al (2013) Theme 2: Long quest for diagnosis** Spouses described a challenging journey to ultimately receiving a diagnosis. This was met with with relief of an explanation for the changes observed in their partner however caregivers' search for information regarding the diagnosis received led to uncertainity and worry. "For me, Pick's Disease didn't mean much, a little Pick's couldn't be that serious... I mean the neurologist said it wasn't Alzheimer's... so we walked away with a sigh of relief, but then when you start searching the internet..." Answers providing both relief and worry regarding prognosis?	**Ducharme et. al (2013) Theme 3: Non-disclosure to others and denial of diagnosis** Diagnosis was hidden due to stigma and taboo associated with the disease which contributed to isolation and desire to avoid social situations. Spouses found it very difficult to tell others, even their children and disclosure came when it was no longer viable to keep the diagnosis hidden due to growing severity of behaviours in their partner. "My children.... it broke my heart.... what broke my heart... most was for my children to see their father like that. How was I going to tell them the truth... their father has what? (Alzheimer's)"	**Ducharme et. al (2013) Theme 4: Grief for loss of spouse, married life and midlife projects** Caregivers realised they had to grieve the loss of numerous things, the relationship with their spouse that existed prior to the disease, their spouse role for the new caregiver role, and a "normal" life "I'm grieving the loss of my husband, of my lover... I know that he'll grow more and more dependent. I'm also grieving the loss of my work"	**Massimo et. al (2013) Theme 1: Identity and role change** Of necessity, but often with resistance, spouses began to take on new roles and responsibilities. This role change can be difficult for spouses as there may be many disruptions to daily life "Most of the time I am sad because I hate the change. I hate that we are going through this and we have to change our entire lives and everything about them. Nothing is the same" Change is very difficult	**Massimo et. al (2013) Theme 4: Facing the future** The diagnosis of FTD quickly forces spouses into new meanings and self-understandings. In order to look forward to the future, caregivers have to radically reinterpret their expectations of that future. Coming to terms with this was difficult. "I don't know if I can do this farm by myself. So it has been very emotional this past year. Sunday night, perfect situation: someone called to take the horse because I don't know if I would be able to take care of it myself. I cried for hours" Facing the future alone is daunting	**Massimo et. al (2013) Theme 3: Anger** The feeling most often expressed in response to behaviours of partners was anger. This was related to violations of social norms and lack of emotional responsiveness. Diminished capacity to empathise may generate even more anger in the partner as non-responsive behaviour/disconnection precipitates anger over infringement of boundaries, meanings and social entitlements. "He doesn't say goodbye. And doesn't kiss anybody or hug anybody anymore. Even with friends or family. If someone dies or is ill, he has no feeling. It's terrible! You want to tear your hair out!" "We're mad at him a lot of the times 'cause I just can't believe... it doesn't	**Johannessen et. al (2017) Theme 1: Sneaking signs at the early stage of dementia** Subtheme: Incomprehensible early signs The development of FLTD usually had a long history. Spouses mentioned unusual changes in behaviour and personality. Their complex and confusing behaviour and personality transformation were incomprehensible and without adequate interpretation for a long time "Does he no longer bother to show consideration for my wishes?" Lack of understanding leads spouses to question partners' care for them	**Johannessen et. al (2017) Theme 2: Life turning upside down at the later stage of dementia** Subtheme: The torment Spouses described their situation at this stage with words like "surrealistic", "awful", "strange" and "impossible". Life gradually became more difficult as the disease progressed. Informants narrated many ways how they became mentally exhausted by the constant consideration for the other's needs. "It is an enormous burden. It is extremely sad. It is a torment. What sort of life is that? It is a constant grief. It is not a life for him either. Death would be a relief. It is hell." Emotional response to dementia is profound
3	Difficulties within relationship / Impact on the relationship	**Lockeridge & Simpson (2013) Theme 1: 'This is not happening': the use of denial as a coping strategy** 2- The use of concealment/denial had a negative impact on relationships with some partners and led to conflict and loss of trust, carers described using 'white lies' which made engagement with services less traumatic and life easier for the couple. However conflict arose as time passed when partners neither understood nor accepted the need for services. Actions taken to cope with situation can cause relationship conflicts Attempts to protect both the status quo and their loved one? Fear of destabilisation?	**Lockeridge & Simpson (2013) Theme 4: 'What will become of me': carers' adaptation to loss** 3 - Some carers felt life was passing them by and yearned for the emotional closeness and companionship of their lost relationship with their partner	**Lockeridge & Simpson (2013) Theme 4: 'What will become of me': carers' adaptation to loss** 4 - carers remained committed to their relationships despite their partners reduced ability to reciprocate "We still go to see classical concerts. I'm not sure what she gets out of it anymore. We go to the ballet. That still gives her pleasure... so we try and do things like that, but fairly obviously one is limited. She's in the terminal stages of early-onset dementia, so it's gradually going to get worse." Striving to maintain the relationship	**Massimo et. al (2013) Theme 2: Isolation** Behavioural changes in their partner contributed to spouses sense of loss of meaning and connection to their spouse. Absence of meaningful connection created feelings of isolation and alienation from their partner "I think what has been the hardest for me is that he doesn't want to talk about it with me. So, it's sort of the elephant in the room. He hasn't wondered how it has affected me" "I never expected to be by myself... all these changes in our lives by myself... not having someone to talk to... not having someone to talk things over with. That is the hardest part"	**Begman et. al (2016) Theme 4: The ambiguous experience of being together** The subthemes of loss of intimacy, being close and feeling a sense of kinship are different expressions of being together, illustrating the complexity of being together yet not being together. There is a prounounced feeling of not taking part and helplessness of a loss of life as it was before. Couples described maintaining togetherness as a way to feel closeness. "It is like being in a glass bubble; I can't reach out. It is like not being able to participate..." "Every evening, we take a walk around the neighbourhood... this is our most important moment, when we just walk without talking so much. We walk together and go hand in hand in the dark: it is a nice touch. We don't need so many words; we know each other"	**Johannessen et. al (2017) Theme 1: Sneaking signs at the early stage of dementia** Subtheme: Lack of self-insight Spouses described their partner as covering up and attempting to defend the image of being well-functioning and that their partner did not show self-insight "He will not have any assistance. He is not ill. It is just me who is crazy and mad. He has no insight, no realisation of his disease" Experience of being criticised for partner's difficulties?	**Pang & Lee (2019) Theme 2: Multiple unanticipated and 'early' losses** The diagnosis of YOD bought multiple unanticipated and 'early' losses to spousal caregivers who were still young and in a more active life phase. Losses discussed included: -Loss of emotional connection with partner: Spouses discussed loss of reciprocal communication which had induced a sense of emotional disconnectedness, accompanied by sadness, frustration and despair. The early 'loss' of a lifelong companion was difficult. "I have never imagined that I would 'lose' my wife at such a young age. I thought we would support each other for lifelong" "She is very emotional now.Whenever I tried to stop her from doing soemthing she wanted, she would shout at me very loudly. I'm sad but I have to tolerate her. I know that I need some time to accept this change"	**Pang & Lee (2019) Theme 3: Finding positives and meaning** Additionally, spouses reviewed their lives and recollected mutual and joyful past memories to regain a sense of connectedness, instead believing that caregiving could be a way to continue their relationship. To re-establish the loss of spousal relationship with care-recipients, caregivers arranged shared activities. "He took good care of me and my whole family before. He was very good. So, I have to take good care of him" Attempts to retain closeness with spouse	**Popok et. al (2022) Theme 1: Adjustment to partners' cognitive and behavioural changes** Partners felt confused about their partners symptoms and frustrated when tasks could not be completed. They also described sadness regarding changes, particularly personality changes. "Just the constant of living with like I said a person that I love but I don't like most of the time. It's hard. It's hard because he looks like my husband. We have all this history of him not being that way, so the personality changes have just been very hard" Experiencing partner as no longer the same person	**Popok et. al (2022) Theme 5: Loss of physical and emotional intimacy with partner** Partners perceived the loss of a deep, complex and humourous relationship with their partner. These changes had a negative impact on their emotional connection and intimacy as a couple. Partners also reported a loss of physical intimacy with their partner; some felt stressed about their changing sexual relationship along with guilt as to whether they should engage sexually with their partner. "So when you talk about having even an intimate relationship; that's all gone, and he now sleeps in his own room. "It's really tough living with someone that you've been married to and there's no affection anymore." "It's no longer- at least	**Popok et. al (2022) Theme 6: Lack of social support and loneliness** Partners felt isolated from friends and other family members because they often knew little about YOD. Combined with increased responsibilites leaving little time to connect with social network, partners expressed increasing isolation. "It's like I don't have a spouse that I can go to at the end of a rough day and have a conversation with. I go home and then I have to immediately go into caregiving mode." Missing shared experiences as a couple	**Thorsen & Johannessen (2023) Theme 2: Distancing - experiencing a transformed spouse and relationship** 1- The changes in the personality of the affected spouse led to a trend of 'distancing'; moving from a partnership initially based on love and cooperation to experiencing the spouse as another person and feelings for the affected spouse changed. Spouses were described to "drift away" and made comparisons to a change in dynamic whereby the metaphor "like a child" was used to describe a husband. "I have one son, and I sense I now have the same feelings for my husband that I had for my son as a kid. I felt that I was the only one able to give him what he needed	**Thorsen & Johannessen (2023) Wife's stories about long caring** This theme captures the emotional journey from diagnosis to a wife's husband going into a care home. 1-The wife describes taking on new roles and responsibilities and this new workload was heavy, demanding and stressful. She describes the emotional impact of doing this alone "I missed someone to share the work with, like repairing the garage and the house. All the 'male jobs'. Furthermore, I did absolutely everything at home, and I also had to look after him, to see that he got washed, got food and went where he should go. It was like having a kid." Loneliness within relationship Relationship redefined	**Binford et. al (2023) Primary concept 2: Moments of Significance** Any "step-down" in changes to identity represents 'moments of significance'. Types of events that elicited most significant meaning were most likely to involve a 'breach' of the relationship "... he was having some behavioral issues where he wasn't acting like a parent, he was acting more like a sibling to my daughter who was like in eighth grade." Relationship redefined as PWEOD becomes incongruent with perception of 'spouse'?	**Binford et. al (2023) Primary Concept 3: Conditions of the Situation - Changes in the Spouse/Interpersonal Dyad Changes** Several changes were identified including behavioural changes, personal care needs, financial concerns, safety concerns in the home etc. These conditions of change exerted a unique toll for participants and challenged each to renegotiate what being a spouse meant to them. Changes were interpreted as 'markers' indicating a threshold of incongruency in being able to fully identify as a spouse. "... the marriage was over long before diagnosis ... it was certainly when she was abusive to the children. Her behaviors towards the kids and me were a betrayal of our marriage. I no longer saw her as my wife." "He's so affectionate... but he's like too affectionate... but you know the relationship changes, too... you know, it's not just a little kiss, it's a big kiss... it's just, it feels like 'blach!'... I see	**Binford et. al (2023) Core Concept 2: Stepwise Progression of Role Identity Change** A step-wise progression in role identity change was described by participants. This did not occur in a particular sequence/time course; for some this occurred gradually over many years or occured over a relatively short course. Moments of significance drive steps in the transition. "It's definitely been more gradual because I can really think about it when we got the diagnosis this is dementia it changed the relationship, but I wouldn't say to caregiver at that time... now I've already transitioned in thinking not really as a spouse
	Identity change / restricted by new role / loss of self-hood / unwanted roles	**Lockeridge & Simpson (2013) Theme 4: 'What will become of me': carers' adaptation to loss** 2 - Carers spoke of becoming 'institutionalised' in the caring role.	**Ducharme et. al (2013) Theme 6: Difficulty planning for future** Still young, spouses expected an uncertain future that differed from their expectations while experiencing feelings of helplessness "Everything is up in the air, there are still so many things that we could have worked on... but now there's no use talking about any of that" "This really changes my life plans and my momentum. It goes against the flow... I now have to take care of someone. This isn't what we	**Ducharme et. al (2013) Theme 5: Difficulty juggling unexpected role and daily life responsibilities** The caregiver role occupied more and more space in the life of spouses who had not been prepared for it, affecting other roles and responsibilities "I don't feel at all like an expert, just overwhelmed. I don't feel young any more, I feel like an old lady. Being a family caregiver isn't where I was at in my life... I'm the mother of a young child"	**Massimo et. al (2013) Theme 1: Identity and role change** Of necessity, but often with resistance, spouses began to take on new roles and responsibilities. This role change can be difficult for spouses as there may be many disruptions to daily life "All of a sudden I went from wife to caregiver. And that label was put on my chest that said 'caregiver now'. And then I accepted it for a little while and then I realised that 'I don't want to be your caregiver'. I really don't want to do that."	**Bergman et. al (2016) Theme 1: The experience of being restricted** This theme included sub-themes of heavy responsibility, additional obligations and a longing for freedom. Spouses discussed feeling restriced by worry and growing responsbilities and obligations. They have to find ways to endure the present and long to spend time on their own as a way to break free from their imprisonment. "Now everything he does	**Johannessen et. al (2017) Theme 2: Life turning upside down at the later stage of dementia** Subtheme: Interference with work Partners often interfered with the spouses ability to maintain their work through both distractions/worries about the partner at home and responsibility/preoccupation with caring tasks. "He called me at work and told me that he had tried to light up the fireplace, and then set the carpet on fire"	**Johannessen et. al (2017) Theme 2: Life turning upside down at the later stage of dementia** Subtheme: Vanishing social relations Spouses gradually lost their partner as an intimate person, parent of shared children, friend and partner in everyday life. Spouses reported taking on new family roles and roles they did not see as their own. Women emphasised the difficulty of their new roles as econominc providers and restoration of family economy. Husbands did not appear overwhelmed with taking new	**Pang & Lee (2019) Theme 2: Multiple unanticipated and 'early' losses** The diagnosis of YOD bought multiple unanticipated and 'early' losses to spousal caregivers who were still young and in a more active life phase. Losses discussed included: -Loss of role: changing roles considered a big challenge and required time to learn and adapt to their new roles e.g., having to become major support for the family and forced	**Pang & Lee (2019) Theme 2: Multiple unanticipated and 'early' losses** The diagnosis of YOD bought multiple unanticipated and 'early' losses to spousal caregivers who were still young and in a more active life phase. Losses discussed included: -Loss of self: caregiving had forced caregivers to sacrifice themselves to provide constant care; caregivers found this frustrating when witnessing friends who were at the same stage of life, travelling and enjoying retirement.	**Popok et. al (2022) Theme 3: Adjustment to increased responsibilities and loss of equal partnership** Many partners experienced a complete shift in familial roles as they adjusted to being a sole parent and exclusively responsible for the well-being of their partner and family. Partners felt stressed about taking on new responsibilties, particularly when they had	**Popok et. al (2022) Theme 4: Exhaustion and burnout from caregiving** Partners experienced physical and mental fatigue due to increased responsibilites. This subsequently impacted their ability to take care of themselves, engage in hobbies or even process the gravity of the situation. Partners also experienced frustration at a lack of gratitude expressed by their partners.	**Thorsen & Johannessen (2023) Theme 2: Distancing - experiencing a transformed spouse and relationship** 2- Additionally, wives described challenges with changes in their own personality or threats to "selfhood" where new aspects of their personality emerged and the self gradually transformed or retracted as their caregiving responsbilities increased; caring spouses mention	**Thorsen & Johannessen (2023) Theme 4: Needing assistance and relief** One aspect of the caregiving spouse's problems is being too "bonded", lacking time for their own interests. For wives, this was less about engaging in valued activity but related to "time for being themselves". Both men and women described wanting time for themselves to engage in either appreciated activities and to relax and recover, to "find themselves". For women, their new caring role became a continuation of their	**Binford et. al (2023) Core concept: The Process of Role Identity Change** Interviews highlighted an underlying psychosocial process of what it means to be the spouse of a PWEOD; a transition in role identity. Over time, and out of necessity, spouses change how they self-identify to try and meet the growing demands of their role. The consequences become a) an increase in their load to manage	**Binford et. al (2023) Primary concept 1: The Situation of Being the Spouse of PWEOD** 2- Being the spouse of a PWEOD leads to questions of self-identity "... I didn't sign up for this kind of thing. I'm uncomfortable with that. So, my whole role is changing, I guess not only in terms of a husband-wife relationship... but my whole kind of role view of myself is having to change ... this is not who I think I am." Incongruence of self-perception vs. reality - challenge to self-	**Binford et. al (2023) Core Concept 2: Stepwise Progression of Role Identity Change** A step-wise progression in role identity change was described by participants. This did not occur in a particular sequence/time course; for some this occurred gradually over many years or occured over a relatively short course. Moments of

