Understanding the experiences of caring for a partner with young onset dementia: An interpretative phenomenological analysis

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Abstract

Young onset dementia, diagnosed before the age of 65 presents unique challenges for individuals and their carers. The prevalence of young onset dementia in the UK is rising (Carter et al., 2018) with Alzheimer's disease being the most common type of dementia (Rosser et al., 2010). Carers of people living with young onset dementia are more likely to be partners than relatives or friends (Ducharme et al., 2015). In comparison with late onset dementia, individuals with young onset dementia are more likely to develop a rarer type of dementia that requires specialist support (Collins et al., 2020) and have significantly different needs. People living with young onset dementia may still be working, parenting children, or have other caring responsibilities and financial commitments (Rabanal et al., 2018). Delays in diagnosis, stigma and a lack of meaningful age-appropriate services present further complexities for people living with young onset dementia. Caring partners face unique challenges, including psychological distress, multiple and diverse losses, and difficulties coping with the impact on their relationships (Parsons, 2019). This research aimed to explore how individuals experience and make sense of caring for a partner with young onset dementia. Findings from previous studies suggest that further research is required to examine the unique subjective experiences of the person caring, and to understand how younger carers cope with changes in their relationship (Lockeridge and Simpson, 2013). This study therefore aimed to expand on previous findings. It is hoped that the exploration of their experiences will help to further understand the thoughts and needs of this client group, raise awareness of young onset dementia through dissemination of findings, inform therapeutic practice with carers, feed into service development for young onset dementia and challenge stigmatised attitudes towards this marginalised group. This qualitative study adopted a critical realist and phenomenological approach as the epistemological position and interpretative phenomenological analysis was employed to explore the experiences of caring for a partner with young onset dementia. Semi-structured interviews were conducted with eight participants (six women and two men), six of which took place virtually via Microsoft Teams, one over the telephone and one in person. Interview transcripts were analysed using interpretative phenomenological analysis following the steps outlined by Smith, Flowers & Larkin (2022). Four group experiential themes (GETs) emerged from the data, each consisting of two to three personal experiential themes (PETs). Theme one '*The long road to diagnosis',* illustrates how the diagnostic journey was experienced. Theme two '*Ignored and forgotten*' highlights the shared experience of the lack of post-diagnostic support and the lack of awareness and understanding from others. The third theme *'So much has changed, everything is different'* explores changes in the couple relationship and identity, and the negative impact of dementia on familial relationships. The final theme four *'Where do I go from here?'* explores ways of coping and adaptations to loss. These findings address a gap in the existing literature, providing valuable contributions to understanding the subjective experiences of caring for a partner with young onset dementia. This study has implications for how services and practitioners engage with people living with young onset dementia and their carers. The implications are multifaceted, encompassing the need for timely diagnosis, targeted psychosocial interventions, raising awareness, and nuanced relationship focused support. By addressing specific challenges faced by caring partners, psychologists and other healthcare professionals can contribute to improving the overall wellbeing of this marginalised group and challenge societal perceptions of young onset dementia.

Chapter 1: Introduction

Background

Defining dementia and young onset dementia

Dementia is a clinical syndrome characterised by global cognitive impairment, which represents a decline from previous levels of functioning, and is associated with impairment in functional abilities and, in many cases, behavioural and psychiatric problems (Gould and Kendall, 2007). It is widely considered to be a major public health issue and a growing national and international concern with associated interpersonal and social implications. Worldwide, around 50 million people have dementia, with nearly 60% living in low-and middle-income countries. Every year, there are nearly 10 million new cases and the total number of people with dementia is projected to reach 82 million in 2030 and 152 million in 2050 (WHO, 2021).

Dementia can also be defined as an umbrella term used to describe a set of symptoms affecting brain function that may include memory loss and difficulties with thinking, problem solving, language and communication. A person living with dementia may also experience changes in their mood or behaviour. Alzheimer's disease, vascular disease, frontotemporal lobar degeneration (FTLD), and dementia with Lewy bodies are the most common diseases that cause dementia in both older and younger people (Rosser et al., 2010). Therefore, the most common subtypes of dementia are: Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia and mixed dementia (Alzheimer’s Society, 2021). Each type will present with specific symptoms, aetiology, risk factors, clinical diagnosis, treatment and support. Alzheimer’s disease is the most common cause of late-onset dementia defined by age of onset of 65 years or older. But it is important to note that dementia is not a normal part of ageing.

Young onset dementia is increasingly recognised as an important clinical and social problem, with frequently devastating consequences for both the person living with dementia and those who care for them (Samson et al., 2004). Young onset dementia is defined as dementia diagnosed under the age of 65 years. It is also referred to as ‘early onset’ or ‘working age’ dementia. Alzheimer’s disease is the most common type of dementia in young onset dementia. However, in people under the age of 45 years, there are few sporadic Alzheimer’s disease cases, and most of these are due to autosomal dominant familial Alzheimer’s disease, also known as young-onset familial Alzheimer’s disease, which is a genetically inherited type of dementia (Masellis et al, 2013). Early symptoms are broad and include depression, behavioural change, neurological disorders, systemic disorders and mild cognitive impairment (MCI) (Draper & Withall, 2016).

In comparison with late onset dementia, people living with young onset dementia are more likely to present with a rarer type of dementia such as frontotemporal dementia (FTD), giving rise to a clinical picture of changes in personality, behaviour and language, which may require specialist support (Collins et al., 2020). In addition, people with Down syndrome and other learning disabilities have a higher risk of developing young onset dementia. Figures show that one in ten people with a learning disability develop young onset Alzheimer’s disease between the age of 50 and 65 years (Dementia UK, 2021), and people with Down syndrome have a substantially increased risk of developing young onset dementia after the age of 35 years (Rosser et al., 2010). Young onset dementia has been found to be more prevalent in the UK Black and Minority Ethnic (BME) population when compared with cases from the majority ethnic population (Regan, 2016). Furthermore, younger people may be at increased risk of developing dementia related to HIV/AIDS, traumatic brain injury or alcohol abuse (McMurtray et al., 2006).

Prevalence rates of young onset dementia in the UK

Current national data underestimates numbers of those living with young onset dementia as it takes no account of those who have grown older (i.e., now aged over 65) with their diagnosis (Carter, 2022). New figures obtained through analysis of primary care health records show a ‘hidden population’ of 70,800 people in the UK who are currently living with young onset dementia – a rise of 28,800 (69 per cent) since 2014 (dementiauk.org, 2022). This is a significant increase from an estimated prevalence in the UK figure of 18,319 derived from a previous study based on census data (Harvey et al., 2003). The number of people living with young onset dementia in the UK is projected to increase by 20% over the next 38 years (Carter et al., 2018). However, given that not all individuals with young onset dementia will present to services, this figure can only be an estimate of the true prevalence.

Needs of people living with young onset dementia compared to late onset dementia

People living with young onset dementia often have different needs to people living with late onset dementia. People living with young onset dementia experience high levels of unmet needs in important areas of life, including daytime activities, social company, intimate relationships, eyesight and hearing/communication, memory, mobility, psychological distress and needs for information (Carter et al., 2018). Individuals living with young onset dementia and their partners are more likely to be in in work at the time of diagnosis and to have financial commitments, caring responsibilities for children and their own parents, and be more active, stronger and fitter than much older people. In addition, people who have a diagnosis of young onset dementia see themselves as distinct from older people with the condition, even if they experience similar symptoms (Rabanal et al., 2018). Services must therefore address the specific needs of people living with young onset dementia and their carers by providing local age-appropriate and meaningful support.

The causes of young onset dementia are typically more varied than late onset dementia, resulting in a broad range of symptoms including neurological, cognitive, behavioural, and psychiatric symptoms frequently resulting in diagnostic challenges for health professionals (Mendez, 2006). Previous research showed that the average time from symptom onset to diagnosis for people with young onset dementia was 4.4 years compared to 1.3 years for people with late onset dementia (Novek et al., 2016). The delay in receiving a diagnosis often results in considerable anxiety for people living with young onset dementia and their carers, as they contemplate alternative explanations for behavioural changes such as marital problems, depression, brain tumour, or midlife crisis (Sampson et al., 2004). Also, in many circumstances, there is a delay in seeking a diagnosis due to a perceived stigma by patients and families (Alzheimer's Association, 2018). Despite their increased visibility in the UK, receiving a timely and accurate diagnosis and gaining access to age-appropriate support remains challenging for younger people as dementia services remain primarily focused upon the needs of older people (Carter et al., 2018).

Impact of young onset dementia on carers

As might be expected, carers of people living with young onset dementia tend to be younger. Many of them are spousal/partner carers, but they can also include parents, young adult children, siblings or friends (Richardson et al., 2016). People living with young onset dementia and their carers may experience significant social and psychological distress, and limited respite and social opportunities due to the lack of age appropriate support available to them. Within the NHS, people living with young onset dementia often fall within the service area of older adult mental health, where dementia care is tailored to older people living with late onset dementia. As a result of this many people living with young onset dementia are cared for at home by their partners, which can lead to significant changes in the couple's relationship (Harris and Keady, 2009). For many reasons such as work commitments, parental roles and other family responsibilities, carers may not be able to fully meet the needs of their partners living with young onset dementia, and can experience high levels of stress, burnout, anxiety, depression and unmet needs (Allen et al., 2017; Ducharme et al., 2013). In addition, previous research found that carers of people living with young onset dementia reported significantly poorer quality of life when compared to carers of people living with late onset dementia (Hvidsten et al., 2019).

Young onset dementia places a particular challenge upon carers. Research shows that carers of people with young onset dementia have higher levels of psychological distress than carers of people with late onset dementia, even when matched for severity of dementia and behavioural disturbance (Freyne et al., 1999; Gronning et al., 2013), and can experience greater difficulty coping with the often accompanying challenging behaviour (Arai et al., 2007). It is known that carers of people with young onset dementia experience high levels of psychological difficulties and problems related to their younger life phase, including relational difficulties, family conflict, parental roles, employment and financial issues (Millennaar, 2016). Therefore, the impact of caring for a person with young onset dementia might be more severe in comparison to late onset dementia. There have been calls to action for specific interventions related to individual needs and circumstances for both young carers and people living with young onset dementia, which advocates a systemic approach to understanding and addressing the impact of this condition (BPS UK, 2021).

Carers of partners with young onset dementia face a dynamic situation of continual, multiple and diverse loss, which may contribute to high levels of emotional distress and stress. The loss of loved ones, as dementia progressively affects their partners and loss of identity and personal freedom are threats to working life and companionship (Parsons, 2019). Kobiske et al., (2019) equated such loss to predeath grief (PDG), which may contribute to high levels of stress that are often reported by carers of partners with young onset dementia. Yet some carers of partners diagnosed with young onset dementia can adapt to these challenges of loss and perceived stress with some even reporting an enhanced meaning in life through the caring experience (Deist & Greeff, 2015).

Chapter 2: Literature Review

Terminology

The language used to talk about people living with dementia can strongly influence how others treat or view them, and how they feel about themselves. For example, referring to people with dementia as 'sufferers' or as 'victims' implies that they are helpless. This not only strips people of their dignity and self-esteem, but it also reinforces inaccurate stereotypes and heightens the fear and stigma surrounding dementia (Dementia UK, 2021). Studies will vary in the terminology used with some using the term 'people living with early onset dementia' and 'people living with late onset dementia'. The term 'presenile dementia', used widely in the published literature until about 10 years ago, is no longer favoured and the terms 'young onset dementia', 'younger onset dementia', and 'younger people with dementia' are now commonly used (Rosser et al., 2010).

Appropriate, non-stigmatising language will be used throughout this literature review. Young onset dementia is a preferable term to 'early onset' dementia so as to avoid confusion with the early stages of dementia generally. In this review, I will use the term 'young onset dementia'. Terms such as 'People living with dementia' and 'younger people living with dementia' will also be used. The Dementia Engagement and Empowerment Project (DEEP) developed guidelines on language about dementia by collaborating with people living with dementia. The language in these guidelines will be adhered to throughout this thesis to ensure that words and descriptions are accurate, balanced and respectful (DEEP, 2014).

Much of the research literature in this area refers to 'spouses', which lacks inclusivity as many couples cohabit and are not married or they have civil partnerships. Moreover, the literature tends to include heterosexual partnerships and falls short in not addressing how more diverse gender and sexual identity couplings need inclusion, e.g. lesbian, gay, bisexual, transgender, queer/questioning, intersex, and asexual (LGBTQIA+) couples. Marriage is decreasing year on year so future studies need to reflect changing attitudes towards intimate relationships. This literature review will use broader terminology to be more inclusive. The term ‘partners’ will be used to include those who are cohabiting, in civil partnerships or married.

Young onset dementia subtypes and trajectory

Young onset dementia encompasses a range of subtypes, most commonly Alzheimer’s disease, followed by vascular dementia and frontotemporal lobar degeneration (Vieira et al, 2013). Young onset dementia, defined by first symptoms of cognitive or behavioural decline occurring before the age of 65 years, is relatively rare compared to late onset dementia, but it is associated with diagnostic difficulty and distress on affected individuals and their informal carers. The progression of dementia severity and cognitive decline are not well characterised in the three most common subtypes of young onset dementia, which include Alzheimer’s dementia, vascular dementia (including mixed Alzheimer’s/vascular dementia), and frontotemporal dementia. However, some studies suggest a faster decline in younger versus older persons with Alzheimer’s disease (Stanley & Walker, 2014). In a longitudinal study to describe and compare the progression of dementia and the decline in cognitive function in people with the three most common subtypes of young onset dementia, Gerritsen et al., (2018) found that the decline in cognitive function was highest in participants living with Alzheimer’s disease, whereas the progression of dementia severity showed no statistically significant differences in the three dementia subtypes. In a large cohort study of community-dwelling adults, men had a higher risk of all-cause dementia than women and this association was stronger for young onset dementia than for late onset dementia (Shang et al., 2023). The prevalence of young onset dementia has been found to vary in men and women at different age categories (Nwadiugwu, 2021). It is more prevalent in men than in women between age 50 and 65 years, unlike late onset dementia which is slightly more prevalent in women than men (Billeter, 2014). The increased prevalence of late onset dementia in women is possibly due to the fact that women live longer, on average, than men (Seshadri et al, 1997). This evidence suggests that carers of partners with young onset dementia who are between 50 and 65 years, are more likely to be women.

Experiences and needs of carers of people living with young onset dementia

People with young onset dementia and their care partners tend to be in their 40s, 50s and 60s. They may be still be in the work force, have young children, and have limited financial means. Changing roles impact relationships within a family and within the larger community. Individuals and carers may experience stigma, in part because of the myth that dementia only impacts older people. Existing health and social care structures are mostly geared towards people with late onset dementia and their carers, therefore, the needs of people with young onset dementia and their carers are rarely met (Kurz, 2016). Together, these factors can lead to social isolation for carers of people living with young onset dementia.

Most people with dementia have at least one carer, often a partner (Janssen et al., 2017). The literature indicates that people with young onset dementia and their carers face a wide range of difficulties during the disease process specifically related to their younger age. These difficulties include problems around the diagnosis, the need for information, barriers in access to care, lack of appropriate services, specific unmet needs, consequences of behavioural changes and impact on the carer and changing relationships within the family (Millenaar et al, 2016). Research has shown that people living with young onset dementia and their care partners generally agree on the areas in which high levels of unmet needs occurred. These areas include daytime activities, social company, intimate relationships and information (Bakker et al., 2014).

There is a higher proportion of partners than relatives or friends among carers of people living with young onset dementia (Ducharme et al., 2015), and to date, few studies have examined the subjective experience of caring partners who are living with a person with young onset dementia and specific subtypes of the condition. Due to the limited amount of research that focuses on the needs of partners of people living with young onset frontotemporal lobe dementia (FTLD), Johannessen (2017) conducted a qualitative analysis using grounded theory to examine partners' experiences and needs for assistance in daily life. The findings showed that extraordinary problems (including torment, interference with work, and vanishing social relations) partners and families of young onset FTLD encounter were related to an unusual, unexpected and rather unknown disease among younger people. This highlights the need for further knowledge, individualised and specialised support throughout the progression of the condition. Ducharme (2013) explored the unique experience of partners in young onset dementia. The aim of this qualitative study was to document the lived experience of partner carers of young people living with dementia in order to inform the development of professional support tailored to their reality. A sample of 12 partners of people diagnosed with dementia before the age of 65 years participated in semi-structured interviews. Six themes emerged from their carer trajectories, namely, difficulty managing behavioural and psychological symptoms, long quest for diagnosis, nondisclosure to others and denial of diagnosis, grief for loss of partner and midlife projects, difficulty juggling unexpected role and daily life responsibilities, and difficulty planning for the future. The findings open up innovative avenues for the development of psychosocial interventions to support these caring partners.

Few studies have examined the quality of life in carers of people living with young onset dementia. Rosness et al., (2011) investigated the quality of life and depression and its correlates in partners caring for and living with people with young onset dementia. Quantitative analysis showed that increased depressive symptomatology in carers was associated with being married, having offspring and caring for a person with dementia and a co-morbid cardiovascular disease. A reduction in depression was seen in carers when the patients received domiciliary nursing care. Partners who are caring or the person living with young onset dementia may have co-morbid mental health diagnoses such as anxiety and depression, either prior to or as a result of the diagnosis of dementia and caring role. This may already be having a significant impact on the couple’s relationship (Kronmuller et al., 2011). Moreover, either one or both partners may be experiencing physical health issues which may also impact the relationship and caring role. Further research is warranted to understand the unique experiences of partners and develop tailored support that may improve their overall quality of life.

Impact of caring for partners living with young onset dementia

A number of studies have explored the impact of young onset dementia on carers. A comparative study of the clinical characteristics of young onset dementia and late onset dementia was conducted by Freyne (1999). The level of carer burden among carers of both groups was measured using a self-rated psychometric scale, ‘The Zarit Burden Interview’. Carer burden was significantly higher among carers of younger people, although there were no significant differences between the groups in terms of clinical features such as severity of dementia or behavioural disturbance. Higher carer burden showed an inverse relationship to patient's age. These results have implications in terms of encouraging community care for people living with dementia, and suggest that further exploration to identify factors associated with burden in younger carers is required. It is important to note that use of the word ‘burden’ is not appropriate language in dementia guidelines (DEEP, 2014), however, this study was carried out a long time ago when this word was frequently used in the literature.

Young onset dementia is not very well studied in terms of clinical effects on the person, and not much is known about the effects on partners and carers. Kaiser (2007) assessed the psychological impact of the diagnosis of young onset dementia on partners. A cross-sectional analysis of questionnaire responses showed that the diagnosis of young onset dementia has a significant impact on partners, characterised by concerns of dependency, fear, and increased depression, especially in the partners of people with frontotemporal lobar degeneration. However, it is important to note that this study was conducted within a Western Australian demographic with participants recruited from a care clinic, which raises concerns about the generalisability of the findings. This study also utilised quantitative methods to analyse responses to psychometric outcome measures, prompting scrutiny regarding the validity of the study’s findings. Furthermore, a number of participants were no longer living with their partners, which provides a rationale for further research on the impact of young onset dementia with co-habiting couples.

Young onset dementia can have a significant impact on parental roles and responsibilities. In a qualitative analysis of how a person’s diagnosis with young onset dementia can affect a partners parenting and children’s experience, Gelman & Rhames (2018) found that mothers assumed all parental roles and responsibilities, along with the stresses of becoming the primary breadwinner and losing the companionship, support, and decision-making assistance of their partner. Children felt compelled to take on roles as carers, earners, and reluctant partners in adult decision-making. This provides one example of the potential impact a diagnosis of young onset dementia can have on family dynamics. However, there is a need to further develop knowledge of the impact of young onset dementia in diverse family constellations such as different cultures and/or different parental gender and sexual identities such as LGBTQIA+ couples.

A growing body of literature suggests that the social context of experiencing dementia at a younger age may influence carers' and particularly partners' subjective experience and coping strategies. Previous qualitative research on the impact of caring for partners with young onset dementia indicates that younger carers need greater emotional and psychological support and more services. Narratives of denial, loss, fear and abandonment are recurring themes and younger carers often resort to emotion and problem focused coping strategies (Lockeridge and Simpson, 2013). Qualitative findings also indicate that partners of people with young onset dementia perceive a significant deterioration in the quality of their relationship over time (Kimura et al., 2015; Massimo et al., 2013). A study employing cross-sectional analysis showed that the diagnosis of young onset dementia has a significant impact on partners, characterized by concerns of dependency, fear, and increased depression (Kaiser and Panegyres, 2007). The prevalence of depression has been reported particularly high in young onset dementia carers, with mild to moderate depression in up to 50% of carers of persons with Alzheimer’s disease and 75–86% in frontotemporal dementia (Kaiser and Panegyres, 2007). A longitudinal quantitative study found that the quality of the relationship as perceived by partners deteriorated over time and was influenced by characteristics of the person with young onset dementia as well as their partner (Bruinsma et al., 2020).

Chiari (2021) investigated clinical, demographical and social determinants of carer distress and how they interact in affecting the psychological (personal psychological wellbeing) and non-psychological (patient symptoms and availability of external support) components of carer distress. Quantitative analyses of questionnaire responses identified that carer distress was positively related to female caregiver sex, partner's relationship to the patient, severity of patient's behavioural symptoms, diagnostic delay, and financial distress of the family. Poor mental health has been consistently linked with the experience of financial hardship and poverty (Kiely et al., 2015), therefore carers who experience financial difficulties and those on low incomes may experience increased psychological distress if they are unable to support their partner and/or family.

Although widespread agreement exists that caring has negative consequences for many carers, positive outcomes have also been observed including a sense of mastery, positive affect, and an improvement in quality of the dyadic relationship between the carer and the care recipient (Beach, Schulz, Yee, & Jackson, 2000; Farran et al., 1997; Sherrell, Buckwalter, & Morhardt, 2001, cited in Montgomery & Kosloski, 2013). Furthermore, the relationship between the person living with young onset dementia and their carer may become 'closer' or 'strengthened' (Harris, 2004; Johannessen & Moller, 2013, cited in Cartwright, 2021).

Gender, culture, sexuality and social class differences in caring for a person living with young onset dementia

Much is known about the impact of caring for a person with young onset dementia. However, the literature falls short in addressing aspects of gender, culture, sexuality and social class in relation to caring roles. Limited research to date has described sex differences in caring and psychological outcomes such as higher reported levels of carer distress in females (Xiong et al., 2020), increased rates of anxiety, depression and grief in female carers compared to male carers (Harvey 1998; Luscombe et al., 1998), and lower levels of stress among male carers (Kramer, 1997). Furthermore, in a review of 93 articles on gender differences in caring studies, Baker & Robertson (2008) reported that most studies concluded that women experience more distress and use more services than men.

These findings could be linked to gendered characteristics and the different ways in which men and women approach their caring roles. For example, traditionally, in many cultures, women usually take more responsibility of the wellbeing of the family from childbearing to caring for older family members. Considering that women are more likely to assume the role of carer and provide significant emotional support to the person they are caring for, it is understandable that women experience more emotional stress when caring for their partner with dementia (Poysti, 2012). However, gender is often simplified as a comparison between men and women, without consideration of individual differences (Schaffler-Schaden et al., 2021).

Conversely, several studies have reported no gender differences in caring for a partner living with dementia (Baker & Robertson, 2008; Baker, Robertson & Connelly, 2010). However, there appears to be little understanding of the individual differences between how male and female partners cope (Baker & Robertson, 2008). The majority of carer research has been criticised for ignoring the importance of individual differences in male and female responses to caring demands (Vitaliano, Scanlan and Zhang, 2003). From a traditional point of view, men might be less capable to adapt to the premature carer role than women, as a sense of self-efficacy in caring has been shown to be positively associated with quality of life (Zhang et al., 2014). In a qualitative study using narrative interviews, Thorsen & Johanessen (2022) found that women care for their partner at home longer than men do and with greater impact on their working career and health. These findings may not be applicable to the unique experience of men and women in non-traditional relationships such as same sex couples. For example, lesbian, gay, bisexual, and transgender (LGBT) carers and partners face unique experiences that are likely to result in different sex and gender differences (Fredriksen-Goldsen & Hooyman, 2007). There is a paucity of research that has explored the lived experience of LGBTQIA+ people with dementia or their care partners. In a scoping review of the sparse literature available, Smith et al (2022) identified that lesbian, gay, bisexual and transgender plus (LGBT+) gender and sexuality diverse people with dementia and their care partners endure overlapping forms of disadvantage. This results in heightened experiences of fear and discrimination, lack of services and compounded social isolation. Importantly, while dementia was embodied as interference and loss by LGBT+ people, it was their gender and sexuality differences that provided solace, even in the face of disadvantage. The increase of more diverse partnerships in today's society warrants further research to increase our knowledge of individual caring experiences in non-traditional couplings. Caregiver identity theory (Montgomery & Koloski 2013) suggests that there are common elements of the carer role while acknowledging that for each individual the carer role is uniquely defined by cultural and familial experiences. The theory is grounded in the fundamental observation that there is no single generic carer role. It also takes into account great diversity among carers as to the type and quantity of tasks they undertake and the duration of time over which they serve in this role. The theory is advanced as a framework to help service providers understand the sources of carer distress, effectively target support services to family carers, and help policy makers to design support systems that are both effective and efficient

There is a dearth of research literature that explores the experiences of caring for partners living with young onset dementia from Black, Asian, and other Minority Ethnic (BAME) communities. In the wider dementia literature, the experience of dementia care services for carers of people living with dementia from three BAME communities in Bristol was explored using a grounded theory approach. The theory that emerged from this study was that carers made an active choice about the services they used, balancing the need for support against a fear of identity diminishment (Baghirathan et al., 2020). Given the increased prevalence of young onset dementia in the UK Black and Minority Ethnic (BME) population, there is a need for further research involving people from BAME communities and diverse cultural backgrounds to explore and understand their multi-faceted experiences of caring in dementia.

Social class and related social inequalities may play an important role in the experience of people living with young onset dementia and their caring partners. Dementia impacts memory and the capacity to maintain and build social relations. This suggests that the social and cultural background to relationships may be an important prism for understanding the lived experience of dementia (Jones, 2017). Carers of lower socio-economic status (SES) may not be able to afford to pay for support such as private counselling/psychotherapy and as such could be more vulnerable to the negative outcomes of caring such as burnout, stress, anxiety and depression. Peet (2014) has argued that individual and specific responses to dementia are understood in the context of structures of social class and gender that shape everyday meanings. However, there is not enough research into the ways in which class may influence the management of changes in behaviour associated with young onset dementia and how social relations are 'maintained' or 'repaired.' Such research could provide important clues to class differences in diagnosis, health-seeking behaviour, access and responses to treatment and care in the field of dementia (Jones, 2017). It is particularly important to be attentive to gendered care norms, religion, migration history, social class, relationship to the care-recipient, and position within the family – and how different intersections of these social categories affect practices of care-sharing (Ahmad et al, 2022). The literature falls short in not addressing how intersecting identities (e.g. gender, culture, sexuality, social class, and ethnicity) may impact on a partner's caring role in young onset dementia.

Stigma experienced by people living with young onset dementia and their carers

Stigma may negatively impact the quality of life of people living with young onset dementia and their caring partners, yet research literature in this area is sparse. Recently, research has focused on understanding the needs of people with young onset dementia and their family carers who often feel stigmatised by their experience of negative and discriminatory attitudes of others towards them and stereotypes such as 'people with dementia are dangerous'. This type of stigma is manifested in different forms, such as public fear and negative social constructions of people living with dementia and their families among general public, or discrimination in health services (Phillipson et al, 2012). In a systematic review of the global literature on understanding public and self-stigma in the context of dementia, Nguyen & Li (2020) identified consistently limited knowledge, as well as stereotype, prejudice, and discrimination of public toward people living with dementia and their family carers. People living with dementia and their family carers also perceived negative stereotype, prejudice, and discrimination from general public and healthcare professionals. They reported negative feelings of themselves and tended to delay help-seeking. However, to date, research has not provided a thorough and deep understanding of the stigma formation process and its implications for this population. Thus, Werner et al., (2020) explored the stigma formation process as experienced by family members as informal carers of people with young onset dementia, and professionals as formal carers who are involved in the development, management and provision of services. Stigmatic experiences emerged as a pervasive and complex phenomenon among formal and informal carers of people with young onset dementia, suggesting the need to develop a comprehensive and integrated approach to reduce them at the individual, professional and societal levels. Some couples may fear the reactions and judgments of others, especially rejection and incomprehension. This is why, once a diagnosis is obtained, they tend to feel helplessness and grow socially isolated, all the more so in that there are no resources available designed specifically for younger couples (Ducharme et al., 2013).

People living with dementia are commonly labelled and stereotyped negatively which does not accurately portray the experience of dementia (Swaffer, 2014). Research that challenges the public perceptions of dementia may help to address negative stereotypes associated with dementia and reduce the stigma people often experience. In a qualitative study exploring employment-related experiences of people living with dementia and their employers, Ritchie et al (2018) found that by continuing employment, participants in the study demonstrated that they were still able to make a contribution to work and to society, and by doing so they addressed the stereotypes of dementia, showing that people with dementia can continue to live well post-diagnosis. Further research on the experience of stigma in young onset dementia is needed as much of the literature focuses on late onset dementia.

Role transitions and selfhood

The transition to carer role may be an emotional and uncertain time for carers as they learn more about dementia and how they can best support their partners going forward. They may seek professional support to help them adjust to their new role. Larochette et al., (2020) assessed a support program based on acceptance, role transition, and couple dynamics for partners of people with young onset dementia. Qualitative feedback from the carers' experience was analysed using thematic analysis. Findings highlighted carers' ability to overcome emotional difficulties through self-care and talking about their experience to others. The results also showed that developing acceptance strategies and having a better understanding of dementia enabled carers to access new ways to support their loved ones and to maintain the quality of their relationship. Greater psychological flexibility achieved through learned acceptance strategies promoted increased communication between partners and improved the ability to adapt to their caring role.

The transition to a caring role may impact on carers' identity and sense of self as they face unique and complex challenges. Harris & Keady (2009) explored selfhood in young onset dementia. This grounded theory study focused on exploring the psychosocial impact of young onset dementia on the selfhoods of the person and the family carer. The majority of carers in the study were partners. It is evident from the shared narratives that all carers, in one way or another, had experienced a transition in their selfhood and identity from the time of diagnosis. Carers' identities as workers, family members, sexual and social beings and as individuals engaged in living were all negatively impacted from the time their loved one was diagnosed with young onset dementia. Earlier work on the loss of self in Alzheimer's disease from a social constructionist viewpoint, suggests that the self of personal identity persists far into the end stage of the disease, and any loss of self is directly related to nothing more than the ways in which others view and treat the person (Sabat and Harre, 1992).

Relational dynamics within the dyadic relationship

Past literature has tended to focus on the negative consequences of caring for a partner living with young onset dementia, such as emotional distress and stress. However, the dyadic relationship itself has received less attention. Young onset dementia has a profound impact on partners. However, little is known about how the quality of the relationship changes over time. In a longitudinal quantitative study, Bruinsma et al., (2020) explored the quality of the relationship perceived by partners of people with young onset dementia, with a focus on how the quality of the relationship changes over time and identifying predictors of this change. The quality of the relationship as perceived by partners deteriorated over time and was influenced by characteristics of the person living with young onset dementia as well as their partner. Helping partners to come to terms with factors that threaten their sense of couplehood might help them to develop a more positive attitude toward their relationship and improve the quality of the relationship and care. However, relational dynamics may be complex, and supporting caring partners to process feelings of loss and accept that their relationship has changed may be beneficial.

The impact of dementia on relationships, intimacy, and sexuality has been documented in later life couples. However, little is known about the experiences of couples living with young onset dementia. Holdsworth & McCabe (2018) examined the literature describing the impact of young onset dementia on relationships, intimacy, and sexuality in midlife couples in a systematic review. Several themes were identified for partners of people living with young onset dementia. This included shifts in roles and increased responsibilities for daily living, declines in perceived relationship quality, changes and decline in areas such as work, family and sexuality which impacted identity and self-esteem, increasing social isolation and loneliness due to a decrease in social activities and loss of friendships and connection with their partner, declines in areas of closeness and intimacy, and reduced sexual activity. Although the impact of young onset dementia is experienced differently by each couple, these results suggest that dementia has a significant impact on the couple relationship. To further understand the impact of young onset dementia on couple relationships, more qualitative research that explores their subjective experiences of the relationship following diagnosis is needed. Research that explores the experiences of both the caring partner and the partner living with young onset dementia would add further breadth to the findings and insight into the couple's relational dynamics. To explore couples' experiences with young onset dementia, an interpretative phenomenological analysis of dyadic dynamics was undertaken by Wawrziczny et al., (2016). More specifically, the study focused on how couples cope with young onset Alzheimer's disease. Seven themes related to the couple's relationship emerged. The couple's interactions were characterized by emotional avoidance and control over symptoms that gradually led to deterioration of couple interactions and the components of marital dissolution.

There is a lack of theoretical understandings applied to dementia research, in particular for the impact of caring and partner relationships in dementia. As such, there is a need for more theory based research in dementia. However, two social psychological theories provide relevant information to conceptualize dyadic relationships and are possibly useful to examine partner caring (Baikie, 2002): Social Exchange Theory and Equity Theory (Walster, Walster, & Berscheid, 1978b) cited in Braun et al., (2009). According to social exchange theory, individuals seek to use exchanges to maximize rewards and minimize their costs through social exchanges (Cook, 1987). Equity theory, an extension of social exchange, posits that reciprocation of exchanges should be perceived as equal or fair to maintain stable relationships. While positive exchanges, such as expressions of esteem, gratitude, admiration, respect, love, and kindness, contribute to the carer's sense of satisfaction in the role, negative exchanges such as expressions of aggression, frustration, anger, intolerance, or socially unacceptable or demanding behaviour contribute to rejection, ambivalence, and conflict (Carruth, 1996). Walster, Walster, and Bersheid (1978) contend that when individuals find themselves participating in inequitable relationships, they will become distressed. Therefore, inequity of exchanges is likely to affect the feelings that caring partners have about their relationship with their partner living with young onset dementia.

