‘On The Scrap Heap’: Exploring Carers’ Perspectives on the Barriers and Facilitators of Employment for People with Young Onset Dementia

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ABSTRACT

Background

Employment concerns for those with young-onset dementia is under researched both globally and in the United Kingdom (UK). Individuals with young-onset dementia are of employment age and face many barriers to maintaining employment with devastating impacts financially and psychologically.

Aims

This research explores the barriers and facilitators to employment for those with young-onset dementia to make practical recommendations to better support them in the workplace, thus aiming to reduce the likelihood of negative consequences such as financial strain and psychological distress.

Methodology

Six semi-structured interviews were conducted with carers to understand the barriers and facilitators to employment that those with young-onset dementia face. A critical realist methodology was taken, and thematic analysis was used to analyse the data.

Results

Several barriers and facilitators to employment were identified. Barriers include the following: The restrictiveness of dementia symptoms, Employers' unhelpful approach and response to dementia, The nature of dementia as a barrier to employment, and Diagnostic process as a barrier. Facilitators include the following: Employers' helpful approach and response to dementia, Renewed understanding of difficulties, Diagnosis as a ticket for support, and Diagnosis as a path forward.

Recommendations

Firstly, workplace education programmes and policy should be developed to raise awareness of the symptoms of young-onset dementia, to reduce associated stigma, and promote the implementation of reasonable adjustments to prevent employment loss. Employers must seek support from organisational structures, such as occupational health and human resources, whilst collaborating with the individual with young-onset dementia to identify personalised workplace adaptations. Finally, professionals working with those with young-onset dementia, such as psychologists and occupational therapists, must consider the impact of employment concerns in their work, as it can have significant implications for one's psychosocial outcomes.

CONTENTS

1. INTRODUCTION

1.1. Chapter Overview

I begin this chapter by describing the terminology existing within the field of dementia, and for clarity, I will state the terminology chosen adopted in this research. I then provide an overview of the context and research around dementia more broadly, exploring the political context, current attitudes, and interventions available, whilst weaving in the impact these have on both the individual with dementia and their carer. Next, I narrow the focus, presenting the context and issues exclusively concerning those with young-onset dementia, including challenges with diagnosis, age-appropriate services, and within familial relationships. I then provide an exploration of different conceptualisations of young-onset dementia, touching upon the biomedical model before paying particular attention to the social theories to understand dementia.

Finally, I review what is known about the employment context for those with young-onset dementia by summarising a systematic literature review. Research from the systematic literature review is grouped into themes, including the experience of employment with a diagnosis of young-onset dementia, challenges faced at work after receiving a diagnosis, workplace attitudes, and workplace initiatives. I summarise and critique the current literature whilst detailing the rationale for the present study.

1.1.1. Terminology

There is a wide variety, and much inconsistency within the literature regarding the terminology used to describe young-onset dementia. Terms such as "early onset dementia" (Arai et al., 2007), "presenile dementia" (Vieira et al., 2013) and "working age dementia" (Rudman et al., 2011) have been used interchangeably to describe individuals diagnosed before the age of 65. These broader terms have been further broken down to describe subtypes of young-onset dementia in the literature, such as "early onset Alzheimer's disease" and "young-onset Alzheimer's disease".

The variety of terms used to describe young-onset dementia in the literature can cause confusion. The use of the term "early" onset dementia could be seen as ambiguous or referring to an *earlier* stage of dementia, rather than the age of onset (Kelley et al., 2008). There is also considerable debate about which term is considered most accurate and up to date. For example, the majority of studies use the term young-onset dementia to describe individuals with a diagnosis aged under 65. This age cut off was determined based on the previous retirement age (Alzheimer's Society, 2020), and could be considered outdated or inaccurate in the current political climate. Other studies advocate for the use of further age subtypes. For example, one study uses the term "young-onset dementia" to refer to those diagnosed with dementia between the ages of 17 and 45 (Kelley et al., 2008). I will use the term young-onset dementia in this study to describe those diagnosed with dementia under the age of 65, in line with the majority of recent literature. The next section will examine the current social and political context surrounding dementia in the UK.

1.2. Political and Social Context of Dementia

1.2.1. Political Context

There is an estimated 944,000 people living with dementia in the UK, with 52% of the population knowing someone with a dementia diagnosis (Alzheimer's Research UK, 2021). In 2007, the charitable organisation Dementia UK was commissioned to produce a report to inform policy makers and service commissioners about the prevalence and economic cost of dementia. This report branded the government initiatives and response to dementia as inadequate and proposed that action is required to rectify this (Alzheimer's Society, 2007). Since then, there have been advances in policy and awareness of dementia, including the Department of Health's National Dementia Strategy which aimed to raise awareness of dementia, make improvements to care, and promote earlier diagnosis (Department of Health, 2009).

Aspects of the government's National Dementia Strategy have been criticised, with some predicting that the drive to promote earlier diagnosis could lead to overdiagnosis (Brunet, 2014). Others suggest there is little empirical evidence to acclaim that early diagnosis is justified without a better understanding of the costs and benefits to both individuals and services (Brayne & Kelly, 2019). However, earlier diagnosis could lead to early intervention (Geldmacher, 2002), and improved statistics regarding prevalence rates could inform policy and service development (Innes & Manthorpe, 2013). Some research demonstrates that early diagnosis and intervention can delay cognitive deterioration, improve quality of life, and allow for advanced care planning (Robinson et al., 2015).

In 2015, following the National Dementia Strategy, the government released the Prime Ministers Challenge on Dementia (Department of Health [DOH], 2015). This aimed to make the UK the “best country in the world for dementia care, support, research and awareness” by proposing an increase in funding and research, and by developing dementia friendly communities. A recent report investigating the progress of the initiative concluded that the plan has partially achieved its goals in some areas, but has room for improvement by including minoritized individuals, non-English speakers, and people with mental or physical health difficulties in awareness and risk reduction plans (Kobierskij, 2021). Governmental strategies have been further criticised as appearing progressive on the surface, overestimating their impact and benefits, whilst failing to consider logistical aspects such as *how* to implement such strategies (Wilcock et al., 2009).

1.2.2. Social Context and Attitudes to Dementia

Public and healthcare professionals’ attitudes to dementia have been widely research following the emphasis in UK policy to develop dementia friendly communities (DOH, 2015). It is important to consider attitudes toward dementia, as improved attitudes are associated with higher quality of care (Travers et al., 2013).

Research has highlighted positive outcomes from dementia training programs, including increased knowledge of and attitudes to dementia, and higher confidence in caring for patients living with dementia (Hughes et al., 2008, Smyth et al., 2013). Other research investigating the knowledge, confidence, and attitudes of 127 general practitioners (GPs) in Scotland found that GPs report a lack of confidence in diagnosing dementia and managing behaviours or other problems associated with dementia. When explored further, GPs attributed their concerns with diagnosing dementia to a lack of time, and perceived dementia care as a specialist service (Turner et al., 2004). These studies emphasise the importance of improving healthcare attitudes to dementia to improve the quality of available support and care.

Public attitudes to dementia in the Bristol and South Gloucestershire area were explored using the Approaches to Dementia Questionnaire (ADQ). From the 794 responses, results suggested that younger people, those with personal experience of dementia, and individuals from white ethnic backgrounds had more positive attitudes towards dementia (Cheston et al., 2016). Similar results were found by researchers in Northern Ireland, suggesting that older individuals were more likely to hold stigmatising views about those with dementia (McParland et al., 2012). The results from

Cheston et al's., (2016) study provided a baseline to track further changes over time, however they must be interpreted with caution, as individuals from marginalised ethnic backgrounds were underrepresented in the sample, limiting the validity of the results.