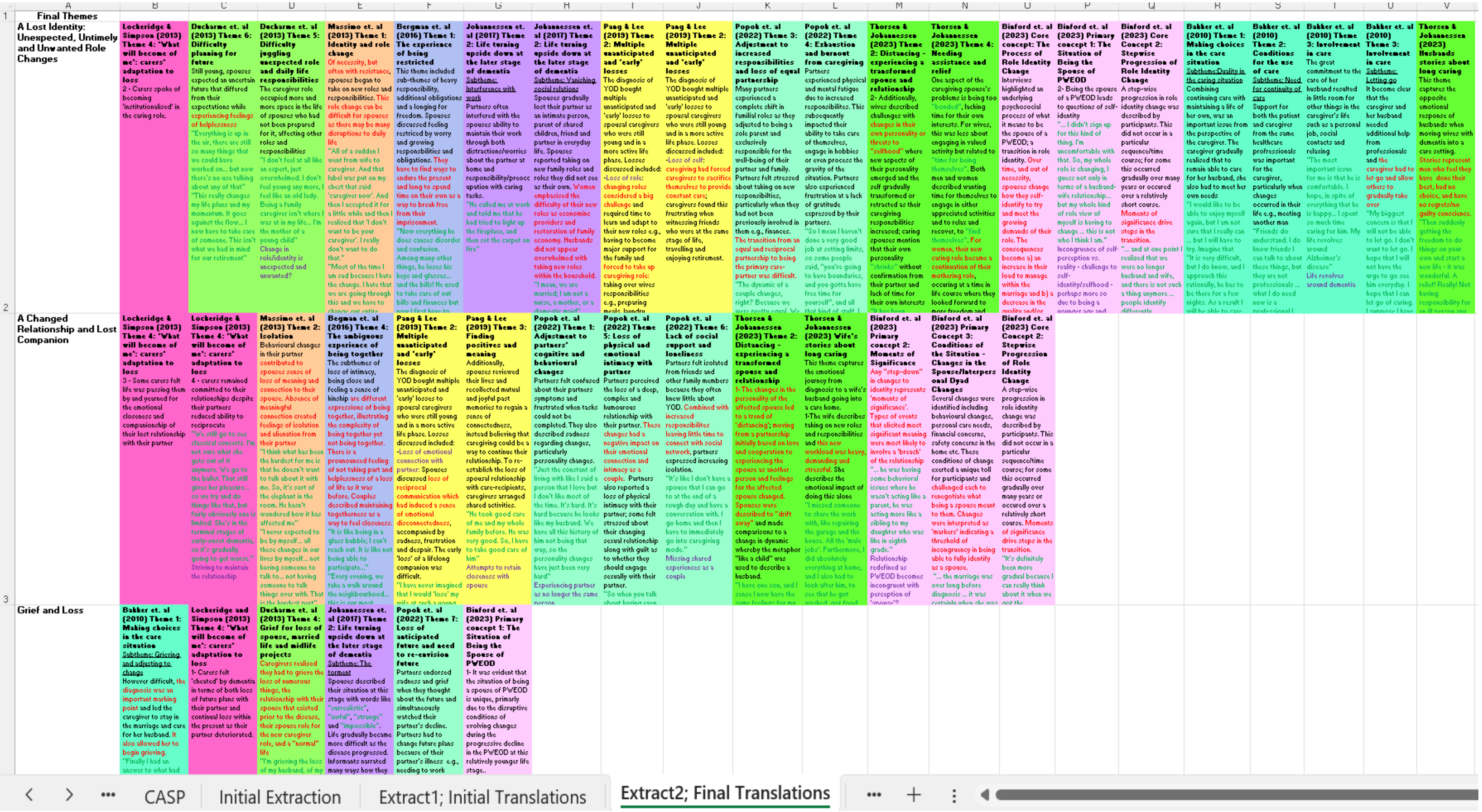
Appendix D. Example of Summary in Phase 5



Instances of identity change/feeling restricted by new role/unwanted roles – Synthesis of papers 1, 2, 3, 4, 5, 6, 7, 8, 9, 10

Findings from paper 1 show that caring for her husband resulted in little room for other things in this caregiver's life. Her life came to revolve around Alzheimer's disease, and she yearned for 'letting go' of this role upon the institutionalisation of her husband. Similarly, findings from paper 2 show the participants spoke of becoming 'institutionalised' in the caring role. Paper 3 highlights similar findings, describing that the caregiver role occupied more and more space in the spouses' lives, who had not been prepared for it. This affected other roles and responsibilities that were important to the spouse. Similarly in paper 4, the role change to caregiver was met with resistance by these spouses and caused a disruption to their sense of identity. In paper 5, spouses described feeling restricted by the heavy responsibility that came with caregiving and 'long to spend time on their own to break free from their imprisonment'. Similar findings are reported in paper 6, where spouses report taking on new family roles that they did not see as their own, and emphasised the difficulty they experienced in accepting these new roles. Paper 7 offers some contradiction to the first 6 papers. Whilst aspects of changing roles were experienced as being difficult, such as taking on previously un-held responsibilities, the role of caregiver was not viewed as a disruption or role to break free from as in the previous studies. This paper notably takes place in a non-Western sample i.e., Chinese, and links are made between cultural values regarding marriage and coping with difficulties, that may make this transition in role and identity a positive. Paper 8 reports similar findings to the first 6 papers, where spouses felt stressed about taking on new responsibilities which left little room in their lives for taking care of themselves or engaging in their own hobbies. Similarly in paper 9, caring spouses mention that their own personality 'shrinks' as their caregiving responsibilities increased. This paper identifies differences between males and females, where females felt their caregiving role extended their mothering role, in a life phase where they were looking forward to more freedom. Paper 10 similarly describes that spouses change in their self-identity to 'caregiver', which occurred out of sync with where they expected to be at this phase of life.