How carers of partners living with young onset dementia cope

Few studies have explored the coping strategies adopted by partners of people living with young onset dementia. They suggest that carers reporting high levels of distress appeared more likely to use an emotion-focused coping strategy, for example, wishful thinking, denial, suppressive feelings, self-blaming and avoidance. Carers with low levels of distress, in contrast, used problem-solving strategies such as acceptance and instrumental coping (Kramer, 1997; Rose et al., 1997). Further research on the coping strategies used by partners of people living with young onset dementia would be helpful to reduce this gap in the literature.

A diagnosis of young onset dementia is a life-altering event for both persons with dementia and their caring partners. Dyadic coping (DC) theoretical models acknowledge that dyads cope with stressors as a unit, and may provide a theoretical underpinning for capturing couples' psychosocial adjustment to conditions such as young onset dementia. These models describe how dyads, including couples, cope or respond to stressors in positive and negative ways. They emphasise that stress and coping processes are interdependent and how individual and shared coping patterns affect the dyad (Bannon et al., 2021). Bannon et al., (2021) explored the lived experiences of couples in young onset dementia using an integrated DC theoretical model (Falconier and Kuhn, 2019) to guide the thematic analysis of joint interviews among 23 couples. The integrated model included: The congruence model (Revenson, 1994), the relationship-focused model (Coyne and Smith, 1991; O'Brien and DeLongis, 1996), the communal coping model (Lyons et al., 1998), the systemic-transactional model (Bodenmann, 1995, 1997), the relational-cultural model (Kayser et al., 2007), and the developmental-contextual coping model (Berg and Upchurch, 2007). Findings revealed that those managing young onset dementia engaged in patterns of coping consistent with dyadic coping theoretical models. Couples described patterns of stress communication and positive and negative coping behaviours (e.g. avoidance and overprotection) enacted by individual partners and the couple as a unit. Although avoidance and overprotection were both positively intentioned, they created more relationship conflict for couples. The findings of this study indicate the imminent need for tailored interventions that target dyadic coping for couples living with young onset dementia. For example, teaching emotion regulation skills may help couples cope with conflicting and difficult emotions and better communicate experiences and needs. To fully capture individual perspectives and develop tailored psychosocial interventions to support couples in young onset dementia, further qualitative research is needed to explore and understand how partners of people living with young onset dementia experience and cope with perceived stressors. Studies that conduct joint interviews with the caring partner and person living with young onset dementia may not fully capture the nuances of individual experiences, as caring partners may share more openly if they are interviewed alone. Arguably, to understand the experience of the couple, research needs to include both parties (Daniels et al., 2007). Studies conducting joint interviews with both the person living with dementia and their partner may offer a nuanced insight into the couple's relational interactions and how they experience and cope with dementia together within the context of their relationship. In a qualitative study which explored the interactional strategies that couples use while they are making sense of a dementia diagnosis, Snow et al., (2015) found that couples undergo an oscillating process through complex patterns of dialogue as they process a dementia diagnosis together. This supports the notion that making sense of a dementia diagnosis is not static or individual, but a fluctuating and ever-changing process experienced by both the person living with dementia and their partner. Therefore, studies that focus on the individual rather than the couple may miss salient and nuanced information about the couple's relationship that may be gathered through dyadic interviewing.

The existing literature acknowledges that the carer journey is markedly different to that of the person living with dementia, particularly in a sense of survival and in terms of decision-making responsibilities and the associated emotional impact. The carer is having to make decisions for the other person that will significantly impact on their life, for instance around the admission to residential care and the potential for carer guilt around that. This transition may evoke feelings of abandonment, failure and survivor guilt in the carer. Thus, carers may face different emotional challenges that are difficult to cope with as they navigate the journey from diagnosis and beyond. In a mixed methods study exploring the unique guilt experiences of partner and adult child carers in the context of transitioning to residential long-term care, participants experienced feelings of guilt when there was a sense of familial duty or cultural responsibility to care for the person at home (Statz et al., 2022). Furthermore, guilt and distress may arise from the change in the relationship with the relative or partner with dementia once the role of carer is taken on, since this implies a change in role relations with the person cared for (Gallego-Alberto et al., 2022). These findings may be helpful to guide the development of therapeutic interventions for carers of people living with young onset dementia.

Resilience theory is described as the motivational force within everyone that drives them to pursue wisdom, self-actualisation, and altruism and to be in harmony with a spiritual source of strength (Richardson, 2002). Using the theoretical framework of Resilience Theory, Kobiske et al., (2019) examined the moderating effect of a protective factor of resourcefulness, both personal and social resourcefulness, between the relationship of the risk factor of pre-death grief and perceived stress of 104 young onset dementia carer partners. Pre-death grief encompasses the losses experienced by a carer of a partner with young onset dementia, and includes multiple losses resulting from the functional, cognitive, and behavioural declines, which can be demanding and stressful. Results from this cross-sectional correlational study indicated a large positive correlation between pre-death grief and carer perceived stress.

Wawrziczny et al., (2017) conducted a mixed methods study to explore caring partners' means of coping with the condition and compared them based on the age of onset of the disease to adapt to support programs. Results indicated that all carers use both acceptance and avoidance strategies to manage difficulties. Certain acceptance strategies were used by both groups and included satisfaction-positive evaluation, seeking social support and seeking information. The planning strategy was used by partner carers of people living with young onset dementia, whereas the re-arranging and humour strategies were used by partner carers of people living with late onset dementia. Both groups of carers used avoidance strategies such as resignation, not talking about it – not thinking about it and getting away from the future. However, certain strategies were specific to each age group. Caring partners of people living with young onset dementia tended to use the refusing help strategy more often, whereas the getting away from the entourage strategy was used more often by caring partners of people living with late onset dementia. Research that further develops knowledge about coping strategies used by carers may support health professionals and psychologists to improve interventions for carer wellbeing.

Support for people living with young onset dementia and their carers

People living with young onset dementia and their family carers remain an overlooked population within the policy and practice priorities of community healthcare. No standard provision of care or support currently exists for those living with young onset dementia and the family carer. Yet family members provide the majority of the full-time care required for this progressive, irreversible illness (Flynn, 2013). Social networks can be a valued source of support for carers, and those with good support from family and friends may be able to better manage their caring roles compared to carers who are isolated and have poor social networks (Francis et al., 2010). The current literature shows that despite their increased visibility in the UK, receiving a timely and accurate diagnosis and gaining access to age-appropriate support remains challenging for younger people as dementia services remain primarily focused upon the needs of older people (Carter et al., 2018). Moreover, few support resources are offered to family carers of people living with young onset dementia and fewer still are tailored to their unique trajectory (Ducharme, 2013). People with young onset dementia can often struggle getting the right support. This is because of their frequently different characteristics and needs compared to people with late onset dementia. Giebel (2020) assessed a memory service for its adaptation to the needs and wishes of people living with young onset dementia and their carers. The findings highlighted several limitations to the provision of post-diagnostic support and a need for further service adaptation and development tailored to the needs and wishes of people living with young onset dementia and their carers. Furthermore, previous findings outlined in a report on the current national and international state of young onset dementia specialist care, found that the UK is in many geographical areas lacking behind providing specialist young onset dementia care (Carter, 2018). The focus on living well with dementia, as demonstrated in the national dementia strategy ‘Living well with dementia’ (Department of Health, 2009) encourages a more positive and empowering approach to dementia care that can improve the experience of living with dementia at any age (Quinn et al., 2022). However, the meaning of living well may differ between people and this warrants a holistic and individualised approach to meet individual needs.

Psychological interventions for carers of people living with young onset dementia

There is a critical need to develop person-centred psychosocial interventions that address both partners’ needs and challenges after a diagnosis of young onset dementia. Grunberg et al., (2022) explored psychosocial treatment preferences of people living with young onset dementia and their partners. Qualitative findings identified that couples endorsed support for a virtual, dyadic intervention delivered shortly after diagnosis focused on providing tools to cope with difficult emotions and symptom progression and enhance communication and meaningful daily living. Further research in this area is needed to gather nuanced information that can directly inform future interventions for people living with young onset dementia and their partners. Due to the occurrence of young onset dementia in middle age, the impact on partners is particularly marked and dyadic-based psychosocial interventions are recommended. Music And Psychology & Social Connections (MAPS) is a novel online intervention, informed by the theory of adaptive coping by Bannon et al (2021) for dyads affected by young onset dementia. MAPS combines therapeutic song writing, cognitive behaviour therapy, and a private social networking group that focuses on the dyads (Loi et al., 2022). The effectiveness of this novel 8 week intervention is currently being assessed using a randomised controlled trial. If the program is successful, the researchers anticipate that the program will be easily scalable and able to benefit more dyads living with young onset dementia.

Sass et al., (2021) explored the potential for providing counselling to people with dementia and their partners through a specialised counselling service, underpinned by a relational therapeutic approach. Following individual semi-structured interviews with people living with dementia and their caring partners, qualitative analysis indicated that counselling is a worthwhile and effective intervention to offer to people living with dementia and caring partners. Research suggests that the relationship between the therapist and client is the most important determinant of successful outcomes in counselling beyond any model of therapy, techniques or interventions (Paul and Haugh, 2008). However, therapists should also be mindful of practical and psychological barriers for family carers to engage in a therapeutic relationship. Individuals may feel cautious about disclosing unwanted feelings associated with the caring role such as resentment or guilt, for fear that this may reflect negatively on their relationship with their relative or partner (Griffiths et al., 2020). In a review of the existing evidence base for individual and group therapy with people affected by dementia, Cheston and Ivanecka (2017) found that the strongest evidence supported the use of short-term group therapy for people in the early stages of dementia. There is a scarcity of research on psychotherapy with individuals or couples living with young onset dementia, as most of the literature is focused on late onset dementia. Therefore, little is known about the specific challenges and benefits of working therapeutically with this population.

The wider literature around couples and family psychotherapy in dementia has expanded considerably in recent years. However, reviews in this field have highlighted several significant shortcomings in the literature. In a review of the literature on family therapy and dementia, Benbow and Sharman (2014) pointed out that much of the literature, which purports to focus on family therapy/ counselling and dementia, in fact focuses on the main carer, and remains linear, rather than systemic in its focus, investigating outcomes for the patient or carer rather than looking at changes in the system in which they are embedded. Furthermore, in a later review of couple-centred interventions in dementia Bielsten and Hellstrom (2019) indicate that joint interventions for people with dementia and care partners are flawed as they lack a genuine dyadic approach where both partners' views of their relationship are valued. In a more recent systematic review of the effectiveness of counselling and psychotherapeutic interventions for people with dementia and their families, Shoesmith et al., (2022) found that a range of psychotherapeutic interventions using different therapeutic modalities can lead to meaningful change for people with dementia and their families, yet the evidence was inconsistent in terms of whether change was achieved. A greater understanding of what meaningful change looks like in this population is needed to confirm how effective interventions might be.

One approach to working with couples where one partner has a dementia is the Living Together with Dementia (or LTwD) project led by Andrew Balfour at the Tavistock Centre for Couple Relationships (Balfour, 2014). This approach applies psychoanalytic thinking to help people with dementia and their partners manage the trauma of the diagnosis, the loss and the changes it brings and to help the couple as much as possible to maintain, or recover, the protective aspects of the relationship, which research indicates are to do with emotional contact and understanding, shared activity and involvement as well as the overall quality of the relationship (Balfour, 2014). The development of a manual and training programme enables a range of healthcare professionals to deliver this structured intervention using Video Interactive Guidance and psychotherapy, however, for many therapists the level of training resources needed is too high for it to become embedded in everyday practice. Nevertheless, it is possible for therapists to adapt psychotherapy techniques from a range of different modalities to achieve the same goals as LTwD – namely to help the person with dementia and their carer to adjust to the challenge of dementia, and to repair the damage that this is causing to their relationship (Cheston, 2022).

Psychological models of person-centred care in dementia

Within the wider dementia care framework, conceptualisations of personhood and selfhood from a social psychology perspective have been applied to care practices. Person-centred care in dementia emphasises understanding and valuing people living with dementia as unique individuals rather than focusing solely on the symptoms they present with. Tom Kitwood (1997) introduced the concept of ‘personhood’, emphasising the importance of acknowledging and respecting the individual’s identity, feelings and relationships. Kitwood argued that maintaining personhood involves recognising the person’s history, relationships, and preferences. His approach addresses the emotional, social and psychological needs of individuals with dementia, promoting human dignity and wellbeing. However, in the conceptualisation of a relational care framework Tieu and Matthews (2024) argue that the contemporary understanding of person centred care may be problematic as it focuses on individualism and autonomy. They suggest that dementia in its various stages is better understood as a condition affecting the closely related concept of selfhood, which can be defined as essentially intersubjective, socially embedded, and depending on continuity of lived experience.

James (1999) expanded on these ideas, proposing a broader framework for person-centred care which emphasises the significance of relationships and communication. ‘The Newcastle Model’ is a biopsychosocial, person-centred, formulation approach that aims to support care staff and family members in order to manage behaviours that challenge by identifying and fulfilling unmet needs of the person with dementia (Rickardsson and Crooks, 2021). The Newcastle Model has been developed over several years as an intervention to address behaviour that challenges in people with dementia (James 2011). The model advocates for a holistic approach that involves both the person living with dementia and their carers, with the view to creating a supportive environment that fosters meaningful connections and enhances the overall quality of life. The information gathered by clinicians to develop a Newcastle Model formulation reflects Kitwood’s (1997) supposition that the person’s experience of dementia and subsequent behaviour is influenced by multiple factors, not only their cognitive impairment (Jackman, 2020). While person-centred care is valuable, its implementation faces challenges in healthcare settings, including time constraints and staff training (James and Birtles, 2020). However, despite these challenges, psychological models of person-centred care have significantly influenced dementia care practices and training, highlighting the importance of individualised, holistic and compassionate approaches to support people living with dementia.

Conclusion

There is a higher proportion of partners among carers of people living with young onset dementia (Ducharme et al., 2015) who are likely to live with their partners for a length of time and thus be greatly impacted by young onset dementia and their role as a carer. The literature to date highlights the subjective experiences of carers of people living with dementia, but emphasises the significant lack of research in this area. The distinctive needs of people living with young onset dementia and the psychological and emotional impact on carers appears well understood. However, although there is a growing body of research on the experiences of family carers of people living with both young and late onset dementia, the literature falls short in addressing the subjective experiences of caring partners and the impact of young onset dementia on their relationship. More specifically, there is a lack of research on people living with young onset dementia and their caring partners in the field of counselling psychology. The literature lacks depth in addressing how caring partners experience the diagnostic process, changes in their relationship post diagnosis, and the experience of stigma. Closing this gap in research could provide valuable insights into the specific needs and challenges faced by caring partners, thus facilitating more tailored support and interventions in young onset dementia care.

Chapter 3: Methodology

Aims of the study

Findings from previous studies suggest that further research is required to examine coping strategies, stigma, and the subjective experience of the person caring for their partner living with young onset dementia, and to understand how younger carers cope with changes in their relationship (Lockeridge and Simpson, 2013). This study therefore aims to expand on previous findings by exploring how individuals make sense of their experience of caring for a partner with young onset dementia. It is hoped that the exploration of their experiences will help to further understand the thoughts and needs of this client group, raise awareness of young onset dementia through dissemination of these findings, inform therapeutic practice, feed into service development and challenge stigmatised attitudes towards dementia and this marginalised group. Understanding the unique perspectives of individual care partners is needed to tailor support that will meet the needs of younger people in a way that is distinctive to older people living with dementia and their care partners.

Previous qualitative research that has looked at the impact of caring for partners with young onset dementia has indicated that younger carers need greater emotional and psychological support and access to more services. Narratives of denial, loss, fear and abandonment are recurring themes in the literature, and younger carers often adopt a range of emotion and problem focused coping strategies to sustain their partner's identity for as long as possible and challenge their experiences of stigma (Lockeridge and Simpson, 2013). Studies suggest that the use of emotion focused coping strategies such as avoidance and denial predict high levels of anxiety and depression in carers (Di Mattei et al., 2008). Qualitative findings also indicate that partners of people with young onset dementia perceive a significant deterioration in the quality of their relationship over time (Kimura et al., 2015; Massimo et al., 2013).

Research that involves carers of partners living with young onset dementia will assist in developing a deeper understanding of the experiences of the individual and the dyad. It is hoped that the current findings will address the needs and support the strengths of the growing population of carers of people living with young onset dementia, whilst developing critical knowledge for psychologists and other healthcare professionals. Furthering our understanding of key issues that may underpin service provision and support therapeutic practice could make a significant difference to their quality of life.

Rationale and Research Question

Sustained campaigns and support from charitable organisations such as the ‘Alzheimer’s Society’ and ‘Young Dementia UK’ mean that the needs of this client group are increasingly being addressed by offering specialist advice, support and research to improve the care and quality of life of people living with young onset dementia and their carers. However, the literature shows that there is a scarcity of research focusing explicitly on the experiences of caring for a partner with young onset dementia - particularly in the field of counselling psychology. Therefore, this study aims to explore this limited area.

Findings have the potential to impact service development and provision in dementia care services and improve support for people living with young onset dementia and their carers. Understanding and awareness of carers’ thoughts and needs is required to improve therapeutic practice and develop the serious lack of provision for this marginalised group.

This study aims to explore the following question:

How do carers experience and make sense of caring for their partner with young onset dementia?

Interpretative phenomenological analysis (IPA)

A qualitative methodology was employed to explore participants’ experiences. Interpretative Phenomenological Analysis (IPA) was considered to be the most appropriate methodology for this research due to the emphasis it places on understanding and making sense of individual lived experiences. The use of IPA will allow exploration of the lived experiences of individuals who are currently caring for a partner with young onset dementia. Understanding how another person makes sense of an experience also appears well suited within the ethos of counselling psychology. IPA has become a well-established qualitative approach to psychological research and can be described as having three broad elements. It represents an epistemological position, offers a set of guidelines for conducting research, and describes a corpus of empirical research (Smith, 2004).

IPA draws on the theoretical underpinnings of phenomenology, hermeneutics and idiography, to inform its distinctive epistemological framework. As such IPA offers a method that is congruent with the existential-phenomenological paradigm and at the same time can link existential-phenomenological research with the wider research literature in psychology (Shinebourne, 2011). IPA’s theoretical underpinnings stem from the phenomenology which originated with Husserl's attempts to construct a philosophical science of consciousness, with hermeneutics (the theory of interpretation), and with symbolic-interactionism, which posits that the meanings an individual ascribes to events are of central concern but are only accessible through an interpretative process (Biggerstaff and Thompson, 2008). As such, IPA acknowledges the ontological independency of the research object from the researcher, and the universality of the particular (Reid, Flowers, & Larkin, 2005). IPA is theoretically rooted in critical realism (Bhaskar, 1978) and predominantly thought to adopt a critical realist approach which is primarily focused on understanding, rather than merely describing social reality. As such, critical realist researchers seek to overcome the dualism of objectivism or subjectivism by distinguishing between ontology (what is real) and epistemology (what we know) (O’Mahoney, 2016). Analysis will be guided by a critical realist position.

A critical realist ontology was appropriate for this research which assumes the belief that reality is ‘out there’, socially and societally embedded, existing in the mind of individuals who experience multiple realities in different ways, captured by broad critical examination, filtered through the mind of the researcher. There are multiple perspectives and causation is determined by interpreted meanings (Cuthbertson, Robb & Blair, 2020). Adopting a critical realist ontology in this study enabled me to explore the diverse participant perspectives. Recognising the absence of a singular, universal reality, I acknowledged the subjectivity and multiplicity of reality as perceived and experienced by each participant, emphasising the search for meaning within their rich qualitative accounts.

IPA is concerned with the detailed examination of personal lived experience and inevitably involves an interpretative process on the part of both researcher and participant, firstly by providing an in-depth account of each case before moving to look for patterns of convergence and divergence across cases, from which themes that respond to the research question(s) are identified (Eatough and Smith, 2008). The basic assumption of IPA is that people are self-interpretive beings in that we have experiences of the world and we make sense of these experiences by reflecting on them (Smith et al., 2009).

Rationale to use interpretative phenomenological analysis

Interpretative phenomenological analysis (IPA) was chosen for this study due to the strong emphasis this methodology places on understanding the lived experiences of individuals and exploring the subjective and personal aspects of individual experiences in-depth. The epistemological framework of IPA will support the exploration of carers experiences and sense making of individual narratives in a context filled with complexity and emotion.

Caring for a partner with young onset dementia is highly individualistic, and the phenomenological approach of IPA is well suited to uncover the nuances of each individual's unique experience. The phenomenological approach is rooted in phenomenology, which seeks to understand the essence of human experiences and how individuals interpret their world. The emphasis phenomenology places on the 'lifeworld' of individuals (Husserl, 1936, 1970) appears particularly valuable in the context of caring. The lifeworld constitutes our relationship with the world, our cultural situation, our sensations, and our meaning-making, and is made up of different dimensions which offer a holistic approach for understanding human experience as it is lived: temporality, spatiality, intersubjectivity, embodiment, identity, and mood (Shaw, Smith and Hiles, 2018). This aligns with the aims of the research, which is to understand how individuals experience and make sense of caring for their partner with young onset dementia.

IPA typically involves conducting in-depth, one-to-one interviews with participants. This allows for a detailed and comprehensive exploration of their experiences, emotions and thought processes. Given the complexity and emotional nature of caring for a partner living with young onset dementia, this depth of analysis is crucial. IPA studies usually consist of small homogenous sample sizes, which can provide a rich contextual understanding of lived experiences, and further understanding of the nuanced emotional, psychological and social dimensions of the carers experience.

IPA considers the broader context in which experiences occur. In the context of caring for partners with young onset dementia, this may include factors such as the couple's relationship history, the partner's current level of cognitive impairment, family dynamics and the social support networks they have in place. These contextual aspects will be explored in order to provide a holistic view of the carers individual experience. Furthermore, IPA seeks to capture the participants' voices without imposing preconceived themes or categories. This aligns with the research aims and will allow participants to express their unique perspectives and interpretations.

Reflexive thematic analysis (RTA) was also considered for this study in addition to IPA as both approaches may be relevant to analyse the data. RTA seeks to uncover patterns of meaning across the data, whilst considering the centrality of researcher subjectivity and reflexivity (Braun and Clarke, 2019). In comparisons of thematic analysis (TA) with IPA Gripsrud (2020) argues that IPA is a more theoretically informed methodology (phenomenology and hermeneutics) and allows for a detailed examination of lived experience, and how individuals make sense of their own world and the social world of which they are part of. However, this diminution of TA is contested by Braun and Clarke (2021) who advise that TA should be recognised as a (more or less, depending on the specific iteration) theoretically flexible, but not atheoretical, approach and one equally suited to experiential and critical orientations for qualitative research.

IPA is considered particularly suitable for exploring topics which are complex and/or emotional. What sets IPA aside from a thematic analysis across cases, is that it examines each particular case in detail (idography) before moving on to the other cases, and eventually a cross-case analysis. IPA goes deep (interpretative, with respect for individual cases), and therefore fewer participants are required (Gripsrud, 2020).

While both IPA and RTA have their strengths and may yield valuable insights, I felt that the choice of IPA was a better fit for my research question due to its explicit focus on the depth of individual experience and its alignment with the phenomenological approach.

There are two important differences between reflexive TA and IPA. The first is that IPA incorporates a dual analytic focus: both a thematic orientation—the identification of themes across cases (participants)—and an idiographic approach—interest in and focus on the particular and unique details of each case. Second, related in part to this idiographic focus, IPA procedures are rather different from TA procedures: IPA involves a detailed focus on the analysis of each case, before developing themes across cases (Braun & Clarke, 2013). This is quite different from theme development in reflexive TA, where themes are developed across cases from codes, following the coding of the entire data set. IPA goes analytically much deeper or further with each data item, before taking an overall thematic orientation to develop themes across the data set (Braun and Clarke, 2021). Overall, it was felt that the use of IPA would be the most suitable approach to capture the nuanced and subjective meanings that participants associate with their lived experiences of caring for their partner with young onset dementia.

Reflexive statement

Reflexivity is a set of continuous, collaborative, and multifaceted practices through which researchers self-consciously critique, appraise, and evaluate how their subjectivity and context influence the research processes (Olmos-Vega et al, 2023). The incorporation of reflexivity in IPA encourages researchers to acknowledge and address their own biases and preconceptions. This level of self-awareness is of paramount importance when studying such a sensitive and emotionally charged topic like caring for a partner with young onset dementia.

Researcher reflexivity is integral to IPA and my own thoughts, emotions and experiences were reflected upon throughout the process in a research diary. To be reflexive means working with subjectivity, and intersubjectivity, throughout the process, staying aware of how these contribute to the evolving field of researcher and researched, and ultimately limit what can be found, or constructed (Douglas et al., 2016). IPA stresses the subjective, particular nature of the participants' and the researcher's meaning and sense makings, this is referred to as the 'double hermeneutic' (Smith, 2004).

My interest in dementia research stems from my work in older adult mental health services in the NHS and my own personal experience of dementia in the family. This experience has provided me with valuable insights into the challenges and complexities of dementia care and influenced my perspective and emotions regarding this often devastating condition. In my work on inpatient and community settings with older adults I noticed how little professional support is available to carers of people living with dementia and the daily challenges they face. I often thought about my late grandmother who had vascular dementia and eventually moved in with my father for 24-hour care. He found it difficult to cope with the practical and emotional challenges of caring, they had no support from services, and did not receive the care they both deserved. I felt a sense of guilt as I was not able to help much due to them living in London and me residing in Wales.

My personal experience fuelled my interest in dementia research and the desire to support carers. I contemplated the insufficient availability of post-diagnostic support for carers, recognising that many may also lack a comprehensive understanding of dementia and how to effectively care for both their loved one and themselves. I was therefore keen to do research that would further understand the experiences of carers in order to develop tailored support and service provision. I thought about the area of dementia that I have the least amount of knowledge and experience in, and that is young onset. So, to broaden my existing knowledge I chose this area.

In this research I am positioned as an outsider to the group being studied, not having young onset dementia or being a caring partner for someone living with young onset dementia. I do, however, have experience of working in the field of dementia care as an assistant psychologist and trainee counselling psychologist in older adult mental health services in the NHS over the last 8 years. I acknowledge that I may carry preconceived notions and emotional responses stemming from my personal experience of dementia in my family and my occupational role in older adult mental health services. It is impossible, for me as a researcher, not to draw upon these experiences in the research process. Continuous reflection throughout this process in a research diary, coupled with invaluable discussions with my supervisors, work colleagues and peers has been helpful to explore my own thought processes, biases, and expectations. These discussions and reflections have encouraged me to be mindful of my preconceptions regarding dementia and maintain a critical stance during data collection and analysis.

IPA requires the researcher’s use of bracketing as means to demonstrate validity in phenomenological research. Bracketing is a methodological device of phenomenological inquiry that requires the deliberate putting aside of one’s own belief about the phenomenon under investigation or what one already knows about the subject prior to and throughout the phenomenological investigation (Carpenter, 2007, cited in Chan et al., 2013). However, although I have attempted to bracket my own personal experiences throughout the research process, I understand that we cannot completely remove our beliefs and values, but we can refrain from judgement, explicitly acknowledge our beliefs and values that would prompt judgement, and use them as sources of insights (Dorfler and Stierand, 2021). As such, I approached each interview with openness and curiosity, allowing the voices and experiences of the participants to take centre stage in the study.

It is important in IPA research for the researcher to stay on top of any explicit and implicit biases that may jeopardise the goal and integrity of the study by bracketing the researcher's personal experience from the 'lived experiences' of the research participants. In addition, for a research study to be authentic and credible, telling a narrative of the journey should be part of the research study's narration (Alase, 2017). My supervisor reviewed my findings and ensured my theme development was consistent with good quality IPA research.

Further Reflexivity

In order to understand how I have influenced the interpretation of the findings and made sense of the participant's narratives, it was important to examine my own preconceptions and assumptions in order to bring a level of self-awareness and transparency to the process. My experience of personal therapy coupled with doctorate training in counselling psychology has been instrumental to the development of my own self-awareness and a means of fostering reflexivity, as I have consistently engaged in personal reflections. Working therapeutically with clients requires me to be aware of my own subjectivity and how this may unfold and impact the dynamics of the therapeutic relationship. Similarly, I have maintained this level of self-awareness through personal reflections whilst engaging in the research process. As previously mentioned, I am positioned as an outsider in this research, but my experiences of working in older adult mental health services and having a grandmother who lived with dementia are likely to influence my interpretation of the findings. Being able to reflect on my own preconceived ideas and biases with my supervisor and peers, coupled with the use of a research diary, has been a salient aspect of the research process.

Throughout my analysis I employed a reflexive approach, constantly acknowledging my own thoughts, feelings and reactions as I engaged with the data. The reflexive process was particularly crucial given the emotionally charged nature of the interviews, which often triggered strong emotional responses for me. For example, during the analysis, one participant described her relationship with her partner in strikingly altered terms. She described their relationship prior to dementia as a romantic fairytale where they were “best friends”, but now she views him as a “weird uncle” she has been “plonked with”. This stark shift in perception was emotionally jarring for me, and I found myself feeling shocked and saddened by the depth of her emotional disconnection from her partner.

To ensure that my emotions did not unduly influence the analysis, I made a conscious effort to stand back from the data. This involved adopting a metaphorical “third viewpoint”, where I imagined myself as an observer watching both the participant and myself as I engaged with the data. This third viewpoint allowed me to maintain a critical distance from my emotional reactions, enabling me to remain curious and open to the participant narratives without imposing my own emotional responses onto them. For instance, when analysing the participant’s description of her partner as a “weird uncle”, I noticed my initial emotional reaction of shock and sadness. Rather than allowing these emotions to cloud my analysis, I acknowledged them and then deliberately shifted my focus back to the participant’s perspective. I asked myself, “What is this person trying to tell me?” By doing so, I was able to concentrate on the participant’s experience of profound loss and the redefinition of her relationship with her partner, rather than getting caught up in my own emotional response. Reflecting on the interviews brought up different feelings of sadness, anxiety and even guilt, as I was reminded of my own grandmother’s experience of dementia. This was a challenging part of the process and I made a concerted effort to hold these feelings in my awareness without allowing them to directly influence the analysis. I did this by regularly stepping back and adopting the third viewpoint, which helped me to maintain a balance between empathy and critical analysis.

While reflexivity was challenging, it also played a crucial role in deepening my understanding of the participants’ experiences. The awareness of my own emotional reactions ultimately enabled me to develop a more empathic understanding of the participants’ narratives. By acknowledging and reflecting on my own emotions, I was able to place myself in the participants’ shoes and see the world through their eyes more clearly. This empathic understanding was particularly important in the analysis of emotionally charged data, as it allowed me to capture the depth and complexity of the participants' experiences. For example, in the case of the participant who described her partner as a "weird uncle", my initial emotional reaction of shock and sadness led me to explore more deeply the sense of loss and disconnection she was experiencing. By standing back and reflecting on my own emotions, I was able to appreciate the profound impact that dementia had on her relationship and the sense of grief she felt over the loss of the partner she once knew. The reflexive process, while challenging, ultimately enhanced my understanding of the participants' experiences, allowing me to produce a more nuanced interpretative phenomenological analysis.

(See Appendix 11 for further reflections on the research journey)

Participants

Adults of any age currently living with and caring for a partner with a diagnosis of young onset dementia were invited to take part in the study. A diagnosis of young onset dementia is given to people under the age of 65. To be included, the partners of participants needed to have received their diagnosis of young onset dementia before the age of 65 and they could have any dementia diagnosis.

I did not stipulate age requirements for participants of the study as the research aim was to understand their experience, and this could be reflected upon at any age. Therefore, the participant could be any age, if their partner was diagnosed with young onset dementia under the age of 65. The partner living with young onset dementia could be over the age of 65 if they have aged since receiving the diagnosis.

The study consisted of six women and two men. Partners were chosen as they are more likely to be in caring roles with a close relationship. According to Smith, Flowers and Larkin (2009), six participants is an appropriate sample size for a student project using IPA. Six to ten participants is considered the ideal number for professional doctorate research studies due to depth of analysis required and time constraints (Smith, Flowers and Larkin, 2022).

Participant demographics

Table 1 provides demographic details of the eight participants. Pseudonyms were used for both participants and their partners to protect anonymity.

Pseudonym	Age	Gender	Ethnicity	Work status	Highest Education	No. of dependent children	Length of relationship (years)
Mary	43	Female	White British	Employed full-time	Degree	2	14
Wendy	55	Female	White British	Employed part-time	O Level	1	31
Edward	66	Male	White British	Retired	A Level	None	44
Caroline	58	Female	White British	Not working	O Level	1	36
Heidi	49	Female	White Latvian	Employed part-time	CSE	1	20
Fiona	62	Female	White British	Working part-time	Degree	None	12
Chris	56	Male	White British	Working full-time	NQF/QCF Level 6	None	36
Barbara	62	Female	White British	Retired	Diploma	None	15

Table 2 provides demographic details of participants partners

Pseudonym	Age	Gender	Ethnicity	Work Status	Highest Education	Diagnosis/level of cognitive impairment	Age at Diagnosis
David (partner of Mary)	53	Male	White British	Not working	High school	Alzheimer's / Mild	53
Paul (partner of Wendy)	59	Male	White British	Working part-time	O Level	Alzheimer's / Mild	56
Maria (partner of Edward)	64	Female	White British	Not working	O Level	Alzheimer's / Severe	62
Martin (partner of Caroline)	61	Male	White British	Not working	None	FTD / Moderate	56
Craig (partner of Heidi)	70	Male	White British	Retired	None	Mixed vascular/ Alzheimer's / Mild-moderate	64
James (partner of Fiona)	65	Male	White British	Retired	College	FTD with LPA Mild	60
Susan (partner of Chris)	56	Female	White British	Employed part-time (on sick leave)	Level 5	Alzheimer's Mild	56
Phillip (partner of Barbara)	61	Male	White British	Retired	Degree	Familial Alzheimer's Severe	49

Recruitment of participants

Eight people who are currently living with and caring for a partner with young onset dementia were recruited for this study through the care and research charity organisation, ‘The Young Dementia Network’ hosted by Dementia UK - ‘Young Dementia UK’. The Young Dementia Network hosted by Dementia UK are able to promote research studies by sharing project information in their monthly newsletter and via their Twitter and Facebook accounts. People who saw the recruitment advert either on social media or in the monthly newsletter and were interested in taking part were invited to contact me using my university email address. Ten people contacted me to express their interest and enquire about taking part. Eight people living with their partner with a diagnosis of young onset dementia were recruited. We arranged a suitable date, time and place to conduct the interview. Two people who expressed an interest in taking part were not recruited as one partner did not have a formal diagnosis, and another partner was residing in a care home.