Individuals from racially minoritized groups have a greater risk of developing dementia, but are more likely to face barriers in accessing dementia care compared to individuals from white ethnic backgrounds (Alzheimer's Association, 2019). Research suggests that stigma and different cultural understandings may impact one's attitudes towards dementia (Parveen et al., 2017). For example, when discussing dementia in a focus group, over half of the individuals from ethnic minority groups attribute dementia symptoms to normal ageing, instead of a disease. Some groups utilise religion, as opposed to mainstream services for support regarding dementia, with some groups viewing services as inaccessible due to language barriers, lack of minority representation and poor cultural awareness. This is further compounded by poor awareness of the available support (Parveen et al., 2017), which inhibits help seeking behaviour (Prins & Mooney, 2014).

Collectively, the literature suggests the attitudes that both professionals and the public have about dementia can influence the quality of care and treatment that they receive (Cheston et al., 2016; Travers et al., 2013). This in turn could impact the quality of life of the individual living with dementia. Factors impacting one's quality of life are discussed next.

1.2.3. Factors Impacting Quality of Life

Understanding the factors which impact the quality of life for those living with dementia is useful for informing government initiatives and service level interventions which are designed to support them. A systematic review of the literature suggests that the quality of life for individuals with dementia is greater for those with positive relationships, good social engagement, and greater functional ability (Martyr et al., 2018). Narrative research specific to individuals with young-onset dementia suggests that lower insight into the illness can serve an adaptive function in preserving one's quality of life; thus raising one's awareness of their dementia must be approached with sensitivity (Thorsen et al., 2020). Furthermore, the quality of life of an individual with dementia can be impacted by the poor mental health of the carer and high levels of behavioural and psychological disturbance for the individual (Banerjee, 2006). People living with dementia also experience worries about their quality of life, particularly when thinking of end-of-life care, valuing advanced end-of-life care planning and being recognised as unique and worthy till the end (Bolt et al., 2022).

It is vital for the government and healthcare providers to champion policy and interventions to support people to 'live well' with dementia (Banerjee, 2010). However, it is necessary to ensure these interventions are effective in improving one's quality of life. An individual's quality of life is routinely used as a measure of the effectiveness of interventions for dementia. Unfortunately, it can be difficult to measure the quality of life for people living with dementia (Moyle et al., 2007), with some studies making implicit assumptions that measures of functioning, such as cognition levels and Behavioural and Psychological Symptoms of Dementia (BPSD)[1] correlate with quality of life (Banerjee, 2006). For example, the Quality of Life-Alzheimer's Disease (QOL-AD) has been criticised for its broad conceptualisation, with the inclusion of memory and functioning items to measure quality of life (Ready & Ott, 2003). Measuring quality of life in this way is likely to miss important factors which could potentially lead to both the positive and negative effects of interventions being missed. Thus, self-reports of quality of life must be used where possible to incorporate multiple perspectives (Burks et al., 2021).

1.3. Supporting People with Dementia and Their Carers

This section outlines various interventions aimed at increasing awareness of dementia and its associated risk factors. It explores existing prevention strategies, and available pharmacological and psychosocial interventions, while evaluating their impact on individuals. Additionally, the psychological impact of caring for someone with dementia, and current interventions designed to address this impact are also considered.

1.3.1. Awareness and Prevention of Dementia

It is an important endeavour to raise awareness of the signs of dementia, as this can support families to seek help earlier, leading to earlier diagnosis (Millard et al., 2011). An earlier diagnosis can have positive benefits for those living with dementia, giving time to plan for disease management (Jackson et al., 2022) and to discuss advanced end-of-life care options (Dassel et al., 2023). An awareness of potential risk factors for dementia can inform prevention strategies, guiding both

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[1] Behavioural and psychological symptoms of dementia are a heterogeneous group of clinical phenomena, such as signs of disturbed perceptions, thought content, behaviour and mood, which vary among individuals with dementia (Richler et al., 2023).

educational programmes and interventions to support those at risk of developing dementia (Spector et al., 2012).

There is a growing body of evidence aiming to identify risk factors for dementia, with some research suggesting there are several modifiable risk factors contributing to up to 40% of dementias worldwide. Examples of modifiable risk factors include diabetes, smoking, air pollution, and obesity (Kivipelto et al., 2018; Livingston et al., 2020). Such research concludes that the potential for the prevention of dementia is high, especially in low to middle-income countries where these risk factors are more prevalent. However, there is a dearth of research supporting the effectiveness of prevention strategies, with some longitudinal studies yielding negative or modest results (Van Middelaar et al., 2018; Yassine & Schneider, 2017). The next section moves away from prevention strategies and discusses interventions to support individuals with a diagnosis of dementia already.

1.3.2. Pharmacological and Psychosocial Interventions

Many pharmacological and psychosocial interventions aim to slow the progression of dementia. These interventions are also used to help manage the Behavioural and Psychological Symptoms of Dementia (BPSD) that can arise due to a decline in one's ability to communicate unmet needs (Dyer et al., 2018). A systematic review summarised the evidence base for the effectiveness of 17 different pharmacological and psychosocial interventions for the management of BPSD. The review highlighted statistically significant reductions of the BPSD for a range of both psychosocial and pharmacological interventions such as functional analysis-based interventions, music therapy, melatonin, analgesics, donepezil, galantamine and atypical antipsychotics (Dyer et al., 2018).

When evaluating the studies included in the review, the authors note that the evidence for the effectiveness of music therapy and analgesics was of poorer quality, thus should be interpreted with caution. There were also conflicting findings regarding the benefits of melatonin, with some research suggesting a dip in mood at around 12 months (Jansen et al., 2006). Furthermore, the research into pharmacological interventions reported adverse events such as urinary tract infections, edema, gait abnormality and in some instances death (Ma et al., 2014), unlike psychosocial interventions which reported no adverse events. Individuals using pharmacological interventions reported weight gain, increased agitation, and worsening cognitive function (Franchi, 2016), further limiting their utility. To enhance the quality of the review, the researchers excluded research which did not score more than 5 on the AMSTAR research quality checklist. Overall, the authors conclude that psychosocial interventions should be used as a first line approach to manage BPSD due to the lack of associated adverse events.

Research reviewing six psychosocial interventions to support those with dementia aimed to summarise the underlying theory and their effectiveness (Kasl-Godley & Gatz, 2000). Interventions such as memory training, reality orientation, support groups, psychodynamic approaches, reminiscence work[2], and behavioural approaches were included within the review. The authors concluded that support groups and cognitive behavioural therapy (CBT) are effective for supporting individuals in their early stages of dementia, whereas reminiscence and life review work best support those in the mild to moderate stages of dementia. Furthermore, behavioural and memory training interventions, such as cognitive restructuring tasks, were most effective for optimising remaining abilities (Kasl-Godley & Gatz, 2000). Overall, the literature demonstrates a preference for the use of psychosocial interventions to support individuals with dementia.