Appendix E. Final Translations Grid

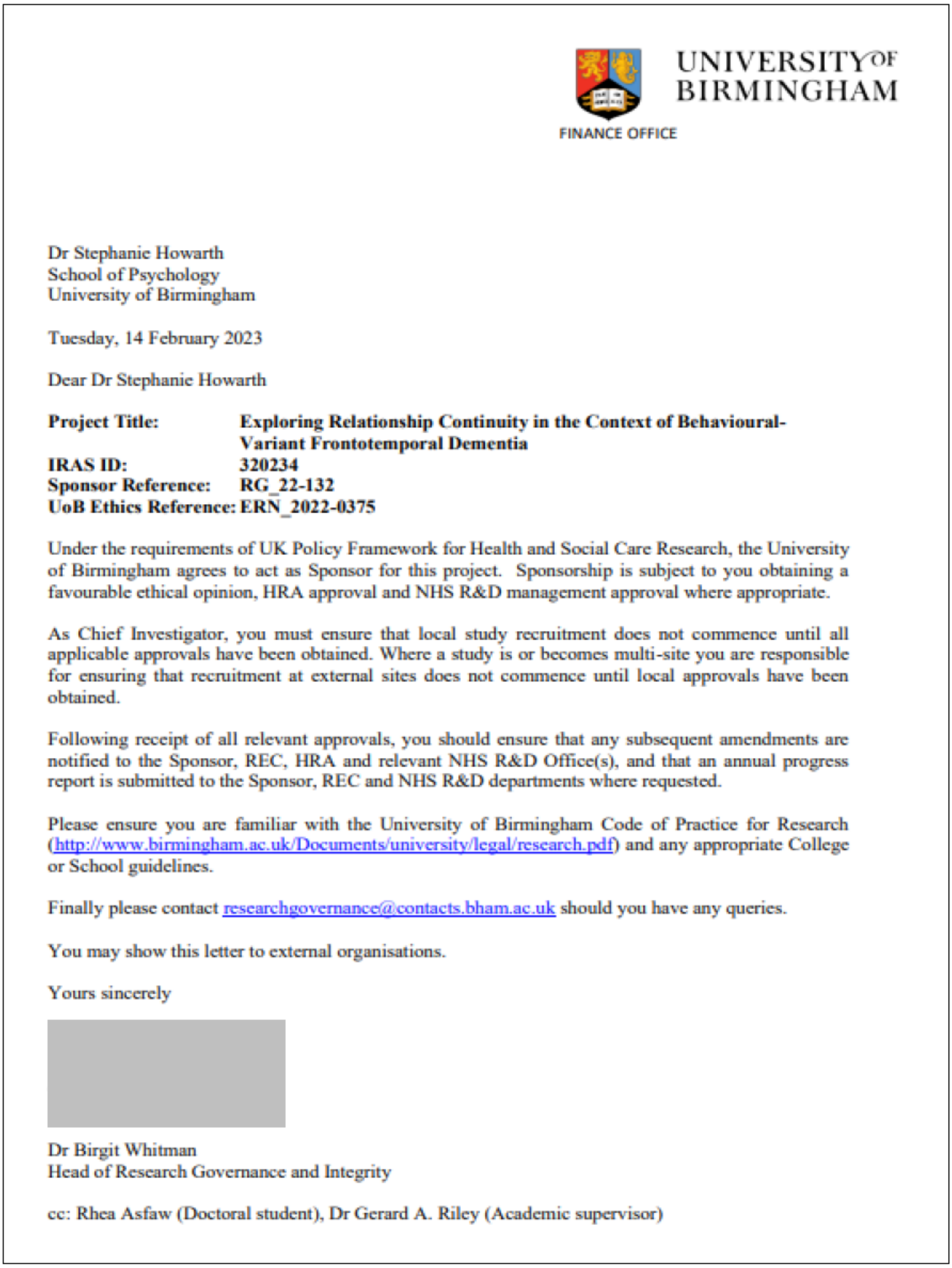


	A	B	C	D	E	F	G	H	I	J	K
1	Final Themes										
2	A Lost Identity: Unexpected, Untimely and Unwanted Role Changes	**Lockeridge & Simpson (2013) Theme 4: 'What will become of me': carers' adaptation to loss** 2 - Carers spoke of becoming 'institutionalised' in the caring role.	**Ducharme et. al (2013) Theme 6: Difficulty planning for future** Still young, spouses expected an uncertain future that differed from their expectations while experiencing feelings of helplessness "Everything is up in the air, there are still so many things that we could have worked on... but now there's no use talking about any of that" "This really changes my life plans and my momentum. It goes against the flow... I now have to take care of someone. This isn't what we had in mind for our retirement"	**Ducharme et. al (2013) Theme 5: Difficulty juggling unexpected role and daily life responsibilities** The caregiver role occupied more and more space in the life of spouses who had not been prepared for it, affecting other roles and responsibilities "I don't feel at all like an expert, just overwhelmed. I don't feel young any more, I feel like an old lady. Being a family caregiver isn't where I was at in my life... I'm the mother of a young child" Change in role/identity is unexpected and unwanted?	**Massimo et. al (2013) Theme 1: Identity and role change** Of necessity, but often with resistance, spouses began to take on new roles and responsibilities. This role change can be difficult for spouses as there may be many disruptions to daily life "All of a sudden I went from wife to caregiver. And that label was put on my chest that said 'caregiver now'. And then I accepted it for a little while and then I realised that 'I don't want to be your caregiver'. I really don't want to do that." "Most of the time I am sad because I hate the change. I hate that we are going through this and we have to change our entire	**Bergman et. al (2016) Theme 1: The experience of being restricted** This theme included sub-themes of heavy responsibility, additional obligations and a longing for freedom. Spouses discussed feeling restriced by worry and growing responsbilities and obligations. They have to find ways to endure the present and long to spend time on their own as a way to break free from their imprisonment. "Now everything he does causes disorder and confusion. Among many other things, he loses his keys and glasses... and the bills! He used to take care of out bills and finances but now I first have to	**Johannessen et. al (2017) Theme 2: Life turning upside down at the later stage of dementia** Subtheme: Interference with work Partners often interfered with the spouses ability to maintain their work through both distractions/worries about the partner at home and responsibility/preoccupation with caring tasks. "He called me at work and told me that he had tried to light up the fireplace, and then set the carpet on fire"	**Johannessen et. al (2017) Theme 2: Life turning upside down at the later stage of dementia** Subtheme: Vanishing social relations Spouses gradually lost their partner as an intimate person, parent of shared children, friend and partner in everyday life. Spouses reported taking on new family roles and roles they did not see as their own. Women emphasised the difficulty of their new roles as econominc providers and restoration of family economy. Husbands did not appear overwhelmed with taking new roles within the household. "I mean, we are married; I am not a nurse, a mother, or a domestic maid"	**Pang & Lee (2019) Theme 2: Multiple unanticipated and 'early' losses** The diagnosis of YOD bought multiple unanticipated and 'early' losses to spousal caregivers who were still young and in a more active life phase. Losses discussed included: -Loss of role: changing roles considered a big challenge and required time to learn and adapt to their new roles e.g., having to become major support for the family and forced to take up caregiving role: taking over wives responsibilities e.g., preparing meals, laundry	**Pang & Lee (2019) Theme 2: Multiple unanticipated and 'early' losses** The diagnosis of YOD bought multiple unanticipated and 'early' losses to spousal caregivers who were still young and in a more active life phase. Losses discussed included: -Loss of self: caregiving had forced caregivers to sacrifice themselves to provide constant care; caregivers found this frustrating when witnessing friends who were at the same stage of life, travelling and enjoying retirement.	**Popok et. al (2022) Theme 3: Adjustment to increased responsibilities and loss of equal partnership** Many partners experienced a complete shift in familial roles as they adjusted to being a sole parent and exclusively responsible for the well-being of their partner and family. Partners felt stressed about taking on new responsibilties, particularly when they had not been previously involved in them e.g., finances. The transition from an equal and reciprocal partnership to being the primary care-partner was difficult. "The dynamic of a couple changes, right? Because we were pretty equal. We
3	A Changed Relationship and Lost Companion	**Lockeridge & Simpson (2013) Theme 4: 'What will become of me': carers' adaptation to loss** 3 - Some carers felt life was passing them by and yearned for the emotional closeness and companionship of their lost relationship with their partner	**Lockeridge & Simpson (2013) Theme 4: 'What will become of me': carers' adaptation to loss** 4 - carers remained committed to their relationships despite their partners reduced ability to reciprocate "We still go to see classical concerts. I'm not sure what she gets out of it anymore. We go to the ballet. That still gives her pleasure... so we try and do things like that, but fairly obviously one is limited. She's in the terminal stages of early-onset dementia, so it's gradually going to get worse." Striving to maintain the relationship	**Massimo et. al (2013) Theme 2: Isolation** Behavioural changes in their partner contributed to spouses sense of loss of meaning and connection to their spouse. Absence of meaningful connection created feelings of isolation and alienation from their partner "I think what has been the hardest for me is that he doesn't want to talk about it with me. So, it's sort of the elephant in the room. He hasn't wondered how it has affected me" "I never expected to be by myself... all these changes in our lives by myself... not having someone to talk to... not having someone to talk things over with. That is the hardest part"	**Begman et. al (2016) Theme 4: The ambiguous experience of being together** The subthemes of loss of intimacy, being close and feeling a sense of kinship are different expressions of being together, illustrating the complexity of being together yet not being together. There is a prounounced feeling of not taking part and helplessness of a loss of life as it was before. Couples described maintaining togetherness as a way to feel closeness. "It is like being in a glass bubble; I can't reach out. It is like not being able to participate..." "Every evening, we take a walk around the neighbourhood... this is our most	**Pang & Lee (2019) Theme 2: Multiple unanticipated and 'early' losses** The diagnosis of YOD bought multiple unanticipated and 'early' losses to spousal caregivers who were still young and in a more active life phase. Losses discussed included: -Loss of emotional connection with partner: Spouses discussed loss of reciprocal communication which had induced a sense of emotional disconnectedness, accompanied by sadness, frustration and despair. The early 'loss' of a lifelong companion was difficult. "I have never imagined that I would 'lose' my wife at such a young	**Pang & Lee (2019) Theme 3: Finding positives and meaning** Additionally, spouses reviewed their lives and recollected mutual and joyful past memories to regain a sense of connectedness, instead believing that caregiving could be a way to continue their relationship. To re-establish the loss of spousal relationship with care-recipients, caregivers arranged shared activities. "He took good care of me and my whole family before. He was very good. So, I have to take good care of him" Attempts to retain closeness with spouse	**Popok et. al (2022) Theme 1: Adjustment to partners' cognitive and behavioural changes** Partners felt confused about their partners symptoms and frustrated when tasks could not be completed. They also described sadness regarding changes, particularly personality changes. "Just the constant of living with like I said a person that I love but I don't like most of the time. It's hard. It's hard because he looks like my husband. We have all this history of him not being that way, so the personality changes have just been very hard" Experiencing partner as no longer the same person	**Popok et. al (2022) Theme 5: Loss of physical and emotional intimacy with partner** Partners perceived the loss of a deep, complex and humourous relationship with their partner. These changes had a negative impact on their emotional connection and intimacy as a couple. Partners also reported a loss of physical intimacy with their partner; some felt stressed about their changing sexual relationship along with guilt as to whether they should engage sexually with their partner. "So when you talk about having even	**Popok et. al (2022) Theme 6: Lack of social support and loneliness** Partners felt isolated from friends and other family members because they often knew little about YOD. Combined with increased responsibilites leaving little time to connect with social network, partners expressed increasing isolation. "It's like I don't have a spouse that I can go to at the end of a rough day and have a conversation with. I go home and then I have to immediately go into caregiving mode." Missing shared experiences as a couple	**Thorsen & Johannessen (2023) Theme 2: Distancing - experiencing a transformed spouse and relationship** 1- The changes in the personality of the affected spouse led to a trend of 'distancing'; moving from a partnership initially based on love and cooperation to experiencing the spouse as another person and feelings for the affected spouse changed. Spouses were described to "drift away" and made comparisons to a change in dynamic whereby the metaphor "like a child" was used to describe a husband. "I have one son, and I sense I now have the same feelings for my
4	Grief and Loss	**Bakker et. al (2010) Theme 1: Making choices in the care situation** Subtheme: Grieving and adjusting to change However difficult, the diagnosis was an important marking point and led the caregiver to stay in the marriage and care for her husband. It also allowed her to begin grieving. "Finally I had an answer to what had	**Lockeridge and Simpson (2013) Theme 4: 'What will become of me': carers' adaptation to loss** 1- Carers felt 'cheated' by dementia in terms of both loss of future plans with their partner and continual loss within the present as their partner deteriorated.	**Ducharme et. al (2013) Theme 4: Grief for loss of spouse, married life and midlife projects** Caregivers realised they had to grieve the loss of numerous things, the relationship with their spouse that existed prior to the disease, their spouse role for the new caregiver role, and a "normal" life "I'm grieving the loss of my husband, of my	**Johannessen et. al (2017) Theme 2: Life turning upside down at the later stage of dementia** Subtheme: The torment Spouses described their situation at this stage with words like "surrealistic", "awful", "strange" and "impossible". Life gradually became more difficult as the disease progressed. Informants narrated many ways how they	**Popok et. al (2022) Theme 7: Loss of anticipated future and need to re-envision future** Partners endorsed sadness and grief when they thought about the future and simultaneously watched their partner's decline. Partners had to change future plans because of their partner's illness e.g., needing to work	**Binford et. al (2023) Primary concept 1: The Situation of Being the Spouse of PWEOD** 1- It was evident that the situation of being a spouse of PWEOD is unique, primarly due to the disruptive conditions of evolving changes during the progressive decline in the PWEOD at this relatively younger life stage..				

	A	L	M	N	O	P	Q	R	S	T	U	V
1	Final Themes											
2	A Lost Identity: Unexpected, Untimely and Unwanted Role Changes	**Popok et. al (2022) Theme 4: Exhaustion and burnout from caregiving** Partners experienced physical and mental fatigue due to increased responsibilites. This subsequently impacted their ability to take care of themselves, engage in hobbies or even process the gravity of the situation. Partners also experienced frustration at a lack of gratitude expressed by their partners. "So I mean I haven't done a very good job at setting limits, so some people said, "you're going to have boundaries, and you gotta have free time for yourself", and all that kind of stuff. I	**Thorsen & Johannessen (2023) Theme 2: Distancing - experiencing a transformed spouse and relationship** 2- Additionally, wives described challenges with changes in their own personality or threats to "selfhood" where new aspects of their personality emerged and the self gradually transformed or retracted as their caregiving responsbilities increased; caring spouses mention that their own personality "shrinks" without confirmation from their partner and lack of time for their own interests "It has been	**Thorsen & Johannessen (2023) Theme 4: Needing assistance and relief** One aspect of the caregiving spouse's problems is being too "bonded", lacking time for their own interests. For wives, this was less about engaging in valued activity but related to "time for being themselves". Both men and women described wanting time for themselves to engage in either appreciated activities and to relax and recover, to "find themselves". For women, their new caring role became a continuation of their mothering role, occuring at a time in life course where they looked forward to more freedom and	**Binford et. al (2023) Core concept: The Process of Role Identity Change** Interviews highlighted an underlying psychosocial process of what it means to be the spouse of a PWEOD; a transition in role identity. Over time, and out of necessity, spouses change how they self-identify to try and meet the growing demands of their role. The consequences become a) an increase in their load to manage within the marriage and b) a decrease in the quality and/or	**Binford et. al (2023) Primary concept 1: The Situation of Being the Spouse of PWEOD** 2- Being the spouse of a PWEOD leads to questions of self-identity "... I didn't sign up for this kind of thing. I'm uncomfortable with that. So, my whole role is changing, I guess not only in terms of a husband-wife relationship... but my whole kind of role view of myself is having to change ... this is not who I think I am." Incongruence of self-perception vs. reality - challenge to self-identity/selfhood - perhaps more so due to being a younger age and	**Binford et. al (2023) Core Concept 2: Stepwise Progression of Role Identity Change** A step-wise progression in role identity change was described by participants. This did not occur in a particular sequence/time course; for some this occurred gradually over many years or occured over a relatively short course. Moments of significance drive steps in the transition. "... and at one point I realized that we were no longer husband and wife, and there is not such a thing anymore ... people identify differently	**Bakker et. al (2010) Theme 1: Making choices in the care situation** Subtheme:Duality in the caring situation Combining continuing care with maintaining a life of her own, was an important issue from the perspective of the caregiver. The caregiver gradually realised that to remain able to care for her husband, she also had to meet her own needs "I would like to be able to enjoy myself again, but I am not sure that I really can ... but I will have to try. Imagine that "It is very difficult, but I do know, and I approach this rationally, he has to be there for a few nights. As a result I will be able to care	**Bakker et. al (2010) Theme 2: Conditions for the use of care** Subtheme: Need for continuity of care Support for both the patient and caregiver from the same healthcare profressionals was important for the caregiver, particularly when changes occurred in their life e.g., meeting another man "Friends do understand. I do know friends I can talk to about these things, but they are not professionals ... what I do need now is a professional I	**Bakker et. al (2010) Theme 3: Involvement in care** The great commitment to the care of her husband resulted in little room for other things in the caregiver's life such as a personal job, social contacts and relaxing "The most important issue for me is that he is comfortable. I hope, in spite of everything that he is happy... I spent so much time caring for him. My life revolves around Alzheimer's disease" Life revolves around dementia	**Bakker et. al (2010) Theme 3: Involvement in care** Subtheme: Letting go It become clear that the caregiver and her husband needed additional help from professionals and the caregiver had to let go and allow others to gradually take over "My biggest concern is that I will not be able to let go. I don't want to let go. I hope that I will not have the urge to go see him everyday. I hope that I can let go of caring. I suppose I have	**Thorsen & Johannessen (2023) Husbands stories about long caring** This theme captures the opposite emotional response of husbands when moving wives with dementia into a care setting. Stories represent men who feel they have done their best, had no choice, and have no regrets/no guilty conscience. "Then suddenly getting the freedom to do things on your own and start a new life - it was wonderful. A relief! Really! Not having responsibility for an ill person any
3	A Changed Relationship and Lost Companion	**Thorsen & Johannessen (2023) Wife's stories about long caring** This theme captures the emotional journey from diagnosis to a wife's husband going into a care home. 1-The wife describes taking on new roles and responsibilities and this new workload was heavy, demanding and stressful. She describes the emotional impact of doing this alone "I missed someone to share the work with, like repairing the garage and the house. All the 'male jobs'. Furthermore, I did absolutely everything at home, and I also had to look after him, to see that he got washed, got food	**Binford et. al (2023) Primary concept 2: Moments of Significance** Any "step-down" in changes to identity represents 'moments of significance'. Types of events that elicited most significant meaning were most likely to involve a 'breach' of the relationship "... he was having some behavioral issues where he wasn't acting like a parent, he was acting more like a sibling to my daughter who was like in eighth grade." Relationship redefined as PWEOD becomes incongruent with perception of 'spouse'?	**Binford et. al (2023) Primary Concept 3: Conditions of the Situation - Changes in the Spouse/Interpersonal Dyad Changes** Several changes were identified including behavioural changes, personal care needs, financial concerns, safety concerns in the home etc. These conditions of change exerted a unique toll for participants and challenged each to renegotiate what being a spouse meant to them. Changes were interpreted as 'markers' indicating a threshold of incongruency in being able to fully identify as a spouse. "... the marriage was over long before diagnosis ... it was certainly when she was	**Binford et. al (2023) Core Concept 2: Stepwise Progression of Role Identity Change** A step-wise progression in role identity change was described by participants. This did not occur in a particular sequence/time course; for some this occurred gradually over many years or occured over a relatively short course. Moments of significance drive steps in the transition. "It's definitely been more gradual because I can really think about it when we got the							
4	Grief and Loss											

APPENDICES FOR CHAPTER TWO: EMPIRICAL RESEARCH PAPER

Appendix A. University Sponsorship and Ethical Approval Letter



UNIVERSITY OF
BIRMINGHAM
FINANCE OFFICE

Dr Stephanie Howarth
School of Psychology
University of Birmingham

Tuesday, 14 February 2023

Dear Dr Stephanie Howarth

Project Title: **Exploring Relationship Continuity in the Context of Behavioural-Variant Frontotemporal Dementia**
IRAS ID: **320234**
Sponsor Reference: **RG_22-132**
UoB Ethics Reference: **ERN_2022-0375**

Under the requirements of UK Policy Framework for Health and Social Care Research, the University of Birmingham agrees to act as Sponsor for this project. Sponsorship is subject to you obtaining a favourable ethical opinion, HRA approval and NHS R&D management approval where appropriate.

As Chief Investigator, you must ensure that local study recruitment does not commence until all applicable approvals have been obtained. Where a study is or becomes multi-site you are responsible for ensuring that recruitment at external sites does not commence until local approvals have been obtained.

Following receipt of all relevant approvals, you should ensure that any subsequent amendments are notified to the Sponsor, REC, HRA and relevant NHS R&D Office(s), and that an annual progress report is submitted to the Sponsor, REC and NHS R&D departments where requested.