The decision to exclude the partner of an individual currently residing in a care home was made after careful consideration and discussion with my research supervisor. The study necessitates participants who are currently cohabiting with and directly caring for their partner to explore their experiences of caring. Thinking of the closeness in the relationship and how directly caring for their partner in the same environment may impact on them. While it is acknowledged that partners of individuals residing in care homes continue to engage in caring, the provision of support for activities of daily living by care home staff significantly alters the nature of this role as most of their needs are being cared for by other people. Consequently, individuals with partners residing in care homes may be less likely to reflect on the present nuanced aspects of caring and its impact on their relationship. However, they were previously living together, and they would have gone through that transition. This study explores the experiences of people who haven’t yet had to face that decision.

A copy of the participant information sheet, consent form and demographic data sheet (see appendices) was sent to prospective participants via email. Participants were required to sign and date the consent form and demographic data sheet and return to my university email address. Participants were informed that their participation is voluntary and that they have the right to withdraw from the research up until the point where analysis has started.

Developing interview questions

A semi-structured interview schedule (appendix 7) was developed based on current literature, areas that I was interested in exploring and in consultation with my supervisor.

The following areas guided the development of the interview schedule:

1. The diagnostic experience and transition to carer role.
2. Coping with changes in the relationship.
3. Experience of stigma and the impact on their relationship.
4. Relational dynamics within the dyad.

During supervision we agreed that I would pilot the interview schedule with the first participant and meet to reflect on how it went. It was thought that piloting the interview schedule would identify any challenges and limitations and increase my confidence in my chosen methodology. I piloted the interview schedule with one participant. This was reviewed with my research supervisor and deemed appropriate to include in the study and continue.

Interviews

I followed guidance by Smith, Flowers and Larkin (2022) on conducting semi-structured in-depth interviews.

Participants were offered the option to engage with the interview in-person (either at the researcher’s workplace or university), via Microsoft Teams or over the telephone. Six interviews took place over Microsoft Teams using my university account, one over the telephone, and one in person in a private room on campus at university (UWE). Participants who took part online and over the phone were in their own homes during the interview. I was also in a quiet and confidential space in my own home. All interviews were audio recorded. The duration of each interview ranged between 60-90 minutes.

I started each interview by building rapport and creating a warm-up discussion about confidentiality, consent and emotional wellbeing during the interview. I ensured that I had established a good enough rapport with each participant before starting the interview questions. I used the interview schedule as my guide but in a flexible manner, listening carefully and attentively to the participants' stories, and responding with sensitivity and empathy. Interviews adopted a semi-structured approach with open-ended questions to facilitate and encourage detailed responses from participants and obtain rich detailed accounts of their lived experiences. I ended each interview by thanking participants for their time, asking how they felt, and providing a space for any questions.

Homogeneity of the sample

Due to the commitment to idiography in IPA research, studies are conducted on small, fairly homogenous sample sizes, for whom the research question will be meaningful. However, it is important to note that this purposive homogenous sampling is not seen as treating the members of the sample as if they were identical (Smith et al., 2022).

The sample in this study is fairly homogenous in that all participants are currently living with and caring for a partner with a diagnosis of young onset dementia. Consideration was given to whether the participants partners needed to present with the same diagnosis of dementia to ensure homogeneity. However, the primary objective of the study was to explore participants experiences of caring, therefore, the decision was made to refrain from restricting the sample to a specific dementia diagnosis. Moreover, the recruitment of caring partners might have posed some challenges, thus further narrowing the sample would have restricted participant numbers.

In IPA other forms of variability within the group can be examined in detail by analysing the patterns of convergence and divergence within the data and thinking carefully about the experiences and contexts of the participants who contribute in distinct ways to those different patterns. This is why the idiographic element in IPA is so important and illuminating (Smith, Flowers & Larkin, 2022).

Ethical considerations

Ethical approval was gained from the University of the West of England and Dementia UK. Firstly, a recruitment advert with details of the study was developed. An information sheet and consent form was provided to each participant prior to interview. Participants were informed that their participation was voluntary and of their right to withdraw from the research up until the time analysis has commenced. Each participant was in receipt of the researcher’s contact details should they have any further questions.

Confidentiality and anonymity were maintained throughout by using pseudonyms and storing all data on an encrypted USB drive used on a password protected computer. Participants were also informed that paperwork relating to the research will be stored securely in a locked filing cabinet and once the research has been completed all interview data will be deleted/shredded. Data was transferred from the USB drive to the cloud at UWE following collection. After transcription all recordings were deleted.

I discussed confidentiality with each participant before starting the interview. I informed each participant that if there was a disclosure of harm, I would discuss this with the participant in the first instance before contacting an appropriate health professional (depending on nature of risk). If a participant became emotionally distressed during an interview, I planned to offer empathy and reassurance, and the opportunity to end the interview and / or reschedule. I also considered signposting participants to support available through Dementia UK and/or local counselling services. I was able to contact my research / workplace supervisor for advice if needed.

Interviewing carers in their own homes, especially when the person with dementia is present or nearby, raises significant ethical and practical issues. Privacy, dignity, consent, and the emotional and psychological impact on both the carer and the person living with young onset dementia should be carefully considered. These issues are particularly pronounced when considering the impact on the person with dementia, who may be aware, at some level that they are being discussed. In one virtual interview the participants partner was briefly on screen as he supported her to get connected to MS Teams, he then left the room. In another two interviews participants called out to their partners who were in other rooms of the house either to answer a question or check on their wellbeing. One telephone interview was carried out over two shorter sessions as the participant was mindful of his partners nearby presence.

One of the primary ethical concerns is the dignity and privacy of the person with dementia. Even if the person is not directly participating in the interview, their presence or awareness that they are being discussed can evoke feelings of paranoia, distress, or confusion. For instance, during the interview with one participant, he told me that his partner was in a nearby room and that she may feel paranoid and upset should she hear him talking about her. This situation required us to pause the interview and reschedule a follow-up call at a suitable time. This highlights the importance of considering the emotional state and awareness of the person with dementia during the interview process.

The partner with young onset dementia might have varying levels of awareness about the interview taking place depending on their cognitive abilities. They might feel confused, anxious, or upset about the presence of an interviewer (even virtually or on the telephone) and the topics being discussed. Hearing their partner discuss the difficulties and challenges of their caring role may negatively impact the person with young onset dementia. They might feel guilty or emotionally distressed, which could lead to relational conflict for the couple. This required me to be sensitive and aware of these potential reactions. There is also the issue of consent. While the carer may have consented to the interview, the person with dementia may not have the capacity to fully understand or consent to being indirectly involved in the research.

The presence or close proximity of the person with dementia during the interview introduces practical challenges that can affect the quality of the data collected. For instance, carers may feel the need to modify their responses or may be less candid if they know that their partner can hear them or might overhear the conversation. I noticed that during the telephone interview, the participant was notably more hesitant and cautious in his responses due to his partner being nearby, focusing more on her location and whether she could hear him rather than on the interview questions. This resulted in a less fluid and possibly less truthful conversation, which could compromise the depth and authenticity of the data.

Furthermore, conducting interviews at home can be practically challenging due to potential interruptions and technological issues. For instance, carers might be distracted by their caring responsibilities, or they might struggle with the technology required for virtual interviews, as seen when one participant needed help to get connected.

Maintaining a flexible, empathetic and non-judgemental interview style fostered an environment that supported the participants to feel comfortable discussing their experiences even with their partner in a nearby room. Ensuring the safety and well-being of both the carer and the person living with young onset dementia during the interview is paramount, especially if discussing sensitive topics might lead to emotional distress.

Transcription and data analysis

Interview data was audio recorded and later transcribed verbatim and analysed using IPA. Interviews that were held via Microsoft Teams had the transcription tool enabled. The first stage of the analysis involved reading the transcript closely a number of times and listening to the recordings whilst annotating what was interesting or significant about the participants' responses. The notes were then transformed into personal experiential statements and documented. The next stage involved looking for connections between experiential statements and clustering them into personal experiential themes (PETs). PETs were used to develop group experiential themes (GETs) across cases. Finally, the research was written into a narrative account explaining each theme using verbatim extracts to support interpretation. Confidentiality and anonymity was maintained by using pseudonyms.

The concept and practice of hermeneutics provides guidelines for the interpretation of qualitative research data. Hermeneutics acknowledges research bias and infuses it into the text, along with the interviewee's perspective, to create a new meaning altogether (Arnett, 2007). Furthermore, unlike quantitative methods that seek objective truth, hermeneutics resists the concept of objective reality by exposing a range of possible meanings (Smith, 2010). It is important to note that the process of analysis in IPA is iterative – we may move back and forth through a range of different ways of thinking about the data, this is known as the hermeneutic circle (Smith et al., 2022).

The analytical process in this study followed Smith, Flowers & Larkin (2022) guidelines for conducting IPA research:

Step 1: Starting with the first case: reading and re-reading

In this step I printed the transcripts and familarised myself with each interview by listening to the audio recording whilst reading the transcript.

Step 2: Exploratory noting

I started underlining anything that stood out to me or seemed important, then wrote my initial thoughts and responses to this in the margin of the transcript, whilst trying to focus on what this was telling me about their lived experience. I made my notes in hand written form for the first transcript. For the second transcript, I tried exploratory noting by embedding comments into a word document, however, I found this more time consuming and less visual so I switched back to hand written note taking.

Step 3: Constructing experiential statements

In this step, I sought to reduce the volume of detail in my exploratory notes by articulating the most important features and turning them into experiential statements. Initially I wrote these experiential statements in the margin of the transcript, I also tried compiling the statements into a table, but then decided the best method for me was to map them out on an A3 sheet of paper. I wrote the corresponding page of the transcript in brackets next to each statement to make it easier to find the participant quotes when needed. The visual format of doing this helped to consolidate my thoughts and support the analysis.

Step 4: Searching for connections across experiential statements

In this step I looked across my A3 map for statements that appeared to be connected or closely aligned. I then proceeded to colour code the connected statements into clusters. Any statements that did not fit into these clusters were discarded.

Step 5: Naming the personal experiential themes (PETs) and consolidating and organising them

Each cluster was given a descriptive title and organised in a master table of personal experiential themes (appendix 9).

Step 6: Continuing the individual analysis of other cases

The steps above were repeated for each individual case.

Step 7: Working with personal experiential themes to develop group experiential themes across cases

In the final step I looked across the master table of PETs for patterns of similarity and differences, convergence and divergence. Personal experiential themes that stood out to me as highlighting the shared and unique features of the participants experience were used to develop the group experiential themes across cases.

See Appendix 8 for theme development participant 1 including extract of annotated transcript; development of personal experiential statements and personal experiential themes (PETs).

Chapter 4: Findings

Through the analysis, four Group Experiential Themes were developed, each comprising 2-3 Personal Experiential Themes (often abbreviated to GETs and PETs: Smith, Flowers & Larkin, 2022, p. 100)

Table 3 Summary of Group Experiential Themes (GETs) and Personal Experiential Themes (PETs)

Group Experiential Theme 1: **The long road to diagnosis**	**Group Experiential Theme 2:** **Ignored and forgotten**	**Group Experiential Theme 3:** **So much has changed, everything is different**	**Group Experiential Theme 4:** **Where do I go from here?**
Personal Experiential Theme 1.1 Living with frustration and anger	**Personal Experiential Theme 2.1** Diagnosed and dumped	**Personal Experiential Theme 3.1** We used to be best friends	**Personal Experiential Theme 4.1** Diverse practical and emotional ways of coping
Personal Experiential Theme 1.2 You're too young so it must be something else	**Personal Experiential Theme 2.2** The young onset dementia story is not being told	**Personal Experiential Theme 3.2** Now I have to get the spiders	**Personal Experiential Theme 4.2** Dementia is a robber and a cheat
Personal Experiential Theme 1.3 The emotional impact of the diagnosis		**Personal Experiential Theme 3.3** Negative impact on family relationships	

Description of Themes

Group Experiential Theme 1 – *“The long road to diagnosis”*

This theme explores the lengthy and frustrating diagnostic journey experienced by carers in a search to understand the unknown changes in memory and/or behaviour in their partner, often navigating multiple assessments and interactions with healthcare professionals. The pre-diagnostic experience leads on to subtheme 1.1 which highlights carers experiences of living with frustration and anger along the way, often in response to these unknown changes. This leads on to subtheme 1.2 which focuses on the common experience of misdiagnosis in young onset dementia. Subtheme 1.3 then explores the emotional impact of the diagnosis felt by carers and how they make sense of it.

The time from noticing initial changes in their partner to receiving the diagnosis was described by carers as a lengthy journey and a frustrating process. Couples tended to follow a similar route to diagnosis with their general practitioner being the first point of contact, followed by multiple assessments and lengthy waiting times in the mental health system of the NHS. For some, the diagnosis was further delayed due to the Coronavirus pandemic:

Mary conveys a sense of frustration and a feeling that David’s diagnostic journey was a challenging and lengthy process for them:

> ***“David was diagnosed with Alzheimer’s in November of last year after having been backwards and forwards to hospitals and doctors and things, but he had been having issues with his memory before that, so it’s taken us partly due to COVID, partly due to him being so young. It’s taken us quite a long time to get where we’re at. It just sort of seemed to go on forever.” (p.3)***

In addition, Mary speaks of David’s diagnosis being speeded up in response to his expression of suicidal thoughts, due to the emotional impact the undiagnosed dementia was having on the family:

> ***“…but getting to that point took a long, long time, and had I not got really upset not knowing what to do that day and David hadn’t said what he said, I think it would have taken much, much longer.” (p.5)***

There is a sense of time to diagnosis being an unnecessarily slow and frustrating experience as Fiona reflects on the long diagnostic journey she and her partner James experienced:

> ***"And this is one of the things I find frustrating, everybody I talk to or we talk to, it all seems to have dragged out between 18 months to two years before anybody gets a diagnosis." (p.3)***

The diagnostic journey for Chris and his partner Susan involves a mixture of both positive and negative emotions, from relief and trust in the GP, to frustration and distress due to hospital waiting times:

> ***"So backwards and forwards to the GP, and the GP was really good, really helpful. So the GP did some bloods and referred to neurology and things like that, but waiting times in our hospital were pretty horrendous to say the least." (p.5)***

Edward reflects on Maria's deep distrust of doctors which likely influenced her reluctance to seek help. The long period of uncertainty Edward speaks of implies that the couple have been living with ambiguity and confusion on their diagnostic journey. In addition, the delay in diagnosis is partly attributed to Covid which highlights how the pandemic disrupted healthcare access:

> ***"Oh she's very distrustful of doctors, and I don't know but I expect she knew something wasn't right for a long time, and I was working up 'til, well I stopped working in March 2020 to look after her. But she didn't get diagnosed until the following year, one because of Covid and two because she refused to go to the doctors. I suspected it was dementia but I didn't know. Sort of five or six years that I thought something was not quite right with her, but she's the sort of person that won't contact the doctors." (p.3)***

Personal Experiential Theme 1.1 – "*Living with frustration and anger*"

This theme explores carers' experiences of living with anger and frustration on their journey to diagnosis and beyond. Many participants described how their partners directed anger towards them as they tried to make sense of unknown changes in their memory and behaviour. Conversely, one participant describes how he directed anger and frustration towards his partner for her unexplainable forgetfulness prior to the diagnosis.

When reflecting on what she noticed the most in the lead up to the diagnosis, Mary places emphasis on David's consistent expression of anger, suggesting a deep emotional turmoil that she and the family felt powerless to:

> ***"Just that he was angry about everything he was, he was angry about, or angry or frustrated, whatever you want to call it, but nobody could do anything right" (p.6)***

Mary also speaks of their joint experience of frustration as simple activities became increasingly difficult for David to manage, and her annoyance at the unknown reason for his decline in cognitive function:

> ***"Things got more and more challenging and I think frustrating for both him and I because he wasn't able to do really simple tasks and I was getting really annoyed with him, because there was no reason for it." (p.4)***

Wendy illuminates Paul's heightened levels of anger in the lead up to the diagnosis and his attempts to cope with emotional distress by excessive alcohol consumption, which had a detrimental effect on their relationship:

> ***"Paul's mood became, oh his anger levels just went through the roof. He was making it really difficult to maintain a relationship. Then Paul suddenly began drinking a lot more, and we didn't know it was that at the time, he was hiding it really, really well. He was just making the relationship really difficult and that's when I said enough is enough, we've got to go back to the doctors, something is not right here." (p.3)***

Caroline reflects on noticing the first signs of speech difficulties in Martin and a long period of living with uncertainty and anger due to Martin's dismissal of the problem:

> ***"The first sign I had was when he used to come home after he finished work. He'd come in and everyday he couldn't speak, as soon as he came through the door he tried to speak and nothing would come out, just his lips would move, and I thought what on earth is the matter with him? And that went on for days, weeks, months, and I tried to***

> ***talk to him about it, but every time I did he dismissed it or he got angry, he just didn't realise it was happening to him at all." (p.1)***

And following the diagnosis Caroline felt threatened by Martin's aggressive behaviour and this led to the distressing experience of him being sectioned and taken to hospital:

> ***"…he had an almighty blow out an anger outburst, which is what he does. That's part of the FTD and he follows a pattern, he has the blow out and then he'll have a day where he'll disappear and he'll just go to bed for a day, and then he'll have three or four days of sulking. And I thought, he's gonna start wrecking the house because sometimes he'd pick things up and smash them. I rang the crisis number. So next thing, they rang me back and they asked what the problem was and they said do you feel threatened and I says yeah I do, and they says right, we're sending an ambulance, so they sent an ambulance, two paramedics and they took him away, and he was sectioned." (p.12)***

Heidi describes how Craig directed his anger towards her in the past when his mood changed. There is a shift in her understanding, moving from a sense of being unfairly treated to one of empathy and recognition of dementia. Heidi also recognises her own limitations regarding her caring role:

> ***"What I don't like, before when Craig was having his mood changes and getting angry, he basically gave all his anger out on me. Being a wife, family member, I forgot that he has dementia. Now he knows that if he will get angry and his mood will be changing and he will become violent, he knows that I am going to send him to a nursing home. I am not keeping him at home, I won't be able to cope." (p.15)***

Edward reflects on what it feels like to care for Maria. This quote illustrates the emotional and physical impact of his caring role:

> ***"I almost don't get time to think about it during the day but then I get frustrated at night, I'm absolutely knackered, I'm always having to think for her all the time. I get off to sleep quickly but then about two three o'clock I'm awake again, and it takes me two or three hours to get back off to sleep so I don't have a, I feel like I'm not sleeping properly but it's just, at times I feel just frustrated by it." (p.4)***

Barbara highlights the intense fear, unpredictability and emotional suppression she has experienced in response to Phillip's violent outbursts. Her use of the phrase 'pointy end of this' indicates how Barbara's distress has reached a critical level:

> ***"…there's some level where you just think this isn't even a safe situation anymore. He's lashed out a few times. The middle time was so scary to me, I literally thought I was having a heart attack from the fear. And each time that that those violent outbursts happened within 5 minutes, no idea at all, no idea. So you can't even berate them there's no bloody come back, you know (laughs). So very, very suppressing for emotions as well. Yeah. So we really are getting to the pointy end of this." (p.15)***

A contrasting position was illustrated by Chris who describes a sense of guilt and regret for directing anger at Susan for her unexplainable memory problems in the lead up to diagnosis:

> ***"I live with a bit of regret that I gave Susan quite a hard time before she had a diagnosis and things like that. I look back and think that I was quite tough on her, and it wasn't her fault. But I don't want to think about that." (p.13)***

Personal Experiential Theme 1.2 – *"You're too young so it must be something else"*

This theme explores the shared key experience of misdiagnosis by healthcare professionals. Most of the participants spoke about noticing first signs of memory loss or personality and behaviour changes in their partner and healthcare professionals expressing uncertainty. As dementia is more often associated with older age, healthcare professionals may attribute ambiguous symptoms to other factors. The misdiagnosis of stress, anxiety and depression is a common narrative that adds further time to reach the diagnosis of young onset dementia and perpetuates feelings of uncertainty and frustration for the couple.

Mary spoke about doctors assuming David's memory issues were a result of anxiety and depression precipitated by the impact of his job redundancy, yet she was not convinced of this:

> ***"The first time we went to the doctor with an issue around David's memory was 2018, um, at that point he'd just been made redundant from a job that he had done for the past 25 years. So the doctors put it down to depression and then they put it down to anxiety. But I knew that that wasn't, that was maybe a small part of it, but he had been having issues with his memory before um that." (p.3)***

Mary spoke of a later visit to the doctors to express concerns about David's memory and healthcare professionals' lack of understanding due to David's age:

> ***"…then during COVID he got an appointment with the psychiatrist, who was a bit kind of like, I don't really know why I'm speaking to you, because he was sort of going into David's past and about things like that, and there's nothing really out of the ordinary, and then we went to see a psychologist I think at the hospital who did another memory test, which he again did dreadfully in, but they were a bit kind of like we don't really know like, don't know where to go or what to do with this, he's a bit young, we don't really know." (p.7)***

Similarly, Wendy recalls the misdiagnosis of depression in the lead up to the Paul's diagnosis:

> ***"And prior to that, we had been under the mental health team and he was being treated for depression. They were convinced it was clinical depression and that they just needed to boost his mood, boost his serotonin levels and all would be well." (p.2)***

Caroline speaks about the first contact with Martin’s GP following a pattern of unusual behaviour. This case illustrates the additional challenges of diagnosing frontotemporal dementia in younger people, where memory decline is not usually the first noticeable symptom. Caroline expresses a sense of guilt and betrayal for seeking help on Martin’s behalf, highlighting the complexities of their diagnostic journey:

> ***“I feel like I'm betraying him. I've never betrayed him in my life. He's got something wrong with him. He can't speak and he's making lots of mistakes and he just. There's something wrong with him. And she said it's most likely depression. And I said I have thought that because his job was getting him down, I know he was starting to hate his job and I said I did wonder if it was depression, and she said that's probably what it is.” (p.2)***

Ten years prior to her partner receiving his diagnosis of young onset dementia, Caroline recalls Martin having an MRI scan related to hearing loss. She reflects on his current MRI scan that eventually led to the diagnosis. In both instances, noticeable brain changes were misattributed by healthcare professionals to excessive alcohol consumption:

> ***“In 2007, so that was ten years before, they queried then about his alcohol consumption. And they said, this man looks like he's got the brain of a heavy drinker. I said have they got you mixed up with somebody else? Because he's never been a drinker, never all his life. So fast forward 10 years, he had his second MRI and they said his brain was different again. Uh, shrunk and there was some atrophy at the front and the temporal, query alcohol consumption again and they kept asking me. I said he doesn't drink and Martin says I’m telling you I rarely have a drink.” (p.6)***

Furthermore, Fiona reflects on her partner’s forgetfulness being attributed to work related stress:

> ***“In 2013 he went to the doctors because he was forgetting things, but at that time he passed the doctor's mental test and they put it down to stress and bit of anxiousness because he was just starting up his business. You know, looking back on it I’m not quite so sure whether stress would really have come into it because, although it was a new thing he was doing, I think if he'd failed the doctors tests I think he would have had his diagnosis possibly two years prior to what we did get it. (p.3)***

Chris tries to make sense of his partner’s forgetfulness by questioning whether it could be due to the menopause or side effects of preventative breast cancer medication. However, their GP misattributes Susan’s symptoms to anxiety and depression, leading to the prescription of antidepressants:

> ***“I thought perhaps that’s what is causing all this brain fog and things like that. So I had a chat with the GP and the GP was more convinced it was anxiety and depression that was leading to symptoms of forgetfulness and a bit of word finding difficulty and things like that, so put her on some antidepressants. I knew Susan, I’ve known her for years and I don’t know what depression looks like, but I didn’t think she was depressed because I saw her with plenty of appetite and things like that, she was just a bit forgetful and a bit confused and things like that.” (p.4)***

Barbara recalls how she linked the first signs of forgetfulness in her partner with depression, due to his recent divorce and work related issues. This sounds like it was supported by the GP who subsequently prescribed antidepressants:

> ***“He was so forgetful. Bloody hell. This is the most forgetful person I've ever met. Here we are at the beginning of our relationship and he's forgotten that we're going out tonight or something like that. Anyway, I just kept going along with it. He was a bit depressed. He'd left his wife and he had two daughters that he adored, had to change jobs couldn't keep up with work. Of course now in hindsight, we understand it's all the disease. But of course, then we didn't understand. So he started on antidepressants and that didn't help.” (p.4)***

Personal Experiential Theme 1.3 – *"The emotional impact of the diagnosis"*

This theme emerged from the emotional impact of the young onset dementia diagnosis felt by carers and their partners. Most participants described a contrasting set of emotions within the dyad, namely shock and denial felt by the partner living with dementia, compared with relief and understanding for the partner caring, as their partner's symptoms could now be explained. Furthermore, some participants spoke of the emotional sense of brutality that was felt upon receiving the diagnosis in writing:

Wendy highlights the sense of relief she felt upon receiving the diagnosis, as there was now an explanation for Paul's behaviour, mood, and his excessive alcohol consumption to cope with the changes he was experiencing. The diagnosis has significant implications for their deteriorating relationship as Wendy expresses a deep sense of commitment and support for Paul, indicating the strength of their bond. This is contrasted with Paul's experience of shock in response to the diagnosis:

> ***"I think Paul was probably more shocked than I was, but I think there was this sense of relief that actually there was something wrong with him. He wasn't just, pardon the pun, just being a dick. There was relief on my part that, you know, that the marriage wasn't going to end because of that diagnosis. The marriage was going to stay because he actually, he needed me now more than ever." (p.5)***

Furthermore Wendy describes a sense of hopelessness after receiving the diagnosis. Yet despite these feelings of loss and despair, she emphasises change and continuity in her life, which demonstrates acceptance and resilience amidst the adversity:

> ***"I just remember leaving the hospital that day thinking that's it, that's my life, it's gone, it's finished, but it's not, it's changed, but it's not over." (p.5)***

Edward describes a sense of relief and understanding upon receiving the diagnosis:

> ***"I was sort of relieved that they actually said it was that, because previously I didn't know what, I knew something wasn't right, but I didn't know what it was, so it was almost a relief." (p.4)***

Caroline illuminates the contrasting set of emotions she and her partner felt on receiving the diagnosis. Through Caroline's own research she had an idea of what the diagnosis might be and her thoughts were confirmed. This provided relief for Caroline but horror, denial and anger for her partner:

> ***“With me, it was relief, it was I was right. With Martin it was horror and total denial, um, anger, he was just, he still now says he isn’t, he’s still in denial.” (p.2)***

Heidi describes feeling shocked and concerned about the future:

> **“My husband didn’t understand what it means actually. For me it was a shock because I work in care so I was researching how long does he have to live, which was quite hard.” (p.5)**

Fiona describes a sense of relief and understanding:

> **“As soon as he had that question mark taken away, it was utter relief. Because it was right ok. Yeah we don't know what we're dealing with, but at least you've got a name. You've got something you can start investigating, you can start getting information on.” (p.3)**

Chris describes a sense of emptiness and reflects on receiving previous bad news:

> **“Just really quite empty, having had bad news in the family before, this was like another blow really. Just the thought that there was no cure and that it’s about living with it.” (p.8)**

Barbara highlights the emotional brutality of receiving the diagnosis in writing followed by disbelief:

> ***“And then we got back and the letter was there waiting for us. And I wasn't even like, anxious. Well, I was a little bit, but I knew what it's gonna say. I just knew by then. So I pretended to be really shocked. But I didn’t have to pretend to be upset. Of course I was upset, because when you see something in writing, it's much more brutal than hearing it or thinking or talking about it. I suppose even though you have it in black and white, you still can't believe it when somebody's so smart and lovely and funny and well liked.” (p.8)***

Group Experiential Theme 2 – *"Ignored and forgotten"*

This theme explores participants' experiences of feeling unheard and unsupported by healthcare professionals and others in the lead up to and following their partner's diagnosis. For all of the participants there was a shared experience of feeling left adrift with little support from healthcare professionals following the diagnosis. This is demonstrated by personal experiential theme 2.1 which focuses on the lack of post-diagnostic age appropriate support available to carers of people living with young onset dementia. Personal experiential theme 2.2 speaks of the lack of awareness and understanding of young onset dementia the participants have noticed in other people.

Edward articulates being ignored and forgotten when comparing young onset with late onset dementia services:

> ***"Something needs to be done, so that people who are in a position for early onset are supported, because services appear to be geared for the extremely elderly. Yeah we just seem to be ignored or forgotten." (p.12)***

Wendy recalled her experience of being dismissed by services following her partner's memory assessment, which further prolonged the time taken to reach the diagnosis:

> ***"We went to our GP who was absolutely fantastic and he immediately said we need to get you seen, referred really quickly to the memory clinic and had a memory assessment by a specialist nurse and she said there were some concerns and referred us to a psychologist, I believe it was under the mental health team, who basically poo poo'd us, said there was nothing wrong, it was normal memory loss for a person of his age and there was no concerns and we were discharged with no follow up, nothing." (p.3)***

Caroline emphasises how she has felt unheard by healthcare professionals in the lead up to the diagnosis and beyond:

> ***"One point, I can't stress enough, listen to partners. If someone goes to the GP and says I think there's something wrong, chances are they are not trying to gaslight that person and have them put away. They've got a genuine concern, they love their partners. Listen. That's the one thing I wish you know, if it hadn't had been for that one nurse listening to me and believing me, I wouldn't have got anywhere. I wish people would listen and the people who come to my house like to see Martin, I wish they would listen because they never have, never ever, never asked me anything. Just make sure Martin's ok make sure he's breathing and he's not bleeding and that's it". (p.4)***

Heidi describes how battling to be heard by healthcare professionals led to feelings of intense frustration:

> ***"It's just the attitude. With GP surgeries it's a constant fight that I need to talk on his behalf. There is a power of attorney being done. It's been registered with the surgery. It's just like basically hitting your head against the wall and nobody is there to listen to you. I hate that, when I need to repeat myself that he has dementia and I'm here to do the best for him. They just don't listen. It's just so frustrating, so frustrating. That's why people die." (p.14)***

Personal Experiential Theme 2.1 – *"Diagnosed and dumped"*

There was a consensus amongst the participants regarding the lack of post diagnostic age-appropriate support offered to people living with young onset dementia and their carers following the diagnosis. This lack of support often leaves carers feeling lost and abandoned by services.

Mary spoke about receiving the diagnosis via letter with no explanations to follow:

> ***"We just got a letter saying that he has this and that was it. And nobody really got like nobody said this is what that is, this is what that means, this can potentially become this. It was just in this letter, there was no chat behind it, it was just in a letter." (p.7)***

Wendy's experience is illustrated with a strong sense of frustration and disappointment:

> ***"The diagnosis is shit, and the support that you get from that diagnosis is appalling." (p.6)***

Edward emphasises Maria's negative emotional response following attendance at local day care services. This highlights her lack of connection with others due to age disparities and the absence of adequate service provisions for people living with young onset dementia:

> ***"…she said she hated it, it was horrible, they were all old people. That's the problem, they were really old people, there's no connection. This is a real problem, and they have other patients who are early onset and they're a lot younger, but there's no, there appears to be no provision for them at all. She hates being with these older people, so she doesn't want to go there again." (p.6)***

The lack of age-appropriate support in the community is echoed by Caroline:

> ***"I did try. I did go to two groups, but when I got there, it was all people who was like my mum's age." (p.15)***

Fiona talks about failures in the healthcare system, describing a felt sense of abandonment following the diagnosis. James' resourcefulness and advocacy attempted to fill the gap left by the lack of support they experienced:

> ***"We fell out of the system as well. We got the diagnosis and that was it. And 18 months later I phoned back up because I thought there were some changes with James and they said 'oh you should still be under us' and we weren't and there was lots of things that we hadn't been offered. We hadn't been visited by anyone from Alzheimer's. There was***

> ***lots of things that should have happened that hadn't happened. And because they hadn't happened and we were left just floundering around on our own. James has always been good with the computer and he started doing his own investigations into stuff and set up his own website with like important numbers and places you might want to contact for people like us, that may just get the diagnosis and then get booted out the door." (p.7)***

Chris expresses a sense of confusion and abandonment following the diagnosis, an experience that had a significant emotional impact:

> ***"…it does feel like Susan was diagnosed and dumped. So we're in a hospital consulting room one moment and the neurologist says his piece and says 'I probably won't need to see you again' and kind of the door is there. We were like, what happens now? We walked out almost thinking, well, there will be a nurse waiting outside and she'll scoop us up and say, come have a cup of tea and we'll have a chat about it or whatever and there was nothing. So we left the hospital and thought, what do we do now? And that was pretty tough, I tell you." (p.5)***

Barbara voices what post diagnostic support would be helpful going forward, expressing the need for a clear pathway. This quote emphasises how the lack of support can leave people feeling lost and overwhelmed:

> ***"I think when you first get the diagnosis, you should get a pathway because, so when we got the diagnosis, as I said, it was by letter. And then like oh right, the next appointment is in six months and I think what should happen is you should never get it by letter firstly. But there needs to be like now this is what's gonna happen. There needs to be more information up front. So you know what you're in for. Because my God, you're just walking in the dark, you know?" (p.22)***

Personal Experiential Theme 2.2 – *"The young onset dementia story is not being told"*

This theme explores the lack of awareness and understanding carers experience from other people in their lives in relation to young onset dementia, coupled with feelings of shame triggered by negative attitudes towards their partner.