1.3.3. Impact on Carers and Associated Interventions

In the UK, there is an estimated 670,000 unpaid carers for people with dementia, saving the government an estimated 11 billion pounds each year (Alzheimer's Society, 2014). Consistent research suggests carers are faced with psychological morbidity, ill physical health, social isolation, and financial hardship (Brodaty & Donkin, 2009; Luscombe et al., 1998). Psychoeducation programmes have demonstrated their effectiveness in supporting caregivers to lower distress levels and manage the needs of both them and the person living with dementia. These programmes can be delivered in group format and via the internet, keeping costs low and material accessible (Cheng et al., 2019). Despite the effectiveness of such interventions, service provision is often inconsistent from diagnosis through to end-of-life (Francis & Hanna, 2022).

Research has explored the unique experience faced by carers in South Asian communities where the prevalence of dementia is more common (Hossain et al., 2020). Carers from South Asian communities face a tension between following religious and cultural practices while honouring the dignity and choice of the person with dementia (Hossain et al., 2022). Research recommends the inclusion of family and cultural context when planning and preparing for dementia care (Jackson et

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[2] Reminiscence and life review approaches aim to facilitate the recall of past experiences to enhance self-understanding and personal continuity. This assists in the improvement of wellbeing (Kasl-Godley & Gatz, 2000).

al., 2022), with a portion of research focusing on honouring cultural practices both in end-of-life care (Nishimura et al., 2022) and eating and drinking choices (Nair et al., 2022).

The next section of this chapter will move away from discussing dementia more broadly and will focus on theory to conceptualise young-onset dementia, whilst describing the unique challenges experienced both by the individuals and their carers.

1.4. Young-onset Dementia

Young-onset dementia is defined as the onset of dementia symptoms before the age of 65 years (Price, 2010). In its early stages, young-onset dementia can present as behavioural changes, psychosis, and depression, with cognitive deficits presenting later in the disease process. These changes can have significant impacts on day-to-day functioning, impacting both the individual and their carer (Mendez, 2006). Young-onset dementia accounts for approximately 8% of all dementia diagnoses (Prince et al., 2015); with rates higher for those from black and minority ethnic backgrounds, and for those with a learning disability (Dementia UK, 2022). However, reliable prevalence estimates are lacking for young-onset dementia, which negatively impacts policy decisions and service provision (Hendriks et al., 2021). This is partly due to the challenges with diagnosing young-onset dementia which will be explored later in this chapter.

1.4.1. Conceptualising Young-onset Dementia

This section describes key biological and psychosocial theories that have been developed to conceptualise dementia. These ideas will be described whilst considering the unique experience that individuals face whilst living with dementia at a younger age.

1.4.1.1. The Biomedical Model

Through a biomedical lens, dementia can be defined as a chronic or progressive disease of the brain, causing disturbances to higher cortical functions such as memory, thinking, orientation, learning, language, and judgement. Changes in cognitive functions can be accompanied by a deterioration in emotional control, social behaviour, and motivation (World Health Organization [WHO], 1992). There are many subtypes of dementia such as Alzheimer’s disease, Vascular dementia, and Lewy-body dementia. Each subtype is distinguished by the age of onset, manifestation in the brain, and resulting symptoms. However, post-mortem results suggest that distinguishing dementia subtypes by their manifestation in the brain may be more complex than first thought, as brains of individuals with Alzheimer's disease often display neuropathology expected in someone with Lewy-body dementia and vice versa (Manthorpe & Iliffe, 2016). Dementia is more prevalent in women than in men (Nichols et al., 2022), however this can differ depending on the subtype of dementia (Cao et al., 2020).

The biomedical view to understand dementia has been challenged by modern schools of thought, prioritising the consideration of the interaction between biological, psychological and social factors as predictors of health (Spector & Orrell, 2010). Kitwood's model of personhood has been influential in guiding these developments, centralising the preservation of one's self-concept, identity, and emotional experience (Kitwood, 1997). This will be discussed further in the next section.

1.4.1.2. Personhood Theory

Ideas developed through a psychosocial lens shape our understanding of dementia. It is common throughout history for many cultures to depersonalise and dehumanise individuals with a disability, in particular individuals with dementia have been labelled as incompetent and burdensome, and are discriminated against at a personal and structural level (Jeanne et al., 2011). Kitwood (1997) developed ideas around personhood in dementia, the notion that we should not dehumanise individuals by defining them by their dementia diagnosis, instead we should focus on the person behind the diagnosis as thinking and feeling individuals with identities, histories, experiences, likes, and dislikes. Accordingly, we must celebrate, respect and value the person behind the dementia diagnosis and focus on what individuals *can* do.

Kitwood (1997) identified five needs that are poorly met in individuals with dementia, leading to psychosocial distress. These are attachment, comfort, identity, inclusion, and occupation. In order to provide person centred care for those with dementia, it is important to sensitively meet this cluster of needs in a way which corresponds with the uniqueness of the individual. Improving the experience of one need can form the start of a "virtuous circle", whereby all other needs are positively impacted. For example, improving an individual's level of inclusion can positively influence their ability to attend to an occupation which can be beneficial for developing a sense of identity. This virtuous circle helps to eradicate anxiety and fear associated with a decline in one's function, leaving space to celebrate remaining abilities.

This example of a virtuous circle supporting an individual to attend to an occupation will be considered in the present study, as these ideas could support the identification of facilitators to employment for individuals with young-onset dementia, and the clinical benefits of this. Re-menting is the notion of improving ones functioning by removing social barriers that contribute to an individual's decline; this may be possible if people with dementia are appropriately supported and scaffolded within society (Kitwood, 1997). The ideas presented are particularly relevant to this research which aims to support an individual to remain in employment. It is hoped that the current research could make recommendations for employers to facilitate the initiation of a "virtuous circle" by supporting an individual with young-onset dementia in employment, which in turn can help to regain a sense of independence, identity, and purpose

1.4.1.3. The Social Model of Disability

The exploration of other social models to understand dementia can help us to consider how social factors can contribute to the severity of one's symptoms. The social model of disability can be used to understand this relationship (Oliver, 1983). This model aims to de-medicalise disabilities by positioning disabled individuals as socially disadvantaged not because of their impairments, but by the negative responses and interactions in society from able-bodied individuals.

Initially, the social model of disability focused on the experience of those with physical disabilities, and considered how disabled individuals are impaired by the design and structure of the physical environment around them. For example, the physical environment is designed and structured in favour of able-bodied individuals, with little to no consideration for those with differences in ability who may require step free access. This lack of consideration places barriers up for individuals with impairments (Blackman et al., 2003). These barriers are further intensified by the negative ideas held about disabled people in society, as physical impairments are often viewed as life limiting and abnormal. Such attitudes lead to the isolation and social exclusion of individuals with a disability (Babik & Gardner, 2021).

The social model of disability has since advanced to include people who are viewed by others as having some form of non-physical impairment, for example individuals with intellectual disabilities and mental health difficulties (Oliver, 2004). Additional barriers that disabled individuals face include inaccessible working environments, healthcare, education, transport, and devaluation through negative images in the media which promote negative attitudes and assumptions (Oliver, 2004). Several writers have applied the social model of disability to better understand dementia, recognising that individuals are disadvantaged due to societal barriers rather than the impairments associated with their illness (Barnes, 2004). For example, society often assumes that an individual with dementia is unable to exercise agency, therefore society reacts by doing things for the individual, rather than drawing on their strengths to support them to do things independently (Boyle, 2014).