Please ensure you are familiar with the University of Birmingham Code of Practice for Research (http://www.birmingham.ac.uk/Documents/university/legal/research.pdf) and any appropriate College or School guidelines.

Finally please contact researchgovernance@contacts.bham.ac.uk should you have any queries.

You may show this letter to external organisations.

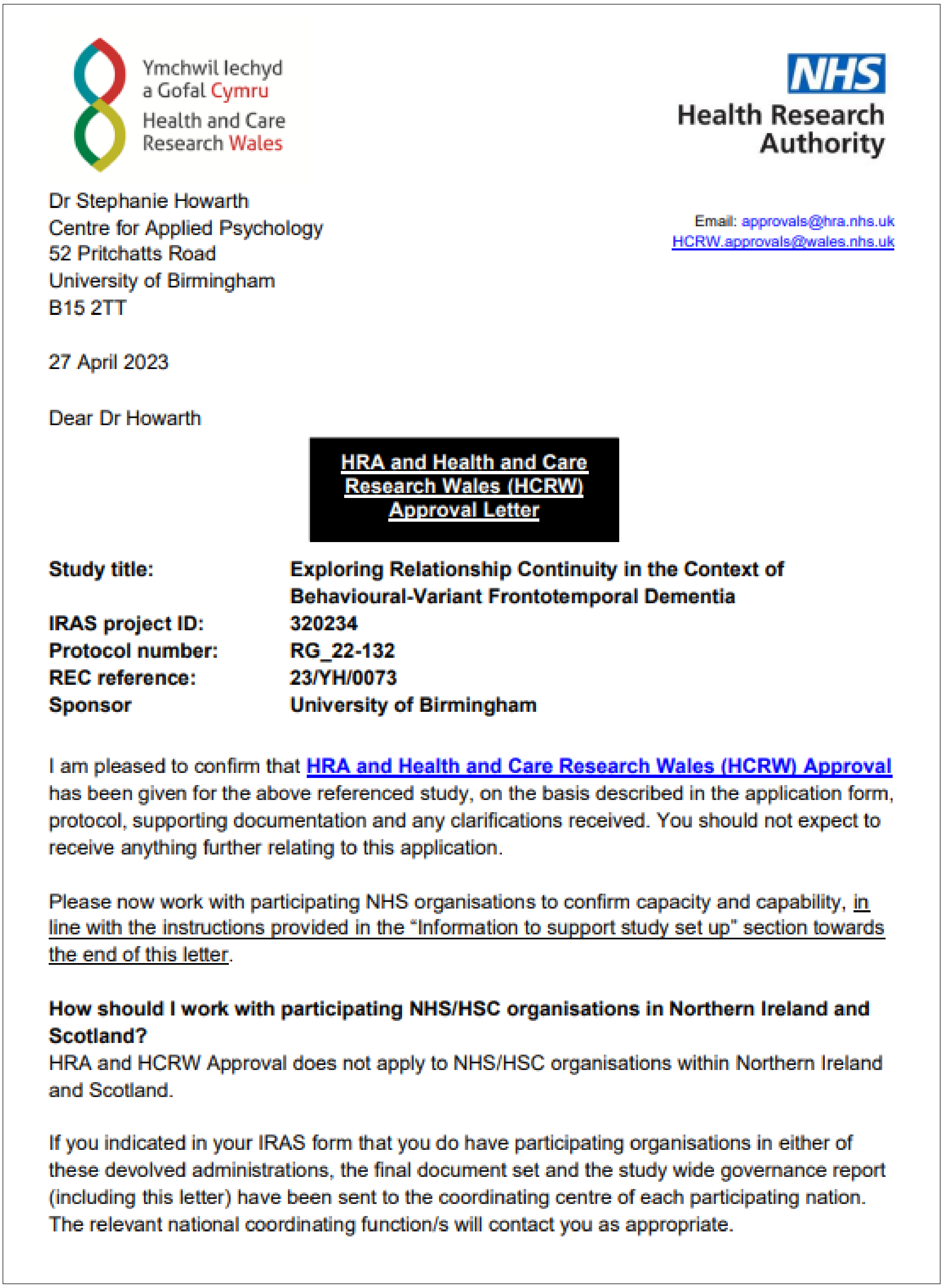
Yours sincerely

[redacted]

Dr Birgit Whitman
Head of Research Governance and Integrity

cc: Rhea Asfaw (Doctoral student), Dr Gerard A. Riley (Academic supervisor)

Appendix B. HRA Approval Letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

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

Dr Stephanie Howarth
Centre for Applied Psychology
52 Pritchatts Road
University of Birmingham
B15 2TT

27 April 2023

Dear Dr Howarth

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

Study title:	**Exploring Relationship Continuity in the Context of Behavioural-Variant Frontotemporal Dementia**
IRAS project ID:	**320234**
Protocol number:	**RG_22-132**
REC reference:	**23/YH/0073**
Sponsor	**University of Birmingham**

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

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

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

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

Appendix C. Participant Information Sheet

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Exploring Relationship Challenges Caused By Behavioural-Variant Frontotemporal Dementia

We would like to invite you to take part in our research. We would like to speak with spouses or long-term partners of individuals with a diagnosis of Behavioural-Variant Frontotemporal Dementia (bvFTD), specifically those who have experienced change within their relationship and within their partner. This may include:

- **Changes in personality** (irritable, blunt, lacking sympathy, impulsive, not doing much, change in humour, emotional outbursts, other unpleasant traits)
- **Changes in behaviour** (shouting, swearing, acting inappropriately in public, aggression, ‘no filter’, making social ‘faux pas’)

What is the purpose of this research?

The aim of this research is to explore relationship changes within the context of bvFTD. This can be a tough diagnosis, especially for partners or spouses. bv-FTD can cause significant changes in personality and behaviour, and this may affect, or change, relationships. At the moment, we don’t know exactly what it is that partners and spouses may find difficult about these behaviours and personality changes and how this influences the relationship between partners.

The wellbeing of carers is important. We hope that by speaking to the partners and spouses of people living with bv-FTD, we can identify the best way to support their mental health.

This research also forms parts of a Clinical Psychology doctoral thesis at the University of Birmingham.

Why have I been invited to take part?

You have been invited to take part because you are the spouse or long-term partner of someone with bvFTD.

What would taking part involve for me?

The study involves taking part in an interview. If you consent to be contacted by the research team, we will call you to go through some preliminary questions to make sure you are eligible to take part. If you meet the eligibility criteria, we will arrange a suitable date and time for your interview. If you are not eligible for the study, we will delete any information we have collected. For your convenience, you will be given one of three options for interview: a virtual interview, interview at home, or if you have been recruited from an NHS hospital you will have the option to be interviewed at the hospital. If you do choose to be interviewed at home, it is important that we are able to speak in a quiet, private space.

Interviews are expected to last between 45-90 minutes. You will be asked questions relating to your experience of your relationship prior to and following the diagnosis, about any significant changes you have experienced within your relationship, and what it is about behaviours or personality changes resulting from bvFTD that have directly influenced your experience of your relationship.

What are the possible benefits of taking part?

We hope that taking part will be an opportunity to talk about your experience with someone who is not part of the clinical team or your close family and friends. It may be a cathartic experience and a chance to express yourself. We also hope that the findings from this research will be used to improve the support that spouses and partners of individuals with bvFTD receive. We understand that this can be a complex diagnosis that can have a significant impact on relationships, and we want to understand this in more detail so we can plan helpful support for individuals and families in the future.

What are the possible risks of taking part?

It is not anticipated that there will be any direct risks. However, we will be asking you about a sensitive topic, and the interview may invoke strong emotions. This could be upsetting or feel quite intense. If you become distressed at any point, we can take a break and you will be free to stop the interview at any point without giving a reason. If we are concerned about your wellbeing, we may take the decision to terminate the interview as your wellbeing is our first priority. Contact details for additional support can be found along with this information sheet. We may also signpost you to seek further support.

If we believe that any risk of harm to self or others is disclosed during the course of the interview or during any contact we have with you, we have a duty of care to report this to the relevant party who will follow this up. Local safeguarding procedures will be followed to ensure your safety and the safety of others. In this instance, confidentiality will be breached in order to share the relevant disclosed information. We will discuss this with you however we will not be able to withhold any information disclosed that indicates risk of harm.

Do I have to take part?

No. It is entirely voluntary. If you do agree, we will ask you to sign a consent form prior to being interviewed. If you do not want to take part, this will have no impact on the standard of care your spouse or partner may be receiving from their clinical team.

What if there is a problem?

If you have any concerns regarding the conduct of the research, please see contact details for the research team at the bottom of this sheet. Alternatively, you may wish to contact the following:

- University of Birmingham Research Governance Team:
    - researchgovernance@contacts.bham.ac.uk
- joindementiaresearch.nihr.ac.uk/contactus

Will my information be kept confidential?

We will need to use information from you for this research project.

This information will include your name, age, contact details and information from the screening questions and the interview,

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. As we are conducting interviews, we will need to use quotes from this to illustrate your experience. We will audio record the interview and create a typed version of your interview and remove any names and places that you may have mentioned. You will be given an alternative name to ensure that any quotes we use will not be identified as coming from you. Your recorded interview will be transferred to a password protected data management system that only the research team will have access to. Once the written version is created, the audio file will be destroyed.

At the end of the interview, your personal details (address, telephone number) will be destroyed however your consent form will be retained. If you wish to receive a copy of the results, your contact details will also be retained until the end of the research.

The research team will have access to your contact details in order to arrange the interviews. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What will happen if I do not want to continue?

You can stop being part of the study at any time, without giving a reason. You are free to withdraw at any time prior to and during the interview. If you do change your mind prior to interview, please let the research team know using the contact details below. If at any time during the interview you would like to stop the interview, this is your decision and will be respected. You are under no obligation to continue if you change your mind.

If you change your mind about the inclusion of your interview in the research, you will have up to one week to inform the research team of this decision. This is due to the analysis of your interview beginning soon after the conclusion of your interview.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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

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

- www.hra.nhs.uk/information-about-patients/
- Our leaflet available from www.hra.nhs.uk/patientdataandresearch
- By asking one of the research team
- By sending an email to dataprotection@contacts.bham.ac.uk

What will happen to the findings from this research?

The research will be written up and published in an academic journal. It may also be presented at conferences. The final report of the research will possibly include direct quotes from your interview however, any quotes will be fully anonymised. The research will also be presented as part of a Clinical Psychology doctoral thesis.

Who is organising and funding this research?

This research is organised by the University of Birmingham (Centre of Applied Psychology) and supported by local NHS Trusts. It is sponsored by the University of Birmingham who have ensured that the necessary insurance and indemnity arrangements are in place.

Who has reviewed and approved this research?

Any research carried out in the NHS is reviewed by an independent group of people called a Research Ethics Committee (REC) who ensure that all measures to protect participants are in place. This research has been reviewed by the South Yorkshire REC, REC reference 23/YH/0073.

What happens next?

If you would like to take part, please complete the consent to contact form provided with this information sheet if you are being recruited from an NHS site. The research team will then call you to answer any further questions you may have, ask some screening questions, and arrange a time for interview. Please contact Rhea Asfaw if you have any further questions.

Thank you for considering taking part in this research.

RESEARCH TEAM CONTACT DETAILS

Miss Rhea Asfaw *(Primary Researcher)*

Removed for confidentiality

Dr Stephanie Howarth *(Research Supervisor – Chief Investigator)*

Removed for confidentiality

Dr Gerard Riley *(Research Supervisor)*

Removed for confidentiality

Useful Contacts and Sources of Support

Please find below a list of services that may be relevant for you. If at any time during your contact with us, concerns about the immediate safety of yourself or another person are indicated, we will act to manage the risk of harm. This may involve contacting emergency and urgent care services. We would always endeavour to discuss this with you.

Carer's support services

ForwardBirmingham Carers Hub

The hub offers a wide range of services including information, advice and support to people who care for friends and family with disabilities. Includes free advice on welfare benefits, form filling, 1:1 appointments on request, assistance to help carers to access grants, social services, equipment, finance, care homes, home care, holidays and leisure.

www.birminghamcarershub.org.uk

0333 006 9711

Carers Emergency Response Service (CERS)

CERS is a FREE emergency back-up service to provide support to those caring for a dependent family member, neighbour or friend living in Birmingham. Once registered, a highly trained team member will assess your caring situation and agree an emergency back-up plan. You'll receive a dedicated emergency contact number for times of crisis so CERS can spring into action when you need them most.

Back up care is provided 'at home' for up to two days, allowing alternative arrangements to be made with family, friends, or social services. You can also benefit from a planned sitting service, so you can get to important appointments, such as at the doctors or hospital.

0121 442 2960

Crossroads Care Birmingham, Sandwell, Walsall, and Wolverhampton

We care about the people we support by providing advice, guidance, and group peer support. In addition, we provide practical respite care so that unpaid carers can take a break from their caring responsibilities, or we provide regular care if the person you care for wishes to remain living in their own home. Staff are highly trained and knowledgeable and provide a quality care service. Crossroads can support you with carer health and wellbeing, support groups / activities, personal care services, respite and carer breaks

0121 553 6483

www.sandwellcrossroads.org

Mental health services

Please contact your GP if you feel you need support with your mental health. Below is a list of some self-referral services.

Birmingham Healthy Minds

Birmingham Healthy Minds is an NHS primary care psychological therapies service. If you are currently experiencing symptoms of low mood, depression and/or anxiety and would like to be able to manage these symptoms better, our service may be able to help you. You can self-refer by calling the number below:

0121 301 2525

Black Country Talking Therapies & Healthy Minds Services

Across the four boroughs, we provide NHS psychological therapy services for people experiencing common mental health problems such low mood, anxiety, stress, and depression. You can self-refer by calling the appropriate number below:

Sandwell – 0303 033 9903

Dudley – 0800 953 0404

Wolverhampton – 0800 923 0222

Walsall – 0800 953 0995

Urgent mental health support

If there is *immediate, serious risk of harm or injury*, please, contact one of the following:

- 999 or attend your local A&E department
- NHS 111
- Your GP
- Samaritans 116 123
- Birmingham and Solihull Urgent Mental Health Helpline (line managed by MIND) 0121 262 3555 or 0800 915 9292; 24 hours a day, 7 days a week

- Black Country Mental Health Crisis Helpline 0800 008 6516 is (managed by Black Country Healthcare NHS Foundation Trust); 24 hours a day, 7 days a week

Dementia/bvFTD specific support

Rare Dementia Support (RDS)

RDS is a world-leading, UK-based service. We aim to empower, guide and inform people living with a rare dementia diagnosis and those who care about them. Their Direct Support Team provide free information, advice and support. They also run peer support groups throughout the UK.