Wendy expresses a sense of concern for what others may think about Paul's diagnosis:

> **"…and people's perception, you know, initially I didn't tell anybody and I still haven't told the world. I just don't see the need for shouting it from the cliff tops." (p.6)**

Furthermore, Wendy describes her experience of negative attitudes from others who are unaware of Paul's dementia. She expresses a concern that the lanyard may draw unwanted attention and negative assumptions, but ultimately, she wishes to encourage empathy and understanding from others:

> ***"…because I was managing all the bags, you know, people make really harsh comments and they were like 'why is that lazy fat bloke at the back not doing anything?', so I've now got him a sunflower lanyard and he doesn't want to wear it, I don't want him to wear it because that can cause people to stare and assume everything else. But I do think there will be some moments in the not too distant future when I might just have to tell somebody, but then I think that's gonna make them feel really bad and that's not my purpose. I just want to tell them please don't judge what you see." (p.7)***

Edward describes a sense of frustration and isolation when connecting with others who may not fully understand the emotional challenges he is facing:

> ***"I get irritated by people I've not seen for a while and, sometimes I contact people on social media, and they say things like 'oh my daughter or sister died unexpectedly and she's got two young children, or my wife had cancer'. I'm not trying to contest as to who's in the worse position, but I just feel that people don't understand. To be fair until you're actually in this position you don't understand it, you just don't know. I wouldn't quite say it's discriminatory but it was sort of, I took it as being well what are you worried about you've still got her." (p.5)***

Furthermore, Edward expresses mixed feelings about discussing dementia in public. He uses subtle disclosure to make others aware of Maria's diagnosis and preserve her dignity:

> ***"I'm not saying I'm embarrassed but I don't like talking about it either and I don't know why that is, if we were in a shop or something and she sort of says, Maria says***

> ***something sort of, when I went to the shops a few weeks back and she said "oh hello how are you?", like shop assistants do, and Maria says "do I know you?" and uh, I said she's got dementia, sort of under my breath so people know." (p.10)***

Caroline highlights the challenges and feelings of embarrassment she experiences when being with Martin in public, pointing to a lack of understanding from others:

> ***"…say we've gone to Starbucks, and he sees someone he knows who he recognises cause he doesn't always recognise people, but if he does he shouts. That's embarrassing, and then you'll get the funny looks and, so that's embarrassing, really embarrassing. You know, he'll shout "hello!" and like he'll shout too loud and too inappropriately, so I tend to not take him. Most of the time people just laugh awkwardly, and they don't know what to say, or they don't understand what's wrong." (p.17)***

This quote highlights Caroline's frustration with the lack of awareness of young onset dementia. She points to a noticeable absence of a narrative about younger people living with dementia:

> ***"Raise awareness, just anything, because it's a story that it doesn't look as if it's being told. I mean we've got older people with dementia, but not younger." (p.19)***

Fiona expresses frustration with the common assumptions and patronising responses other people often make about a person's abilities when they discover dementia or other difficulties might be present:

> ***"A lot of people suddenly think you're deaf or you have some kind of learning difficulties, so all of a sudden their speech goes really slow. And it's like it's very difficult for you to understand what they're going to ask you. You think to yourself. Just speak normally please. If I don't get what you're saying, I'll ask you to repeat it that I did find that very frustrating, but I think that's not just dementia that that can be anything. As soon as they find out there's some kind of challenge or disability, they could have amputation, but all of a sudden that means they're deaf as well doesn't it, you know?" (p.16)***

Fiona indicates further feelings of frustration with the varying levels of sympathy and understanding people may receive dependent upon their age:

> ***"It does make me very cross. I think probably a lot of people have sympathy, maybe with again if it had been an elderly person. I think people tend to have a little bit more***

> ***sympathy. If somebody doesn't look the typical old person. And I think some sympathy empathy whatever goes out the window. And people tend to get a bit more shirty about something." (p.16)***

Chris reflects on challenges and misunderstandings from others in public settings who were unaware that Susan is living with dementia. He hopes that by wearing the disability lanyard Susan's abilities will be more visible and thus promote support and understanding from others. Chris highlights the lack of expectation for disabilities in younger able-bodied people:

> ***"So we've got a disability lanyard for Susan, having had a couple of just unpleasant experiences, one in a supermarket and one at a railway station, Susan just didn't get what she needed to do, and members of staff were being quite rude and impatient with her, it obviously wasn't her fault, but they weren't to know. People just don't expect it do they. They might anticipate it with an older person, but not with somebody that's young and 56 years old and able-bodied." (p.17)***

Group Experiential Theme 3 – *"So much has changed, everything is different"*

This theme explores changes in the couple's relationship and identity following the diagnosis of young onset dementia. These changes also include changing roles within the relationship and the negative impact on family relationships. Young onset dementia has a significant impact on the couple relationship, and reflections on the relationship quality prior to dementia, highlight the emotional impact of the change in relational dynamics.

Personal Experiential Theme 3.1 – *"We used to be best friends"*

This theme highlights the perceived differences in the dyadic relationship prior to and following the progression of dementia, and the impact these changes have on carers' identities and emotions. Participants reflected upon what their relationship was like before dementia in comparison to their current relationship. This reflection often evoked feelings of sadness and tearfulness for participants as the differences were illuminated.

Mary reflects on the changing dynamics in her relationship with David due to dementia. She describes a sense of emotional disconnection and a shift in her identity from being a partner to a carer:

> ***"We used to go to a lot of things together. We used to go on holidays and different places. We used to talk about everything. And then we were at Bryan Adams and he was really enjoying it, he was loving the music, but he could have been there with anybody, it didn't matter. So that was really hard because it felt like I wasn't really there as his wife, I was there as somebody looking after him." (p.11)***

Wendy reflects on profound changes in her relationship with Paul who used to be her emotional anchor and source of support:

> ***"He used to be my rock, you know. He used to be my go to. He used to be my confidante. He used to make me strong. And it's all changed. There are still moments when I see him, I see my husband, but it's just so different, yeah so different." (p.9)***

Feelings of loneliness and isolation are illuminated by Wendy here:

> ***"..I said I feel alone. And I do feel alone because, you know, at 9 o'clock at night I'm sat down here Billy no mates. Our eldest son works away a lot and I do feel alone. When Paul said he was going to bed last night at 9 o'clock I just said, great, another night Billy no mates, and he went, and I said it's not much fun for me being left down here by myself Paul." (p.10)***

Edward reflects on his relationship with Maria prior to her developing dementia compared to what it is like now, and how his identity as a husband has changed:

> ***"Oh we had a really good time, we could sort of bounce off each other, she had a wicked sense of humour and it was just great. But now it's just so difficult and it's very hard work being with her." (p.5)***
>
> ***"We've got three boys, she doesn't remember their names, she doesn't know the names of the grandchildren. I've given up my name, I'm 'him'. I don't know if she associates me with husband or not. I mean she doesn't wear her wedding ring now, whether it's because I'm here all the time and she accepts me, I really don't know." (p.2)***
>
> ***"As I say I'm more of an entertainer now, she just wants to know what are we going to do today? So I have to keep finding things to go and do" (p.8)***

Caroline reflects on her relationship with Martin before dementia and how they used to be best friends:

> ***"Lovely, absolutely lovely, he was my best friend. I loved him to bits, and he loved me. He would buy me the most beautiful presents. Thoughtful. He couldn't do enough for me. He'd buy me red roses on Valentine's Day. I've got cards to my beautiful wife with the most soppiest verses in. He wrote me poems. We was best friends. He'd do anything for me. We had a lovely relationship. Just ordinary. Just, but I can't say, I mean, don't get me wrong, we had arguments, same as anybody but, we always made up, we was best friends. I was loyal to him, he was loyal to me, I trusted him, he trusted me, it was lovely." (p.14)***

This quote reflects Caroline's complex emotions and perceptions of Martin. She uses the analogy of a 'weird uncle' to describe their relationship, emphasising a lack of emotional connection and a perceived age difference:

> ***"…he's sort of, I can't say he's like a brother or a child. He's sort of like a weird uncle that you've sort of been plonked with, that you've gotta look after. Because I don't feel that connection that closeness to him. So that's how it is. It's like looking after a weird older relative cause he's aged as well, so I feel disconnected to him in that sense. He seems a lot older than me now, you know, he's four years older than me. You'd think he was 20 years older than me, but so yeah, it's like as I say, a weird uncle that you've been lumped with." (p.18)***

Caroline’s complex emotions and shifting perceptions are further highlighted in this quote. Despite these challenges she is committed to caring for Martin, especially when she has a glimpse of the person he used to be:

> ***“I took my wedding ring off cause I thought, it, that symbolises intimacy, and a partnership and a man and, you know, two people together, whether it be man and woman, two women, two men, whatever I can’t, and I can't look at him in that way anymore, he looks, I can say I look at him as a child or a brother, because again I treat my brother and my children different, he's just this person who I still love, but I don't like. Some days I hate him, when he's being hateful towards me or the kids. Some of the things he says there's no need, but it's his illness. But I can't turn my back on him, cause some days you still get little bits of Martin.” (p.11)***

Fiona reflects on a significant change in the dynamics of her relationship with James. Previously their relationship provided an intense togetherness and physical closeness, always holding hands. However, Fiona expresses a sense of loss as this closeness has seemingly vanished overnight. This shift is particularly noticeable to Fiona as their intimate physical connection has changed:

> ***“We used to be very, very together, very close. Whenever we went out, we would always hold hands. There would always be that closeness. That just seems to have disappeared. Kind of like overnight, if we go out we just we walk side by side. But physical just doesn't seem to be there.” (p.12)***

Fiona shares a nuanced experience related to James’ bedtime routine. She uses the term ‘sofa widow’ which suggests feelings of loneliness and separation, in the absence of shared time together in the evening. Furthermore, she describes how James is no longer the person she fell in love with:

> ***“Now he's in bed. 8:30 till 9:00 o'clock. So I feel very much like a sofa widow. In that respect, and that does affect. That has affected me. Because I don't feel we share anything in that kind of way. I do miss the evening time, not having him around.” (p.10)***
>
> ***Because he's not the James that I met. He's not the James that I fell in love with. I do still love him, but he is a different person. And it can be quite frustrating sometimes you say something and literally minutes later it's totally gone. It's like you've never said anything.” (p.11)***

Personal Experiential Theme 3.2: ***"Now I have to get the spiders"***

This theme explores the changing roles in the dyadic relationship due to their partners decline in cognitive abilities. Many participants spoke about changing roles or role reversal and how this impacts on their other roles and responsibilities. The change often reflected stereotypical gender roles for men and women. As the dementia progressed, many participants implied that the relationship with their partner evolved into more of a parent-child dynamic.

Heidi talks of the profound impact of changing roles with Craig and how this impacts on her independence. She highlights a sense of autonomy but also alludes to this being difficult. The phrase "there is nobody to ask" suggests a lack of social support networks, possible isolation, and self-reliance. Heidi also refers to putting nails in the wall which could be perceived as a task more typically associated with men:

> **"A lot has changed. Everything has changed because I do absolutely everything in the house, in the garden. I pay all the bills. Everything has changed, yes. If that nail needs to go in a wall, I'm doing that. There is nobody to ask." (p.7)**

Chris indicates a shift in Jane's ability to handle simple recipes. He suggests a practical adaptation to this change, possibly driven by a desire to maintain a sense of normality:

> ***"She was a fantastic cook, a really good baker, but simple recipes seem to become quite difficult. So I find it easier now if I just do the cooking." (p.15)***

Wendy describes a significant shift in her household responsibilities and adjustment to her new role. She tells me that she is a farmer's daughter which reveals an aspect of her identity and background that may influence her attitude towards these responsibilities:

> ***"Before he would have been very hands on. I wouldn't have had to do anything like that. I'm now doing it, which is, I don't mind doing it, I'm a farmer's daughter, but it's just new to me. You know, I work three days a week. I would previously be able to leave instructions for a meal to be cooked. I can't do that now. I have to have everything done, so that when I walk in the door, I do it." (p.6)***

Wendy has taken on further responsibilities to keep Paul in work as he is no longer able to do these things. This suggests a strong commitment to support him and maintain normality in life, possibly driven by a sense of care and responsibility:

> ***“With regard to work, I write in his diary to let him know his shift pattern. I organise his holidays, I do his end of month mileage returns, all the things that he used to be able to do. And I’m doing it all because I want to keep him in work.” (p.7)***

Wendy describes a noticeable shift in roles when going on holiday that is “completely different”, indicating a marked change in the dynamics of their relationship:

> ***“…another thing that’s complete role reversal now, if we go to an airport, I’m the one that’s in charge, I’m the one that sorts everything out and that’s completely different.” (p.7)***

Caroline reflects on the role reversal between her partner and son. The change in household dynamics prompts a negative emotional response from Martin as he feels that he is no longer the man of the house:

> ***“Andrew is now the man of the house, and Martin don’t like that, because Andrew has to get the spiders, put the shelf up, whereas Martin used to.” (p.15)***

Fiona indicates that changing roles adds to her responsibilities. Expression of her inner thoughts suggests a heightened awareness and sense of responsibility for these extra tasks:

> ***“There are things that James used to do that I now do, nothing major but it be all these extra little things. I think no, no, I don’t want to forget something.” (p.14)***

Personal Experiential Theme 3.3 – "*Negative impact on family relationships"*

This theme explores the negative impact of dementia on relationships between the partner living with dementia and their children, and the impact this has on family dynamics.

Mary reflects on a transformative shift in her family dynamics. Initially, the inability to leave the house due to conflicts between David and their children created a stressful situation. Her reflection on fights, arguments and distressing phone calls conveys a sense of helplessness and an urgency to return home. Use of the words 'chaos' and 'disaster' suggests an intensely emotional situation. However, Mary then contrasts this with how things are in the present, indicating a positive shift in family dynamics due to the establishment of routine and individual responsibilities:

> ***"I wasn't able to go out at all and leave the kids and David in the house because they would just fight and argue and you'd come home and it would be chaos or I would get a crying phone call from my oldest, going you need to come home Dad's fighting with Rachel, and it's all disaster. Whereas now we're in a bit more of a routine and everybody has their own responsibilities." (p.10)***

Mary highlights a significant shift in David's involvement in family life. She speaks of a noticeable change where David has become disinterested in engaging with the children, and a reluctance to join in with anything he doesn't personally enjoy. Mary goes to on talk about the negative impact this change has had on the children, who were used to having an actively involved and fun relationship with their father. Mary conveys a sense of disappointment for both her and the children, she tries to compensate for David's altered fathering by spending more time with them:

> ***"…sometimes you do a story because David's not interested in having anything to do with the children in any way shape or form really. He will not do anything he does not want to do. He does not see why he should take our children to a park because he does not want to go. He does not see why he should queue for an ice cream because the kids want an ice cream, because he's not bothered with it. He won't read a bedtime story because he says 'what am I wanting to read that story for?' So I suppose that's the biggest change for the kids, that has been really difficult for them. They have a dad that used to be really involved and play games and take them places and do things with them, and now they quite often say 'oh you'll only do something with us if it's***

> ***something you want'. So that's probably the biggest change for us, so I do try and spend more time with the girls." (p.10)***

Wendy talks about how Paul's behaviour negatively impacted on family relationships in the lead up to the diagnosis. Use of the word 'ostracising' implies a deliberate attempt by Paul to alienate the children. Wendy describes a strong emotional response to this from her eldest son and links to decisions made by Paul under the influence of alcohol, which might have intensified the impact on their relationship:

> ***"He was ostracising the children and making it really, really difficult to have any sort of relationship. In fact, I would say my eldest didn't want anything to do with dad. He was mortified by the decisions dad was making, particularly when it came out around the drink." (p.4)***

Furthermore, Wendy speaks of her middle son's feelings of anxiety and how it usually remains in the background. Wendy's use of metaphor indicates that anxiety is present but not at the forefront of her sons experience. However, Paul's diagnosis has brought attention to their son's experience of anxiety, indicating a significant emotional impact:

> ***"…he has grown up into a fantastic young man, and most of the time his anxiety sits on the back burner. But Paul's diagnosis sort of highlighted all that." (p.10)***

Heidi talks about Craig's change of behaviour and the emotional impact on her youngest son who did not understand. The decision to seek counselling implies a recognition of the emotional distress her son experienced:

> ***"My sons didn't understand. My youngest son, he's still in secondary school. He was receiving counselling because of that, because Craig was very up and shouting and verbally aggressive. He'd never ever been like that before." (p.9)***

Barbara reflects on her stepdaughter's reaction upon being told about the diagnosis. She describes a distressing situation where her stepdaughter has an intense emotional response to the disclosure of her father's diagnosis of familial Alzheimer's disease, which poses a high genetic risk factor. The daughter's reaction is characterised by disbelief, anger, a sense of betrayal and profound loss regarding her ability to have children. This led to a devastating rupture in the father-daughter relationship:

> ***"The other daughter screamed and shouted at him. Like ohh God, dad. I can't believe you've done that to me. Now I can never have children. I can't believe you've given me this awful disease. And she went on and on like she doesn't even have it like she might***

not have it and she hung up on him and that was devastating. The relationship has never recovered." (p.10)

Group Experiential Theme 4 – *"Where do I go from here?"*

This theme makes sense of carers' coping strategies and adaptations to loss. Personal experiential theme 4.1 explores the diverse coping strategies that carers have employed to navigate the emotional and practical challenges of caring. Personal experiential theme 4.2 then illustrates the multiple losses that carers often experience under the metaphorical representation of dementia being a robber and a cheat.

Personal Experiential Theme 4.1 – "*Diverse practical and emotional ways of coping"*

Partners spoke of diverse ways of coping with changes in their partner and caring for them. Practical ways of coping such as the use of organisers and assistive technology, and also cognitive and emotion focused ways of coping with distressing emotions such as avoidant thinking and externalising. Many participants spoke of reaching a point of acceptance enabling them to cope better and providing the strength to carry on. Participants also spoke of what they felt would help them cope better going forward. The need to connect with others in a similar situation plays an important role here. Some participants are also accessing support from local groups and counselling services.

Mary speaks of a heavy reliance on technology to support David in his daily routine due to her full-time working. This practical way of coping highlights the challenges that Mary faces in caring for David independently:

> ***"…our Alexa is the most hard worked Alexa in the world. Because I have to set timers for or reminders for him to do things or go places, um, because I'm working full-time so I need to rely on Alexa, to tell him what he needs to do, at certain points. (p.9)***

Mary acknowledges the positive impact of counselling and an appreciation for the therapeutic process:

> ***"I think having the counselling helps 'cause it means you are talking about it and things and I think that's, I think that's a good thing. That's why I sort of offered to do this because I think it's helpful. I'll always, um, have a chat with somebody about things and it triggers something else off in my head that I hadn't really thought of, before, so I think it's quite good to do." (p.15)***

Mary reveals a reluctance to talk about her future relationship with James. There is a sense of avoidance as she describes how her thoughts are 'stuck in a box' at the back of her head, suggesting emotional discomfort should they be at the forefront of her mind.

Mary’s laughter may serve as a way of coping and lifting the emotional distress attached to thoughts about the future:

> ***“I kinda don't think about that. I don't know (laugh) probably just more of his carer, um, but I’ve probably not got around to thinking about that yet. It's firmly stuck in a box at the back of my head, and one day I will need to deal with it, but it will not be today (laughs).” (p.15)***

Wendy makes a conscious effort to avoid thinking about her multiple responsibilities due to the impact it has on her wellbeing:

> ***“…so I try not to think about all my responsibilities, because it just puffs my head, but it’s impacting big time.” (p.8)***

Edward takes an externalising approach to enable him to cope. By attributing the emotional challenges associated with his caring role to ‘the disease’ rather than to Maria:

> ***“…it’s just very trying, but it’s not how she normally is or how she is, but it’s just the disease, I just keep telling myself it’s the disease, the disease, it’s the only way I can get by.” (p.5)***

Edward talks about how he has coped with changes in their relationship. There is a narrative of acceptance, pragmatism and resilience as he navigates the emotional impact of caring. The tension between acknowledging the difficulty and actively working towards acceptance provides insight into the intricate nature of his lived experience:

> ***“just the acceptance that um she’s a different person, um, not pleasant, not pleasant at all, um, yeah (sigh).” (p.8)***
>
> ***I just have to get on with it, um, which isn’t the right answer I know, but um, yeah it’s just something it’s just looking at it again, um, in all it’s darkness and um understanding and accepting that this is what it is. We are where we are, and there’s nothing I can do about it, um. I just try and think about the good times we had, how it used to be.” (p.11)***
>
> ***“And normally I can put it off and uh park it somewhere, but talking about it is quite stark.” (p.11)***

This quote highlights Caroline’s narrative of shock, disbelief and a sense of unpreparedness. Her reference to coping with a physical illness provides a contrast, and a perception that caring for a person with a physical illness would be easier than caring for a person with young onset dementia. This illuminates the emotional impact of her caring role:

> ***"I never thought I would get into my 50s and be doing this. I never, never dreamt, you know that it would happened to us. Because I've never heard of someone so young getting dementia. A physical accident disability illness I can cope with that, but not, not this." (p.5)***

Caroline talks about feeling stronger and better able to cope after having time apart from Martin, when he was admitted to older adult mental health services for a number of months. She describes how grieving for Martin enabled her to develop inner strength and acceptance:

> ***"I think I'd realised that him not being there wasn't the end of the world and that I could cope without him being there cause I think I was clinging on, to him. Having to get the spiders, put the shelves up and things like that, and I think I just developed strength. I think I just grieved. That when I, Dr Google again (laughs) and I thought I've gone through the grieving process. Um, I just sort of. I don't know. I just I felt better, not better, stronger." (p.13)***
>
> ***"Like an end. Acceptance. And you get like an inner peace, and you think oh it's gone. I've just got to deal with it and move on. It's the moving on now that I'm finding difficult because it's like where do I go from here?" (p.13)***

Caroline speaks of the change in her way of coping from unhelpful to helpful:

> ***"When he was first diagnosed, I started drinking a lot, um, a bottle of wine a night, sometimes more. Every night, every night it was like I had to have it and that was my way of just relaxing. But coping now, I've stopped drinking now. I don't drink at all and it's been over a year and Martin's never been a drinker. The way I cope now, count to ten, walk out the room, just ignore him, tell him to go to bed, cook. Just find something to enjoy that I can enjoy, in the house. My son Andrew he's a God send cause he can drive, if he knows I've had a bad day or he'll say shall we go for spin? And he'll just drive me round somewhere for an hour and he lets me moan." (p.15)***

Heidi speaks about normalising her emotions, describing a sense of acceptance and being present:

> ***"I am sometimes quite tearful and it's normal because it's just tough. It's tough to go through this. So that's why I'm not planning for the future. What will be will be. We take it week by week." (p.19)***

Fiona contemplates her and James' relationship going forward with a positive mindset:

> ***"Going forward it will just be looking at the things we can do and not looking at the things we cannot do. If you're negative it's just going to drag you down into that whirlpool and you'll end up not doing anything at all." (p.17)***

Chris avoids thinking about the future as it brings up difficult emotions:

> ***"I do sometimes have to now go outside and take a deep breath and have a bit of a reset, it can be quite stressful. But yes, the future is not easy to think about. I don't think about it too much, I just think about tomorrow or next week or something like that. " (p.14)***

Chris describes how his work helps him cope as this provides some distance from his thoughts and emotions:

> ***"I can immerse myself in my job to the point where I just forget absolutely everything else. I can absolutely lose myself in my job and it feels like I'm having a complete break from what's going on at home." (p.16)***

Barbara speaks of distancing herself from and avoiding her emotions to cope. She supresses her emotions in the presence of her partner to avoid any emotional upset:

> ***"I suppose I always work on the practical side, probably trying to escape from my emotions or keep them sort of sectioned off a little bit somewhere, but I don't have that luxury of being emotional or crying or screaming or because he's there. And he won't understand it. It'll just upset him. But my main aim, keep him happy at all costs because the the fallout otherwise is not worth it. Yeah, and negative emotions stay in their mind longer than positive emotions. So I avoid any negative emotion. You know as much as I can." (p.21)***

Barbara's reflections offer a unique perspective on resilience and gratitude. Her acknowledgement of the love she shared with Phillip and the positive aspects of the relationship, illustrates a nuanced coping mechanism. This contrasts with the expressed loneliness and emotional needs of other participants, emphasising their individual differences in ways of coping:

> ***I feel lucky that I've got my children and my grandchildren, all my friends, that I will still have a life after this. I just have to keep on reminding myself that, that I've had a love that most people don't even know exists (tearful) But I'm so glad I've had it, that even though I'm sounding upset. I'm actually really happy because. I'd rather be this upset and have had the relationship rather than not have it at all. So all in all, I actually feel lucky that I've had this relationship." (p.21)***

Personal Experiential Theme 4.2 – *“Dementia is a robber and a cheat”*

This theme explores participants’ experiences of loss. Loss of autonomy; sex life and intimacy; future plans; coupled with altered perceptions and ultimately loss of the relationship they once shared. Reflections on loss reveal a narrative rich in emotional complexity, shifting dynamics, and the profound impact of dementia on various facets of their relationship. For most participants, the relationship is continuously evolving, and the changes are often leading to a complex experience of loss.

The participant narratives provide a deep insight into the emotional distress they navigate, balancing love for their partners with the evolving impact of young onset dementia on their relationship. Nuanced layers of the carers experience unfold as the participants reflect on their experiences. The intertwining of physical health issues with the cognitive decline of young onset dementia adds a layer of complexity to Fiona’s sense of solitude. The evolving dynamics in intimate relationship, point to profound emotional adjustments and difficulties in reconciling past expectations with the present reality. Barbara’s poignant reflections extend beyond the realm of intimacy, expanding into the broader landscape of her life. The loss of shared dreams and the recognition of the limitations her caring role places upon her, yet amidst these difficulties her sense of resilience shines through. The acknowledgment of a unique and profound love offers a glimpse into the complexity of emotions, where both grief and gratitude coexist. Additionally, Barbara’s contemplation of the future, marked by uncertainty and change, reveals the deeply emotional impact of caring for her partner. The struggle to articulate the impending loss, and the challenge of envisioning a life without her partner become central to her narrative.

Loss of autonomy and social isolation is highlighted in the following quote from Edward which reflects a palpable sense of isolation and his loss of freedom. His description of feeling trapped points to the emotional impact of caring and the personal limitations this places upon him. There was a sense of Edward feeling like a prisoner to his home and caring role as he and Maria rarely go out:

> ***“I sort of don’t get out anywhere now, we just stay in. Ah it’s just horrendous actually. I mean at times I feel sort of trapped because I can’t do anything.” (p.2)***

Further quotes from Wendy, Heidi and Barbara echo these sentiments, illustrating the significant lifestyle changes and social isolation experienced by carers:

> ***“I don’t go out of an evening, I don’t go to the gym. So it all impacts on me, because I used to love all that, you know. I needed it to make me feel better about myself and yeah, it’s gone. That’s not to say that it won’t come back at some point, but for now, it’s gone.” (Wendy, p.8)***

> ***“I lost all my friends because they just don’t understand. I can’t just go and have a day out somewhere normal.” (Heidi, p.6)***

> ***“…he can't even chew. Like what are we gonna do? So what that does is then you don't go out. And you don't want to have friends over when you're eating because as I said, at some level, he's aware that he's not functioning properly, but also it's very off putting to eat when somebody in front of you is not eating properly. So now I think going forward it's very life limiting for me.” (Barbara, p.15)***

The narratives around sexual intimacy and the reflections on a ceased sex life unveil the complex challenges faced by carers in maintaining intimate connections with their partners:

> ***“He is not kissing me no more. We haven’t had sex I think for six years.” (Heidi, p.7)***

> ***“We don’t have sex anymore. I can’t. Um, before his diagnosis, when we was still sexually active it was getting a problem for him. And he couldn't, um, he couldn't maintain an erection. Then he couldn't finish, um, I thought is it me? And then that was at the same time I was thinking no there's definitely something wrong with him. And then it just, it just died the death and I thought no, and then I can't look at him the same way since he’s had his diagnosis. I can’t look at him as a sexual being as a partner in that sense.“ (Caroline, p.11)***

> ***“There's no sexual relationship at all. And I think partly that started with the spinal issues. Again that seems to have interrupted a lot of stuff, but I think the dementia diagnosis has just kind of finished that off if you know what I mean. So I do feel I do feel very alone sometimes and sometimes all I want is a hug. And it's not forthcoming. Even sat on the sofa sometimes I could just try to hold his hand. But his hand doesn't respond back. So it's not holding my hand. It would be there and then gradually the hand will move away.” (Fiona, p.12)***

Barbara speaks of the gradual decline of intimacy in her relationship with Phillip. This quote captures the evolving challenges in their sexual life, marked by physical difficulties and eventually, a complete cessation of their sexual relationship. The mention of Phillips confusion and inability to continue during intimate moments highlights the emotional strain the impact of dementia has on a fundamental aspect of their connection:

> ***"…that's about when our sex life stopped around about the first Covid year, so 2020 'cause we were you know still carrying on but it kind of got like. I don't. It's hard to explain it. He didn't know what he was doing. Or he'd stop halfway. And then and not keep going. And I was like okay, this isn't working. It's just making him confused. And so I kind of put a distance between us and then it stopped. So that was the end of that as well." (p.19)***

Barbara further articulates the loss of their shared future plans:

> ***"We had so many things that we could have done, we were gonna do volunteer work. We were going to do all these amazing things for people and for ourselves and travelling and you know. Yeah. Because it's too hard. (p.21)***

Barbara reflects on the broader systemic consequences of young onset Alzheimer's disease, recognising the extensive losses experienced by individuals and their families:

> ***"…so many, including me, haven't had any normal relationship with them. So I can see that, you know, young onset Alzheimer's is completely ruinous. Completely because unlike older people, when you get it when you're younger, you lose your house, you lose your marriage, you lose your job, your children, your whole life plummets and those people that were in your family also suffer. So Phillip's children didn't really have a father. His wife had no chance with him, you know. It's really terrible. Yeah, it's terrible." (p.14)***

When talking about Phillip's decline, Barbara contemplates her future loss and change of identity which highlights the profound impact on her sense of self and the emotional upheaval associated with anticipated loss. As such, Barbara struggles to articulate the depth of these feelings. The contemplation of her own identity and life without Phillip adds a layer of existential questioning, emphasising the transformative impact of caring:

> ***"There's no word to describe it because. It's so emotional. Even just trying to think about it. See, now I'm getting upset trying to, thinking of trying to think of a word to describe it is upsetting. Because it's like it's gonna be the end of my life as I know it. And then what do I mean when Phillip is no longer with me? I know I can exist by myself like I was a bloody feminist back in the 70s, you know. But it's you've found the perfect person." (p.20)***

The loss of future plans and accompanied feelings of anger is echoed in Fiona’s narrative

> ***“When we met and we got married. I really thought you know this is going to be a lovely long relationship left, we would you know, be able to spend our time together when we were retired doing this that and the other, you know we had some plans. And selfishly, I do get angry sometimes. I think, you know, the dementia has had him more than what I've had him. (p.11)***

Chapter 5: Discussion

Research Aims

Findings from previous studies suggest that further research is required to examine coping strategies, stigma, and the subjective experience of the person caring for their partner living with young onset dementia, and to understand how younger carers cope with changes in their relationship (Lockeridge and Simpson, 2013). This study therefore aims to expand on previous findings by exploring how individuals make sense of their experience of caring for a partner with young onset dementia. It is hoped that the exploration of their experiences will help to further understand the thoughts and needs of this client group, raise awareness of young onset dementia through dissemination of these findings, inform therapeutic practice, feed into service development and challenge stigmatised attitudes towards dementia and this marginalised group. Understanding the unique perspectives of individual care partners is needed to tailor support that will meet the needs of younger people in a way that is distinctive to older people living with dementia and their care partners.

Summary of findings

Four overarching Group Experiential Themes (GETs) each comprising two to three Personal Experiential Themes (PETs) were generated:

(i) ***"The long road to diagnosis",*** which illustrates how the diagnostic journey was experienced and has three personal experiential themes ('*living with frustration and anger*', '*you're too young so it must be something else*' and '*the emotional impact of the diagnosis*').

(ii) ***"Ignored and forgotten"*** which highlights the shared experience of the lack of post-diagnostic support and the lack of awareness and understanding from others, and has two personal experiential themes ('*diagnosed and dumped*' and *'the young onset dementia story is not being told').*

(iii) ***"So much has changed, everything is different"*** which explores changes in the couple relationship and the negative impact of dementia on familial relationships, and has three personal experiential themes ('*we used to be best*

friends', 'now I have to get the spiders' and 'negative impact on relationships with children').

(iv) ***"Where do I go from here?"*** which explores ways of coping and adaptations to loss and has two personal experiential themes ('*diverse practical and emotional ways of coping'* and '*dementia is a robber and a cheat'.*

While the group experiential themes that emerged highlight the participants' multifaceted experiences of caring, they cannot be understood as separate static entities, but as intertwined experiences that develop an overall narrative of the complexity of caring for a partner with young onset dementia. Participants and their relationships were impacted in both similar and different ways by young onset dementia. There was notable convergence and divergence in the participants' narratives, which is demonstrated in the findings.

Diagnostic process challenges

The first group experiential theme in this study explores the nuanced experiences of carers navigating the diagnostic journey of young onset dementia with their partners, highlighting the complex emotional and psychological terrain they navigate in search for understanding. The findings in this theme extend the current literature on diagnostic experiences in young onset dementia by exploring how caring partners experienced the pre-diagnostic period and the diagnostic process.

These findings align with existing qualitative research highlighting the significance of the role healthcare professionals play in both the diagnostic and post-diagnostic journey, particularly in terms of supporting patients with young onset dementia and their family carers (Lai et al, 2023)**.** Diagnostic process challenges in young onset dementia lead to significantly and unnecessarily long journeys towards the diagnosis that are fuelled on an emotional tidal wave. The GP was the first healthcare professional that participants and their partners made contact with to seek an explanation for changes in mood, behaviour and memory. This highlights the importance of the GP's role in recognising young onset dementia. In a case-control study that investigated how people with young onset dementia present at the GP up to five years before diagnosis, Hendriks et al., (2022) found that people with young onset dementia present with different symptoms than people without young onset dementia. However, GPs may still face diagnostic difficulties since the same symptoms may also occur in people with other conditions.