Unfortunately, there has been little research into the relationship between the social model of disability and young-onset dementia, with some suggesting that this may be due to social scientists continuing to view dementia through a biomedical lens (Priestley, 2003). Others suggest that the lack of research may be due to a failure to attend to individuals with young-onset dementia (Milligan & Thomas, 2016). This research will attempt to consider the social model of disability, and the way that it conceptualises barriers within society, to understand how the current practices in employment may be reducing the opportunity for those with young-onset dementia to remain in employment. This research aims to add to the limited research between the social model of disability and dementia, whilst viewing dementia through a social rather than a biomedical lens.

1.5. Challenges Associated with Young-onset Dementia

This section explores the unique challenges experienced by those living with young-onset dementia, as opposed to individuals living with older-age dementia. This is important to consider as the literature suggests that the experiences and needs of individuals with young-onset dementia are different (Rabanal et al., 2018).

1.5.1. Delayed or Differential Diagnosis

Individuals living with young-onset dementia experience several unique challenges. Firstly, there are often difficulties in obtaining the correct diagnosis. Robust diagnostic procedures are required to accurately diagnose young-onset dementia, including gaining an individual’s cognitive and family history, assessing one's mental health and cognitive state, and combining this with neuroimaging (Mendez, 2006). Additionally, further diagnostic tests may be required to identify reversible causes of young-onset dementia, such as blood tests, cerebrospinal fluid analysis, and tissue biopsy (Mendez, 2006). Diagnosis can be further complicated as a wide range of difficulties mimic the signs of young-onset dementia, such as traumatic head injury and other neuropsychiatric symptoms (Mendez, 2006). A large proportion of those with young-onset dementia experience significant depressive symptoms and are misdiagnosed with persistent depression (Rosness et al., 2010).

However, this could otherwise be attributed to apathy and social withdrawal which is associated with frontal-executive impairment in dementia (Draper & Withall, 2016).

A thematic synthesis of research in this area revealed that some challenges regarding diagnosis could be due to a delay in accessing help and misattribution of symptoms by the clinician (O'Malley et al., 2021). Unfortunately, those living with young-onset dementia often experience a delay in diagnosis compared to those with later-onset dementia (Loi et al., 2022). This delay may be attributed to the wide pattern of presentations within young-onset dementia which contribute to misdiagnosis, and a low expectation from clinicians that dementia may be the underlying cause at a young age (Vliet et al., 2013). Receiving a diagnosis of young-onset dementia can be met with many different reactions, ranging from relief that one's symptoms can be explained to shock and destabilisation (O'Malley et al., 2021).

1.5.2. Access to Age-appropriate Services

Those living with young-onset dementia have different needs, warranting specialist support (Cahill et al., 2012). However, individuals often face challenges in accessing specialist age-appropriate services. Post-diagnostic services are routinely designed for older adults living with dementia, with a lack of available services tailored to support younger individuals with dementia (Clemerson et al., 2014; Johannessen & Möller, 2013). Often services for those with young-onset dementia are hampered by short-term project based commissioning and ad-hoc service delivery (Mayrhofer et al., 2018). This lack of continuity in service provision can leave those with young-onset dementia and their carers feeling unsupported, isolated, and vulnerable, leading to higher levels of distress (Millenaar et al., 2016).

Specialist services are required for those with young-onset dementia to effectively target the distinctive and wide-ranging needs due to the individuals' age, the range of rare diagnoses within young-onset dementia, and one's life stage (Greenwood & Smith, 2016). Individuals consistently accessing tailored specialist services for young-onset dementia report improved satisfaction and overall quality of care (Stamou et al., 2021). However, few specialist services are available for both diagnostic and post-diagnostic support, with only 25% of individuals able to access age-specific post diagnostic support (Rodda & Carter, 2016).

1.5.3. Changes Within Relationships

The impact of dementia on relationships and intimacy has been researched in later life; however, there is little known about the changes in relationships for those with young-onset dementia (Holdsworth & McCabe, 2018), with much of the literature criticised for exploring experiences from only one partner (Holdsworth & McCabe, 2018). With the onset of dementia, the relationship with one's partner can transition to a caregiving relationship. This sudden change to the relationship and family structure can cause significant uncertainty regarding one's role and the future, leading to anticipatory grief (Kilty et al., 2019). Some carers experience a sense of loss and difficulty with accepting the dementia diagnosis (Hellström et al., 2007; O'Shaughnessy et al., 2010). A dementia diagnosis has the potential to impact certain qualities within a relationship, including a decline in reciprocity, shared activities, and communication. This can impact the carers' mood, perceived ability, and can lower the functional ability of the individual with dementia. However, some positive aspects of the relationship remain, including warmth, love, and affection (Ablitt et al., 2009).

With the increase in diagnostic rates for young-onset dementia, there is also an increase in the number of children and young people who have a parent with young-onset dementia. This can significantly impact the children emotionally and financially, and can cause disruption in many aspects of their lives, including education and wider social relationships (Gelman & Rhames, 2020). Some young people report that a parental diagnosis of young-onset dementia has impacted their social relationships, with many choosing not to tell their peers due to ignorance and a media focus on dementia as an older person's illness (Sikes & Hall, 2018). Many young people also experience feelings of grief for their parents' lost abilities, whilst also reporting anticipatory grief due to the terminal nature of dementia (Lindauer & Harvath, 2014).

The rest of this chapter focuses on the impact of young-onset dementia on one's employment and describes the psychosocial consequences of losing one's employment at a young age.

1.6. Impact of Young-onset Dementia on Employment and Associated Implications

Individuals with young-onset dementia face a wide range of challenges when managing the difficulties associated with dementia at work. The challenges faced by individuals with young-onset dementia in employment inspired me to develop the present research project, with the aim of identifying ways to minimise these difficulties, and better support these individuals. Therefore, to provide context regarding the rationale for the present project, this section will describe the difficulties faced in employment whilst critiquing the current initiatives and related policies

1.6.1. Challenges Faced by Those with Young-onset Dementia in Employment

People living with young-onset dementia are of employment age, often a diagnosis has negative consequences for one's employment which can have devastating impacts on both the person living with dementia, and their loved ones who care for them (Svanberg et al., 2011). In many cases, individuals with young-onset dementia report feeling more tired and stressed at work. This can worsen their memory and concentration, impacting their ability to participate in work activity (McCulloch et al., 2016). Some individuals with young-onset dementia may be required to leave employment due to the progression of their dementia symptoms and their workplace's inability to adapt to the individual's needs (Silvaggi et al., 2020). Other individuals are required to take early retirement, with support for both the individual with dementia and their family necessary to mitigate this risk (Hirano et al., 2021).

Losing one's employment can reduce the amount of meaningful activity an individual engages in. This can exacerbate the challenges faced by living with dementia, contributing to social exclusion, mental health challenges, and disempowerment (Greenwood & Smith, 2016). Employment loss can lead to adverse financial outcomes, with some individuals unable to sustain financial commitments such as mortgages and household bills (Carter et al., 2018). Carers are also often required to leave their employment, or reduce their working hours with the increase in caring responsibilities (Bayly et al., 2021; Couzner et al., 2022), thus further contributing to the financial strain faced by the family. The increase in caring responsibilities for carers of those living with young-onset dementia can be overwhelming, as carers are often balancing competing care needs of young children and ageing parents too (Cations et al., 2017).