Telephone: 020 3325 0828

Dementia UK / Admiral Nurses

As dementia specialists, Admiral Nurses help families manage complex needs, considering the person living with dementia and the people around them. When friends and family are worried about a loved one, they give them the confidence to manage their future with dementia. Admiral Nurses help support the people caring for loved ones so that they will have the strength to cope with the bad days, and the energy to enjoy the good days.

Telephone: 0800 888 6678

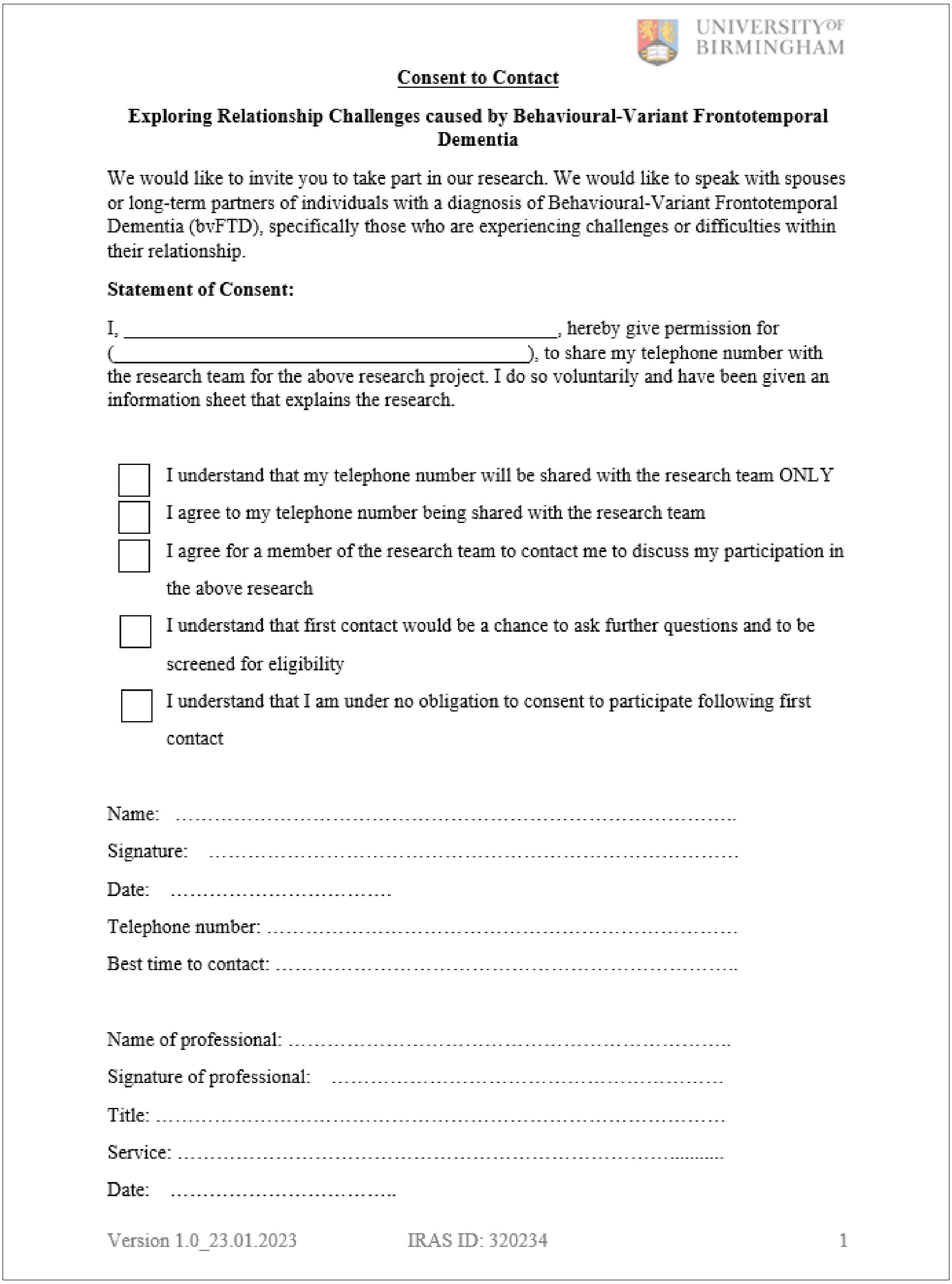
Email: helpline@dementiauk.org

Alzheimer’s Society

Dementia Connect support line for personalised information, support, and advice

Telephone: 0333 150 3456

Appendix D. Consent to Contact Form



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Consent to Contact

Exploring Relationship Challenges caused by Behavioural-Variant Frontotemporal Dementia

We would like to invite you to take part in our research. We would like to speak with spouses or long-term partners of individuals with a diagnosis of Behavioural-Variant Frontotemporal Dementia (bvFTD), specifically those who are experiencing challenges or difficulties within their relationship.

Statement of Consent:

I, ____, hereby give permission for (____), to share my telephone number with the research team for the above research project. I do so voluntarily and have been given an information sheet that explains the research.

☐ I understand that my telephone number will be shared with the research team ONLY

☐ I agree to my telephone number being shared with the research team

☐ I agree for a member of the research team to contact me to discuss my participation in the above research

☐ I understand that first contact would be a chance to ask further questions and to be screened for eligibility

☐ I understand that I am under no obligation to consent to participate following first contact

Name: …………………………………………………………………………….

Signature: …………………………………………………………………………

Date: ………………………………

Telephone number: ……………………………………………………………….

Best time to contact: ……………………………………………………………..

Name of professional: ……………………………………………………………..

Signature of professional: …………………………………………………….

Title: ……………………………………………………………………………….

Service: …………………………………………………………………………..........

Date: ………………………………..

Version 1.0_23.01.2023 IRAS ID: 320234 1

Appendix E. NHS Study Advert Poster

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Trust Logo(s)

Are you the spouse or partner of someone with Behavioural-Varaint Frontotemporal Dementia (bvFTD)?

We would like to speak with you

We are exploring how behaviour and personality change resulting from bvFTD can impact relationships. To provide the best support to spouses, we need to know more about this.

What would taking part involve?

This research involves taking part in an interview for approximately 45-90 minutes. You will be asked questions about your experience of your relationship and potential challenges you have faced

Who can take part?

Men and women aged 30-95

Have been in a relationship for 5+ years and live with your partner

Have noticed 1 or more behaviour/personality change in your partner

Version number 2.0 20.04.2023 IRAS ID: 320234

If you are interested and would like to know more, please scan the QR code using your mobile phone camera or contact the researcher using the details below

Contact details removed for confidentiality

Appendix F. Join Dementia Research Lay Summary

The researcher is only looking for volunteers who are a spouse or partner of a person with a diagnosis of Behavioural-Variant Frontotemporal Dementia. If this applies to you, please tick 'I am interested' and the researcher will contact you.

Aims and Background:

Behavioural-Variant Frontotemporal Dementia (bvFTD) can be a difficult diagnosis, not only for the individual, but also for their loved ones. We want to understand more about how bvFTD impacts the relationship between spouses or partners so that we can learn how to best support couples. Spouses / partners often take on a caregiving role. It is important that we know more about how this diagnosis affects relationships so that the right support can be provided.

The aims of the research are to explore the impact that challenging behaviours and personality characteristics in the context of bvFTD have on the relationship between spouses / partners.

We know that some symptoms of dementia can be very difficult changes to live with. Symptoms such as aggression, acting in a socially inappropriate way and loss of empathy, are linked to more distress amongst spouses / partners. Some of these symptoms are more associated with particular types of dementia such as bvFTD. However, it is not clear what it is about these challenging behaviours and personality characteristics in the context of bvFTD that cause such difficulties within relationships. We hope to develop an understanding of this experience by interviewing spouses / partners to answer some of the unknown questions about this experience.

What You Will Do:

You will be invited to be interviewed by the researcher for 45-90 minutes. You will only be required to do this once. There be no further follow up visits or interviews . You can choose whether to be visited at your home or online via a video-conferencing platform such as Microsoft Teams. If you choose to be interviewed at home, it is important that there is a private and quiet space to be interviewed where there will be no disturbances during this time.

Who We Are Looking For:

You **must be** be the spouse or partner of someone who has been diagnoised with behavioural-variant frontotemporal dementia (bvFTD).

You have been in a relationship with your spouse/partner for a miniumum of 5 years.

You should live with your spouse/partner.

You my be able to identify at least one challenging behaviour/peronsality change as a result of bvFTD in your spouse/partner.

Patient and Public Involvement, and Dissemination:

As this research has been developed and is being conducted as part of a doctoral thesis, the researcher has been responsible for all elements of the study development. Volunteers will be given a different name so they will not be identified in any aspect of the study write-up.

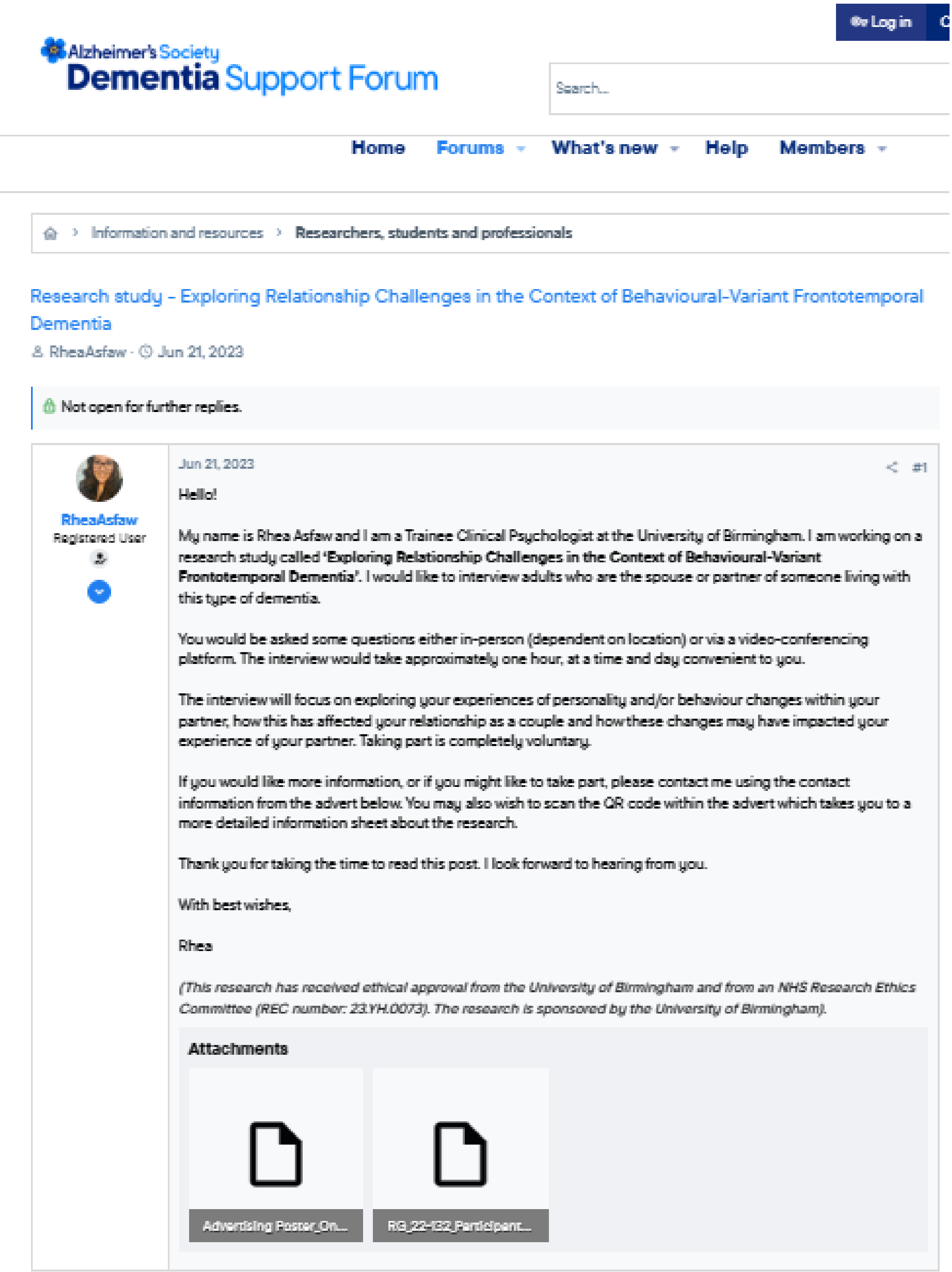
The final research report will be written as part of a Clinical Psychology doctoral thesis. It will also be published in a scientific research journal for either qualitative health research or for dementia research. Any personally identifiable information will be removed from any written reports.

The results from the research may also be presented at research conferences in the future.

Volunteers can also choose whether they would like to receive a summary of the results however they are under no obligation to agree to this.

The results from this research will add to the developing knowledge base of bvFTD and the impact it has within relationships. This will enable clinical researchers to develop evidence-based interventions and support for individuals and their loved ones, to enable them to live well with dementia.

Appendix G. Alzheimer's Society Study Advert



Research study - Exploring Relationship Challenges in the Context of Behavioural-Variant Frontotemporal Dementia

RheaAsfaw · Jun 21, 2023

Not open for further replies.

Jun 21, 2023

Hello!

My name is Rhea Asfaw and I am a Trainee Clinical Psychologist at the University of Birmingham. I am working on a research study called **'Exploring Relationship Challenges in the Context of Behavioural-Variant Frontotemporal Dementia'**. I would like to interview adults who are the spouse or partner of someone living with this type of dementia.

You would be asked some questions either in-person (dependent on location) or via a video-conferencing platform. The interview would take approximately one hour, at a time and day convenient to you.

The interview will focus on exploring your experiences of personality and/or behaviour changes within your partner, how this has affected your relationship as a couple and how these changes may have impacted your experience of your partner. Taking part is completely voluntary.

If you would like more information, or if you might like to take part, please contact me using the contact information from the advert below. You may also wish to scan the QR code within the advert which takes you to a more detailed information sheet about the research.