Misdiagnosis of other issues such as stress, anxiety and depression due to the younger age of individuals is a key factor in prolonging this quest, and inflating feelings of uncertainty for carers as they try to make sense of their partner's symptoms. Within the participants' narratives, uncomfortable emotions such as anger and frustration are a dominant presence as the journey slowly ebbs towards the diagnosis – the emotional impact of which is felt differently within the dyad. Hospital waiting times and disruption of services due to the coronavirus pandemic also added time to the already lengthy diagnostic journey.

The personal experiential theme *"living with frustration and anger"* encapsulates the initial emotional distress experienced by carers as they attempt to make sense of cognitive and behavioural changes in their partners. This frustration often stems from the difficulties in obtaining an accurate diagnosis promptly due to diagnostic process challenges in young onset dementia. In a review article for primary healthcare professionals, Lam et al., (2019) highlight the diagnostic challenges in young onset dementia, emphasising the need for increased awareness among healthcare professionals to recognise early symptoms. The delay in diagnosis can intensify carers' emotional distress, as echoed in the participants' narratives. If dementia is undiagnosed, it is hidden away in the shadows, unheard and unsupported. Receiving a timely diagnosis and access to age appropriate support is crucial for people living with young onset dementia and their carers to learn how they can live well with the condition. Two participants caring for partners with frontotemporal dementia and one participant caring for her partner in the advanced stages of familial young onset Alzheimer's disease described a more emotionally challenging experience of anger and aggression being directed towards them, compared with other participants. This highlights the impact that different types of dementia and different stages of dementia may have on the person caring. Frontotemporal dementia is characterised primarily by impaired judgment, erratic behaviour, loss of executive function, mood swings, and changes in personality stemming from atrophic changes in the frontal lobe of the brain (UCSF, 2012). Thus, carers of partners with frontotemporal dementia may face different emotional experiences compared to carers of partners with Alzheimer's disease. Previous findings consistently demonstrate higher levels of carer distress and depression in carers of people living with frontotemporal dementia when compared with carers of people living with Alzheimer's disease (Mioshi et al., 2009; Wong et al., 2012). Carers of partners with frontotemporal dementia experience a loss of emotional attachment to their partner because of their partner's behavioural symptoms. This loss gives rise to feelings of isolation and anger as carers assume new roles and reimagine their future (Massimo et al., 2013).

The second personal experiential theme *“you’re too young so it must be something else”* highlights the prevailing misconception that dementia only affects older people. A study by Quinn et al., (2008) emphasises the need for healthcare providers to overcome age biases and consider young onset dementia as a potential diagnosis in younger people presenting with cognitive decline. The present findings align with this study, illustrating the frustration carers experience when concerns regarding their partners are dismissed due to age related assumptions, delaying the critical diagnostic process. Younger people under the age of 65 years who present to services with memory issues create a diagnostic conundrum for healthcare professionals who are uncertain whether the presenting issues may be linked to young onset dementia or mental health. Under-recognition of and awareness about dementia in younger people, together with misattribution of symptoms are both major contributing factors to the much longer delays in receiving a diagnosis for a younger adult compared to older adults (O’Malley et al., 2019).

In the current study, misattribution of symptoms to alcohol abuse, work related stress, and the menopause was heard in the narratives of participants. Furthermore, misdiagnosis of anxiety and depression was a shared experience for the majority of participants. Age related assumptions play a part here as healthcare professionals may not be considering the possibility of dementia when the person is younger than 65 years. Although depression may be experienced by individuals in the early stages of young onset dementia, it is frequently represented in the literature as a misdiagnosis (O’Malley et al., 2021). Misdiagnosis may be more common in frontotemporal dementia due to the further complexities this type of dementia presents with.

The third personal experiential theme, “*the emotional impact of the diagnosis*” explores a complex interplay of emotions within the dyadic relationship which profoundly influences their lived experiences. The findings reveal a significant duality in emotional responses within the dyad. Participants spoke of their partners’ experience of emotions such as shock and denial in response to the diagnosis. These emotions are congruent with previous research on the emotional impact of a dementia diagnosis (Aminzadeh et al., 2007). Receiving a life altering diagnosis of young onset dementia in the prime of life can be psychologically overwhelming, contributing to responses such as shock, disbelief, and fear (Johannessen and Moller, 2013). Conversely, participants experienced feelings of relief, understanding and reassurance as there was now an explanation for their partner's cognitive decline and/or behaviour and personality changes. The relief experienced by caring partners may stem from gaining clarity on the source of the changes in their partners cognition and the opportunity to provide necessary support. Understanding the diagnosis may empower carer's to engage in adaptive coping strategies such as cultivating acceptance and promoting normalcy, fostering a sense of control amidst the uncertainty (Bannon et al., 2022). One participant in the current study voiced that receiving the diagnosis had saved the deteriorating relationship with her partner, as there was now an explanation for his behaviour. This is echoed in the findings of a study exploring couple's lived diagnostic journeys to young onset dementia where a confirmed diagnosis helped to put couples on the same page, so they could move forward together (Grunberg et al., 2022). The contrasting set of emotions experienced within the dyad aligns with research that explores the diagnostic journey in young onset dementia from perspectives of both the person living with dementia and their partner (Lai et al., 2023).

Another salient aspect of the emotional impact is the brutality associated with receiving the diagnosis in writing. The literature on the delivery of dementia diagnoses suggests that the manner in which the diagnosis is communicated and the language used significantly influences emotional reactions. A scoping review of the lived experiences of receiving a diagnosis of young onset dementia found that the impact of diagnosis is influenced by the language used by the clinician, and younger people diagnosed with dementia and their families' reactions to the diagnosis vary from feelings of reassurance (in that their symptoms have now been explained), to shock and destabilisation (O'Malley et al., 2021). Some participants described the written format as "brutal", potentially intensifying the emotional distress experienced during an already challenging time. This aligns with a qualitative study by Beattie et al., (2004) revealing that the delivery of a young onset dementia diagnosis by clinicians has the potential to cause emotional distress, emphasising the importance of the use of language and sensitive communication in the diagnostic process.

Receiving a diagnosis of young onset dementia by letter is highly inappropriate and fails to meet the professional standards set by organisations such as the Memory Services National Accreditation Programme (MSNAP). MSNAP (2022) emphasises the importance of delivering a diagnosis of dementia through face-to-face consultations, ensuring that individuals receive the necessary emotional support and immediate access to follow-up care and information. Delivering such life-altering news in a letter disregards the need for compassionate communication and fails to provide a platform for service users and their families to ask questions and understand the implications of the diagnosis. This approach is particularly concerning for younger individuals who may be less prepared for a diagnosis of dementia and require more comprehensive support. Adhering to professional standards ensures that the diagnostic process is handled with the sensitivity and compassion it deserves, fostering a more supportive and understanding environment for people affected by dementia.

Lack of post-diagnostic support

Group experiential theme two "*Ignored and forgotten*" highlights the profound challenges faced by carers following their partners diagnosis of young onset dementia. This theme encompasses two poignant personal experiential themes, "diagnosed and dumped" and "the young onset dementia story is not being told", shedding light on the inadequacies in post-diagnostic support and the broader societal understanding of young onset dementia.

The *"diagnosed and dumped"* theme encapsulates the stark reality of carers who describe feeling abandoned by healthcare professionals after the diagnosis. This finding resonates with previous research highlighting the insufficient post-diagnostic support for individuals with young onset dementia and their families (Stamou et al., 2018). Furthermore, people with young onset dementia and their families report that formal community care services (such as day care, education and support groups) do not meet their personal and psychological needs (Cations et al., 2017). These findings emphasise the importance of comprehensive and ongoing support services for carers, suggesting that the current healthcare landscape often falls short in addressing the multifaceted needs of those caring for individuals with young onset dementia. Literature agrees that post-diagnostic services for people living with young onset dementia need to be age-appropriate, but there is insufficient evidence of 'what works' to inform service design and delivery (Mayrhofer et al., 2018). Using a qualitative approach based on appreciative inquiry, 'The Angela Project' gathered detailed information about post-diagnostic services experienced as helpful by those with young onset dementia and family carers. They concluded that needs for flexibility and a collaborative stance may be particularly important for those under 65 years with dementia, who have full lives and are used to being in control; to be age-appropriate, helpful services need to provide activities and opportunities suitable for active middle-aged people; and to be holistic, services need to provide for needs associated with rare dementias and be family-centred (Stamou et al., 2022).

Furthermore, *“the young onset dementia story is not being told”* theme represents wider societal misunderstandings and lack of awareness surrounding young onset dementia. Findings from a qualitative study of family carers’ and professionals’ stigmatic experiences in young onset dementia (Werner et al., 2020) highlight the lack and/or inadequacy of the services available to persons with young onset dementia and to their formal and informal carers (i.e. structural stigma), reflecting the lack of preparedness at the societal level to support this population, and the need to develop a comprehensive and integrated approach at the individual, professional and societal levels. However, although some participants in the current studied experienced negative attitudes towards their partner living with young onset dementia, this tended to occur when other people were not aware of the condition. This poses the question of whether their attitudes might have been different given the knowledge of the diagnosis and understanding of the difficulties they might be facing. The combined impact of these themes emphasises the urgent need for a holistic approach to support carers of individuals with young onset dementia.

The evolving nature of relationships and identities

The third group experiential theme “*so much has changed, everything is different*” captures the profound shifts in the dynamics of the couple relationship and personal identity following the diagnosis of young onset dementia. The exploration of this theme led to three poignant personal experiential themes reflecting participants experiences; *“we used to be best friends”, “now I have to get the spiders”,* and *“negative impact on relationships with children”.* Each theme reflects the unique challenges faced by caring partners in navigating the complexities of caring for a partner with young onset dementia, and highlights the evolving nature of their relationships and identities.

The theme *“we used to be best friends”* speaks to the emotional dissonance experienced in the relationship as caring for their partner disrupts the unique foundation of relational connection they once shared together. This resonates with existing research highlighting the emotional impact on partner relationships when facing young onset dementia (Holdsworth and McCabe, 2018). The emotional disconnection in the relationship was powerfully articulated by Caroline whose perception of her partner has changed to “a weird uncle that you’ve sort of been plonked with”. Other participants spoke about how a fleeting glimpse of the person their partner used to be serves as a reminder of the loving connection they once shared.

This shift in emotional connection and difficulties in partner relationships highlights the need for therapeutic interventions that address the evolving dynamics of couple relationships as young onset dementia progresses. In a review of the literature on couple’s therapy in dementia, Bielsten and Helstrom (2019) thought that joint interventions for people with dementia and their care partners were lacking a genuine dyadic approach where both partners’ views of their relationship are valued. One approach to couple’s therapy that places more focus on the couple relationship is the Living Together with Dementia project led by Andrew Balfour at the Tavistock Centre for Couple Relationships (Balfour, 2014). Living Together with Dementia (or LTwD) draws upon video-based methods that have been used with parents and children, as well as in psychoanalytic couple psychotherapy, to develop an intervention to assist emotional contact, communication and understanding in couples living with dementia (Balfour, 2014). This approach highlights the importance of holding a relational perspective to inform the development of therapeutic interventions for couple relationships in dementia. A qualitative study exploring the experiences of couples living with dementia who had engaged with LTwD highlighted that couples living with dementia are curious about the self and their couple relationship. LTwD encourages this curiosity which in turn helps to strengthen the relationship (Winter, 2020), providing further support for the need for a relational approach to dementia care. In other approaches to couples therapy, Auclair et al., (2009) found that six sessions of couples counselling involving transactional analysis and Gestalt approaches offered in the early stages of Alzheimer’s disease was sufficient to shift the couples into a mode in which they could face the future together more optimistically and collaboratively. Working with the relationship between couples in therapy, can have a power and reach beyond what is often possible in individual therapy – it can enhance the process by which people come to terms with their dementia (Cheston, 2022).

The theme *"now I have to get the spiders"* explores role reversal and illustrates the impact of caring on carers identity and relationship dynamics. Participants spoke about how they have adapted their daily responsibilities in the context of role reversal. Many spoke about assuming full responsibility for all activities of daily living such as maintaining the home, parenting children and managing personal finances. One participant described how her son had now assumed the position of 'man of the house' as her partner could no longer fulfil roles that she typically associated with this title such as general DIY work. The extra responsibilities placed on the caring partner may lead to feelings of stress and anxiety as they juggle multiple tasks. The shift in roles experienced by participants is consistent with previous findings on the experience of carers transitions in selfhood and identity from the time of diagnosis in young onset dementia (Harris and Keady, 2009).

The theme *"negative impact on family relationships"* explores the impact of young onset dementia on family dynamics. Mary described how her partner has become less involved and interested in family life following the progression of young onset dementia, and as such, she spends more quality time with her two young children to compensate for absent fathering. The diminished involvement of the person living with young onset dementia in family life aligns with previous research highlighting the transformative effects of dementia on family dynamics (Svanberg et al., 2011). Furthermore, these findings are echoed in a qualitative study of the impact of young onset dementia on the partner's parenting where Gelman and Rhames (2020) found that mothers increasingly assume all parental responsibility to minimise the impact of young onset dementia on their children. The negative impact on family dynamics experienced by participants is echoed in the existing literature, which suggests that the difficulties faced by families due to young onset dementia are often amplified by delayed diagnoses and insufficient support services (Carter et al., 2018). More recently, Chirico et al., (2022) found that family relationships in young onset dementia were significantly challenged since the diagnostic period, during which delays in diagnosis increased family conflicts with symptoms being blamed on the patient rather than on dementia. The findings align with the call by the British Psychological Society (BPS UK, 2021) for tailored interventions addressing the complex needs of families affected by young onset dementia.

Caring for a person with young onset dementia affects everyone in the family unit. A review of the literature exploring the experiences of family carers of people with young onset dementia support increasing evidence that despite the stress of caring for a person with young onset dementia, family members have the capacity to cope, adapt, and grow through their experiences (Cabote et al., 2015). Difficulties faced by families living with young onset dementia highlight the need for family therapy interventions. In a review of the effectiveness of counselling and psychotherapeutic interventions for people with dementia and their families, Shoesmith et al (2022) found that a range of psychotherapeutic interventions can lead to meaningful change for people with dementia and their carers on a range of outcomes, including depression, anxiety and quality of life.

Coping and adaptations to loss

Caring for a partner with young onset dementia can be profoundly challenging, particularly as the condition progresses and the relationship dynamic undergoes significant changes. In this study, participants faced a range of challenges in coping with the evolving nature of the relationship with their partners, including changes in behaviour, personality and cognitive functioning. One significant factor impacting coping strategies is the level of cognitive impairment displayed by the partner with young onset dementia. The majority of participants in this study reported mild to moderate cognitive impairment in their partners, while two participants' partners were facing severe cognitive decline. Coping with the challenges of caring for a partner with young onset dementia may become increasingly complex as cognitive impairment declines and the caring partner assumes full responsibility for all of their partner's activities of daily living.

Furthermore, different types of dementia may present with different symptoms which may impact on caring and how people cope. In this study, two participants were caring for a partner with frontotemporal dementia, which is characterised by progressive changes in behaviour, personality, judgment, language, and cognition (Wittenberg et al., 2008). People living with frontotemporal dementia may present with symptoms such as aggression, impulsivity, and socially disruptive behaviour (Miller et al., 1997) which can be emotionally distressing for carers. The experience of aggression in partners with frontotemporal dementia, voiced by two participants in this study, highlights the heightened emotional distress and coping difficulties associated with their caring roles. This aligns with more recent findings from a longitudinal study on the influence of dementia aetiology on carer distress, which demonstrated that carers of people living with frontotemporal dementia experienced greater levels of carer distress compared to carers of people living with Alzheimer’s disease (Huang et al., 2022). Therefore, caring for a partner with frontotemporal dementia may pose unique challenges compared to caring for a partner with mild Alzheimer’s disease.

Participants in this study employed various coping strategies to navigate the challenges of caring for their partner. Practical strategies, such as the use of organisers and assistive technology to support their partners’ memory and maintain a sense of normalcy in daily life were highlighted. This aligns with previous research demonstrating the benefits of assistive technology in addressing the practical, emotional and relational challenges of everyday life, and thus become successfully incorporated in the everyday lives of people living with young onset dementia and their carers (Arntzen et al., 2014). This reflects a proactive approach in managing the impact of caring for a partner with young onset dementia and points to the growing body of literature on technological interventions in dementia care (Pappada et al., 2021). Assistive technologies have been identified as having many benefits in dementia care such as sustaining a person’s cognitive abilities required for daily activities (Nishiura et al., 2019), and increasing safety by sustaining independence while respecting dignity (Brittain et al., 2010).

Furthermore, the coping strategies employed by participants reflect cognitive and psychological processes identified in the stress and coping literature. Avoidant thinking and externalising emotions are consistent with coping strategies described by carers of individuals with young onset dementia (Lockeridge and Simpson, 2013). These strategies may help carers manage the emotional distress associated with caring responsibilities, although they may not always be adaptive in the long term. While little is understood about carers’ coping strategies in young onset dementia, the Lazarus and Folkman (1984) model of coping in ill health generally has frequently been utilised in order to understand how older carers cope with dementia (Lockeridge and Simpson, 2013). In their theory of stress and coping, Lazarus and Folkman (1984) propose that adaptation to stress is mediated by appraisal of that stress, and by the coping strategies employed by the individual. Coping strategies are considered to be of two main types; emotion-focused and problem-focused, and can include the use of avoidance and distancing amongst other factors (Kneebone and Martin, 2003). This links with the narratives of some participants in this study who tended to engage in emotion-focused strategies such as avoidance or distancing themselves from difficult thoughts and emotions, to cope with their caring role and the impact of dementia on their relationship.

Some participants described how they have developed of a sense of acceptance to cope with changes in their relationships and psychological resilience as they learn to adapt to their partners needs and the challenges of caring. Acceptance has been reported as an adaptive coping strategy used by caring partners in young onset dementia. In a qualitative study of lived experiences in young onset dementia, caring partners explained how acceptance helps reduce their "struggle" with the progressive disease (Popok et al., 2022). This expands on prior qualitative research which endorses the importance of cultivating acceptance of the young onset dementia diagnosis and associated changes (Castano, 2020). In previous research, psychological resilience has been proposed as a protective factor against negative outcomes for carers of people with dementia (Shuter, Beattie, & Edwards, 2014). However, in a qualitative study on resilience in informal dementia care, Jones et al., (2018) found that resilience does not protect carers from distress, yet high levels of resilience aids recovery from setbacks. In a review to further understand the factors associated with resilience in dementia care, Cherry et al., (2013) found that carers' resilience depends on social and cultural factors, properties of the caring relationship and carers' psychological characteristics.

The importance of social support systems in coping with the challenges of caring for a partner with young onset dementia cannot be overstated. Participants expressed a need to connect with others in similar situations, highlighting the role of peer support in providing validation, understanding and practical advice (Sullivan et al., 2022).

The theme *"dementia is a robber and a cheat"* illuminates the multifaceted impact of dementia on the couple's intimacy, identity and shared plans for the future. The loss of a sexual connection in the relationship becomes a poignant focal point in these narratives, reflecting the emotional challenges encountered, particularly when a decline in both physical and cognitive health intertwines. Research shows that co-morbidity is an important risk factor for poor quality of life in people living with dementia (Nelis et al., 2019), which adds further complexity to the experience of caring.

The metaphorical representation of dementia as a robber and a cheat vividly captures the multitude of losses experienced by caring partners in young onset dementia. The loss of physical intimacy and sexual activity described by participants aligns with a systematic review by Holdsworth and McCabe (2018) which analysed the literature describing the impact of young onset dementia on relationships, intimacy and sexuality in mid-life couples. The relational losses experienced by couples due to the cognitive and functional decline in the partner living with dementia is a recurring theme in the wider literature on dementia (Colquhoun et al, 2019).

Loss of reciprocity in the relationship and accompanied loneliness was experienced by participants. Everyday pleasures such as talking to each other and watching television shows of an evening were lost. One participant described how she felt like a ‘sofa widow’ as her partner often retires to bed early in the evening, and they no longer share these moments together. This loss of communication appears to disrupt these everyday experiences that were once cherished. This can be linked to the findings of a qualitative study that explores experiences of relational intimacy in long term relationships when one partner has dementia (Youell et al., 2015). Youell et al., (2015) found that it was the small everyday interactions which were probably taken for granted before the diagnosis which now become a focus for a sense loss in these relationships. Previous research has shown that partners of people living with young onset dementia experience changes in the quality of the relationship due to a decline in reciprocity and changes in sexuality (Lockeridge and Simpson, 2013). As social relationships are continuously redefined, a loss in the emotional connection with the person living with young onset dementia may deteriorate the quality of the relationship perceived by caring partners (Bruinsma et al., 2020).

Although participants in the current study were clearly impacted by the loss of reciprocity in their relationships, most described how they actively try to preserve the sense of closeness they once shared. Some participants also spoke of the loss of physical intimacy which included not only sexual intimacy but the closeness they once felt from holding their partners hand – described by one participant as a hand that no longer wants to be held.

Limitations and directions for future research

While this study offers valuable insights into the complex experiences of caring for a partner with young onset dementia, several limitations and directions for future research should be considered.

While the use of multiple modes of interviewing offered a comprehensive approach to data collection, each method brought its own set of challenges that impacted the depth and quality of the data. The in-person interview offered a unique opportunity for building rapport, as the physical presence allowed for the observation of non-verbal cues such as body language and facial expression. This mode facilitated a deeper connection with the participant leading to richer and more nuanced data. However, in-person interviews can be logistically challenging, particularly for participants who are already overwhelmed by caring responsibilities. The requirement to meet in a specific location may limit participation to people who have the time and means to travel, potentially skewing the sample. The telephone interview provided flexibility, allowing the participant to engage from the comfort of his own home without the need for travel. This mode can also reduce the pressure some participants might feel in face-to-face interviews, potentially leading to more open and honest responses. A significant limitation of telephone interviews is the lack of visual cues, which can hinder the researcher's ability to gauge the participant's emotional responses and the depth of their engagement. Moreover, telephone interviews may be shorter and less detailed, as participants might be less inclined to elaborate without visual feedback. Interviews conducted via MS Teams or other video platforms offer a middle ground, allowing for some visual cues while also enabling the participant to manage the environment more effectively, such as by moving to a different room to avoid potential emotional distress for the person with dementia. Virtual interviews provide the convenience of remote communication while still allowing for some level of visual interaction. This mode enabled participants from diverse geographical locations to take part, enhancing the representativeness of the study sample. Despite these advantages, technical issues such as poor internet connectivity, software familiarity, and distractions in the participant's environment disrupted the flow of the interview at times. Furthermore, the presence of a screen can sometimes create a sense of distance, which may affect the depth of the data obtained.

The presence or close proximity of the participant's partner during some interviews presented both practical and ethical challenges. On the one hand, their presence might have influenced the responses of the participant, potentially leading to less open discussion due to concerns about upsetting or betraying their partner. This could result in a more guarded account of their caring experiences, thereby affecting the authenticity and richness of the data. On the other hand, having their partner nearby offered opportunities for observing the dynamics of their relationship and provided additional context to the carer’s experience. However, the risk of compromised data quality due to altered responses cannot be overlooked.

On reflection, the exclusion of one individual whose partner resides in a nursing home was a limitation. Carers in these situations often face unique challenges, such as dealing with the emotional distress of being physically separated from their partner, navigating the healthcare system, and ensuring quality care in a nursing home setting. Their exclusion may have led to an incomplete understanding of the full spectrum of caring experiences in young onset dementia. Future research could benefit from a more inclusive approach, ensuring that the voices and experiences of all types of carers are represented.

The participants in this study were predominantly of white British ethnicity, with the exception of one white Latvian participant. This may restrict the transferability of findings to carers from diverse cultural backgrounds as they do not fully capture the diverse experiences of caring across different ethnic and cultural backgrounds. Future research could include a more ethnically and culturally diverse sample to better understand how the dynamics of caring may vary across different ethnic and cultural contexts. Collaborating with community organisations and support networks could facilitate reaching a broader range of carers from diverse backgrounds.

Another pertinent aspect is the gender imbalance within the sample with a predominant representation of female carers. While this aligns with broader trends in the dementia care literature, exploring the experiences of caring from a male perspective could provide invaluable insights into gender dynamics within caring relationships in young onset dementia. Thus, future research should strive to incorporate a more balanced representation of male and female carers to capture the full spectrum of caring experiences.

The participants in the study can be described as a fairly homogenous sample in that they are all living with and caring for a partner with young onset dementia. However, participants had significant differences in their experience of caring depending upon which type of dementia their partner is living with and which stage of cognitive decline they are within (i.e. mild, moderate or severe). It is important to note, that a person with frontotemporal dementia may present with different symptoms (such as changes in behaviour and personality) compared to a person living with Alzheimer's disease where memory decline may be more noticeable. Furthermore, the partners' level of cognitive impairment may have a variable impact on the caring partner as it may be more challenging to care for a person within the severe stage of cognitive decline compared to the mild/moderate stage.

This study explored the experiences of caring for a partner with four different types of young onset dementia, namely Alzheimer's disease, frontotemporal dementia, mixed dementia (vascular and Alzheimer's) and familial Alzheimer's disease. Therefore, the findings do not encompass the lived experiences of caring for a partner with other types of young onset dementia. Research that explores the experience of caring for a partner with other less common types of young onset dementia could offer further nuanced understanding of the complexities of caring, and expand our understanding of the diverse challenges faced by carers. This could involve qualitative studies focused on specific types of dementia. Although I am aware that the partners diagnosis and level of cognitive impairment had a variable influence on participants caring experiences, my interest was in the carers' experiences and perspectives, regardless of the type of diagnosis, and the potential to identify similarities across diversity.

It is important to note that other demographic differences among participants may have influenced their caring experiences. Firstly, variations in work status, ranging from full-time employment to retirement, could have impacted the availability of time, resources, and support for caring responsibilities. Participants who are still in the work force may face additional challenges in balancing work and caring responsibilities compared to those who are retired or not working. Secondly, differences in educational backgrounds could have influenced participants' levels of understanding, coping strategies, and access to information and support services. Individuals with higher levels of education may have greater access to resources and networks to navigate the complexities of caring. Furthermore, the presence or absence of dependent children at home could significantly shape participants' caring experiences. Those with dependent children may have experienced added stressors and responsibilities in juggling caring responsibilities alongside parenting duties, while those without children living at home may have more time and energy to devote to caring for their partner. Lastly the age range of participants spanning from 43 to 66 years suggests potential differences in life experiences, perspectives and support networks, which could influence their approaches to caring and the difficulties they encounter. For future research, it would be valuable to delve deeper into how these demographic differences intersect with caring experiences. Specifically, researchers could explore how factors such as work status, educational background, presence of dependent children, and age impact coping mechanisms, access to support services, and overall wellbeing of carers. Additionally, investigating how these demographic factors interact with other contextual factors, such as cultural background and socioeconomic status, could provide further insights into the complex nature of caring for a partner with young onset dementia. Furthermore, future research should consider the impact of intersectional identities on the caring experience, including the challenges faced by carers with physical and /or intellectual disabilities or from marginalised backgrounds, to ensure a comprehensive understanding of care dynamics and support needs.

All participants in this study are in heterosexual partnerships. Future research could explore the experiences of caring partners in LGBTQIA+ couples. Understanding the unique experiences of LGBTQIA+ couples in the context of young onset dementia would further expand on this very limited area of research and address the existing gaps in the literature. Furthermore, all participants in the study were in long term relationships and marriages, potentially overlooking the unique experiences of carers in newer relationships or those whose relationships may have ended following the diagnosis. Future research that explores participants’ experiences at various relationship stages could enrich our understanding of how caring dynamics evolve over time. Few studies have explored how people living with young onset dementia and their partners experience changes in their relationship over time and the impact this may have on caring and couplehood. More qualitative longitudinal studies may be helpful in capturing couples lived experiences of the relationship as young onset dementia unfolds. The inclusion of both the person living with young onset dementia and the caring partner may lead to a deeper understanding of the couple’s relational experiences. Furthermore, gaining a better understanding of the evolving dynamics of the relationship as young onset dementia progresses can inform the development of targeted interventions to support couples throughout their journey.

While this study focused on the perspectives of caring partners, further research could explore the shared experiences of both the person living with young onset dementia and their partner. This approach could offer a more holistic understanding of the relational dynamics and support needs within couples. Research that explores the shared experience of couples following the onset of young onset dementia symptoms may support the development of interventions that meet the couple's needs simultaneously.

This study explored the diagnostic journey experience for caring partners, an area that is relatively under researched. Future research could explore the diagnostic experiences of both the individual living with young onset dementia and their caring partner to identify gaps in current practices and improve the diagnostic process. Theme one *'the long road to diagnosis'* highlights the multifaceted challenges faced by carers and emphasises the importance of timely and accurate diagnosis, challenging age-related stereotypes, and addressing the emotional impact of the diagnosis. Future research and interventions could focus on refining diagnostic practices, raising awareness, and providing comprehensive support to mitigate the emotional distress on carers of individuals with young onset dementia. To improve the diagnostic process, it may be helpful for future studies to compare people with young onset dementia to a group of people with depression or burn-out, since symptoms between these overlap and distinction is difficult for a GP (Hendriks et al., 2022). Existing studies tend to focus on the emotional responses to a diagnosis of young onset dementia, future research could consider exploring the longer-term psychological adjustment and coping following the diagnosis.

Lastly, the sample was recruited through the Young Dementia Network, and therefore may not represent the voices of carers who are not signed up to this support network. Future research could look at advertising the study more widely to increase the transferability of the findings.

Implications for Practitioners

The findings of this study have significant implications for healthcare practitioners, particularly those involved in dementia care, in addressing the unique challenges faced by individuals living with young onset dementia and their carers.

There is a pressing need for improved awareness and education among healthcare professionals regarding the occurrence of dementia in younger people. Early recognition and diagnosis along with timely interventions and support are pivotal for both the affected individual and their carers wellbeing. Healthcare professionals, particularly psychologists working in dementia services, play a pivotal role in providing targeted therapeutic interventions to individuals and their carers following a diagnosis of young onset dementia. This may involve offering immediate emotional support post-diagnosis, facilitating coping mechanisms, and providing psychoeducation to address the emotional needs of both of both the person living with young onset dementia and their carer. Moreover, interventions addressing the emotional needs of carers during the diagnostic process and beyond are crucial for fostering resilience and effective coping mechanisms. Psychologists working in dementia services in the NHS are in position to provide teaching and training to other healthcare professionals and work collaboratively to develop psychosocial interventions that will support this client group going forward. Collaborative and relational approaches between healthcare professionals are essential in reshaping support systems and societal perceptions surrounding young onset dementia. By working together, practitioners can develop comprehensive care plans tailored to the specific needs of individuals and carers, ultimately enhancing their overall wellbeing and quality of life.

Improving recognition and therefore timely and accurate diagnosis of young onset dementia is an important goal for healthcare professionals in primary care services. A new decision-making tool developed by the Young Dementia Network UK has been specifically designed to guide diagnosis and raise awareness of key red flags to diagnosis (youngdementianetwork.org, 2017). Practitioners should utilise the available resources to make informed diagnostic decisions. Furthermore, practitioners must be sensitive to the potential shock, denial, and emotional distress experienced by individuals with young onset dementia and their carers in response to the diagnosis. Clear and empathetic communication, both verbal and written, is essential in ensuring that diagnoses are conveyed with sensitivity. Having the opportunity to speak to a healthcare professional in person who can offer emotional support immediately after the diagnosis could be highly beneficial for both the person living with young onset dementia and their care partner. In addition, psychosocial interventions offering emotional support for partners of individuals facing young onset dementia may help couples to maintain the quality their relationship (Larochette et al., 2020).

Unmet carer needs influence carers' psychological well-being and ability to provide appropriate care and support and have implications for the psychological health of both the carer and the person living with dementia (Cherry et al., 2013). Healthcare professionals must address these needs proactively, offering counselling services, practical assistance, and access to support networks to alleviate carer distress and enhance their resilience. There needs to be more specific support for individuals living with young onset dementia and their carers – meeting their needs in a way that is more distinctive to older adults, considering that younger people may still be employed with young families.

Given the anticipated rise in prevalence of young onset dementia (Carter et al., 2018), healthcare practitioners must adopt a proactive approach to diagnosis, understanding, and support. This study emphasises the need for a paradigm shift in the way individuals living with young onset dementia are diagnosed, understood and supported by healthcare professionals, highlighting the importance of early intervention and holistic care approaches.

Implications for Counselling Psychology

Individuals who care for a partner with young onset dementia may seek counselling and relationship work. Counselling psychologists working in dementia services in the NHS, third sector, and private practice may all work with carers of people living with young onset dementia. Counselling psychology is committed to listening to marginalised groups and stigmatised populations, and is well placed to offer specialised mental health input to carers.

For the most part, when psychologists work with someone living with dementia, they do not simply have a choice of *whether* they work with the person’s partner or carer. Instead, the decision they face is *how* to work with this relationship – that is whether or not to focus on change at an individual level or within the relationship itself (Cheston, 2022). Psychologists may face important clinical decisions about whether to work individually with either carer, the person with dementia or couples and/or families, and the different psychological tasks that therapy may need to address such as promoting resilience within relationships, processing emotional distress, and providing support and containment for both the person with dementia and their partner in adjusting to the diagnosis (Balfour, 2014).

The experience of caring for a partner with young onset dementia involves navigating a complex emotional journey that may include grief, guilt, and a sense of loss. One of the primary tasks in therapy with carers is helping them to express, process, and manage the anticipatory grief that accompanies the gradual loss of the partner they once knew. As highlighted by the participant who referred to her partner as a “weird uncle,” the transformation of a loved one into someone almost unrecognisable can be deeply distressing. This metaphor encapsulates the emotional dissonance experienced by many carers, where the partner they care for no longer resembles the person they originally fell in love with. The therapeutic process, therefore, might need to focus on validating these feelings of loss and helping carers adjust to changes in their partner and relationship.