1.6.2. Critique of Current Employment Policy

Employment, financial, and legal issues are under-recognised for those with young-onset dementia (Mayrhofer et al., 2018). Information available to support these issues is often limited, ambiguous, and not specific to young-onset dementia (Jones et al., 2018). General policy suggests that individuals who develop a disability or illness while in employment are entitled to protection under the Equality Act (2010). This entitles them to receive reasonable adjustments in the workplace. However, sadly the definition of reasonable adjustments is subjective. Whilst intended to be used in a facilitatory manner, evidence suggests it can be used in a punitive way (Chaplin & Davidson, 2016), with some individuals dismissed from work without being offered reasonable adjustments (Brechin, 2004). There is a clear need for more specific guidance and information regarding employment rights for individuals with young-onset dementia (Kilty et al., 2023). The following sections of this report detail a literature review conducted to summarise research focusing on young-onset dementia and employment more specifically.

1.7. Literature Search Strategy

A review of the literature regarding the employment related concerns for individuals with young-onset dementia was necessary to summarise the limited research that has been conducted in this area already (Mayrhofer et al., 2018). A systematic literature review was conducted in August 2022 using the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) protocol (Page et al., 2021). Electronic databases, such as Ebscohost (Psychinfo, Cinahl and Academic Search Complete) and Google Scholar were searched, alongside reference lists of relevant papers to identify missing or grey literature. The following search terms were combined using an "OR" command: dementia, early onset, and young onset. The following search terms were also combined using an "OR" command: employ, work, job, career, vocation, occupation, and profession. These two searches were combined using an "AND" command. Across all search domains, 183 papers were yielded. 10 papers remained following the removal of papers based on the exclusion criteria and duplicates. Full details of the search strategy, inclusion, and exclusion criteria are available in Appendix A. The following sections of this paper will critically review the results from the literature search and will be arranged into themes.

1.7.1. Experience of Employment with Young-onset Dementia

Employment issues are common for those with young-onset dementia, as they are of working age. Harris (2004) conducted face-to-face in-depth interviews, online interviews and focus groups with 23 individuals diagnosed with young-onset dementia in the USA. The aim of the study was to understand the subjective experience of young-onset dementia, particularly in two areas: the unique experience of dementia at a young age, and the utility of specific guidelines and services for those with young-onset dementia. Results identified several common themes which considered the unique experience of those with young-onset dementia. Individuals with young-onset dementia can face poor insight into their illness, making it difficult to obtain the correct diagnosis. Concerns around work and retirement were also evident, for example an individual within the study who was forced to take early retirement shared feeling abandoned by their employer and struggles to accept that they are financially dependent on their partner. This links to the remaining themes identified in the study which state that those with young-onset dementia experience a lack of meaningful occupation, changes to relationships within the family, issues with self-esteem, marginalisation, and dependency on others. The authors concluded that there is a need for tailored services and workshops for those with young-onset dementia to address the unique needs identified.

Some of the themes identified in Harris's (2004) research have also been identified within the literature concerning older age dementia, such as the challenges with obtaining a timely and correct diagnosis (Vliet et al., 2013), and a lack of meaningful occupation and marginalisation (Martyr et al., 2018). However, the study identified other themes, such as work and retirement concerns, which are not present within the literature concerning older age dementia. This emphasises the exclusive experience of young-onset dementia and warrants further research to explore this. Unfortunately, the transferability of the findings in this study may be limited due to the small sample size and the use of only Caucasian participants from the USA.

Other research into the experience of living with young-onset dementia identified key issues regarding employment, in particular the transition out of purposeful activity following a diagnosis. Roach and Drummond (2014) conducted nine semi-structured interviews with families living with young-onset dementia in Canada. This study aimed to explore how individuals with young-onset dementia can maintain work, purposeful activity, or volunteering. Four themes emerged from a framework approach to qualitative analysis. These themes focused on diagnosis, finances, relationships, and meaningful activity. Two smaller subthemes emerged from the fourth theme, these were the traumatic cessation of work, and a need for purposeful activity. Some individuals described the sudden and unexpected nature of transitioning out of work as a traumatic event in their lives. They described the decline in meaningful activity as having a significant impact on all other areas of life, including family finances and relationships. Finally, changes within oneself were often identified within one's place of employment, which fortunately most often led to help-seeking behaviour and subsequent diagnosis.

Overall, the authors concluded that age specific dementia services or charities must support individuals with young-onset dementia to maintain a purposeful role as this has significant clinical implications. These include improving the individual's sense of self, and enabling family members to continue to both work, and support the person with dementia. This structured support may result in positive outcomes for the government, including a reduction in the direct and indirect costs associated with dementia. The results from this study are particularly significant for the present study, as they demonstrate the importance of better understanding the key role of employment in supporting an individual financially, within relationships, and with the diagnostic process.

Both studies included within this section of the systematic literature review were published in different global locations, making the results difficult to apply solely to the UK legislative and social care context. Further research must be conducted in the UK to contribute to the global literature, and to influence the development of tailored support for those living in the UK.

1.7.2. Challenges Faced at Work After a Diagnosis

The literature considered the employment experience that people living with dementia face after a diagnosis. Chaplin and Davidson (2016) conducted five interviews with people in the UK to understand the experience of developing young-onset dementia while still in employment. Four superordinate themes were developed using Interpretive Phenomenological Analysis (IPA). These were: the realisation that something is wrong, managing the situation in the workplace, trying to make sense of change, and coming to terms with retirement or unemployment.

When individuals within the interviews became to realise something was wrong, they often described a change to their functioning in the workplace, with all participants describing how their dementia related symptoms led to them making mistakes. All individuals attributed these changes to work pressures or changes to work roles initially, before realising something more serious was wrong. To manage their situation in the workplace, individuals attempted to engage in self-management strategies, including spending more time and effort to plan and organise themselves. Some individuals felt they were under extra scrutiny and were being watched by colleagues and employers. Despite this extra observation, none of the participants were offered reasonable adjustments, or were referred to a disability employment advisor.

When trying to make sense of the changing situation, some individuals felt that if better supported, they would have been able to remain in employment for longer and felt resentful that they were not given this opportunity. Other individuals felt they were no longer competent and felt upset about how absent their employer had been when they were on sick leave. When coming to terms with their retirement or unemployment, all participants said that this had impacted their relationships with their family, some experienced increasing levels of worry and financial hardship. Despite this, all participants described a positive outlook for the future, with some taking opportunities to reignite old hobbies or join young-onset dementia related groups.

Overall, the authors conclude that those who develop young-onset dementia do not always receive the reasonable adjustments that they are entitled to under the Equality act (2010) and often feel as though they have been treated poorly in the workplace. The authors consider the need for more specialised advice and support regarding employment related concerns for both the employer and employee. More specifically, the authors recommend that staff working in dementia specific services should understand employment law to best support them in the workplace. To increase the validity of the findings, the authors verified the analysis with an external individual, and checked the themes with the participants to ensure they matched their experience. However, for some participants, considerable time had lapsed since they were last in employment. Therefore, some of the data may be outdated or rely on retrospective accounts.