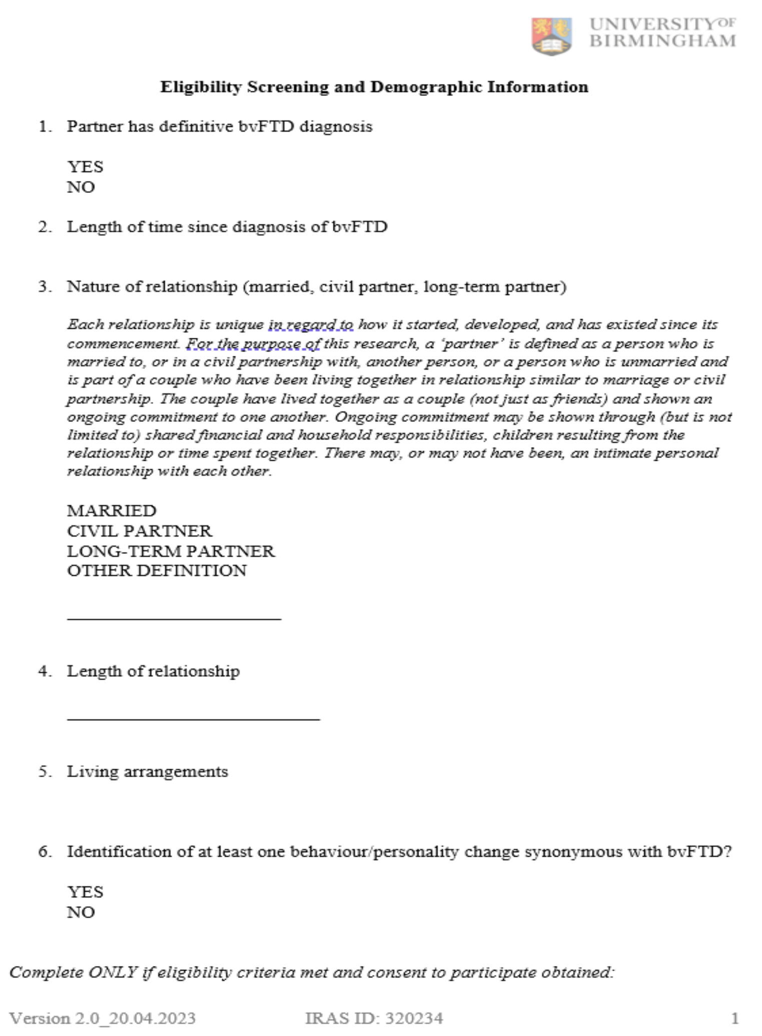
Thank you for taking the time to read this post. I look forward to hearing from you.

With best wishes,

Rhea

(This research has received ethical approval from the University of Birmingham and from an NHS Research Ethics Committee (REC number: 23.YH.0073). The research is sponsored by the University of Birmingham).

Appendix H. Eligibility Form



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Eligibility Screening and Demographic Information

1. Partner has definitive bvFTD diagnosis

   YES
   NO

2. Length of time since diagnosis of bvFTD

3. Nature of relationship (married, civil partner, long-term partner)

   Each relationship is unique in regard to how it started, developed, and has existed since its commencement. For the purpose of this research, a 'partner' is defined as a person who is married to, or in a civil partnership with, another person, or a person who is unmarried and is part of a couple who have been living together in relationship similar to marriage or civil partnership. The couple have lived together as a couple (not just as friends) and shown an ongoing commitment to one another. Ongoing commitment may be shown through (but is not limited to) shared financial and household responsibilities, children resulting from the relationship or time spent together. There may, or may not have been, an intimate personal relationship with each other.

   MARRIED
   CIVIL PARTNER
   LONG-TERM PARTNER
   OTHER DEFINITION

   ____

4. Length of relationship

   ____

5. Living arrangements

6. Identification of at least one behaviour/personality change synonymous with bvFTD?

   YES
   NO

Complete ONLY if eligibility criteria met and consent to participate obtained:

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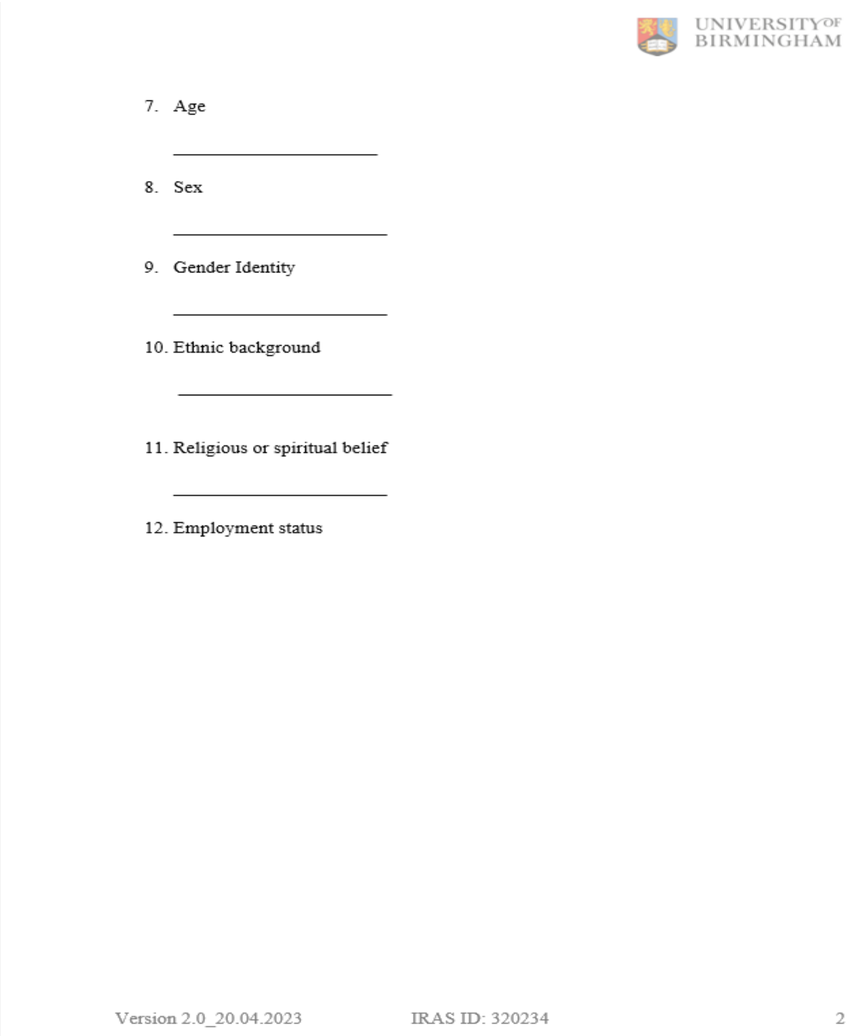

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7. Age

   ____

8. Sex

   ____

9. Gender Identity

   ____

10. Ethnic background

    ____

11. Religious or spiritual belief

    ____

12. Employment status

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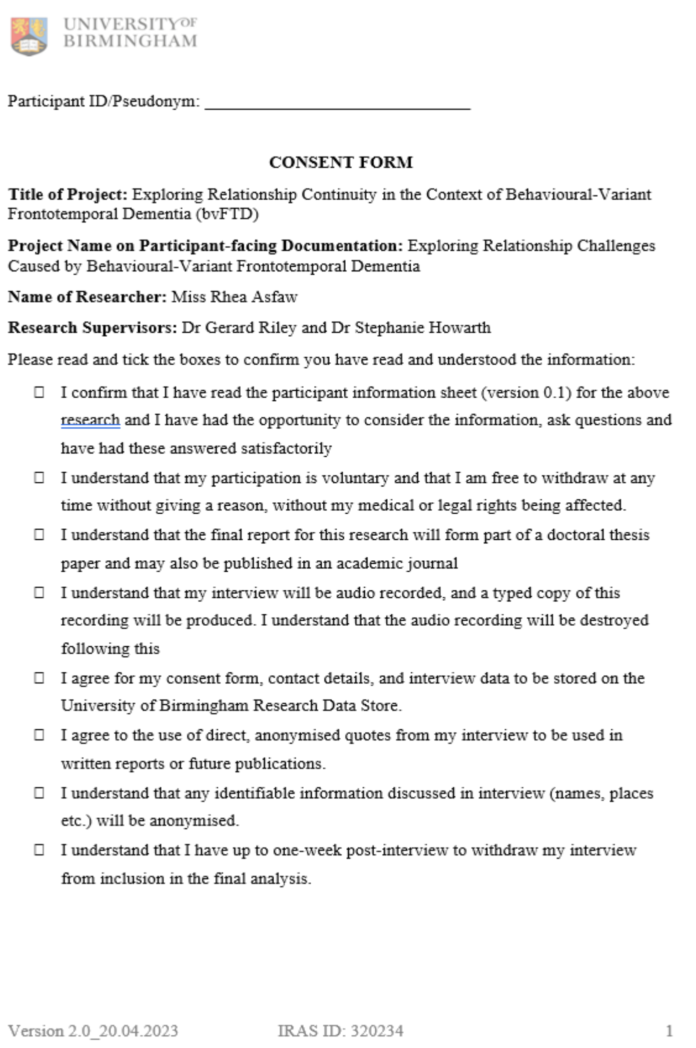
Appendix I. Consent Form



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Participant ID/Pseudonym: ______________________________

CONSENT FORM

Title of Project: Exploring Relationship Continuity in the Context of Behavioural-Variant Frontotemporal Dementia (bvFTD)

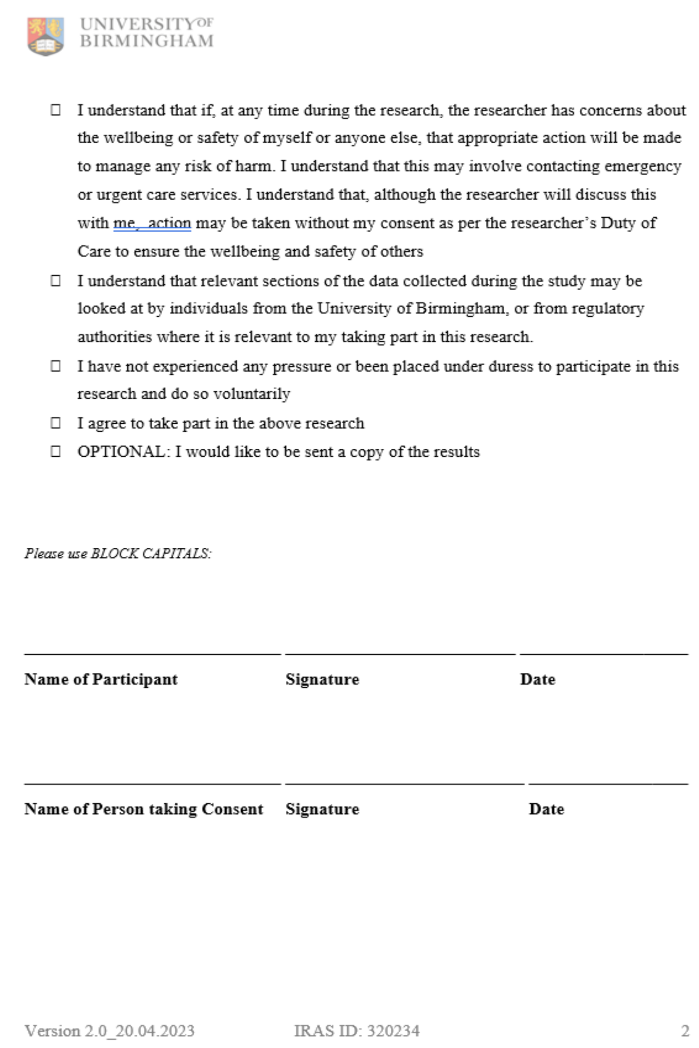
Project Name on Participant-facing Documentation: Exploring Relationship Challenges Caused by Behavioural-Variant Frontotemporal Dementia

Name of Researcher: Miss Rhea Asfaw

Research Supervisors: Dr Gerard Riley and Dr Stephanie Howarth

Please read and tick the boxes to confirm you have read and understood the information:

- ☐ I confirm that I have read the participant information sheet (version 0.1) for the above research and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily
- ☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical or legal rights being affected.
- ☐ I understand that the final report for this research will form part of a doctoral thesis paper and may also be published in an academic journal
- ☐ I understand that my interview will be audio recorded, and a typed copy of this recording will be produced. I understand that the audio recording will be destroyed following this
- ☐ I agree for my consent form, contact details, and interview data to be stored on the University of Birmingham Research Data Store.
- ☐ I agree to the use of direct, anonymised quotes from my interview to be used in written reports or future publications.
- ☐ I understand that any identifiable information discussed in interview (names, places etc.) will be anonymised.
- ☐ I understand that I have up to one-week post-interview to withdraw my interview from inclusion in the final analysis.



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- ☐ I understand that if, at any time during the research, the researcher has concerns about the wellbeing or safety of myself or anyone else, that appropriate action will be made to manage any risk of harm. I understand that this may involve contacting emergency or urgent care services. I understand that, although the researcher will discuss this with me, action may be taken without my consent as per the researcher's Duty of Care to ensure the wellbeing and safety of others
- ☐ I understand that relevant sections of the data collected during the study may be looked at by individuals from the University of Birmingham, or from regulatory authorities where it is relevant to my taking part in this research.
- ☐ I have not experienced any pressure or been placed under duress to participate in this research and do so voluntarily
- ☐ I agree to take part in the above research
- ☐ OPTIONAL: I would like to be sent a copy of the results

Please use BLOCK CAPITALS:

Name of Participant	**Signature**	**Date**
Name of Person taking Consent	**Signature**	**Date**

Appendix J. Interview Schedule

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Relationship Continuity in the Context of Behavioural-Variant Frontotemporal Dementia

Interview Schedule

Introducing the Interview

Thank you for agreeing to speak with me today. We know that bvFTD leads to significant changes and will likely have an impact on all areas of the individual's life including their closest relationships. We are interested to know how changes in behaviour and personality caused by bvFTD affects romantic relationships i.e., spouses/partners. I will be asking questions about your experience of these changes, and how they have impacted your relationship with your partner/spouse/wife/husband.

There are a number of topics related to this that I will ask questions about. I may ask you for specific examples to help gain a deeper understanding of your experience of these changes. One of the symptoms of bvFTD is changes in how a person acts and behaves. The first topic we will discuss is your experience of behaviour changes in your partner/spouse/wife/husband.

Topic 1: Experience of Behaviour Changes

Question 1 – Could you tell me about any changes in the way X acts or behaves now that are particularly challenging or very different to how they behaved previously?

(Prompts: shouting/swearing in public, making insensitive comments, lack of manners, staring at other people, making sexually explicit comments, verbal or physical aggression, loss of inhibition, making inappropriate jokes)

Question 2 – What impact do these actions or behaviours have on you emotionally?