In addition to grief, carers often experience guilt – guilt for struggling with their role, for considering alternative care options, or for feeling disconnected from their partner. An approach in therapy could involve working through these complex emotions, helping carers to give themselves permission to transition to different forms of care with less guilt. This transition might involve their partner moving from home care to a residential care setting or accepting additional support. Therapy can play a crucial role in facilitating this shift by reframing it as a necessary step in both the carer’s wellbeing and the partner’s care.

For couples, a significant task in therapy is fostering reconnection and maintaining emotional contact despite the relational changes brought about by young onset dementia. This study’s findings suggest that while young onset dementia creates substantial barriers to intimacy and mutual understanding, there remains a potential for couples to reconnect in new ways. Therapy can support couples in finding these new forms of connection, whether through shared activities, communication strategies, or simply by acknowledging and accepting the changes in their relationship. Engaging with couples living with young onset dementia in such in a meaningful and respectful way actualises the humanistic ethic which is at the core of counselling psychology practice (Cooper, 2009). Supporting the couple to explore and define their evolving relationship on their own terms appears well suited to Rogerian, humanistic and non-directive approaches, however, couple's may also benefit from the structure provided by more directive approaches. Counselling psychologists must, therefore, be flexible in their approach, drawing on a range of therapeutic modalities depending on the specific needs of the client(s).

Therapy for couple’s living with young onset dementia must also address the difficulties in discussing the future, as these conversations are often fraught with anxiety and sadness. A directive approach may be necessary here, guiding the couple in addressing uncomfortable but essential topics such as long-term care planning, and the emotional implications of such decisions. By facilitating these conversations, the therapist can help the couple to negotiate the inevitable transitions that young onset dementia will bring, ensuring that both partners feel heard and understood. Moreover, counselling psychology must recognise that dementia, while ever-present, does not define the entirety of a couple’s life. Therapy should aim to help couple’s build resilience in their relationship, enabling them to continue to enjoy aspects of their life together. This might involve helping them to set realistic and meaningful goals, engage in activities that they can still enjoy together, and find new ways to express love and affection. It is important to acknowledge that dementia will always be there, but their lives have the potential to grow around the dementia.

Ultimately, the role of counselling psychology in supporting carers and couples living with young onset dementia is twofold: to promote reconnection where possible and to help individuals and couples acknowledge and cope with loss and change. For some, this might mean finding new ways to connect emotionally with their partner whose personality and behaviour have altered dramatically. For others, it might involve coming to terms with the fact that their relationship as they once knew it has irrevocably changed and learning to navigate this new reality with compassion and understanding. A relational perspective reframes dementia as those living with it being able to live well when held in connection with others (Winter, 2020). By helping couples to reconnect, communicate and make decisions about the future, counselling psychology can play a crucial role in enhancing the wellbeing of both carers and people living with young onset dementia.

The findings of this study may be of particular interest to counselling psychologists who assume leadership roles within the NHS as they will be at the forefront of service development and facilitating positive changes for the support provided to people living with young onset dementia and their carers. Furthermore, the findings may be helpful to inform the teaching practices of counselling psychologists who assume roles in academia and engage students with discussions and reflections regarding the topic of dementia. This poses the question of whether more teaching on dementia should be incorporated into counselling psychology doctorate programmes across the UK.

Conclusion

This study makes a significant and original contribution to the field of counselling psychology by focusing on the deeply relational experiences of carers who support their partners with young onset dementia. A nuanced exploration of their journeys highlights the profound relational, emotional and societal challenges they face – particularly during the diagnostic journey, the subsequent lack of post diagnostic support, and the ongoing transformation of their relationships and identities. As dementia progresses, the relationship between carer and partner shifts in fundamental ways, altering the dynamics of their connection. Carers often experience a deep sense of loss – not only the gradual loss of the partner they once knew but also the loss of their own sense of self as their roles evolve.

The findings emphasise the relational nature of these experiences and highlight the importance of a compassionate, person-centred, and holistic approach to support people living with young onset dementia. Psychologists working in dementia care have a unique role in providing spaces where carers can express and process these complex relational dynamics, including grief, guilt, loss, and identity shifts. By offering relationally attuned interventions, psychologists and other healthcare professionals, can help carers build resilience in their relationships, foster connection, and navigate the profound psychological adjustments required in their evolving relationships. The provision of timely and meaningful support can enhance the quality of life for both carers and their partners, making it possible to live well with young onset dementia.

References

Ahmad, M., van den Broeke, J., Saharso, S. and Tonkens, E., (2022). Dementia care-sharing and migration: An intersectional exploration of family carers' experiences. *Journal of Aging Studies*, *60*, p.100996.

Alase, A. (2017). The interpretative phenomenological analysis (IPA): A guide to a good qualitative research approach. *International Journal of Education and Literacy Studies*, *5*(2), 9-19.

Allen, A. P., Curran, E. A., Duggan, A., Cryan, J. F., Chorcorain, A. N., Dinan, T. G., . Clarke, G. (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive biological markers of stress. Neuroscience & Biobehavioral Reviews, 73, 123-164. doi:10.1016/j.neubiorev.2016.12.006

Alzheimer's Association (2018). Available from: https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf [Accessed 12 November 2021]

Alzheimer's Society (2021). Available from: https://www.alzheimers.org.uk/about-dementia/types-dementia [Accessed 22 December 2021].

Aminzadeh, F., Byszewski, A., Molnar, F. J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: exploring persons with dementia and caregivers' perspectives. *Aging and Mental Health*, *11*(3), 281-290.

Arai, A., Matsumoto, T., Ikeda, M., & Arai, Y. (2007). Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared with late onset dementia? International Journal of Geriatric Psychiatry, 22, 1255–1261.

Arnett, R. C. (2007). Interpretive inquiry as qualitative communications research. Qualitative Research Reports in Communication, 8(1), pp. 29-35. http://dx.doi.org/10.1080/17459430701617887 (cited in Muganga, L. (2015). The importance of hermeneutic theory in understanding and appreciating interpretive inquiry as a methodology. *Journal of Social Research & Policy*, *6*(1), 65.)

Arntzen, C., Holthe, T., & Jentoft, R. (2016). Tracing the successful incorporation of assistive technology into everyday life for younger people with dementia and family carers. *Dementia*, *15*(4), 646-662.

Auclair, U., Epstein, C., & Mittelman, M. (2009). Couples counseling in Alzheimer's disease: additional clinical findings from a novel intervention study. *Clinical Gerontologist*, *32*(2), 130-146.

Baghirathan S, Cheston R, Hui R, Chacon A, Shears P and Currie K (2020) A grounded theory analysis of the dementia experiences of people from three BME communities: balancing the need for support against fears of being diminished, Dementia: the International Journal of Social Research and Policy, 19 (5), 1672-1691, doi: 10.1177/1471301218804714.

Baker, K. L., & Robertson, N. (2008). Coping with caring for someone with dementia: Reviewing the literature about men. *Aging and Mental Health*, *12*(4), 413-422.

Baker, K.L., Robertson, N and Connelly, D. (2010). "Men caring for wives or partners with dementia: masculinity, strain and gain," Aging and Mental Health, vol. 14, no. 3, pp. 319–327.

Bakker, C., de Vugt, M. E., Vernooij-Dassen, M., Van Vliet, D., Verhey, F. R., & Koopmans, R. T. (2010). Needs in early onset dementia: a qualitative case from the NeedYD study. *American Journal of Alzheimer's Disease & Other Dementias®*, *25*(8), 634-640.

Bakker, C., de Vugt, M. E., van Vliet, D., Verhey, F. R., Pijnenburg, Y. A., Vernooij-Dassen, M. J., & Koopmans, R. T. (2014). The relationship between unmet care needs in young-onset dementia and the course of neuropsychiatric symptoms: a two-year follow-up study. *International Psychogeriatrics*, *26*(12), 1991-2000.

Balfour, A. (2014). Developing therapeutic couple work in dementia care–the living together with dementia project. *Psychoanalytic Psychotherapy*, *28*(3), 304-320.

Bannon, S. M., Grunberg, V. A., Reichman, M., Popok, P. J., Traeger, L., Dickerson, B. C., & Vranceanu, A. M. (2021). Thematic analysis of dyadic coping in couples with young-onset dementia. *JAMA network open*, *4*(4), e216111-e216111.

Bannon, S. M., Reichman, M., Popok, P., Grunberg, V. A., Traeger, L., Gates, M. V., . & Vranceanu, A. M. (2022). Psychosocial stressors and adaptive coping strategies in couples after a diagnosis of young-onset dementia. *The Gerontologist*, *62*(2), 262-275.

Beattie, A., Daker-White, G., Gilliard, J., & Means, R. (2004). 'How can they tell?' A qualitative study of the views of younger people about their dementia and dementia care services. *Health & social care in the community*, *12*(4), 359-368.

Bell, J. (5th ed.) (2010). Doing your research project, a guide for first-time researchers in education, health and social sciences. Berkshire: Open University Press.

Benbow, S. M., & Sharman, V. (2014). Review of family therapy and dementia: twenty-five years on. *International Psychogeriatrics*, *26*(12), 2037-2050.

Bhaskar, R. (1978). On the possibility of social scientific knowledge and the limits of naturalism. *Journal for the Theory of social Behaviour*, *8*(1), 1-28.

Bielsten, T., & Hellström, I. (2019). An extended review of couple-centred interventions in dementia: Exploring the what and why—Part B. *Dementia*, *18*(7-8), 2450-2473.

Bielsten, T., & Hellström, I. (2019). A review of couple-centred interventions in dementia: Exploring the what and why–Part A. *Dementia*, *18*(7-8), 2436-2449.

Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative research in psychology*, *5*(3), 214-224.

Billeter, J., (2014). Dementia-A state of the nation report on dementia care and support in England.

Bowen, M. (1978). Family therapy in clinical practice. New York: Aronson

BPS UK (2021). Evidence briefing: Psychological needs of people with young-onset dementia. Available from: https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/Evidence%20Briefing%20-%20Psychological%20Needs%20of%20People%20with%20Young-Onset%20Dementia.pdf [Accessed 11 November 2021)

Braun, V., & Clarke, V. (2013). Successful qualitative research: A practical guide for beginners. Sage.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative research in sport, exercise and health*, *11*(4), 589-597.

Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and psychotherapy research*, *21*(1), 37-47.

Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis?. *Qualitative research in psychology*, *18*(3), 328-352.

Brittain, K., Corner, L., Robinson, L., & Bond, J. (2010). Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. *Sociology of health & illness*, *32*(2), 272-287.

Bruinsma, J., Peetoom, K., Millenaar, J., Köhler, S., Bakker, C., Koopmans, R., ... & De Vugt, M. (2020). The quality of the relationship perceived by spouses of people with young-onset dementia. *International Psychogeriatrics*, 1-10.

Bruinsma, J., Peetoom, K., Bakker, C., Boots, L., Millenaar, J., Verhey, F., & de Vugt, M. (2021). Tailoring and evaluating the web-based ‘Partner in Balance’ intervention for family caregivers of persons with young-onset dementia. *Internet Interventions*, *25*, 100390.

Cabote, C. J., Bramble, M., & McCann, D. (2015). Family caregivers’ experiences of caring for a relative with younger onset dementia: A qualitative systematic review. *Journal of Family Nursing*, *21*(3), 443-468.

Carpenter, D. R. (2007). Phenomenology as method. In H. J. Streubert & D. R. Carpenter (Eds.), Qualitative research in nursing: Advancing the humanistic imperative (pp. 75- 99). Philadelphia, PA: Lippincott.

Carter, J. E., Oyebode, J. R., & Koopmans, R. T. C. M. (2018). Young-onset dementia and the need for specialist care: a national and international perspective. *Aging & Mental Health*, *22*(4), 468-473.

Carter, J., (2022). Prevalence of all cause young onset dementia and time lived with dementia: analysis of primary care health records. *Journal of Dementia Care*, *30*(3), pp.1-5.

Cartwright, A.V., Stoner, C.R., Pione, R.D. and Spector, A., 2021. The experiences of those affected by parental young onset dementia: A qualitative systematic literature review. *Dementia*, *20*(7), pp.2618-2639.

Carruth, A.K., (1996). Motivating factors, exchange patterns, and reciprocity among caregivers of parents with and without dementia. *Research in nursing & health*, *19*(5), pp.409-419.

Castaño, E. (2020). Discourse analysis as a tool for uncovering the lived experience of dementia: Metaphor framing and well-being in early-onset dementia narratives. *Discourse and Communication,* 14(2), 115–132. doi: 10.1177/1750481319890385

Cations, M., Withall, A., Horsfall, R., Denham, N., White, F., Trollor, J., ... & Draper, B. (2017). Why aren't people with young onset dementia and their supporters using formal services? Results from the INSPIRED study. *PLoS One*, *12*(7), e0180935.

Chan, Z. C., Fung, Y. L., & Chien, W. T. (2013). Bracketing in phenomenology: Only undertaken in the data collection and analysis process. *The qualitative report*, *18*(30), 1-9.

Cherry, M. G., Salmon, P., Dickson, J. M., Powell, D., Sikdar, S., & Ablett, J. (2013). Factors influencing the resilience of carers of individuals with dementia. *Reviews in clinical gerontology*, *23*(4), 251-266.

Cheston, R. (2022). *Dementia and Psychotherapy Reconsidered*. McGraw-Hill Education (UK).

Cheston, R., & Ivanecka, A. (2017). Individual and group psychotherapy with people diagnosed with dementia: a systematic review of the literature. *International journal of geriatric psychiatry*, *32*(1), 3-31.

Chiari, A., Pistoresi, B., Galli, C., Tondelli, M., Vinceti, G., Molinari, M. A., ... & Zamboni, G. (2021). Determinants of Caregiver Burden in Early-Onset Dementia. *Dementia and Geriatric Cognitive Disorders Extra*, *11*(2), 189-197.

Chirico, I., Ottoboni, G., Linarello, S., Ferriani, E., Marrocco, E., & Chattat, R. (2022). Family experience of young-onset dementia: the perspectives of spouses and children. *Aging & Mental Health*, *26*(11), 2243-2251.

Clemerson, G., Walsh, S., & Isaac, C. (2014). Towards living well with young onset dementia: an exploration of coping from the perspective of those diagnosed. *Dementia*, *13*(4), 451-466.

Collins, J. D., Henley, S. M., & Suárez-González, A. (2020). A systematic review of the prevalence of depression, anxiety, and apathy in frontotemporal dementia, atypical and young-onset Alzheimer's disease, and inherited dementia. *International Psychogeriatrics*, 1-20.

Cook, K. (Ed.). (1987). Social exchange theory. Newbury Park, CA: Sage.

Colquhoun, A., Moses, J., & Offord, R. (2019). Experiences of loss and relationship quality in couples living with dementia. *Dementia*, *18*(6), 2158-2172.

Cooper, M. (2009). Welcoming the other: Actualising the humanistic ethic at the core of counselling psychology practice. Counselling Psychology Review, 24(3,4), 119–129

Cuthbertson, L. M., Robb, Y. A., & Blair, S. (2020). Theory and application of research principles and philosophical underpinning for a study utilising interpretative phenomenological analysis. *Radiography*, *26*(2), e94-e102.

Daniels, K., Lamson, A., & Hodgson, J. (2007). An exploration of the marital relationships and Alzheimer's disease: One couple's story. Families, Systems & Health, 25(2), 162–177

Deist, M., & Greeff, A.P. (2015). Resilience in families caring for a family member diagnosed with dementia. Educational Gerontology, 41(2), 93-105.

Dementia UK (2022). Available from: https://www.dementiauk.org/about-dementia/young-onset-dementia/about-young-onset-dementia/facts-and-figures [Accessed 12 October 2022]

Dementia Engagement and Empowerment Project. (2014). Dementia words matter: Guidelines on language about dementia.

Department of Health. Living Well With Dementia: A National Dementia Strategy. Department of Health; 2009.

Di Mattei, V. E., Prunas, A., Novella, L., Marcone, A., Cappa, S. F., & Sarno, L. (2008). The burden of distress in caregivers of elderly demented patients and its relationship with coping strategies. *Neurological sciences*, *29*(6), 383-389.

Dörfler, V., & Stierand, M. (2021). Bracketing: A phenomenological theory applied through transpersonal reflexivity. *Journal of Organizational Change Management*, *34*(4), 778-793.

Douglas, B., Woolfe, R., Strawbridge, S., Kasket, E., & Galbraith, V. The Handbook of Counselling Psychology. (2016) (4th Eds). Sage.

Draper, B., & Withall, A. (2016). Young onset dementia. *Internal medicine journal*, *46*(7), 779-786.

Ducharme, F., Kergoat, M. J., Antoine, P., Pasquier, F., & Coulombe, R. (2013). The unique experience of spouses in early-onset dementia. *American Journal of Alzheimer's Disease & Other Dementias®*, *28*(6), 634-641.

Ducharme, F., Kergoat, M. J., Coulombe, R., Lévesque, L., Antoine, P., & Pasquier, F. (2014). Unmet support needs of early-onset dementia family caregivers: a mixed-design study. *BMC nursing*, *13*(1), 49.

Ducharme, F., Lachance, L., Kergoat, M. J., Coulombe, R., Antoine, P., & Pasquier, F. (2015). A comparative descriptive study of characteristics of early- and late-onset dementia family caregivers. American Journal of Alzheimer's Disease & Other Dementias, 31, 48–56. doi:10.1177/ 1533317515578255

Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. *The Sage handbook of qualitative research in psychology*, *179*, 194.

Etters, L., Goodall, D. and Harrison, B.E., (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of the American Academy of Nurse Practitioners*, *20*(8), pp.423-428.

Falconier MK, Kuhn R. Dyadic coping in couples: a conceptual integration and a review of the empirical literature. Front Psychol. 2019;10:571.

Flynn, R., & Mulcahy, H. (2013). Early-onset dementia: the impact on family care-givers. *British Journal of Community Nursing*, *18*(12), 598-606.

Francis, L. E., Worthington, J., Kypriotakis, G., & Rose, J. H. (2010). Relationship quality and burden among caregivers for late-stage cancer patients. Supportive Care in Cancer, 18(11), 1429–1436

Fredriksen-Goldsen, K. I., & Hooyman, N. R. (2007). Caregiving research, services, and policies in historically marginalized communities. Journal of Gay & Lesbian Social Services, 18, 129– 145. doi:10.1300/J041v18n03_08

Freyne, A., Kidd, N., Coen, R., & Lawlor, B. A. (1999). Burden in carers of dementia patients: higher levels in carers of younger sufferers. *International journal of geriatric psychiatry*, *14*(9), 784-788.

Gallego-Alberto, L., Losada, A., Cabrera, I., Romero-Moreno, R., Pérez-Miguel, A., Pedroso-Chaparro, M. D. S., & Márquez-González, M. (2022). "I feel guilty". Exploring guilt-related dynamics in family caregivers of people with dementia. *Clinical Gerontologist*, *45*(5), 1294-1303.

Gelman, C., & Rhames, K. (2020). “I have to be both mother and father”: The impact of young-onset dementia on the partner’s parenting and the children’s experience. *Dementia*, *19*(3), 676-690.

Gerritsen, A.A., Bakker, C., Verhey, F.R., Bor, H., Pijnenburg, Y.A., de Vugt, M.E. and Koopmans, R.T., (2018). The progression of dementia and cognitive decline in a Dutch 2-year cohort study of people with young-onset dementia. *Journal of Alzheimer's Disease*, *63*(1), pp.343-351.

Giebel, C., Eastham, C., Cannon, J., Wilson, J., Wilson, J., & Pearson, A. (2020). Evaluating a young-onset dementia service from two sides of the coin: staff and service user perspectives. *BMC health services research*, *20*(1), 1-7.

Gould, N., & Kendall, T. (2007). Developing the NICE/SCIE guidelines for dementia care: The challenges of enhancing the evidence base for social and health care. *British Journal of Social Work*, *37*(3), 475-490.

Griffiths, A. W., Shoesmith, E., Sass, C., Nicholson, P., & Charura, D. (2020). Relational counselling as a psychosocial intervention for dementia: Qualitative evidence from people living with dementia and family members. Dementia, 1–8.

Gripsrud, Birgitta. (2020). Re: Thematic Analysis or Interpretative Phenomenological Analysis?. Retrieved from: https://www.researchgate.net/post/Thematic_Analysis_or_Interpretative_Phenomenological_Analysis/5fba958f2d8155542e74761a/citation/download.

Gronning, H., Kristiansen, S., Dyre, D., Rahmani, A., Gyllenborg, J., & Hogh, P. (2013). Caregiver burden and psychosocial services in patients with early and late onset Alzheimer’s disease. *Dan Med J*, *60*(7), A4649.

Grunberg, V. A., Bannon, S. M., Popok, P., Reichman, M., Dickerson, B. C., & Vranceanu, A. M. (2022). A race against time: couples’ lived diagnostic journeys to young-onset dementia. *Aging & mental health*, *26*(11), 2223-2232.

Harris, P. and Keady, J. (2009). Selfhood in younger onset dementia: transitions and testimonies. Aging and Mental Health, 13, 437–444. doi: 10.1080/13607860802534609.

Harvey RJ, Skelton-Robinson M, Rossor MN. (2003). The prevalence and causes of dementia in people under the age of 65 years. Journal of Neurology, Neurosurgery & Psychiatry

Harvey, R., Skelton-Robinson, M., Rossor, M. N., & Garralda, E. (1998). Young onset dementia: Clinical symptoms, family burden, support and outcome. London: Dementia Research Group, Imperial College School of Medicine.

Hattangady, E., & Oliverio, R. (2016). P2-368: Impact of a Wellness Program for People with Young Onset Dementias and their Care Partners. *Alzheimer's & Dementia*, *12*, P786-P786.

Hendriks, S., Peetoom, K., Tange, H., Van Bokhoven, M. A., Van Der Flier, W. M., Bakker, C., ... & De Vugt, M. (2022). Pre-diagnostic symptoms of young-onset dementia in the general practice up to five years before diagnosis. *Journal of Alzheimer's Disease*, *88*(1), 229-239.

Holdsworth, K., & McCabe, M. (2018). The impact of younger-onset dementia on relationships, intimacy, and sexuality in midlife couples: a systematic review. *International psychogeriatrics*, *30*(1), 15-29.

Huang, W. C., Chang, M. C., Wang, W. F., & Jhang, K. M. (2022). A comparison of Caregiver Burden for different types of dementia: an 18-Month Retrospective Cohort Study. *Frontiers in Psychology*, *12*, 798315.

Husserl, E, 1936/1970, The crisis of european sciences and transcendental phenomenology: an introduction to phenomenological philosophy, (trans. D Carr), Evanston, IL, Northwestern University Press.

Hvidsten, L., Engedal, K., Selbaek, G., Wyller, T. B., Bruvik, F., & Kersten, H. (2019). Quality of life of family carers of persons with young-onset compared to late-onset dementia. *Aging & Mental Health*, 1-8.

Hvidsten, L., Engedal, K., Selbæk, G., Wyller, T. B., Šaltytė Benth, J., & Kersten, H. (2019). Quality of life of family carers of persons with young-onset dementia: A Nordic two-year observational multicenter study. *Plos one*, *14*(7), e0219859.

Jackman, L. (2020). Extending the Newcastle Model: how therapeutic communication can reduce distress in people with dementia. *Nursing Older People*, *32*(2).

James I (2011) Understanding Behaviour in Dementia that Challenges: A Guide to Assessment and Treatment. Jessica Kingsley, London.

James, I. A., & Birtles, H. (2020). Twenty-one years of creativity and development: The evolving Newcastle model. *Psychology of Older People. The FPOP Bulletin*, *152*(2), 62-69.

James, I. A., & Jackman, L. (2017). *Understanding behaviour in dementia that challenges: A guide to assessment and treatment*. Jessica Kingsley Publishers.

Janssen, E. P. C. J., de Vugt, M., Kohler, S., Wolfs, C., Kerpershoek, L., Handels, R. L. H., Verhey, F. R. (2017). Caregiver profiles in dementia related to quality of life, depression and perseverance time in the European Actifcare study: The importance of social health. Aging & Mental Health, 21(1), 49–57.

Jeong, H., & Othman, J. (2016). Using interpretative phenomenological analysis from a realist perspective. *The Qualitative Report*, *21*(3), 558-570.

Johannessen, A., & Möller, A. (2013). Experiences of persons with early-onset dementia in everyday life: a qualitative study. *Dementia*, *12*(4), 410-424.

Johannessen, A., Helvik, A. S., Engedal, K., & Thorsen, K. (2017). Experiences and needs of spouses of persons with young-onset frontotemporal lobe dementia during the progression of the disease. *Scandinavian journal of caring sciences*, *31*(4), 779-788.

Jones, I. R. (2017). Social class, dementia and the fourth age. *Sociology of Health & Illness*, *39*(2), 303-317.

Jones, S. M., Mioshi, E., & Killett, A. (2019). Coping but not allowing the coping to be everything: Resilience in informal dementia care. *Health & Social Care in the Community*, *27*(4), e289-e297.

Kaiser, S., & Panegyres, P. K. (2007). The psychosocial impact of young onset dementia on spouses. *American Journal of Alzheimer's Disease & Other Dementias®*, *21*(6), 398-402.

Kiely, K.M., Leach, L.S., Olesen, S.C. and Butterworth, P., 2015. How financial hardship is associated with the onset of mental health problems over time. *Social psychiatry and psychiatric epidemiology*, *50*(6), pp.909-918.

Kimura, N. R., Maffioletti, V. L., Santos, R. L., Baptista, M. A. T., & Dourado, M. C. (2015). Psychosocial impact of early onset dementia among caregivers. *Trends in psychiatry and psychotherapy*, *37*(4), 213-219.

Kitwood T (1997) Dementia Reconsidered: The Person Comes First. Open University Press, Buckingham.

Kneebone, I. I., & Martin, P. R. (2003). Coping and caregivers of people with dementia. *British journal of health psychology*, *8*(1), 1-17.

Kobiske, K. R., & Bekhet, A. K. (2018). Resilience in caregivers of partners with young onset dementia: A concept analysis. *Issues in mental health nursing*, *39*(5), 411-419.

Kobiske, K. R., Bekhet, A. K., Garnier-Villarreal, M., & Frenn, M. (2019). Predeath grief, resourcefulness, and perceived stress among caregivers of partners with young-onset dementia. *Western journal of nursing research*, *41*(7), 973-989.

Kramer, B. J. (1997). Differential predictors of strain and gain among husbands caring for wives with dementia. *The Gerontologist*, *37*(2), 239-249.

Kronmüller, K.T., Backenstrass, M., Victor, D., Postelnicu, I., Schenkenbach, C., Joest, K., Fiedler, P. and Mundt, C., (2011). Quality of marital relationship and depression: Results of a 10-year prospective follow-up study. *Journal of Affective Disorders*, *128*(1-2), pp.64-71.

Kurz, A., Bakker, C., Böhm, M., Diehl-Schmid, J., Dubois, B., Ferreira, C., ... & de Vugt, M. (2016). RHAPSODY–Internet-based support for caregivers of people with young onset dementia: program design and methods of a pilot study. *International Psychogeriatrics*, *28*(12), 2091-2099.

Lai, M., Jeon, Y.H., McKenzie, H. and Withall, A., (2023). Journey to Diagnosis of Young-Onset Dementia: A Qualitative Study of People with Young-Onset Dementia and their Family Caregivers in Australia. *Dementia*, *22*(5), pp.1097-1114.

Lam, K., Chan, W.S., Luk, J.K. and Leung, A.Y., 2019. Assessment and diagnosis of dementia: a review for primary healthcare professionals. *Hong Kong Medical Journal*, *25*(6), p.473.

Langdridge, D. (2007). Phenomenological psychology: Theory, research, and method. Harlow, England: Prentice Hall.

Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal and coping. New York: Springer.

Larkin, M., Flowers, P., & Smith, J. A. (2022). Interpretative phenomenological analysis: Theory, method and research.

Larochette, C., Wawrziczny, E., Papo, D., Pasquier, F., & Antoine, P. (2020). An acceptance, role transition, and couple dynamics-based program for caregivers: A qualitative study of the experience of spouses of persons with young-onset dementia. *Dementia*, *19*(8), 2714-2731.

Lockeridge, S., & Simpson, J. (2013). The experience of caring for a partner with young onset dementia: How younger carers cope. *Dementia*, *12*(5), 635-651.

Loi, S. M., Flynn, L., Cadwallader, C., Stretton-Smith, P., Bryant, C., & Baker, F. A. (2022). Music and Psychology & Social Connections Program: Protocol for a Novel Intervention for Dyads Affected by Younger-Onset Dementia. *Brain Sciences*, *12*(4), 503.

Luscombe, G., Brodaty, H. and Freeth, S. (1998). Younger people with dementia: diagnostic issues, effects on carers and use of services. International Journal of Geriatric Psychiatry, 13, 323–330.

Malmqvist, J., Hellberg, K., Möllås, G., Rose, R., & Shevlin, M. (2019). Conducting the pilot study: A neglected part of the research process? Methodological findings supporting the importance of piloting in qualitative research studies. *International Journal of Qualitative Methods*, *18*, 1609406919878341.

Masellis, M., Sherborn, K., Neto, P. R., Sadovnick, D. A., Hsiung, G. Y. R., Black, S. E., ... & Gauthier, S. (2013). Early-onset dementias: diagnostic and etiological considerations. *Alzheimer's Research & Therapy*, *5*(1), 1-22.

Massimo, L., Evans, L. K. and Benner, P. (2013). Caring for loved ones with frontotemporal degeneration: the lived experiences of spouses. Geriatric Nursing, 34, 302–306. doi: 10.1016/j.gerinurse.2013.05.001.

Mayrhofer, A., Mathie, E., McKeown, J., Bunn, F., & Goodman, C. (2018). Age-appropriate services for people diagnosed with young onset dementia (YOD): a systematic review. *Aging & Mental Health*, *22*(8), 933-941.

McLeod, J. (2003). Doing Counselling Research (2nd Ed). London: Sage.

McMurtray, A., Clark, D.G., Christine, D. and Mendez, M.F., (2006). Early-onset dementia: frequency and causes compared to late-onset dementia. *Dementia and geriatric cognitive disorders*, *21*(2), pp.59-64.

Mendez, M. F. (2006). The accurate diagnosis of early-onset dementia. *The International Journal of Psychiatry in Medicine*, *36*(4), 401-412.

Millenaar, J.K., Bakker, C., Koopmans, R.T., Verhey, F.R., Kurz, A. and de Vugt, M.E., (2016). The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: a systematic review. *International journal of geriatric psychiatry*, *31*(12), pp.1261-1276.

Millenaar, J. K., de Vugt, M. E., Bakker, C., van Vliet, D., Pijnenburg, Y. A., Koopmans, R. T., & Verhey, F. R. (2016). The impact of young onset dementia on informal caregivers compared with late onset dementia: results from the NeedYD study. *The American Journal of Geriatric Psychiatry*, *24*(6), 467-474.

Miller, B. L., Darby, A., Benson, D. F., Cummings, J. L., & Miller, M. H. (1997). Aggressive, socially disruptive and antisocial behaviour associated with fronto-temporal dementia. *The British journal of psychiatry*, *170*, 150.

Mioshi, E., Bristow, M., Cook, R., & Hodges, J. R. (2009). Factors underlying caregiver stress in frontotemporal dementia and Alzheimer’s disease. *Dementia and geriatric cognitive disorders*, *27*(1), 76-81.

Mitchell, W. (2022). *What I Wish People Knew about Dementia: From Someone who Knows*. Bloomsbury Publishing.

Montgomery, R. J., & Kosloski, K. D. (2013). Pathways to a caregiver identity and implications for support services. In *Caregiving across the lifespan* (pp. 131-156). Springer, New York, NY.

MSNAP. (2022) Memory Services National Accreditation Programme. *Quality Standards for Memory Services* (8th ed., J. Jethwa, M.Fern, C. Abhayaratne, & K. Wariabharaj, Eds). Royal College of Psychiatrists.

Nelis, S. M., Wu, Y. T., Matthews, F. E., Martyr, A., Quinn, C., Rippon, I., ... & Clare, L. (2019). The impact of co-morbidity on the quality of life of people with dementia: findings from the IDEAL study. *Age and Ageing*, *48*(3), 361-367.

Nguyen, T. and Li, X., (2020). Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia*, *19*(2), pp.148-181.

Nishiura, Y., Nihei, M., Nakamura-Thomas, H., & Inoue, T. (2021). Effectiveness of using assistive technology for time orientation and memory, in older adults with or without dementia. *Disability and Rehabilitation: Assistive Technology*, *16*(5), 472-478.

Novek, S., Shooshtari, S., & Menec, V. H. (2016). Comparing the overall health, stress, and characteristics of Canadians with early-onset and late-onset dementia. *Journal of aging and health*, *28*(6), 1016-1037.

Nwadiugwu M. 2021. Early-onset dementia: key issues using a relationship-centred care approach *Postgraduate Medical Journal* 2021;97:598-604.

O'Mahoney, J. (2016). Critical Realism and Qualitative Research: An Introductory Overview.

O'Malley, M., Parkes, J., Stamou, V., LaFontaine, J., Oyebode, J., & Carter, J. (2019). Young-onset dementia: scoping review of key pointers to diagnostic accuracy. *BJPsych Open*, *5*(3), e48.

O'Malley, M., Carter, J., Stamou, V., LaFontaine, J., Oyebode, J., & Parkes, J. (2021). Receiving a diagnosis of young onset dementia: A scoping review of lived experiences. *Aging & mental health*, *25*(1), 1-12.

Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2023). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical teacher*, *45*(3), 241-251.

Oyebode, J., Jones, B., Blakey, H., Parveen, S., Bakker, C., Millenaar, J., & Gage, H. (2016). Service needs in young onset dementia: How closest relatives balance being a carer, being a care manager and meeting their own needs. In *Journal of Neurochemistry* (Vol. 138, pp. 261-261).