A study conducted in Australia exploring the experience of young-onset dementia emerging in the workplace reported similar challenges. Evans (2019) conducted semi-structured interviews to understand the experience of 10 people, aged between 49-64, from the onset of dementia symptoms to the time of leaving the workforce. The findings from the study suggested that the emergence of dementia at work was initially unnoticed by colleagues. However, as an individual's symptoms developed, their job performance began to decline, and others within the workplace began to notice a problem. This led to challenges with relationships in the workplace, particularly with managers who viewed the individual struggling as a "poor worker", failing to understand the true underlying concern. Individuals in the interviews raised concerns about the lack of opportunities for those who develop young-onset dementia in the workplace, with few individuals able to work beyond their diagnosis. Some individuals expressed their disappointment of being unable to retain their employment, instead choosing to take part in other engagement opportunities elsewhere.

The authors concluded that individuals with young-onset dementia experience a lack of support in the workplace and are afforded little opportunity to continue working beyond their diagnosis. They also suggest that workplaces are not well equipped to support individuals with dementia, and advocate for more information to be made available about how workplaces can identify and support those with declining cognitive function. Although the authors describe obtaining rich data from the interviews, much of the information relied on retrospective accounts, or the use of diaries to develop a timeline of events. This may impact the accuracy of the data collected, thus impacting the validity of results.

Further research has examined the experience that people with young-onset dementia face when remaining in employment. Sakata and Okumura (2017) conducted a matched cohort study which followed 143 employees who were recently diagnosed with young-onset dementia for around 600 days. Compared to control participants, those with young-onset dementia were more likely to leave their jobs, with 14% of the individuals with young-onset dementia compared to 7% of control participants leaving their jobs within one year. These findings are similar to the rate of job loss for other health conditions, including cancer or stroke (Maaijwee et al., 2014; Taskila-Åbrandt et al., 2005). The authors state that this job loss could be attributed to what they describe as inevitable and preventable factors, such as impaired performance (Evans, 2019), and the shock of receiving a diagnosis (Chaplin & Davidson, 2016).

When considering the research findings, and conclusions drawn from previous research, the authors recommend that employers should be providing tailored support in the form of reasonable adjustments and specialist employment related advice as soon as they are aware of the diagnosis of young-onset dementia, as many individuals retain the ability to work if they receive accommodations and adjustments (Chaplin & Davidson, 2016; Sakata & Okumura, 2017). Providing tailored support could help to minimise the harm caused by unemployment, such as lower self-esteem, poor sleep, lower mood, and income related concerns (Richardson et al., 2016). The findings and recommendations made in the research by Sakata and Okumura (2017) were based on a study in Japan, which has a much lower retirement age of 60. Therefore, the individuals selected to take part in the study were aged 59 years and below which is not reflective of the UK retirement age. The recommendations therefore are useful and contribute to the small evidence base, but also must be considered carefully when applying to the UK context.

1.7.3. Workplace Attitudes to Dementia

A portion of the literature focusses on workplace attitudes to dementia, including the consideration of dementia as a workplace concern as our working lives extend. Egdell et al. (2021) investigated if employers considered dementia as a workplace concern and was interested to find out if policies and practices were available to support those with dementia. The researchers used a mixed method for data collection. A total of 30 semi-structured interviews were conducted, and 331 employers from a range of workplaces, including social enterprises, third sector, public sector, and private sector organisations, responded to an online survey which was distributed across 4500 human resource departments in Scotland.

Most survey respondents indicated that dementia was not a workplace concern and would not be in the future. They also noted that there were currently no policies in development or in place to support individuals with dementia at work. Some respondents felt as though dementia was not a concern due to the young age of their workforce, suggesting a poor awareness of young-onset dementia. However, some employers did demonstrate some dementia literacy, with some understanding the symptoms and progressive nature of the illness. Others could acknowledge that they may have individuals working for them with a diagnosis of dementia, or who may have chosen to leave without disclosing a diagnosis. However, much of the employer’s knowledge about dementia was gained through personal experiences rather than through training at work.

The findings from the study suggest that employers are not consistently upholding the rights of those living with dementia, despite there being a legal and human rights obligation to do so. The authors recommend policy development and awareness training to prepare organisations to support an individual with dementia in their workforce at a practical level. This would enable employers to uphold basic human and legal rights requirements that are currently being overlooked. The authors note that the research was restricted to participants in Scotland and felt as though the response rate was low, with only 331 valid responses despite disseminating the questionnaire to 4500 employers. The authors suggest that the low response rate may reflect employer’s attitudes that dementia is not a workplace concern. They recommend scaling up the study by improving the response rate and increasing the geographical scope to produce a more representative picture.

1.7.4. Workplace Initiatives for Those with Young-onset Dementia

Several studies investigating young-onset dementia in the workplace have been conducted internationally and will be explored in this section. A study conducted in Japan examined the workplace experiences of people living with young-onset dementia with the aim of identifying options for employment support (Ikeuchi et al., 2022). Semi-structured interviews were conducted with those living with young-onset dementia and were analysed qualitatively. Four categories were identified; experiencing a crisis from continuing to work, seeking support, overcoming workplace challenges, and reaffirming a sense of purpose through resuming work or social participation.

Findings suggest that individuals living with young-onset dementia who informed others of their diagnosis could seek support from colleagues, healthcare, and welfare professionals. By seeking support from those with a knowledge of young-onset dementia, individuals could reaffirm a sense of purpose by receiving support to resume work or transition to socially active lives after leaving their job. The authors suggest that the findings indicate a need for awareness raising within the workplace to promote an understanding of young-onset dementia and consider the importance of accessing professional support.

Another workplace initiative called “Side by Side” was developed in Australia to assess the feasibility and safety of workplace engagement for those with young-onset dementia (Robertson et al., 2013). Employees of a hardware store were given dementia training, and each were paired up with nine individuals with young-onset dementia in a buddy-style system for one day a week. At the start of the shift, duties were negotiated and included things such as serving customers, restocking, and assembling displays. A mixture of observations, interviews, work journals, and focus groups with both the individual and their carer were used to gather qualitative data.

Evaluation of the initiative revealed that all of the individuals with young-onset dementia could safely adapt to the workplace when supported with an appropriate framework, with no adverse events reported. Carers noted a positive impact on self-esteem and life satisfaction of the individual as a result. The authors conclude that it is possible to offer meaningful activity for people with mild dementia when using a supportive framework, and advocate for similar models of social inclusion to be developed for those with young-onset dementia. These conclusions provide justification of the utility of the present study which aims to identify potential adaptations which can be made in the workplace to support individuals with young-onset dementia to remain in employment, and also to challenge stigmatising views of people with young-onset dementia (Batsch & Mittelman, 2012).

A mixed methods study investigating the outcomes of a group gardening program for 12 individuals with young-onset dementia in the UK found similar results to the international initiatives discussed. Hewitt et al. (2013) aimed to understand the impact of the gardening program on individuals with young-onset dementia by analysing quantitative measures of wellbeing which were completed by the staff members running the initiative. Qualitative data from semi-structured interviews with carers both before and after the intervention were also analysed to understand the impact of the intervention on the individual. The program involved a weekly group for one year, whereby the individual with young-onset dementia was responsible for completing structured tasks which were allocated according to one's ability. The group would end with a meeting designed to discuss progress and promote group belonging.

The main findings from the study suggested that scores of wellbeing were maintained, despite a decline in an individual's cognitive function. Furthermore, carers reported that the project had a positive influence on the individual with young-onset dementia, particularly enhancing one's sense of independence, enjoyment, achievement, and value. Carers also reported a reduction in anxiety for the individual with young-onset dementia. Overall, the authors concluded that meaningful occupation for individuals with young-onset dementia is beneficial for maintaining or improving wellbeing, despite a decline in the individual's level of cognition. Unfortunately, much of the research on workplace initiatives is short term and is unable to track changes longitudinally. Hewitt's et al. (2013) study only tracked changes over a period of one year, leaving a gap in the literature to understand the longer-term benefits of the initiative, and how it could be adapted as one's cognition declines further.