(Prompts: Are there any particular emotions you feel in response to these behaviours, what is your emotional reaction when X behaves in this way, what is it about these behaviours that you find particularly distressing or challenging to live with)

Question 3 – How do you respond when X behaves this way?

Question 4 – How do you cope with X behaving this way?

Compassionate statement: Thank you for sharing this with me. This must be difficult to live with. Do you feel okay to continue? (If no) Offer a break + pause recording. (If yes) I will now ask you about changes in personality characteristics and your experience of this.

Topic 2: Experience of Personality Changes

Question 5 – How would you describe X personality during your relationship, prior to noticing changes?

Possible prompts – Were they sociable/outgoing/caring/loving/supportive/particular, how would you describe them to somebody who didn't know them?

Question 6 – Are there aspects of X personality that have changed significantly or are distinctly different to their natural self?

(Possible prompts – change in sense of humour, seeming unmotivated, selfishness, appearing cold, not showing sympathy to others, irritability, not caring about their appearance or hygiene, hostility

Question 7 – What impact have these changes had on you emotionally?

Question 8 – How have you coped with these changes to their personality?

Compassionate statement: This must be very tough for you to live with. Can we take a little pause to check on how you're doing talking about this? (Offer opportunity for a break). I am going to ask you more about how these changes have impacted your relationship as husband and wife/partners.

Topic 3: Impact of Changes on Relationship

Question 9 – Could you tell me how the changes we have discussed have impacted on your relationship as partners/spouses?

(Prompts – are there activities/situations you engaged in previously that you no longer do, are there particular aspects of your relationship that have changed, what is the most challenging aspect of these changes)

Question 10 – Can you give an example of times where these changes have particularly impacted your relationship?

Compassionate statement: I understand that it must be really difficult to discuss this – thank you for being so open. How are you doing? (Offer opportunity for a break). We know that when Dementia enters a relationship that there will be an inevitable change. All couples will experience these changes differently. I am going to ask you more about your view of your relationship and X now.

Topic 4: Impact of Changes on Relationship Continuity

Question 11: You've described some changes in X's behaviour and personality. Do these changes affect how you see him/her as a person? Does s/he feel like essentially the same person they were before the dementia – despite these changes, or does s/he feel very different?

- *If answer suggests that they are fundamentally changed*: What is it about these changes in particular that make it feel like X is a different person? Does this have any impact on your feelings towards X? Does it affect your relationship in any way?
- *If answer suggests that the participant perceive the person as essentially the same despite the changes*: Can you explain more about this: You've described some marked changes in X. How are you able to see him/her as essentially the same person?

Question 12: *(Pick the behavioural or personality change that is most challenging for the participant)* What is your understanding of why X is like this? What role does the dementia play, and what role does the person play? Do you feel X can control this? What do you think motivates X to behave in this way? *(Look for different options to follow up with further questions)*

- *If the answer suggests an understanding that X can control the behaviour and/or is motivated by hostility and an intention to hurt/challenge/upset others*: How does this make you feel about X? Do you blame X for in any way for behaving like this? Has this affected your relationship? Does it feel like you vs. X rather than the pair of you working as a team?
- *If the answer suggests an explanation just in terms of the dementia*: Do you feel that X's personality has any role to play in this? *If personality plays little role*: Does this make it easier to deal with, do you think – the fact that this is just the dementia making X behave in this way?
- *If the answer suggests a more empathic understanding in terms of an interaction between the dementia and the characteristics of the person with dementia*: How does this make you feel towards X? Does this make it easier to forgive X for the way they behave? Does it make it easier to cope with the behaviour?

Question 13: You mentioned before about how these behaviours make you feel A/B/C. Does this affect how you feel towards X? Does it affect your relationship? Do you find it hard to switch off these feelings and feel more loving and affectionate to X?

Question 14: A lot of people in your situation do find it hard not to take these things personally e.g., it's hard not to feel angry when someone you are making such an effort to look after and care for pays you back by being aggressive. From what you described before it seems that…

  - *If they do manage to get less upset and not to take things personally*: How have you managed to do this? Do you feel less close to X than before the dementia? Do you think feeling less close makes it easier not to take things personally?
  - *If they do take it personally*: How does this make you feel towards X? How do you think it has affected your relationship?

Question 15: Do you get less enjoyment out of the time you spend with X because of these behaviours? Do you think you have fewer good times together because of the behaviours? Do you think you spend less time with X because of these behaviours?

- *If yes*: What effect do you think this has on your relationship? Does it feel like a marriage/partnership still?

Closing the Interview

Question 16: Is there anything that I haven't asked you about that you think is important for me to understand the impact these changes have had on your relationship as spouses/partners?

Appendix K. Reflexive Journal Extracts

Phase 1: Familiarisation

“I recall sharing Alice’s shock when she verbalised that her husband of 30 plus years had cheated on her. This was an immediate and ‘kneejerk’ in-the-moment response during the interview where I responded, ‘oh my gosh’. I felt really sorry for Alice in this moment and as the first interview, this really highlighted some of the realities of living with FTD. My shock is also likely informed by my own value of monogamy within relationships, and I feel this appears to align with Alice as her describing being ‘cheated’ on was expressed as shocking and unbelievable, indicating that this went against her beliefs of what she expected from her husband, Jim. Her use of the word ‘cheated’ is commonplace in circumstances of infidelity and to be ‘cheated’ expresses deceit and unfairness. This makes me think of relationship rules, boundaries, and often unspoken, implicit assumptions we have about how we should or should not engage within relationships and expectations of how our partners should/should not behave.”

Phase 2: Coding

“Reflections on first coding round: there is a massive amount of complexity within the dataset and a real diversity of experiences. My codes feel very fine-grained and maybe a little bit too descriptive. I can notice patterns within the data but I’m not sure this is reflected in the code labels so far. I think I need to re-visit and bring my research questions to mind more.”

Phase 3: Generating Initial Themes

“I’m starting to see clear patterns such as potential themes around a lack of feeling settled with partners, the influence of how spouses interpret their partners behaviours, how communication between spouses is affected, the loss of connection between partners, the experience of many different emotional responses and a felt sense of spouses and relationships being fundamentally changed. There is some repetition between themes, and I think I need to work on identifying sub-themes to highlight the complexity of themes.”

Phase 4: Developing and Reviewing Themes

“Really helpful to get feedback from research supervision. I can see how a couple of subthemes would be better placed under other themes that better represent their underlying concept. I think this will help with the story-telling of the analysis. It was initially quite tricky to move things around again as I had spent so long trying to get things ‘perfect’. But having outsider eyes on my interpretations has helped me ‘step-out’ of the analysis and develop my analysis further by again going back to the research question and asking myself what I am trying to achieve.”

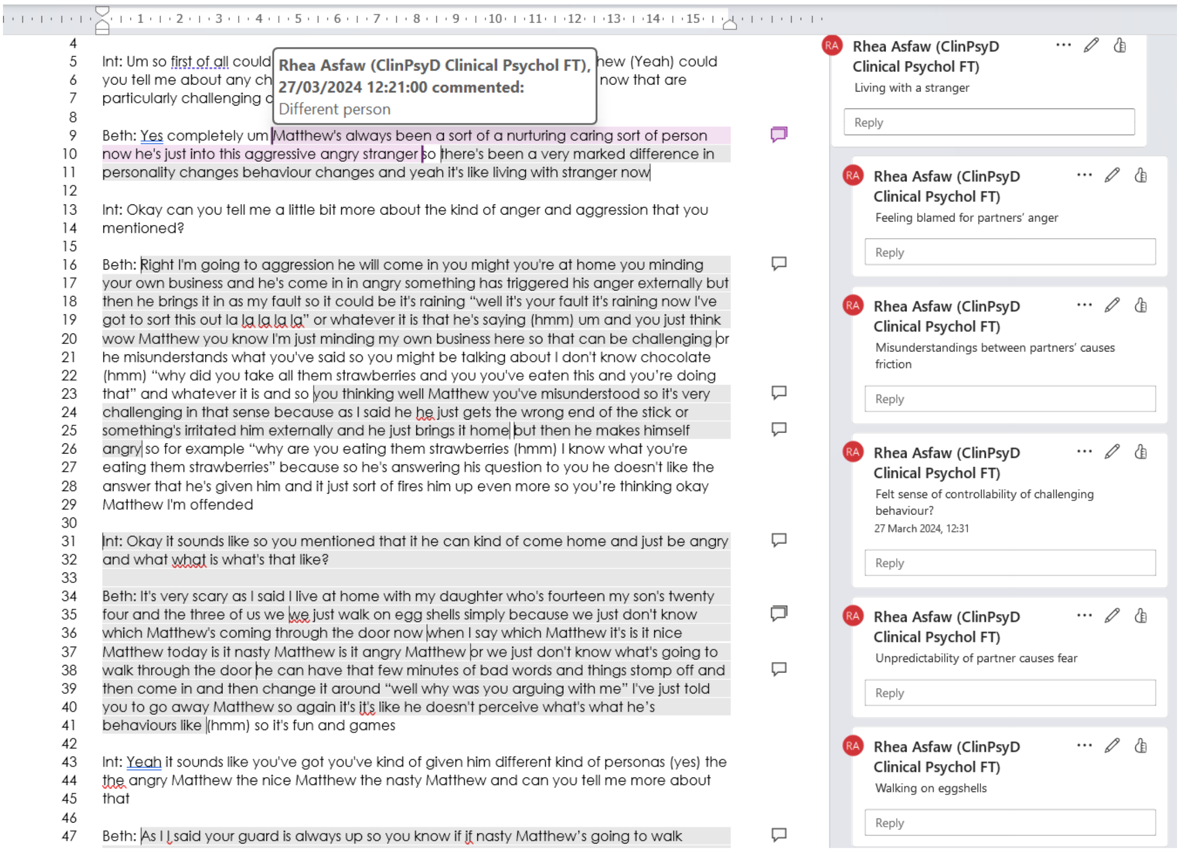
Phase 5: Refining, Defining and Naming Themes

“I’ve really enjoyed naming the themes and feel like this phase has been crucial to ‘seeing’ the story of the participants unfold. I’m excited to see the analysis coming together and hope I have captured the voices of the participants.”

Phase 6: Writing the Report

“I am finding the writing phase challenging. I am plagued by doubts of the coherence of my analysis and want to make sure that I represent the diversity within the dataset whilst acknowledging the themes that I identified. I keep reminding myself of Braun & Clarke’s assertion that qualitative research requires becoming acquainted with the discomfort of uncertainty! It is exciting to consider how the themes can contribute to future research and in clinical practice.”

Appendix L. Initial Coding Example



Int: Um so first of all could
you tell me about any ch
particularly challenging c

hew (Yeah) could
now that are

Rhea Asfaw (ClinPsyD Clinical Psychol FT), 27/03/2024 12:21:00 commented:
Different person

Beth: Yes completely um Matthew's always been a sort of a nurturing caring sort of person now he's just into this aggressive angry stranger so there's been a very marked difference in personality changes behaviour changes and yeah it's like living with stranger now

Int: Okay can you tell me a little bit more about the kind of anger and aggression that you mentioned?

Beth: Right I'm going to aggression he will come in you might you're at home you minding your own business and he's come in in angry something has triggered his anger externally but then he brings it in as my fault so it could be it's raining "well it's your fault it's raining now I've got to sort this out la la la la la" or whatever it is that he's saying (hmm) um and you just think wow Matthew you know I'm just minding my own business here so that can be challenging or he misunderstands what you've said so you might be talking about I don't know chocolate (hmm) "why did you take all them strawberries and you you've eaten this and you're doing that" and whatever it is and so you thinking well Matthew you've misunderstood so it's very challenging in that sense because as I said he he just gets the wrong end of the stick or something's irritated him externally and he just brings it home but then he makes himself angry so for example "why are you eating them strawberries (hmm) I know what you're eating them strawberries" because so he's answering his question to you he doesn't like the answer that he's given him and it just sort of fires him up even more so you're thinking okay Matthew I'm offended

Int: Okay it sounds like so you mentioned that it he can kind of come home and just be angry and what what is what's that like?

Beth: It's very scary as I said I live at home with my daughter who's fourteen my son's twenty four and the three of us we we just walk on egg shells simply because we just don't know which Matthew's coming through the door now when I say which Matthew it's is it nice Matthew today is it nasty Matthew is it angry Matthew or we just don't know what's going to walk through the door he can have that few minutes of bad words and things stomp off and then come in and then change it around "well why was you arguing with me" I've just told you to go away Matthew so again it's it's like he doesn't perceive what's what he's behaviours like (hmm) so it's fun and games

Int: Yeah it sounds like you've got you've kind of given him different kind of personas (yes) the the angry Matthew the nice Matthew the nasty Matthew and can you tell me more about that

Beth: As I I said your guard is always up so you know if if nasty Matthew's going to walk

Rhea Asfaw (ClinPsyD Clinical Psychol FT)
Living with a stranger

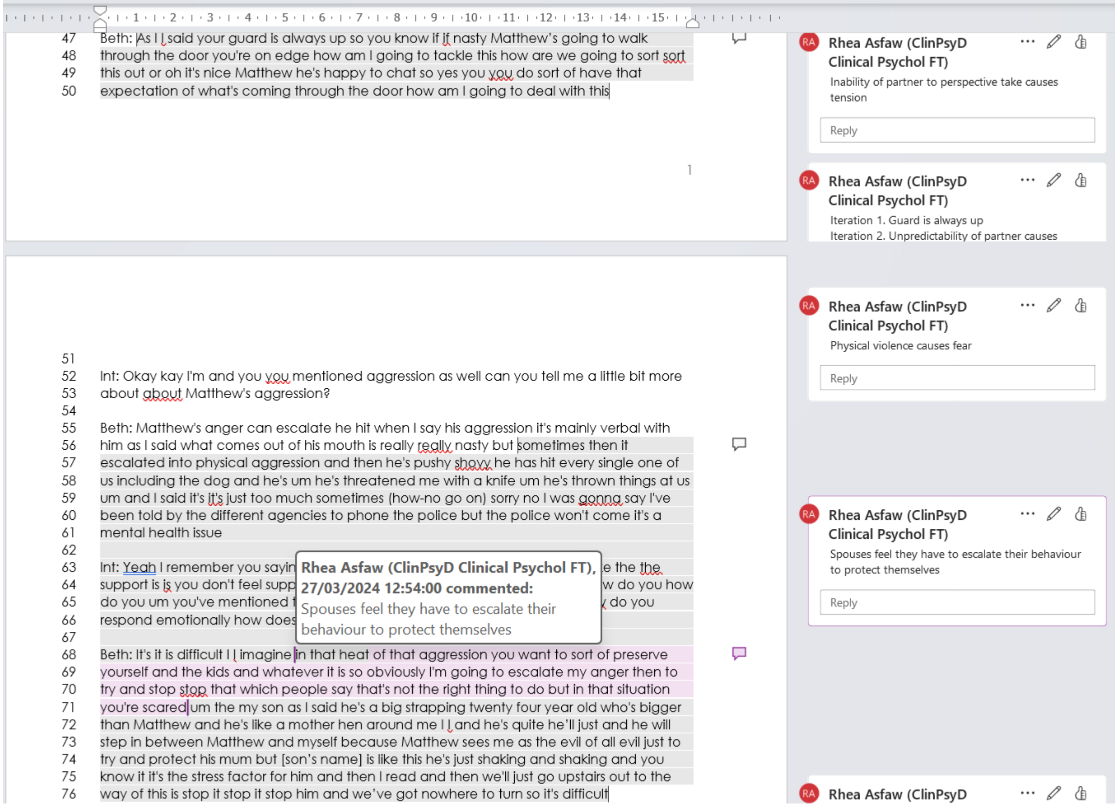
Rhea Asfaw (ClinPsyD Clinical Psychol FT)
Feeling blamed for partners' anger

Rhea Asfaw (ClinPsyD Clinical Psychol FT)
Misunderstandings between partners' causes friction

Rhea Asfaw (ClinPsyD Clinical Psychol FT)
Felt sense of controllability of challenging behaviour?
27 March 2024, 12:31

Rhea Asfaw (ClinPsyD Clinical Psychol FT)
Unpredictability of partner causes fear

Rhea Asfaw (ClinPsyD Clinical Psychol FT)
Walking on eggshells



Beth: As I I said your guard is always up so you know if if nasty Matthew's going to walk through the door you're on edge how am I going to tackle this how are we going to sort sort this out or oh it's nice Matthew he's happy to chat so yes you you do sort of have that expectation of what's coming through the door how am I going to deal with this

1

Int: Okay kay I'm and you you mentioned aggression as well can you tell me a little bit more about about Matthew's aggression?