Pappadà, A., Chattat, R., Chirico, I., Valente, M., & Ottoboni, G. (2021). Assistive technologies in dementia care: An updated analysis of the literature. *Frontiers in psychology*, *12*, 644587.

Parsons, G, S. (2019). Help seeking increases stress among caregivers of partners with young-onset dementia. *Evidence-based nursing*.

Paul, S., & Haugh, S. (2008). The relationship not the therapy? What the research tells us. In S. Paul, & S. Haugh (Eds.), The therapeutic relationship: Perspectives and themes (pp. 9–22). PCCS Books.

Peet, J. (2014) The influence of social location on the experience of early dementia. Unpublished PhD thesis. University of Kent

Popok, P. J., Reichman, M., LeFeber, L., Grunberg, V. A., Bannon, S. M., & Vranceanu, A. M. (2022). One diagnosis, two perspectives: Lived experiences of persons with young-onset dementia and their care-partners. *The Gerontologist*, *62*(9), 1311-1323.

Pöysti, M.M., Laakkonen, M.L., Strandberg, T., Savikko, N., Tilvis, R.S., Eloniemi-Sulkava, U. and Pitkälä, K.H., (2012). Gender differences in dementia spousal caregiving. *International journal of Alzheimer's disease*, *2012*.

Quinn, C., Clare, L., Pearce, A., & Van Dijkhuizen, M. (2008). The experience of providing care in the early stages of dementia: An interpretative phenomenological analysis. *Aging and Mental Health*, *12*(6), 769-778.

Quinn, C., Pickett, J. A., Litherland, R., Morris, R. G., Martyr, A., & Clare, L. (2022). Living well with dementia: What is possible and how to promote it. *International Journal of Geriatric Psychiatry*, *37*(1).

Rabanal LI, Chatwin J, Walker A. (2018) Understanding the needs and experiences of people with young onset dementia: a qualitative study. *BMJ Open* 2018;8:e021166. doi: 10.1136/bmjopen-2017-021166.

Regan, J.L., (2016). Ethnic minority, young onset, rare dementia type, depression: a case study of a Muslim male accessing UK dementia health and social care services. *Dementia*, *15*(4), pp.702-720.

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. Psychologist, 18, 20-23.

Richardson, G.E., (2002). The metatheory of resilience and resiliency. *Journal of clinical psychology*, *58*(3), pp.307-321.

Richardson, A., Pedley, G., Pelone, F., Akhtar, F., Chang, J., Muleya, W., & Greenwood, N. (2016). Psychosocial interventions for people with young onset dementia and their carers: a systematic review. *International Psychogeriatrics*, *28*(9), 1441-1454.

Rickardsson, N., & Crooks, S. (2021). Using the Newcastle model to understand and manage behaviors that challenge in dementia: A case study. *Clinical Case Studies*, *20*(6), 452-467.

Ritchie, L., Tolson, D., & Danson, M. (2018). Dementia in the workplace case study research: understanding the experiences of individuals, colleagues and managers. *Ageing & Society*, *38*(10), 2146-2175.

Rose, S. K., Strauss, M. E., Neundorfer, M. M., Smyth, K. A., & Stuckey, J. C. (1997). The relationship of self-restraint and distress to coping among spouses caring for persons with Alzheimer's disease. *Journal of Applied Gerontology*, *16*(1), 91-103.

Rosness, T. A., Mjørud, M., & Engedal, K. (2011). Quality of life and depression in carers of patients with early onset dementia. *Aging & mental health*, *15*(3), 299-306.

Rossor, M. N., Fox, N. C., Mummery, C. J., Schott, J. M., & Warren, J. D. (2010). The diagnosis of young-onset dementia. *The Lancet Neurology*, *9*(8), 793-806.

Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing & Society*, *12*(4), 443-461.

Sampson, E. L., Warren, J. D., & Rossor, M. N. (2004). Young onset dementia. *Postgraduate medical journal*, *80*(941), 125-139.

Sass, C., Griffiths, A. W., Shoesmith, E., Charura, D., & Nicholson, P. (2022). Delivering effective counselling for people with dementia and their families: Opportunities and challenges. *Counselling and Psychotherapy Research*, *22*(1), 175-186.

Schaffler-Schaden, D., Krutter, S., Seymer, A., Eßl-Maurer, R., Flamm, M., & Osterbrink, J. (2021). Caring for a relative with dementia: Determinants and gender differences of caregiver burden in the rural setting. *Brain Sciences*, *11*(11), 1511.

Seshadri, S., Wolf, P. A., Beiser, A., Au, R., McNulty, K., White, R., & D'agostino, R. B. (1997). Lifetime risk of dementia and Alzheimer's disease: the impact of mortality on risk estimates in the Framingham Study. *Neurology*, *49*(6), 1498-1504.

Shang, X., Roccati, E., Zhu, Z., Kiburg, K., Wang, W., Huang, Y., Zhang, X., Zhang, X., Liu, J., Tang, S. and Hu, Y., (2023). Leading mediators of sex differences in the incidence of dementia in community-dwelling adults in the UK Biobank: a retrospective cohort study. *Alzheimer's Research & Therapy*, *15*(1), p.7.

Shaw, R. L., Smith, L. J., & Hiles, D. R. (2018). Exploring the felt sense of chronic ill-health: dialoguing between IPA, lifeworld theory and narrative inquiry to make sense of feelings and affect. *Qualitative research in psychology*.

Shinebourne, P. (2011). The Theoretical Underpinnings of Interpretative Phenomenological Analysis (IPA). *Existential Analysis: Journal of the Society for Existential Analysis*, *22*(1).

Shnall, A. N. (2015). *When least expected: Stories of love, commitment, loss and survival-the experience and coping strategies of spouses of people with an early-onset dementia* (Doctoral dissertation).

Shoesmith, E., Griffiths, A. W., Sass, C., & Charura, D. (2022). Effectiveness of counselling and psychotherapeutic interventions for people with dementia and their families: A systematic review. *Ageing & Society*, *42*(4), 962-989.

Shuter, P., Beattie, E., & Edwards, H. (2014). An exploratory study of grief and health-related quality of life for caregivers of people with dementia. American Journal of Alzheimer's Disease & Other Dementias®, 29(4), 379–385. https://doi.org/10.1177/1533317513517034

Smith, J. (2007). Hermenutics, human sciences and health: Linking theory and practice. International Journal of Qualitative Studies on Health and Well-being, 2(1), pp. 3-11. http://dx.doi.org/10.1080/17482620601016120 (cited in Muganga, L. (2015). The importance of hermeneutic theory in understanding and appreciating interpretive inquiry as a methodology. *Journal of Social Research & Policy*, *6*(1), 65.)

Smith, A. J., Flowers, P., & Larkin, M. (2009). Interpretative Phenomenological Analysis . London: Sage .

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. Qualitative Research in Psychology, 1(1), 39-54. doi: 10.1191/1478088704qp004oa

Smith, J. A. (2007). Qualitative psychology: a practical guide to research methods. London: Sage.

Smith, J. A. (2011). “We could be diving for pearls”: The value of the gem in experiential qualitative psychology. Qualitative Method in Psychology Bulletin, 12, 6-15.

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), Qualitative psychology: A practical guide to methods (pp. 53-80). London, UK: Sage.

Smith, J. A., Flowers, P., & Larkin, M. (2022). Interpretative phenomenological analysis: Theory, method and research. London, UK: Sage.

Smith, L., Chesher, I., Fredriksen-Goldsen, K., Ward, R., Phillipson, L., Newman, C.E. and Delhomme, F., (2022). Investigating the lived experience of LGBT+ people with dementia and their care partners: a scoping review. *Ageing & Society*, pp.1-24.

Snow, K., Cheston, R., & Smart, C. (2016). Making sense of dementia: Exploring the use of the Markers of Assimilation of Problematic Experiences in Dementia scale to understand how couples process a diagnosis of dementia. *Dementia*, *15*(6), 1515-1533.

Stamou, V., La Fontaine Papadopoulos, J. H., Oyebode, J. R., Jones, B., Gage, H., O'Malley, M., ... & Carter, J. (2018). The ANGELA Project: Improving diagnosis and post-diagnostic support for younger people with dementia and their families/supporters.

Stamou, V., La Fontaine, J., O'Malley, M., Jones, B., Parkes, J., Carter, J., & Oyebode, J. R. (2022). Helpful post-diagnostic services for young onset dementia: findings and recommendations from the Angela project. *Health & social care in the community*, *30*(1), 142-153.

Stanley K, Walker Z (2014) Do patients with young onset Alzheimer’s disease deteriorate faster than those with late onset Alzheimer’s disease? A review of the literature. Int Psychogeriatr 26, 1945-1953.

Statz, T. L., Peterson, C. M., Birkeland, R. W., McCarron, H. R., Finlay, J. M., Rosebush, C. E., ... & Gaugler, J. E. (2022). “We moved her too soon”: Navigating guilt among adult child and spousal caregivers of persons living with dementia following a move into residential long-term care. *Couple and Family Psychology: Research and Practice*, *11*(4), 300.

Sullivan, M. P., Williams, V., Grillo, A., McKee-Jackson, R., Camic, P. M., Windle, G., ... & Rare Dementia Support (RDS) research team. (2022). Peer support for people living with rare or young onset dementia: An integrative review. *Dementia*, *21*(8), 2700-2726.

Svanberg, E., Spector, A., & Stott, J. (2011). The impact of young onset dementia on the family: a literature review. *International Psychogeriatrics*, *23*(3), 356-371.

Swaffer, K. (2014). Dementia: Stigma, language, and dementia-friendly. *Dementia*, *13*(6), 709-716.

Thorsen, K. and Johannessen, A., (2022). How gender matters in demanding caring for a spouse with young-onset dementia. A narrative study. *Journal of Women & Aging*, pp.1-17.

Tieu, M., & Matthews, S. (2024, February). The relational care framework: Promoting continuity or maintenance of selfhood in person-centered care. In *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine* (Vol. 49, No. 1, pp. 85-101). US: Oxford University Press.

University of California San Francisco, UCSF (2012). The Challenges of FTD vs. Alzheimer's. Retrieved from: http://memory.ucsf.edu/ftd/ livingwithftd/caregiving/challenges/single.

Vieira, R. T., Caixeta, L., Machado, S., Silva, A. C., Nardi, A. E., Arias-Carrión, O., & Carta, M. G. (2013). Epidemiology of early-onset dementia: a review of the literature. *Clinical practice and epidemiology in mental health: CP & EMH*, *9*, 88.

Vitaliano, P.P., Scanlan, J.C., & Zhang, J. (2003). Is caregiving hazardous to one's physical health? A metaanalysis. Psychological Bulletin, 129, 1–27.

Van Vliet, D., de Vugt, M. E., Bakker, C., Koopmans, R. T., & Verhey, F. R. (2010). Impact of early onset dementia on caregivers: a review. *International journal of geriatric psychiatry*, *25*(11), 1091-1100.

Walster, E., Walster, G., & Berscheid, E. (1978). Equity theory and research.

Wawrziczny, E., Antoine, P., Ducharme, F., Kergoat, M. J., & Pasquier, F. (2016). Couples' experiences with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics. *Dementia*, *15*(5), 1082-1099.

Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M. J., & Antoine, P. (2017). Do spouse caregivers of persons with early-and late-onset dementia cope differently? A comparative study. *Archives of Gerontology and Geriatrics*, *69*, 162-168.

Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M. J., & Antoine, P. (2017). Do spouse caregivers of young and older persons with dementia have different needs? A comparative study. *Psychogeriatrics*, *17*(5), 282-291.

Wawrziczny, E., Berna, G., Ducharme, F., Kergoat, M. J., Pasquier, F., & Antoine, P. (2017). Modeling the distress of spousal caregivers of people with dementia. *Journal of Alzheimer's Disease*, *55*(2), 703-716.

Wawrziczny, E., Berna, G., Ducharme, F., Kergoat, M. J., Pasquier, F., & Antoine, P. (2018). Characteristics of the spouse caregiving experience: Comparison between early-and late-onset dementia. *Aging & mental health*, *22*(9), 1213-1221.

Werner, P., Shpigelman, C.N. and Raviv Turgeman, L., (2020). Family caregivers' and professionals' stigmatic experiences with persons with early-onset dementia: a qualitative study. *Scandinavian journal of caring sciences*, *34*(1), pp.52-61.

WHO (2021). Available from: https://www.who.int/news-room/fact-sheets/detail/dementia [Accessed 18 December 2021]

Winter, B. (2020). *Exploring the Relationship of Couples Living with Dementia and the Role of Couples Therapy: A Thematic Analysis* (Doctoral dissertation, University of the West of England).

Wittenberg, D., Possin, K. L., Rascovsky, K., Rankin, K. P., Miller, B. L., & Kramer, J. H. (2008). The early neuropsychological and behavioral characteristics of frontotemporal dementia. *Neuropsychology review*, *18*, 91-102.

Wong, C., Merrilees, J., Ketelle, R., Barton, C., Wallhagen, M., & Miller, B. (2012). The experience of caregiving: differences between behavioral variant of frontotemporal dementia and Alzheimer disease. *The American Journal of Geriatric Psychiatry*, *20*(8), 724-728.

Xiong, C., Biscardi, M., Astell, A., Nalder, E., Cameron, J.I., Mihailidis, A. and Colantonio, A., (2020). Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: A systematic review. *PLoS One*, *15*(4), p.e0231848.

Youell, J., Callaghan, J. E., & Buchanan, K. (2016). 'I don't know if you want to know this': carers' understandings of intimacy in long-term relationships when one partner has dementia. *Ageing & Society*, *36*(5), 946-967.

Young Dementia Network. A Decision-Making Guide for GPs. Young Dementia Network, 2017 (https://www.youngdementiauk.org/gp-guide).

Youngdementiauk (2021). Available from: https://www.youngdementianetwork.org [Accessed on 21 November, 2021]

Zhang S, Edwards H, Yates P, Li C, Guo Q. Self-efficacy partially mediates between social support and health-related quality of life in family caregivers for dementia patients in Shanghai. Dement Geriatr Cogn Disord. 2014; 37(1–2):34–44.

Appendices

Appendix 1: Ethical approval to proceed

This appendix has been removed as it contains personal information.

Appendix 2: Recruitment flyer and email to dementia charities

Angela Goldsmith
Trainee Counselling Psychologist
Dr Antonietta DiCaccavo
Practitioner Counselling Psychologist

Research participants needed

The Experiences of Caring for a Partner with Young Onset Dementia

I am conducting research to explore the personal experiences of individuals who are caring for a partner living with Young Onset Dementia. You will be asked to take part in an individual audio recorded interview lasting for up to one hour. The focus is to explore how you experience and make sense of:

- The transition to caregiver role
- Coping strategies used to adapt to changes in your relationship
- Your experience of stigma and the impact it may have on your relationship
- The dynamics in your relationship

I appreciate that it may be difficult to talk about your experiences, but I am keen to hear your voice in order to further understand and make a positive difference to individuals affected by Young Onset Dementia.

If you are currently living with and caring for a partner with Young Onset Dementia then I would be really interested to hear and talk about your experiences. If you would like to know more about this research, then please email me:

angela2.goldsmith@live.uwe.ac.uk

Thank you for your interest.

Recruitment email to dementia charity:

(Email will be sent from researchers university email address)

Hello,

I previously got in touch to tell you about my research on the experiences of caring for a partner with young onset dementia. You kindly offered to advertise my study through your monthly newsletter and social media channels. Would this still be possible? If so, could I please forward you a recruitment flyer? I am looking for a maximum of 8 participants who would be willing to talk about their experiences of caring for a partner with young onset dementia, either face to face, online or via telephone.

It is not advised for me to have direct contact with participants so please could any communication between myself and potential participants be made via a specific member of staff at your charity?

Please let me know if you need any further information.

Kind regards

Angela Goldsmith

Trainee Counselling Psychologist studying at The University of the West of England.

Appendix 3: Participant information sheet

Participant Information Sheet

The Experiences of Caring for a Partner with Young Onset Dementia:

You are being invited to take part in some research. Before you decide whether or not to participate, it is important for you to understand why the research is being conducted and what it will involve. Please read the following information carefully.

What is the purpose of the research?

I am conducting research to explore the personal experiences of individuals who are caring for a partner with young onset dementia. The focus is to explore how you experience and make sense of:

- The transition to caregiver role.
- Coping strategies used to adapt to changes in your relationship.
- Your experience of stigma and the impact it may have on your relationship.
- The dynamics in your relationship.

It is hoped that the research will generate and develop critical knowledge, evidence and further questions to make a positive difference to individuals affected by young onset dementia.

The research requires a maximum of eight participants, so not everyone returning a consent form may be able to take part.

Who is carrying out the research?

The data is being collected by myself, Angela Goldsmith. I am a Trainee Counselling Psychologist studying on a Professional Doctorate in Counselling Psychology at The University of the West of England (UWE) and it is for the purpose of my Doctoral Research.

What happens if I agree to take part?

The research will require you to take part in an interview where you will be asked to talk about your personal thoughts and experiences of caring for your partner. If you require any additional information, feel free to ask questions at any point. I understand that discussing these sensitive issues may lead to some uncomfortable emotional reactions. If you feel that you have been affected by anything we talk about in the interview, I will signpost you to additional support services such as ‘NHS’, ‘MIND’ and ‘Samaritans’.

The interview will last for approximately one hour. It will be recorded using an electronic voice recording device and later written up word for word. It. The interview can be held in a number of different ways and locations and it is your decision as to which option you feel would best suit you. Firstly, interviews can be held face-to-face (COVID-19 dependent) in a private room at the researcher's workplace in Swansea Bay University Health Board, South Wales. The location will either be Tonna Hopsital in Neath, or Port Talbot Resource Centre in Port Talbot (depending on availability of rooms). Face-to-face interviews may also be held at a private room on Frenchay campus at The University of the West of England in Bristol. Secondly, there is the option for the interviews to be conducted via video platforms Microsoft Teams or Zoom, and thirdly, the interviews can be conducted via telephone. Participants can conduct video and telephone calls from a place of their choosing but it is important that this is a confidential space and free from potential distractions.

Is participation voluntary and what if I wish to later withdraw?

Your participation is entirely voluntary – you do not have to participate if you do not wish to. If you decide to participate, but later wish to withdraw from the study, then you are free to withdraw within four weeks of completing the interview, without giving a reason. After four weeks it will not be possible to withdraw as analysis of the data will have commenced. If you do decide to take part, you will be given an electronic copy of this information sheet to keep and will be asked to sign an electronic consent form and fill in an electronic demographics form.

If you would like to ask any further questions, please feel free to contact me (contact details are at the bottom of this information sheet).

What will happen to the information I provide?

All information you provide will only be used as part of this study, and not for any other purpose. The information you provide will not be shared with anyone, unless we think it is necessary to protect your health and wellbeing or to protect the health and wellbeing of someone else. If this matter arises we will discuss it with you in the first instance. All anonymous information gathered as part of this study will only be made available to my research supervisors at The University of the West of England.

Any personal identifiable information (such as names and places) will be changed when the interview is written up to ensure your confidentiality is preserved.

An analysis of the information will take place and form part of my report at the end of the study. The study may be presented to interested parties and published in psychology journals and related media. The completed report will be available on The University of the West of England's open-access Research Repository.

Quotations from interviews may be used in research reports to illustrate themes, however, please note that if information you have provided was used in a report, you would not be named.

UWE is the sponsor for this study based in the United Kingdom. I will be using information from you in order to undertake this study and will act as the data controller for this study. This means I am responsible for looking after your information and using it properly.

Confidentiality and anonymity will be further maintained by changing identifiable information to a participant number and storing all data on an encrypted USB drive which will be used on a password protected computer. Once the interview data has been uploaded from the voice recorder to the computer, it will be deleted from the voice recording device. Any paperwork relating to the research will be stored securely in a locked filing cabinet in the researcher's home office. Once the research has been submitted and assessed by UWE, and any publications written up, all paperwork will be shredded. Interview data will be stored electronically for 3 years before deletion.

Who has reviewed this study?

Approval has been sought by the UWE Research Ethics Committee and the relevant dementia organisation you were recruited from in order for me to carry out this research. All work within this research is discussed and approved by my supervisory team.

Any comments, questions or complaints about the ethical conduct of this study can be addressed to my Director of Studies Dr Toni DiCaccavo.

What if there is a problem?

If there is a problem of any kind you will be able to stop the interview at any point and take a break if you need to.

I do not foresee any problems from your taking part in the study. However, if there is anything you are not happy with, please contact me where I will do my best to answer your questions.

If you would like to make a complaint you can contact UWE Research Ethics department via email on:

researchethics@uwe.ac.uk

Thank you for agreeing to take part in this study.

You will be given a copy of this Participant Information Sheet and your signed Consent Form to keep.

Angela Goldsmith

Researcher

Trainee Counselling Psychologist

University of the West of England

Angela2.Goldsmith@live.uwe.ac.uk

Dr Antonietta DiCaccavo

Director of Studies & Research Supervisor

Chartered Psychologist

Practitioner Counselling Psychologist

CBT Psychotherapist

University of the West of England

Toni.Dicaccavo@uwe.ac.uk

Appendix 4: Participant consent form

THE EXPERIENCES OF CARING FOR A PARTNER WITH YOUNG ONSET DEMENTIA:

PARTICIPANT CONSENT FORM

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet, and had the opportunity to ask any questions before you provide your consent to take part in this study. If you have any questions please contact a member of the research team, whose details are set out on the Participant Information Sheet

If you are happy to take part in an individual interview, you will be asked for your agreement to the following points:

- I have read and understood the information in the Participant Information Sheet which I have been given to read.
- I have been given the opportunity to ask questions about the study.
- I have had my questions answered satisfactorily by the research team.
- I agree that anonymised quotes from the interview may be used in the final report of this study.
- I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason.
- I agree for my anonymised data to be stored onto the University's data repository and understand that this data, subject to authorisation, may be reanalysed for scientific purposes.
- I agree for the interview to be audio recorded.
- I agree for my contact details to be retained so that I can be updated about the outcome of the study
- I agree that my contact details may be passed to other members of the research team and that they may contact me to discuss taking part.
- I agree to take part in the research

Name (printed): …………………………………………………………………

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

Date: ……………………………………………………………………………..

Appendix 5: Demographic data sheet

Please could you provide the following details:

Age of participant: ……………………………………………………………………………………………………..

Age of partner: ………..

Partner's dementia diagnosis:…………………………………………………………………………………..

Partner's level of cognitive impairment (i.e. mild/moderate/severe):…………………………..

Gender of participant: …………………………………………………………………………………………..

Gender of partner: ………………………………………………………………………………………………….

Length of relationship between you and your partner: ………………………………………………

Ethnicity of participant: ………………………………………………………………………………………..

Ethnicity of partner: ………………………………………………………………………………………………..

Number of dependent children: ……………………………………………………………………………

Work status of participant: …………………………………………………………………………………..

Work status of partner: …………………………………………………………………………………………

Highest educational attainment of participant: ……………………………………………………….

Highest educational attainment of partner: ……………………………………………………………

Do you consider yourself or your partner to have a disability? If so please provide details:

………

Name (printed): ……

Signature: ……………………………………………………………………………Date: ……………………………………

Appendix 6: Risk assessment form and health and safety arrangements

University of the West of England
BRISTOL

GENERAL RISK ASSESSMENT FORM

Ref:

Describe the activity being assessed: Conducting individual interviews to explore participants experiences of caring for their partner with young onset dementia, either face to face, via telephone or video call (dependent on participant preference).	**Assessed by:** Dr Antonietta DiCaccavo	**Endorsed by:** Dr Zoe Thomas
Who might be harmed: Participants and Researcher. **How many exposed to risk:** 6 – 10 participants plus 1 researcher	**Date of Assessment:** 25.11.21	**Review date(s):** 20.10.2022

Hazards Identified *(state the potential harm)*	Existing Control Measures	S	L	Risk Level	Additional Control Measures	S	L	Risk Level	By whom and by when	Date completed
The researcher will interview participants as above. (Psychological harm) Participants may find it emotionally overwhelming and distressing to talk about their experiences.	Each participant will be required to provide informed consent and sign a form. They will be provided with a participant information sheet. Participants will be briefed prior to the interview and debriefed at the end. Participants will be provided with both the researchers and Director of Studies contact details and they will also be signposted to relevant support services should they require it (e.g. Samaritans and Mind). Participants can withdraw from the study within 4 weeks of completing the interview without giving a reason. Participants will be offered a break or option to end the interview / continue at a later date if they become distressed.	1	3	3						Ongoing

The researcher will interview participants as above. (Physical harm)	The researcher will work with the relevant dementia organisation workers to identify appropriate interviewees and an appropriate location for interviews so that all participants and the researcher feel safe and have privacy. The location will either be face to face, via video or telephone call, depending on participant preference. Contact numbers for research supervisors will be kept on the researcher at all times. The research supervisors will also be made aware of when and where the researcher is conducting the interviews and the researcher will contact the research supervisors to confirm that the interviews have been conducted and that she has left the location. UWE's safety for social research guidance (G017) will also be adhered to. The interviews with all participants will take place in a private meeting room in either the researchers place of work (Swansea Bay University Health Board) or the relevant dementia organisation base. These will be pre-booked by relevant staff (e.g. administration staff at Swansea Bay University Health Board or the relevant dementia organisation).	1	3	3						Ongoing
SARSCov-2 leading to Covid	Throughout the fieldwork period, the researcher will follow any relevant UWE, Swansea Bay University Health Board, local government and national government guidance regarding covid safety measures.	3	3	9	In line with UWE policy, the researcher will take lateral flow tests twice weekly. The researcher will wear a face mask while conducting the interviews and ventilate the room as much as possible (e.g. opening windows). The	3	2	5	Researcher	Twice weekly

					researcher and participant will be seated at least two metres apart. Participants will also be asked to wear a mask and will have access to hand gel / hand washing facilities before and after the interview.				Researcher	At time of interviews
Researcher lone working - If the participant chooses to carry out the interview face-to-face.	If the researcher requires any immediate support, there will always be staff nearby (e.g. staff working at the dementia charity or researchers work colleagues / supervisor at Swansea Bay University Health Board). The researcher can call the emergency duty contact number or contact emergency services if needed. The researcher will inform both UWE research supervisor and clinical supervisor at work of my location and time of interviews. The UWE lone working policy (G033) as well as the health boards lone working policy will be adhered to and will be integral to the implementation of all aspects of the project.	1	1	1						At time of interviews
Researcher distress	The researcher can contact the DOS - Dr Antonietta DiCaccavo as well the second supervisor – Dr Nancy Zook for support if required. The researcher is also aware of the staff wellbeing services in Swansea Bay University Health Board and how to access these if necessary.	1	3	3						Ongoing

	The researcher is currently having weekly personal therapy.									

RISK MATRIX: (To generate the risk level).

Very likely **5**	**5**	**10**	**15**	**20**	**25**
Likely **4**	**4**	**8**	**12**	**16**	**20**
Possible **3**	**3**	**6**	**9**	**12**	**15**
Unlikely **2**	**2**	**4**	**6**	**8**	**10**
Extremely unlikely **1**	**1**	**2**	**3**	**4**	**5**
Likelihood (L) ↑ → **Severity (S)**	**Minor injury – No first aid treatment required** **1**	**Minor injury – Requires First Aid Treatment** **2**	**Injury - requires GP treatment or Hospital attendance** **3**	**Major Injury** **4**	**Fatality** **5**

ACTION LEVEL: (To identify what action needs to be taken).

POINTS:	RISK LEVEL:	ACTION:
1 – 2	NEGLIGIBLE	No further action is necessary.
3 – 5	TOLERABLE	Where possible, reduce the risk further
6 - 12	MODERATE	Additional control measures are required
15 – 16	HIGH	Immediate action is necessary
20 - 25	INTOLERABLE	Stop the activity/ do not start the activity

Appendix 7: Interview Schedule

The experiences of caring for a partner with young onset dementia

Interview guide

1. Can you tell me a bit about your partner?

   Possible prompts: How would you describe them?

   How long have you been together?

The transition to caregiver role.

2. Can you tell me about your partner's diagnosis?
3. What did you and your partner notice in the lead up to diagnosis?
4. How did you go about getting diagnosed?
5. How did you and your partner feel when you first received the diagnosis?
6. Can you tell me about your partners current support needs and what it is like to care for them?
7. How does your experience of caring affect your other roles and responsibilities? Such as: work life, relationship, identity, childcare and parenting.

Relational dynamics within the dyad (How participant relates, interacts and communicates with their partner)

8. What do you think has changed since your partner developed dementia?
9. What was your relationship like before dementia and what is it like now?
10. Have some things stayed the same? What is different?
11. How do you think your partner sees you?

Coping strategies used to adapt to changes in their relationship.

12. Can you describe how you have coped with changes in your relationship? Possible prompts: these can be both emotional and physical/practical ways of coping.
13. Can you tell me about any current support you and your partner are receiving / or if none what support do you think would be helpful going forward? (i.e. from family, health professionals and / or dementia charities).

Experience of stigma and the impact on their relationship.

14. Have you ever experienced any negative or discriminatory attitudes towards you and your partner in relation to dementia? If so how did this make you feel?

Future

15. Can you tell me how you see your relationship with your partner in the future?

Ending

16. How have you felt talking about these issues today? Is there anything that you would like to add?

Appendix 8: Theme development participant 1

This appendix has been removed to protect participant anonymity.

This appendix has been removed to protect participant anonymity.

Appendix 9: Master table of Personal Experiential Themes (PETs)

Master Table of Personal Experiential Themes (PETs) for participants

Personal Experiential Themes (PETs)	**Participant**	**Key words from transcript & page number**
Living with uncertainty Not knowing Frustration Anger	Mary	He was angry and frustrated about everything (6)
	Wendy	His anger levels went through the roof (3)
	Edward	I feel frustrated by it (4)
	Caroline	He had an almighty blow out (12)
	Heidi	He gave all his anger out on me (15)
	Barbara	He's lashed out a few times (15)
Misdiagnosis You're too young It must be anxiety or depression Prolongs the journey to diagnosis	Mary	The doctors put it down to depression (3)
	Wendy	They were convinced it was depression (2)
	Caroline	It's most likely depression (2)
	Fiona	They put it down to stress and anxiety (3)
	Chris	GP was convinced it was anxiety and depression (4)
	Barbara	He started antidepressants and that didn't help (4)
Diagnosis provides relief and understanding Shock and denial for partner Emotional impact is huge	Mary	There was this sense of relief (5)
	Wendy	Paul was more shocked (5)
	Edward	I was sort of relieved (4)
	Caroline	With me it was relief, with Martin horror and denial (2)

Receiving the diagnosis in writing was brutal	Heidi	For me it was a shock (5)
	Fiona	It was utter relief (3)
	Barbara	When you see it in writing it's brutal (8)
Lack of post-diagnostic support Dumped by services Walking in the dark Ignored and forgotten Age inappropriate services	Wendy	The support you get is appalling (6)
	Edward	We just seem to be ignored or forgotten (12)
	Caroline	I wish they would listen (4)
	Heidi	They just don't listen (14)
	Fiona	Left floundering then booted out the door (7)
	Chris	Diagnosed and dumped (5)
	Barbara	Walking in the dark (22)
Lack of awareness and understanding from others Misperceptions of dementia Negative attitudes	Wendy	People's perception, you know (6)
	Edward	People don't understand (5)
	Caroline	They don't understand what's wrong (17)
	Fiona	People have more sympathy for the elderly (16)
	Chris	People don't expect it in a young person (17)
Changes in relationship and identity From partner to carer Role reversal Loneliness We used to be best friends	Mary	We used to talk about everything (11)
	Wendy	He used to be my rock (9)
	Edward	I've given up my name, I'm him (2)
	Caroline	We was best friends (14) he's like a weird uncle (18) Andrew has to get the spiders (15)
	Heidi	I do absolutely everything now (7)

	Fiona	I feel like a sofa widow (10)
	Chris	It’s easier if I do the cooking now (15)
We were robbed by dementia Loss of future plans Loss of sex life and intimacy Loss of emotional connection Loss of partner Loss of friendships Loss of autonomy Social isolation	Edward	I can’t go anywhere (2)
	Caroline	We don’t have sex anymore (11)
	Heidi	I lost all my friends (6) we haven’t had sex for 6 years (7)
	Fiona	There’s no sexual relationship (12) dementia has had him longer than I have (11)
	Barbara	We were going to do all these amazing things (21)
Coping with changes Assistive technology Avoidance Acceptance Externalising – it’s the dementia Developing resilience Need to connect with similar people Counselling helps	Mary	Need to rely on Alexa (9) Counselling helps (15)
	Wendy	I try not to think about it (8)
	Edward	It’s just the disease (5)
	Caroline	Acceptance, strength and inner peace (13)
	Heidi	What will be will be (19)
	Chris	I don’t think about it (14)
	Barbara	I avoid any negative emotion (21)
Impact on family is negative Strain on relationships with children Children don’t understand	Mary	They would just fight and argue (10) He’s not interested in the children (10)
	Wendy	He was ostracising the children (4)
	Heidi	My sons didn’t understand (9)
	Barbara	The relationship has never recovered (10)

Appendix 10: Research diary entry

Date: 24/10/22

Today I interviewed participant number 4 in person, on campus at UWE, as requested by the participant. The dedication she showed by travelling all the way from Wolverhampton with her son emphasised the importance of this research. I met with my participant and her son prior to the interview and bought them a coffee. They were very warm and friendly people. My participant's son took a walk around the campus while we went off to the interview room. The personal connection we established in person added depth to our meeting, in contrast to the virtual interviews conducted thus far on teams and over the phone. There is something about being in the same space that virtual sessions just can't replicate. Holding the interview in person brought a sense of relaxation and confidence for me that the virtual/phone interactions lacked.