Other research focused on developing digital initiatives to support individuals with young-onset dementia in the workplace. Marashi et al. (2020) conducted six interviews with those experiencing mild cognitive impairment and young-onset dementia in employment. The interviews aimed to explore how the needs, goals and interests of the individual could be integrated into the design of a digital tool to support task management at work, a common challenge noted by individuals with cognitive decline. The interviews were conducted in two phases, the first set of interviews focused on exploring the individuals unique experience of cognitive decline in the workplace. A second set of interviews focused on understanding the individual's workflow and useful problem-solving strategies that were already in place. A follow up study further exploring the design of the digital tool was conducted some years later (Shastri et al., 2022). Two participatory sessions were facilitated with three participants with young-onset dementia and their carers.

Results from both of the studies suggest that the needs of individuals with young-onset dementia in the workplace are complex, thus the design of a digital tool is also complex and must be personalised to the individual, taking into consideration the interaction between one's impairment, the resources available, and the nature of one's job role. For example, the needs and technological preferences of one individual in the study, who preferred the use of day books and phones, was not in line with the needs and technological preferences of another individual in the study, who preferred the use of electronic tablets to support them at work. The authors concluded that the use of technology in the workplace could prove useful in supporting those with young-onset dementia and cognitive decline to continue functioning well at work. However, technology developed must be personalised to the individual, considering both their needs and preferences. To reduce the stigma associated with cognitive decline, the authors suggest designing a digital tool to be used by everyone in the workplace. Overall, although relatively small sample sizes existed within both of the studies, the research adds to the small body of knowledge regarding potential adaptations to support an individual with young-onset dementia in the workplace.

1.8. Rational and Aims of the Research

1.8.1. Clinical Relevance and Rationale

There are several limitations noted within the current evidence base which this research aims to address. Firstly, this study will contribute to the limited research on young-onset dementia. Unfortunately, there is a dearth of awareness and research focussing on young-onset dementia generally (Harris, 2004), despite calls for increased attention by organisations and the individuals affected. There is even less research investigating the unique challenges that those with young-onset dementia face in employment, with most of this research conducted internationally (Ikeuchi et al., 2022; Robertson et al., 2013; Yaeda & Sunami, 2022). Furthermore, much of the research available focuses on the positive impact of workplace initiatives (Robertson et al., 2013), rather than also identifying the barriers impacting one’s ability to remain in employment. Therefore, the current research project will contribute to the lack of research in the UK employment context, focusing uniquely on identifying what helps individuals with young-onset dementia remain in employment, whilst also considering the socially constructed barriers which may get in the way (Oliver, 1983). The outcome of this research, and emphasis on considering the psychosocial benefits of maintaining employment, will be clinically relevant for psychologists to consider when working therapeutically with those with young-onset dementia. Furthermore, the aim of identifying workplace support and adaptations for individuals with young-onset dementia will be useful for clinical psychologists to be aware of when designing and shaping relevant service provision.

Informal carers can provide unique insights into the preferences and needs of those living with dementia, and can advocate for the individual whilst interacting with the healthcare system (Beardon et al., 2018). Carers play a key role in improving dementia care overall by facilitating the integration of care and communication across professionals (Smith et al., 2021). Carers also play an important role in improving person-centred care for those with dementia by encouraging the consideration of personhood (Kitwood, 1997), with some carers expressing a responsibility to communicate personal insights and advocate for the needs of the individual (Fetherstonhaugh et al., 2021). This research draws upon the expertise and knowledge that carers have about the individuals they are caring for and asks them to share the barriers and facilitators that individuals with young-onset dementia face in employment. By asking the carers to speak from the perspective of the individual with dementia, this research draws upon a key aspect of the VIPS framework[3] (Brooker, 2003) which values looking at the world from the perspective of the person with dementia to enhance person-centred care.

1.8.2. Research Aims

This research aims to interview carers to understand the barriers and facilitators that individuals with young-onset dementia have faced regarding their employment when receiving a diagnosis. This study aims to be clinically relevant by producing useful and practical information that can support those living with young-onset dementia to stay in employment for longer, thus addressing some of the psychological and practical concerns noted in the literature regarding unemployment, such as low self-esteem, poor sleep, low mood, and income related concerns. It is hoped that the results from the study can support individuals to remain in employment or meaningful occupation for longer, providing a sense of purpose and self-esteem. The current research will have practical implications, aiming to not only raise awareness of the issues regarding maintaining employment with a diagnosis of young-onset dementia, but also to offer guidance for employers to address them.

1.9. Research Questions

The research seeks to answer three research questions from the perspective of the carer:

1. What are the barriers to employment for those with young-onset dementia?
2. What are the facilitators to employment for those with young-onset dementia?
3. What adaptations could employers make to support those with young-onset dementia to remain in employment?

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[3] The VIPS framework was developed to support the application of the person-centred care model into practice. This framework focusses on valuing those with dementia, treating them as individuals, looking at the world from the perspective of the individual with dementia, and encouraging a positive social environment to enhance wellbeing (Brooker, 2003).

2. METHODOLOGY

2.1. Chapter Overview

I begin this chapter by detailing the methodological approach to the research project, and by describing the epistemological position framing the research. The epistemological position adopted within the research will be linked to the chosen methodology and procedures throughout. This chapter also describes the ethical review process and measures adopted to maintain ethical practice. For the purpose of confidentiality, information regarding specific organisations or individuals involved has been anonymised throughout. I end this chapter by offering a thorough explanation of the analytic approach used within this research, whilst considering my reflexive position as a researcher and how this may have influenced the research project as a whole.

2.2. Epistemology and Philosophical Assumptions

To understand the epistemological position adopted in this research, two areas of philosophy are relevant, these are ontology and epistemology. Ontology is concerned with the nature of reality. It determines whether or not reality exists separately from human practice and understanding, and therefore whether reality is objective or reflects an individual's perspective (Braun & Clarke, 2013). Epistemology is concerned with the nature of knowledge, and how it is discovered (Bunge, 2012), for example what is possible for us to know, and how we go about this (Willig, 2008).

Ontological and epistemological concepts form a continuum from naïve realism to extreme relativism (Sullivan, 2010; Willig, 2013). Realism states that there is an external world separate from our thoughts, perceptions and beliefs, whereas relativism states there are multiple constructed realities which differ across time and context (David & John, 1999). A critical realist position sits between the realist and relativist paradigms. It assumes a realist ontology, where there is an observable and measurable objective reality that sits independently of one's own beliefs (Willig, 2016). However, it also acknowledges the subjective reality of an individual's experience, and acknowledges the influence of the researcher (Willig, 2016). Critical realism organises these seemingly opposing ideas by acknowledging that there is a real and knowledgeable world which 'sits behind' the subjective and socially located knowledge that can be accessed through research (Madill & Gough, 2008).

A critical realist position was adopted in this research project. By taking a critical realist approach, this research seeks to co-construct a description of the experience of employment for those with young-onset dementia through the accounts of their carers and loved ones, whilst recognising the researcher's context and influence on the knowledge produced. My active role as a researcher in the development, analysis, and reporting of the research project will have implications for the knowledge that has been produced, which fits with the underlying principles of critical realism. I further examine my active role as a researcher later in this chapter.