Beth: Matthew's anger can escalate he hit when I say his aggression it's mainly verbal with him as I said what comes out of his mouth is really really nasty but sometimes then it escalated into physical aggression and then he's pushy shovy he has hit every single one of us including the dog and he's um he's threatened me with a knife um he's thrown things at us um and I said it's it's just too much sometimes (how-no go on) sorry no I was gonna say I've been told by the different agencies to phone the police but the police won't come it's a mental health issue

Int: Yeah I remember you sayin
support is is you don't feel supp
do you um you've mentioned t
respond emotionally how does

e the the
w do you how
do you

Rhea Asfaw (ClinPsyD Clinical Psychol FT), 27/03/2024 12:54:00 commented:
Spouses feel they have to escalate their behaviour to protect themselves

Beth: It's it is difficult I I imagine in that heat of that aggression you want to sort of preserve yourself and the kids and whatever it is so obviously I'm going to escalate my anger then to try and stop stop that which people say that's not the right thing to do but in that situation you're scared um the my son as I said he's a big strapping twenty four year old who's bigger than Matthew and he's like a mother hen around me I I and he's quite he'll just and he will step in between Matthew and myself because Matthew sees me as the evil of all evil just to try and protect his mum but [son's name] is like this he's just shaking and shaking and you know it it's the stress factor for him and then I read and then we'll just go upstairs out to the way of this is stop it stop it stop him and we've got nowhere to turn so it's difficult

Rhea Asfaw (ClinPsyD Clinical Psychol FT)
Inability of partner to perspective take causes tension

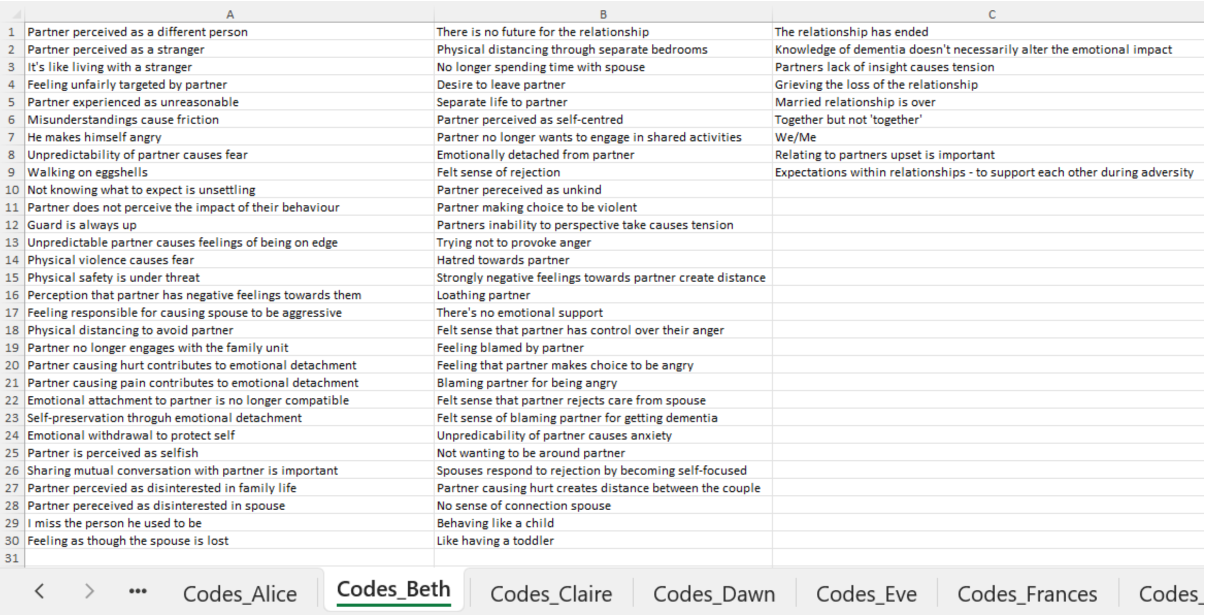
Rhea Asfaw (ClinPsyD Clinical Psychol FT)
Iteration 1. Guard is always up
Iteration 2. Unpredictability of partner causes

Rhea Asfaw (ClinPsyD Clinical Psychol FT)
Physical violence causes fear

Rhea Asfaw (ClinPsyD Clinical Psychol FT)
Spouses feel they have to escalate their behaviour to protect themselves

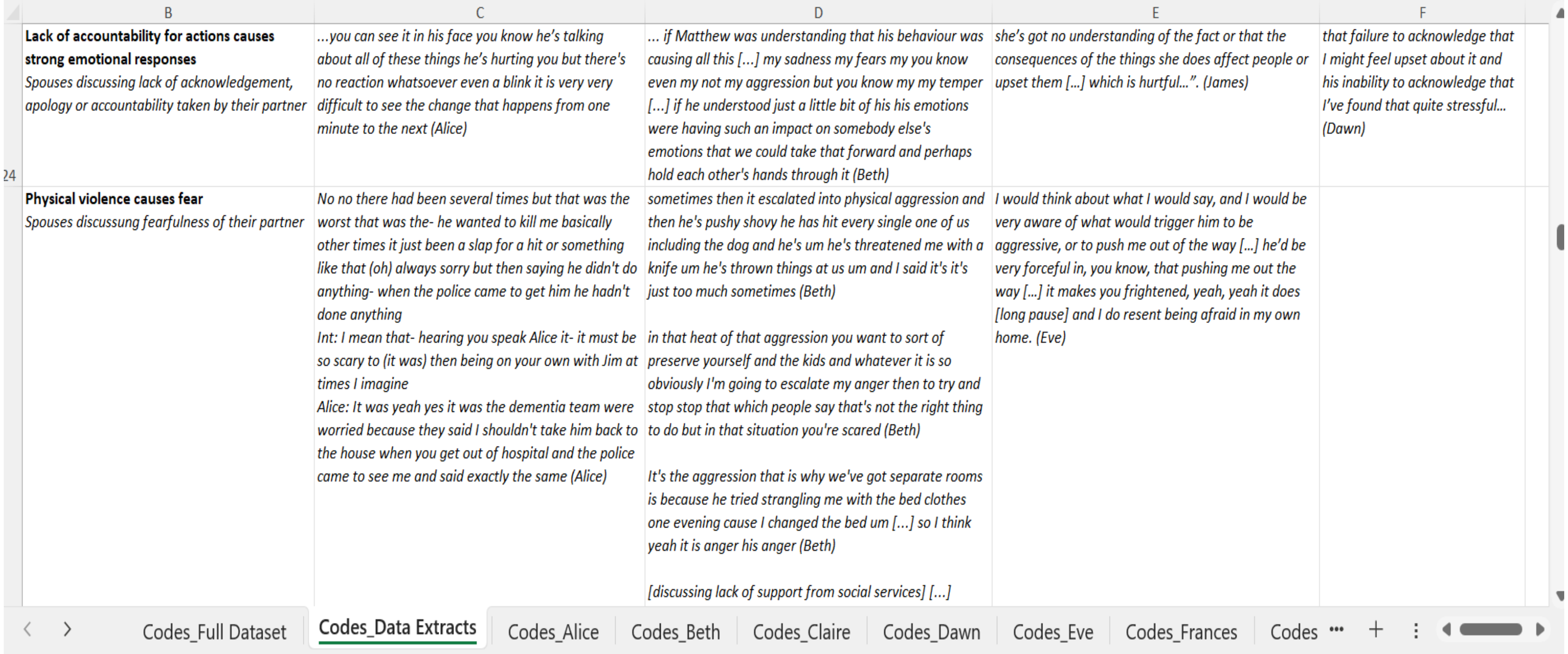
Rhea Asfaw (ClinPsyD

Appendix M. Excel Sheet of Individual Codes



	A	B	C
1	Partner perceived as a different person	There is no future for the relationship	The relationship has ended
2	Partner perceived as a stranger	Physical distancing through separate bedrooms	Knowledge of dementia doesn't necessarily alter the emotional impact
3	It's like living with a stranger	No longer spending time with spouse	Partners lack of insight causes tension
4	Feeling unfairly targeted by partner	Desire to leave partner	Grieving the loss of the relationship
5	Partner experienced as unreasonable	Separate life to partner	Married relationship is over
6	Misunderstandings cause friction	Partner perceived as self-centred	Together but not 'together'
7	He makes himself angry	Partner no longer wants to engage in shared activities	We/Me
8	Unpredictability of partner causes fear	Emotionally detached from partner	Relating to partners upset is important
9	Walking on eggshells	Felt sense of rejection	Expectations within relationships - to support each other during adversity
10	Not knowing what to expect is unsettling	Partner pereceived as unkind	
11	Partner does not perceive the impact of their behaviour	Partner making choice to be violent	
12	Guard is always up	Partners inability to perspective take causes tension	
13	Unpredictable partner causes feelings of being on edge	Trying not to provoke anger	
14	Physical violence causes fear	Hatred towards partner	
15	Physical safety is under threat	Strongly negative feelings towards partner create distance	
16	Perception that partner has negative feelings towards them	Loathing partner	
17	Feeling responsible for causing spouse to be aggressive	There's no emotional support	
18	Physical distancing to avoid partner	Felt sense that partner has control over their anger	
19	Partner no longer engages with the family unit	Feeling blamed by partner	
20	Partner causing hurt contributes to emotional detachment	Feeling that partner makes choice to be angry	
21	Partner causing pain contributes to emotional detachment	Blaming partner for being angry	
22	Emotional attachment to partner is no longer compatible	Felt sense that partner rejects care from spouse	
23	Self-preservation throguh emotional detachment	Felt sense of blaming partner for getting dementia	
24	Emotional withdrawal to protect self	Unpredicability of partner causes anxiety	
25	Partner is perceived as selfish	Not wanting to be around partner	
26	Sharing mutual conversation with partner is important	Spouses respond to rejection by becoming self-focused	
27	Partner percevied as disinterested in family life	Partner causing hurt creates distance between the couple	
28	Partner pereceived as disinterested in spouse	No sense of connection spouse	
29	I miss the person he used to be	Behaving like a child	
30	Feeling as though the spouse is lost	Like having a toddler	
31			

Appendix N. Codes with Data Extracts



	B	C	D	E	F
24	**Lack of accountability for actions causes strong emotional responses** *Spouses discussing lack of acknowledgement, apology or accountability taken by their partner*	*...you can see it in his face you know he's talking about all of these things he's hurting you but there's no reaction whatsoever even a blink it is very very difficult to see the change that happens from one minute to the next (Alice)*	*... if Matthew was understanding that his behaviour was causing all this [...] my sadness my fears my you know even my not my aggression but you know my my temper [...] if he understood just a little bit of his his emotions were having such an impact on somebody else's emotions that we could take that forward and perhaps hold each other's hands through it (Beth)*	*she's got no understanding of the fact or that the consequences of the things she does affect people or upset them [...] which is hurtful...". (James)*	*that failure to acknowledge that I might feel upset about it and his inability to acknowledge that I've found that quite stressful... (Dawn)*
	Physical violence causes fear *Spouses discussung fearfulness of their partner*	*No no there had been several times but that was the worst that was the- he wanted to kill me basically other times it just been a slap for a hit or something like that (oh) always sorry but then saying he didn't do anything- when the police came to get him he hadn't done anything* *Int: I mean that- hearing you speak Alice it- it must be so scary to (it was) then being on your own with Jim at times I imagine* *Alice: It was yeah yes it was the dementia team were worried because they said I shouldn't take him back to the house when you get out of hospital and the police came to see me and said exactly the same (Alice)*	*sometimes then it escalated into physical aggression and then he's pushy shovy he has hit every single one of us including the dog and he's um he's threatened me with a knife um he's thrown things at us um and I said it's it's just too much sometimes (Beth)* *in that heat of that aggression you want to sort of preserve yourself and the kids and whatever it is so obviously I'm going to escalate my anger then to try and stop stop that which people say that's not the right thing to do but in that situation you're scared (Beth)* *It's the aggression that is why we've got separate rooms is because he tried strangling me with the bed clothes one evening cause I changed the bed um [...] so I think yeah it is anger his anger (Beth)* *[discussing lack of support from social services] [...]*	*I would think about what I would say, and I would be very aware of what would trigger him to be aggressive, or to push me out of the way [...] he'd be very forceful in, you know, that pushing me out the way [...] it makes you frightened, yeah, yeah it does [long pause] and I do resent being afraid in my own home. (Eve)*	

Appendix O. Generating Initial Themes