Witnessing my participant's gratitude for the opportunity to take part highlighted the therapeutic nature of the interview. She was genuinely grateful for being part of this study, and it made me think of the potential positive impact this study could have on my participants. This felt warm and satisfying. What surprised me most is how therapeutic she reported the interview being for her; she saw it as a means to contribute to the development of support for carers of people living with young onset dementia, and others in a similar position to her who might be struggling to care for their partner. She reported that the interview served as an escape from her demanding caring role, which made me think of the challenges she must face on a daily basis. The session ran slightly over the planned time but enabled me to gather a wealth of rich data. It turned out to be an incredibly rewarding experience for both me and my participant.

Appendix 11: Further reflections on the research journey

Initially I thought about researching the experiences of caring for a partner with late onset dementia, as my occupational background in psychology involved working with people living with late onset dementia and their carers. However, through discussions with my supervisor I came to the realisation that I had little experience of working with people living with young onset dementia and their carers. Therefore, I chose to focus my research in this area to broaden my existing knowledge of dementia. I was also mindful that the occupational path I would pursue post doctorate would likely be in older adult mental health services and that having research experience in this area would support my career goals. Furthermore, as young onset dementia was a new area of learning for me, I felt that it would fuel and maintain my interest for the entire research journey.

At the start of my research journey discussions with my supervisor led me to consider recruitment of participants either via the NHS or via dementia charities. I contacted a consultant psychiatrist in older adult mental health who holds a clinic for people living with young onset dementia in the health board I work in. I thought about asking if this could be a possible recruitment route. However, due to lack of response, I decided to contact two well-known dementia charities to discuss recruitment, namely ‘The Alzheimer’s Society’ and ‘Dementia UK’. Both charities responded promptly and offered to advertise the study. The communication I had from Dementia UK was very helpful and they informed me that they also host ‘The Young Dementia Network’ – an online community of people living with young onset dementia, their family, friends and professionals. As such I chose to advertise the study via this network initially, then, if further participants were required, my plan was to advertise via ‘The Alzheimer’s Society’. Thankfully I managed to recruit all participants via The Young Dementia Network. I had a good response to the study and was able to recruit and interview everyone who expressed an interest and met the study inclusion criteria. I conducted the interviews over the next few months and felt excited about the wealth of rich data I had to explore.

Each interview was a rewarding and heartfelt experience and left me with great admiration for the participants. I felt grateful to meet each participant who openly shared their experiences with me. Some participants became a little tearful during the interview as they told their stories and reflected on their relationships. I found that when I asked the question of what their relationship with their partner was like before dementia and what it is like now, it often triggered emotionally difficult reflections and feelings of sadness. I responded with empathy and compassion and felt the slight tension of wanting to respond as a therapist yet maintaining my stance as a researcher. When reflecting after each interview, I found myself feeling sad and annoyed about the lack of post-diagnostic support carers receive in comparison to other chronic illnesses. One participant reflected on the amount of care and support he and his family received from health care services for family members' experiences of cancer, in comparison to the lack of care and support he and his partner had for dementia. All participants reported that it had been helpful to talk about their experiences, and it was clear to see that they had benefited therapeutically from taking part. Most participants expressed that they would like to read the thesis/journal article when finished. This was a very rewarding aspect of the research process for me. Following each interview, I noted any thoughts and feelings coming up for me in my research diary (see Appendix 10). Documenting my reflections was a helpful way of developing my own self-awareness and noting any biases coming up for me so as not to impact the analysis and maintain the quality and integrity of the research.

One interview was held in person, and this was a very different experience to the others held online and over the phone. The personal connection we established in person added depth to our meeting, in contrast to the virtual interviews conducted thus far on teams and over the phone. There is something about being in the same space that virtual sessions just cannot replicate. Holding the interview in person brought a sense of relaxation and confidence in me that the virtual/phone interactions lacked. Witnessing my participant's gratitude for the opportunity to take part highlighted the therapeutic nature of the interview. This participant was genuinely grateful for being part of the study, and I contemplated the potential positive impact this study could have on my participants. This felt warm and satisfying. What surprised me most is *how* therapeutic she reported the interview being for her; she viewed it as a means to contribute to the development of support for carers of people living with young onset dementia, and others in a similar position to her who might be struggling to care for their partner. She also reported that travelling far to attend the interview in person served as an escape from her demanding caring role, which highlighted the existential challenges some carers face daily. This session ran slightly over the planned time but enabled me to gather a wealth of rich data. It turned out to be an incredibly rewarding experience for both me and my participant. The interviews held on teams went smoothly with some minor technical issues in getting connected. The one telephone interview had poor call quality and this presented difficulties in the transcribing phase as I had to keep rewinding the audio file to ensure I had heard correctly. During one virtual interview I was able to say hello to my participants partner as he helped her get connected to Teams, in another two interviews I heard my participants calling out to their partners to either answer a question or check they were ok. This made me wonder what the interviews would have been like if both partners were present.

The transcription phase proved to be a lengthy process. Although Teams had transcribed the interviews as they took place, some participants had broad accents and the narrative was interpreted and transcribed incorrectly. This meant that I had to go over each audio file carefully to ensure accurate verbatim transcription. At that time I was juggling two clinical placements, research, and being a single parent so this phase proved to be particularly time consuming and took a number of months to complete. However, spending so much time re-listening to the interviews enabled me to become fully absorbed in the data and supported the analytical phase. I am extremely grateful to my supportive line manager who gave me extended time during work hours to focus on my research once my final clinical placements had ended.

During the analysis phase I noticed that the personal experiential themes (PETs) for each participant were very similar. The similarities in their experience illuminated the group experiential themes (GETs). Feedback from my supervisor on the write-up of my findings suggested that my quotes were too lengthy. I endeavoured to edit and shorten the quotes but found this difficult as it felt like I was removing rich information from the participant voices. The use of IPA worked well as it allowed me to explore each participants lived experiences and develop an in-depth understanding of the complexities of caring.

I can see two sides to dementia. It is devastating, full of distress, challenges and sadness but people can also live well with dementia given the right support at the right time. I found myself immersed in learning more about young onset dementia on my research journey and sought books and films about people with lived experiences. One participant told me that watching the film ‘Still Alice’ (2014) about a professor who develops young onset dementia, helped her to further understand the condition. Watching the film also helped to further my understanding of the impact of young onset dementia on the person and their family. Wendy Mitchell, a woman living with young onset dementia who lives alone, and has support from her daughters and assistive technology, has written two books about living with young onset dementia and often speaks about her experiences in public events and conferences. ‘What I Wish People Knew About Dementia: From Someone Who Knows’ (Mitchell, 2022) is a story of lived experience that provides hope and inspiration to other people living with young onset dementia and those who care for them. In her book titled ‘What dementia teaches us about love’, Nicci Gerrard (2019) writes about her father’s dementia and what dementia means for people who live with it and those who care for them. These evocative and powerful accounts of lived experience led to further personal reflections, and although these books were compelling to read, they left me feeling sad at times as I reflected on the difficulties people living with dementia and their loved one’s face. On the other hand, Kate Swaffer, a woman living with young onset dementia, has argued that an early diagnosis can be regarded as empowering, enabling and assisting the individual to remain independent for longer (Swaffer, 2016).

As I come to the end of my research journey, I am glad that I chose this topic. I am now employed as a counselling psychologist in an older people’s community mental health team in the NHS. The knowledge gained from my research experience has further ignited my passion for dementia care and I am currently engaging in discussions with the team about re-establishing the multidisciplinary young onset dementia service in Swansea Bay University Health Board. Being able to share my findings with other practitioners, use it to support my own practice, re-establish a much-needed service in my local community, and hopefully publish the study and add to the literature in this area gives me an enormous amount of satisfaction. This study has therefore highlighted to me the importance of engaging in qualitative research for my professional development and shaping my identity as a counselling psychologist.

Appendix 12 Journal article

Understanding the experiences of caring for a partner with young onset dementia: *An interpretative phenomenological analysis*

Abstract

Young onset dementia, diagnosed before the age of 65, presents unique challenges for individuals and their carers, particularly those who are partners. The prevalence of young onset dementia in the UK is increasing, with Alzheimer's disease being the most common type. Caring partners face psychological and emotional distress, multiple losses, and difficulties coping with the impact on their relationships. This research aimed to explore how individuals experience and make sense of caring for a partner with young onset dementia. The study used a critical realist and phenomenological approach, conducting semi-structured interviews with eight participants. Four group experiential themes emerged from the data: *'The long road to diagnosis', 'Ignored and forgotten', 'So much has changed everything is different', and 'where do I go from here?'* Each group experiential theme contained two to three subthemes. These findings address a gap in existing literature and provide valuable insights into the subjective experiences of caring for a partner with young onset dementia. The implications are multifaceted, including the need for targeted psychosocial interventions, raising awareness, and improving therapeutic practice. This paper is about one of the themes from this larger research project.

Introduction

Background

Defining dementia and young onset dementia

Dementia is a global cognitive impairment characterised by memory loss, difficulty in thinking, problem-solving, language and communication, and behavioural and psychiatric disturbances (Gould and Kendall, 2007). It affects around 50 million people worldwide, with 60% living in low and middle income countries (WHO, 2021). The most common subtypes of dementia include Alzheimer's disease, vascular dementia, frontotemporal dementia (FTD), dementia with Lewy Bodies, and mixed dementia (Alzheimer's Society, 2021).

Young onset dementia is a growing public health issue with devastating consequences for both the person living with dementia and those who care for them (Samson et al., 2004). Young onset dementia is diagnosed under the age of 65, and is more likely to present with a rarer type of dementia such as frontotemporal dementia, which may require specialist support (Collins et al., 2020). People with Down syndrome and other learning disabilities have a higher risk of developing young onset dementia (Rosser et al., 2010), and young onset dementia is more prevalent in the UK Black and Minority Ethnic (BME) population (Regan, 2016). Furthermore, younger people with dementia may also be at increased risk of developing dementia related to HIV/AIDS, traumatic brain injury, or alcohol abuse (McMurtray et al., 2006).

Prevalence rates of young onset dementia in the UK

The UK's current national data underestimates the number of people living with young onset dementia as it does not account for those with a diagnosis who have grown older over the age of 65 (Carter, 2022). New data from primary care health records shows a 'hidden population' of 70,800 people living with young onset dementia, a 69% increase since 2014 (Dementiauk.org, 2022). This is a significant increase from the previous estimated prevalence of 18,319 based on census data (Harvey et al., 2003). The number of people living with young onset dementia is projected to increase by 20% over the next 38 years (Carter et al., 2018). However, this figure is only an estimate of the true prevalence as not all individuals with young onset dementia will present to services.

Impact of young onset dementia on carers

As might be expected, carers of people living with young onset dementia tend to be younger. Many of them are spousal/partner carers, but they can also include parents, young adult children, siblings or friends (Richardson et al., 2016). People living with young onset dementia and their carers may experience significant social and psychological distress, and limited respite and social opportunities due to the lack of age appropriate support available to them. Within the NHS people living with young onset dementia often fall within the service area of older adult mental health, where dementia care is tailored to older people living with late-onset dementia. As a result of this many people living with young onset dementia are cared for at home by their partners, which can lead to significant changes in the couple’s relationship (Harris and Keady, 2009). For many reasons such as work commitments, parental roles and other family responsibilities, carers may not be able to fully meet the needs of their partners living with young onset dementia and can experience high levels of stress, burnout, anxiety, depression and unmet needs (Allen et al., 2017; Ducharme et al., 2013). In addition, previous research found that carers of people living with young onset dementia reported significantly poorer quality of life when compared to carers of people living with late onset dementia (Hvidsten et al., 2019).

Methodology

Aims of the study

Findings from previous studies suggest that further research is required to examine coping strategies, stigma and the subjective experience of the person caring for their partner with young onset dementia, and to understand how younger carers cope with changes in their relationship (Lockeridge and Simpson, 2013). This study therefore aims to expand on previous findings. It is hoped that the exploration of caring partners’ experiences will help to further understand the thoughts and needs of this client group, raise awareness of young onset dementia through dissemination of findings, inform therapeutic practice, feed into service development and challenge stigmatised attitudes towards dementia and this marginalised group.

Participants

Adults of any age currently living with and caring for a partner with a diagnosis of young onset dementia were invited to take part in the study. A diagnosis of young onset dementia is given to people under the age of 65. To be included, the partners of participants needed to have received their diagnosis of young onset dementia before the age of 65 and they could have any dementia diagnosis.

I did not stipulate age requirements for participants of the study as the research aim was to understand their experience, and this could be reflected upon at any age. Therefore, the participant could be any age, if their partner was diagnosed with young onset dementia under the age of 65. The partner living with young onset dementia could be over the age of 65 if they have aged since receiving the diagnosis.

The study consisted of six women and two men. Partners were chosen as they are more likely to be in caring roles with a close relationship. According to Smith, Flowers and Larkin (2009), six participants is an appropriate sample size for a student project using IPA. Six to ten participants is considered the ideal number for professional doctorate research studies due to depth of analysis required and time constraints (Larkin, Flowers and Smith, 2022).

Recruitment of participants

Eight people who are currently caring for a partner with young onset dementia were recruited for this study through the care and research charity organisation, ‘The Young Dementia Network’ hosted by Dementia UK - ‘YoungDementia UK’. The Young Dementia Network hosted by Dementia UK are able to promote research studies by sharing project information in their monthly newsletter and via their Twitter and Facebook accounts. People who were interested in taking part contacted me using my university email address to make arrangements.

A copy of the participant information sheet, consent form and demographic data sheet was sent to prospective participants via email. The participant was required to sign and date the consent form and demographic data sheet and return to me via email. Participants were informed that their participation is voluntary and that they have the right to withdraw from the research up until the point where analysis has started.

Participants were offered the option to engage with the interview in-person (either at the researcher’s workplace or university), via Microsoft Teams or over the telephone. Six interviews took place over Microsoft Teams using my university account, one over the telephone, and one in person in a private room on campus at university (UWE).

Transcription and data analysis

Interview data was audio recorded and later transcribed verbatim and analysed using IPA. Interviews that were held via Microsoft Teams had the transcription tool enabled. The first stage of the analysis involved reading the transcript closely several times and listening to the recordings whilst annotating what is interesting or significant about the participants' responses. The notes were then transformed into personal experiential statements and documented. The next stage involved looking for connections between experiential statements and clustering them into personal experiential themes (PETs). PETs were used to develop group experiential themes (GETs) across cases. Finally, the research was written into a narrative account explaining each theme using verbatim extracts to support interpretation. Confidentiality and anonymity was maintained by changing identifiable information to a pseudonym. The analytical process in this study followed Smith, Flowers & Larkin (2022) guidelines for conducting IPA research.

Findings

Group Experiential Theme 1 – *"The long road to diagnosis"*

This theme explores the lengthy and frustrating diagnostic journey that carers have been on in search for understanding the unknown changes in memory and behaviour their partner is experiencing, often navigating multiple assessments and interactions with healthcare professionals. The pre-diagnostic experience leads on to subtheme 1.1 which highlights carers experiences of living with frustration and anger along the way, often in response to these unknown changes. This leads on to subtheme 1.2 which focuses on the common experience of misdiagnosis in young onset dementia. Subtheme 1.3 then explores the emotional impact of the diagnosis felt by carers and how they make sense of it.

The time from noticing initial changes in their partner to receiving the diagnosis was described by carers as a lengthy journey and a frustrating process. Couples tended to follow a similar route to diagnosis with their general practitioner being the first point of contact, followed by multiple assessments and lengthy waiting times. For some, the diagnosis was delayed due to the Coronavirus pandemic:

Mary conveys a sense of frustration and a feeling that David's diagnostic journey was a challenging and lengthy process for them:

> ***"David was diagnosed with Alzheimer's in November of last year after having been backwards and forwards to hospitals and doctors and things, but he had been having issues with his memory before that, so it's taken us partly due to COVID, partly due to him being so young. It's taken us quite a long time to get where we're at. It just sort of seemed to go on forever." (p.3)***

There is a sense of time to diagnosis being an unnecessarily slow and frustrating experience as Fiona reflects on their long diagnostic journey:

> ***"And this is one of the things I find frustrating, everybody I talk to or we talk to, it all seems to have dragged out between 18 months to two years before anybody gets a diagnosis." (p.3)***

The diagnostic journey for Chris and his partner Susan involves a mixture of both positive and negative emotions, from relief and trust in the GP, to frustration and distress due to hospital waiting times:

> ***"So backwards and forwards to the GP, and the GP was really good, really helpful. So the GP did some bloods and referred to neurology and things like that, but waiting times in our hospital were pretty horrendous to say the least." (p.5)***

Personal Experiential Theme 1.1 – *"Living with frustration and anger"*

This subtheme explores carers' experience of living with anger on their journey to diagnosis and beyond. Many participants described how their partners directed anger towards them as they tried to make sense of unknown changes in their memory and behaviour. Conversely, one participant describes how he directed anger and frustration towards his partner for her unexplainable forgetfulness prior to the diagnosis.

When reflecting on what she noticed the most in the lead up to the diagnosis, Mary places emphasis on David's consistent expression of anger, suggesting a deep emotional turmoil that she and the family felt powerless to:

> ***"Just that he was angry about everything he was, he was angry about, or angry or frustrated, whatever you want to call it, but nobody could do anything right" (p.6)***

Wendy illuminates Paul’s heightened levels of anger in the lead up to the diagnosis and his attempts to cope with emotional distress by excessive alcohol consumption, which had a detrimental effect on their relationship:

> ***“Paul’s mood became, oh his anger levels just went through the roof. He was making it really difficult to maintain a relationship. Then Paul suddenly began drinking a lot more, and we didn’t know it was that at the time, he was hiding it really, really well. He was just making the relationship really difficult and that’s when I said enough is enough, we’ve got to go back to the doctors, something is not right here.” (p.3)***

Following the diagnosis Caroline felt threatened by Martin’s aggressive behaviour and this led to the distressing experience of him being sectioned and taken to hospital:

> ***“…he had an almighty blow out an anger outburst, which is what he does. That's part of the FTD and he follows a pattern, he has the blow out and then he’ll have a day where he'll disappear and he'll just go to bed for a day, and then he’ll have three or four days of sulking. And I thought, he's gonna start wrecking the house because sometimes he’d pick things up and smash them. I rang the crisis number. So next thing, they rang me back and they asked what the problem was and they said do you feel threatened and I says yeah I do, and they says right, we’re sending an ambulance, so they sent an ambulance, two paramedics and they took him away, and he was sectioned.” (p.12)***

Personal Experiential Theme 1.2 – *“You’re too young so it must be something else”*

This subtheme explores the shared key experiences of no explanations and misdiagnosis by health care professionals. Most of the participants spoke about noticing first signs of memory loss or personality and behaviour changes in their partner and health care professionals not knowing. As dementia is more often associated with older age, health care professionals may attribute ambiguous symptoms to other factors. The misdiagnosis of stress, anxiety and depression is a common narrative that adds further time to reach the diagnosis of young onset dementia and perpetuates feelings of uncertainty and frustration for the couple.

Mary spoke about doctors assuming David’s memory issues were a result of anxiety and depression precipitated by the impact of his job redundancy, yet she was not convinced of this:

> ***“The first time we went to the doctor with an issue around John's memory was 2018, um, at that point he’d just been made redundant from a job that he had done for the past 25 years. So the doctors put it down to depression and then they put it down to anxiety. But I knew that that wasn't, that was maybe a small part of it, but he had been having issues with his memory before um that.” (p.3)***

Similarly, Wendy recalls the misdiagnosis of depression in the lead up to the young onset dementia diagnosis:

> ***“And prior to that, we had been under the mental health team and he was being treated for depression. They were convinced it was clinical depression and that they just needed to boost his mood, boost his serotonin levels and all would be well.” (p.2)***

Caroline speaks about the first contact with Martin’s GP following a pattern of unusual behaviour. This case illustrates the additional challenges of diagnosing frontotemporal dementia in younger people, where memory decline is not usually the first noticeable symptom. Caroline expresses a sense of guilt and betrayal for seeking help on Martin’s behalf, highlighting the complexities of their diagnostic journey:

> ***“I feel like I'm betraying him. I've never betrayed him in my life. He's got something wrong with him. He can't speak and he's making lots of mistakes and he just. There's something wrong with him. And she said it's most likely depression. And I said I have thought that because his job was getting him down, I know he was starting to hate his job and I said I did wonder if it was depression, and she said that's probably what it is.” (p.2)***

Personal Experiential Theme 1.3 – *“The emotional impact of the diagnosis”*

This theme emerged from the emotional impact of the young onset dementia diagnosis felt by carers and their partners. Most participants described a contrasting set of emotions within the dyad, namely shock and denial felt by the partner living with dementia, compared with relief and understanding for the partner caring and reassurance that their partner’s symptoms have now been explained. Furthermore, some participants spoke of the brutality of receiving the diagnosis in writing:

Wendy highlights the sense of relief she felt upon receiving the diagnosis as there was now an explanation for Paul’s behaviour, mood, and excessive alcohol consumption to cope with the changes he was experiencing:

> ***"I think Paul was probably more shocked than I was, but I think there was this sense of relief that actually there was something wrong with him. He wasn't just, pardon the pun, just being a dick. There was relief on my part that, you know, that the marriage wasn't going to end because of that diagnosis. The marriage was going to stay because he actually, he needed me now more than ever." (p.5)***

Edward describes a sense of relief on receiving the diagnosis:

> ***"I was sort of relieved that they actually said it was that, because previously I didn't know what, I knew something wasn't right, but I didn't know what it was, so it was almost a relief." (p.4)***

Caroline illuminates the contrasting emotions she and her partner felt on receiving the diagnosis. Through Caroline's own research she had an idea of what the diagnosis might be and this confirmed it:

> ***"With me, it was relief, it was I was right. With Martin it was horror and total denial, um, anger, he was just, he still now says he isn't, he's still in denial." (p.2)***

Discussion

The current study reinforces existing qualitative research on the critical role healthcare professionals play in the diagnostic and post-diagnostic journey for people with young onset dementia and their family carers (Lai et al., 2023). The study highlights significant challenges in the diagnostic process, often leading to long, emotionally distressing journeys toward a diagnosis. GPs, as the first point of contact, are crucial in recognising early symptoms of young onset dementia. However, they may encounter diagnostic difficulties due to the overlap of symptoms with other conditions (Hendriks et al., 2022).

Misdiagnosis, often attributing symptoms to stress, anxiety, or depression due to the younger age of individuals, prolongs the diagnostic journey, intensifying feelings of frustration and uncertainty. The emotional impact of this prolonged journey is considerable, with participants expressing anger and frustration. The disruption of healthcare services due to the covid pandemic also added time to the already lengthy diagnostic journey.

The theme "living with frustration and anger" captures the initial emotional distress experienced by carers due to delays in obtaining an accurate diagnosis. This frustration is also reflected in the literature, where Lam et al., (2019) emphasise the need for greater awareness among healthcare professionals to recognise young onset dementia symptoms early. For carers, the delay not only heightens emotional distress but also leads to feelings of isolation and anger, particularly in cases of frontotemporal dementia, where behavioural changes can severely impact the carers emotional attachment to their partner (UCSF, 2012; Mioshi et al., 2009; Massimo et al., 2013).

The theme “you’re too young so it must be something else” highlights the prevalent misconception that dementia primarily affects older adults, leading to diagnostic delays for younger individuals. A study by Quinn et al., (2008) highlights the need for healthcare providers to overcome age biases and consider young onset dementia in younger patients presenting with cognitive decline. The present study echoes these findings, revealing how age-related assumptions contribute to the misdiagnosis of conditions like anxiety and depression, further delaying the critical diagnostic process (O’Malley et al., 2019, 2021).

The third theme, “the emotional impact of the diagnosis,” explores the complex emotions experienced by both the person with young onset dementia and their carer. For the person diagnosed, emotions such as sock, denial, and fear are common (Aminzadeh et al., 2007; Johannessen and Moller, 2013). Conversely, carers often feel relief and reassurance, as the diagnosis provides an explanation for their partner’s cognitive and behavioural changes, allowing them to adopt coping strategies and support their partner more effectively (Bannon et al., 2022; Grunberg et al., 2022).

A particularly distressing aspect highlighted by two participants in the study is the manner in which the diagnosis is communicated. One participant described receiving the diagnosis in writing as “brutal”, which intensified their emotional distress. This aligns with previous research by Beattie et al. (2004), which emphasises the importance of sensitive communication and appropriate language in delivering a dementia diagnosis. The study critiques the delivery of young onset dementia diagnoses via letter, which fails to meet professional standards set by organisations like the Memory Services National Accreditation Programme (MSNAP, 2022).

Limitations and directions for future research

While this study offers valuable insights into the complex experiences of caring for a partner with young onset dementia, several limitations and areas for further research should be considered. The predominantly white British sample, primarily female and in long-term relationships, may not fully represent the diversity of caring experiences across cultural backgrounds, gender identities, relationship stages, and different types of dementia. Future research could involve more diverse samples, including LGBTQ+ couples and those with less common types of young onset dementia, to provide a comprehensive understanding of caring dynamics. Longitudinal studies involving both partners could elucidate evolving relationship dynamics, while exploring the diagnostic journey and psychological adjustment post-diagnosis could inform interventions and support services. Additionally, efforts to broaden recruitment beyond specific support networks could enhance the transferability of findings.

Implications for Practitioners

The study’s findings have significant implications for healthcare practitioners, especially those in dementia care services. There is a critical need for increased awareness among healthcare professionals about young onset dementia, emphasising early recognition, diagnosis, and timely interventions to support both patients and carers. Psychologists working within dementia services play a pivotal role in providing tailored therapeutic interventions, including emotional support, and nuanced relationship focused work. Collaborative efforts among healthcare professionals are essential in reshaping support systems and societal perceptions surrounding young onset dementia, facilitating the development of comprehensive care plans. Improving recognition and accurate diagnosis through available resources and decision-making tools is crucial. Sensitivity and clear communication are vital in conveying diagnoses, while proactive addressing of unmet carer needs, including counselling and practical assistance, is imperative to enhance their resilience. With the anticipated rise in young onset dementia prevalence, a proactive approach to diagnosis, understanding and support is essential, highlighting the necessity for a paradigm shift towards early intervention and holistic care approaches within healthcare.

Conclusion

This study contributes significantly to counselling psychology by focusing on the deeply relational experiences of carers supporting partners with young onset dementia. It explores the profound emotional, societal, and relational challenges carers face, particularly during the diagnostic journey, the lack of post-diagnostic support, and the ongoing transformation of their relationships and identities. As dementia progresses, the evolving roles and dynamics between carers and their partners lead to a deep sense of loss for both the partner and the carers own identity. This study highlights the need for compassionate, person centred, and holistic support, emphasising the unique role psychologists play in helping carers navigate these complex dynamics, build resilience, and maintain connection, ultimately improving the quality of life for both carers and their partners.

References

Allen, A. P., Curran, E. A., Duggan, A., Cryan, J. F., Chorcorain, A. N., Dinan, T. G., . Clarke, G. (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive biological markers of stress. Neuroscience & Biobehavioral Reviews, 73, 123-164. doi:10.1016/j.neubiorev.2016.12.006

Alzheimer’s Society (2021). Available from: https://www.alzheimers.org.uk/about-dementia/types-dementia [Accessed 22 December 2021].

Aminzadeh, F., Byszewski, A., Molnar, F. J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: exploring persons with dementia and caregivers’ perspectives. *Aging and Mental Health*, *11*(3), 281-290.

Bannon, S. M., Reichman, M., Popok, P., Grunberg, V. A., Traeger, L., Gates, M. V., . & Vranceanu, A. M. (2022). Psychosocial stressors and adaptive coping strategies in couples after a diagnosis of young-onset dementia. *The Gerontologist*, *62*(2), 262-275.

Beattie, A., Daker-White, G., Gilliard, J., & Means, R. (2004). ‘How can they tell?’ A qualitative study of the views of younger people about their dementia and dementia care services. *Health & social care in the community*, *12*(4), 359-368.

Carter, J. E., Oyebode, J. R., & Koopmans, R. T. C. M. (2018). Young-onset dementia and the need for specialist care: a national and international perspective. *Aging & Mental Health*, *22*(4), 468-473.

Carter, J., (2022). Prevalence of all cause young onset dementia and time lived with dementia: analysis of primary care health records. *Journal of Dementia Care*, *30*(3), pp.1-5.

Collins, J. D., Henley, S. M., & Suárez-González, A. (2020). A systematic review of the prevalence of depression, anxiety, and apathy in frontotemporal dementia, atypical and young-onset Alzheimer’s disease, and inherited dementia. *International Psychogeriatrics*, 1-20.

Dementia UK (2022). Available from: https://www.dementiauk.org/about-dementia/young-onset-dementia/about-young-onset-dementia/facts-and-figures [Accessed 12 October 2022]

Ducharme, F., Kergoat, M. J., Antoine, P., Pasquier, F., & Coulombe, R. (2013). The unique experience of spouses in early-onset dementia. *American Journal of Alzheimer's Disease & Other Dementias®*, *28*(6), 634-641.

Gould, N., & Kendall, T. (2007). Developing the NICE/SCIE guidelines for dementia care: The challenges of enhancing the evidence base for social and health care. *British Journal of Social Work*, *37*(3), 475-490.

Grunberg, V. A., Bannon, S. M., Popok, P., Reichman, M., Dickerson, B. C., & Vranceanu, A. M. (2022). A race against time: couples’ lived diagnostic journeys to young-onset dementia. *Aging & mental health*, *26*(11), 2223-2232.

Harris, P. and Keady, J. (2009). Selfhood in younger onset dementia: transitions and testimonies. Aging and Mental Health, 13, 437–444. doi: 10.1080/13607860802534609.

Harvey RJ, Skelton-Robinson M, Rossor MN. (2003). The prevalence and causes of dementia in people under the age of 65 years. Journal of Neurology, Neurosurgery & Psychiatry.

Hendriks, S., Peetoom, K., Tange, H., Van Bokhoven, M. A., Van Der Flier, W. M., Bakker, C., ... & De Vugt, M. (2022). Pre-diagnostic symptoms of young-onset dementia in the general practice up to five years before diagnosis. *Journal of Alzheimer's Disease*, *88*(1), 229-239.

Hvidsten, L., Engedal, K., Selbaek, G., Wyller, T. B., Bruvik, F., & Kersten, H. (2019). Quality of life of family carers of persons with young-onset compared to late-onset dementia. *Aging & Mental Health*, 1-8.

Johannessen, A., & Möller, A. (2013). Experiences of persons with early-onset dementia in everyday life: a qualitative study. *Dementia*, *12*(4), 410-424.

Lai, M., Jeon, Y.H., McKenzie, H. and Withall, A., (2023). Journey to Diagnosis of Young-Onset Dementia: A Qualitative Study of People with Young-Onset Dementia and their Family Caregivers in Australia. *Dementia*, *22*(5), pp.1097-1114.

Lam, K., Chan, W.S., Luk, J.K. and Leung, A.Y., (2019). Assessment and diagnosis of dementia: a review for primary healthcare professionals. *Hong Kong Medical Journal*, *25*(6), p.473.

Larkin, M., Flowers, P., & Smith, J. A. (2022). Interpretative phenomenological analysis: Theory, method and research.

Lockeridge, S., & Simpson, J. (2013). The experience of caring for a partner with young onset dementia: How younger carers cope. *Dementia*, *12*(5), 635-651.

Massimo, L., Evans, L. K. and Benner, P. (2013). Caring for loved ones with frontotemporal degeneration: the lived experiences of spouses. Geriatric Nursing, 34, 302–306. doi: 10.1016/j.gerinurse.2013.05.001.

McMurtray, A., Clark, D.G., Christine, D. and Mendez, M.F., (2006). Early-onset dementia: frequency and causes compared to late-onset dementia. *Dementia and geriatric cognitive disorders*, *21*(2), pp.59-64.

Mioshi, E., Bristow, M., Cook, R., & Hodges, J. R. (2009). Factors underlying caregiver stress in frontotemporal dementia and Alzheimer’s disease. *Dementia and geriatric cognitive disorders*, *27*(1), 76-81.

MSNAP. (2022) Memory Services National Accreditation Programme. *Quality Standards for Memory Services* (8th ed., J. Jethwa, M.Fern, C. Abhayaratne, & K. Wariabharaj, Eds). Royal College of Psychiatrists.

O'Malley, M., Parkes, J., Stamou, V., LaFontaine, J., Oyebode, J., & Carter, J. (2019). Young-onset dementia: scoping review of key pointers to diagnostic accuracy. *BJPsych Open*, *5*(3), e48.

O’Malley, M., Carter, J., Stamou, V., LaFontaine, J., Oyebode, J., & Parkes, J. (2021). Receiving a diagnosis of young onset dementia: A scoping review of lived experiences. *Aging & mental health*, *25*(1), 1-12.

Quinn, C., Clare, L., Pearce, A., & Van Dijkhuizen, M. (2008). The experience of providing care in the early stages of dementia: An interpretative phenomenological analysis. *Aging and Mental Health*, *12*(6), 769-778.

Regan, J.L., (2016). Ethnic minority, young onset, rare dementia type, depression: a case study of a Muslim male accessing UK dementia health and social care services. *Dementia*, *15*(4), pp.702-720.

Richardson, A., Pedley, G., Pelone, F., Akhtar, F., Chang, J., Muleya, W., & Greenwood, N. (2016). Psychosocial interventions for people with young onset dementia and their carers: a systematic review. *International Psychogeriatrics*, *28*(9), 1441-1454.

Rossor, M. N., Fox, N. C., Mummery, C. J., Schott, J. M., & Warren, J. D. (2010). The diagnosis of young-onset dementia. *The Lancet Neurology*, *9*(8), 793-806.

Sampson, E. L., Warren, J. D., & Rossor, M. N. (2004). Young onset dementia. *Postgraduate medical journal*, *80*(941), 125-139.

Smith, J. A., Flowers, P., & Larkin, M. (2009). Interpretative phenomenological analysis: Theory, method and research. London, UK: Sage.

University of California San Francisco, UCSF (2012). The Challenges of FTD vs. Alzheimer's. Retrieved from: http://memory.ucsf.edu/ftd/ livingwithftd/caregiving/challenges/single.

WHO (2021). Available from: https://www.who.int/news-room/fact-sheets/detail/dementia [Accessed 18 December 2021]