2.3. Research Design

Qualitative research is concerned with studying the nature, quality and meaning of human experience. Data is obtained through observations and accounts, and is presented through the patterns of data, or themes which emerge (Miller, 2016). Qualitative methodologies seek to provide an understanding of people's experiences and the meanings associated with them (Willig, 2019). A qualitative approach using semi-structured online interviews was used in the present study to address the explorative nature of the research questions which aim to uncover the barriers and facilitators to employment experienced by those with young-onset dementia. A qualitative approach aligns with the critical-realist epistemological position adopted in this research. Furthermore, much of the literature on young-onset dementia adopts a qualitative approach (Greenwood & Smith, 2016; Mendez, 2006; Rabanal et al., 2018). This indicated a suitability and appropriateness for the approach and influenced my decision to choose this.

2.4. Participants

2.4.1. Inclusion Criteria

Initially, I aimed to recruit individuals with young-onset dementia, however, after consulting with a variety of young-onset dementia specific community groups, charities, and my research supervisor at the time, I was advised that recruiting individuals with young-onset dementia would be challenging and unlikely given the time constraints of a doctoral thesis. When attempting to recruit through young-onset dementia community groups, I was advised that the individuals attending were in later stages dementia, experiencing many cognitive and communication difficulties, making participation in interviews challenging. When contacting different charities to advertise my study to a larger group of individuals with young-onset dementia, I was told that I would have to register for approval to advertise my study which could take months, this avenue was not possible due to the time constraints of the thesis. This will be explored further in the discussion chapter.

Instead, I agreed with my supervisor that an appropriate option to continue with the project would be to interview carers of individuals with YOD to hear their perspective of employment matters for those with YOD. It was felt that carers would be in a good position to share the impact of employment matters on both the individual and the family due to their close involvement. I used social media to recruit formal and informal carers. The two formal carers who took part in the study were paid healthcare professionals working closely to support the individual with young-onset dementia and their family. The four informal carers who took part in the study were unpaid family members and partners of the individual with young-onset dementia. To adhere to data protection and storage requirements, participants were recruited from the UK only. Individuals were excluded from the study if the individual they cared for did not have a diagnosis of young-onset dementia or were located outside of the UK.

2.4.2. Recruitment Strategy

A range of recruitment avenues were explored. Firstly, I created new secure social media accounts on Facebook, Instagram, and Twitter to advertise the study. These accounts were created using a university email account to maintain the security and confidentiality of the data. A short study advertisement (see Appendix B) was posted in a variety of young-onset dementia pages on social media. Alongside this, various dementia charities and organisations, such as Dementia UK and Alzheimer’s society, were approached to advertise the study within their newsletters and groups. A snowball sampling technique was adopted once recruitment had begun; participants were given the opportunity to share the study advertisement with anyone they thought might like to take part in the research. Participants were invited to respond to the study advertisement by emailing me, or privately messaging the social media accounts. To protect the participants' data, the social media accounts were deactivated once the recruitment phase ended.

2.5. Procedure

2.5.1. Initial Contact

Once potential participants made contact, they were sent a brief document with further information about the study and were invited for a telephone call to ask questions about the research. When a participant expressed an interest in taking part, they were sent a participant information sheet and a consent form (see Appendix C and D). A date for the online interview was then arranged. Participants were given another opportunity to ask questions at the start of the interview and were reminded about their rights to withdraw from the study.

2.5.2. Consent

Participants were required to read the information sheet and provide written consent prior to the interview. To give consent, they were asked to place their initials in a box next to the relevant information on the form and provide the date and a signature at the end. The consent form was then returned and signed by me prior to the interview commencing.

2.5.3. Interviews

At the start of the online interview, participants were reminded to ensure that they were in a private space and that the interview would be recorded for the purpose of the research. An interview schedule (see Appendix E) was used to guide the discussion in line with the research questions. Between six to ten interviews are noted in the literature as appropriate for small scale projects using thematic analysis (Braun & Clarke, 2013) with previous studies confirming data saturation after six interviews (Isman, Ekéus, et al., 2013; Isman, Mahmoud Warsame, et al., 2013). This number allows for enough data to demonstrate patterns within the text, whilst keeping the amount of data manageable. A total of six interviews took place via Microsoft Teams, with each interview taking approximately 60-75 minutes to complete. At the end of the interview, each participant was given a verbal debrief and this was followed up with an email containing a debrief document (see Appendix F).

2.5.4. Transcription

The transcribe function on Microsoft Teams was used to obtain individual transcripts of the interviews. I carefully considered the data in accordance with transcription guidance (Bailey, 2008). This guidance states that transcription is an interpretative process whereby the researcher considers what level of detail is required, whether to include visual data, and how to present the data. I chose an orthographic approach to transcription, which focuses on developing a complete record of the spoken words, along with other features such as partial words or stutters. Visual data and social discourse at the beginning of the interview were not included in the transcript. Brief contextual information such as the participant's identification code and important demographic characteristics was included at the top of the transcript. However, potentially identifiable information such as names and places were anonymised throughout to protect patient confidentiality. A new line was used to differentiate between speakers and to help increase readability. Transcription errors are common and may have consequences for interpretation and analysis of the data (Poland, 1995). To ensure accuracy of the data, I checked the transcripts against the recordings and corrected any mistakes. Where something was not decipherable, a best guess approach was adopted to complete the data. Aspects of Braun and Clarke (2013) transcription notation system was utilised in the current research to enhance the readability of the data.

2.6. Ethical Approval

The study was registered with the University of East London after undergoing an ethical review. The design and implementation of the study were considered against the British Psychological Society's (BPS, 2014; 2021) Code of Human Research Ethics. This code stipulates the conditions which research must adhere to in order to minimise potential harm. Ethical approval was granted prior to the commencement of the research.

2.6.1. Informed Consent

To gain informed consent, prospective participants must be provided with full and accessible information about the research project that they are invited to take part in (Crow et al., 2006). The participant must also be given the opportunity to consent freely to this information, whilst having the opportunity to decline or withdraw from the study without consequence. Informed consent can improve research findings by improving the regulations and procedures adopted in research (Kent et al., 2002).

Informed consent was obtained by providing all participants with a full and detailed information sheet. This detailed the purpose of research, what to expect when taking part, and the benefits and the drawbacks of participating. It also included details about their right to withdraw from the study within three weeks of the interview, and information about confidentiality and data protection.

Participants were given a sufficient amount of time to read the information sheet and ask any questions using the email provided. They were then directed to sign the consent form if they wished to take part.

2.6.2. Confidentiality and Data Governance

Participants were informed about the procedures around confidentiality and data storage in the participant information sheet. This sheet stated that personally identifiable data would be anonymised throughout the data collection, analysis, writing, and storage phases of research. Anonymised data would only be accessible by the research team, and this information would be stored securely on a private password protected device. A back up of the data would be stored on a private university drive in a password protected file. Participants were informed that all research data will be stored on a password protected file for three years in line with the Data Protection Act (2018) and the Caldicott Principles (National Data Guardian, 2020). A verbal reminder of this information was provided at the start of each interview.

The limits of confidentiality, and the precautions in place to protect this were discussed with the participants. Personally identifiable data, such as consent forms, were kept separate from the anonymised data to remove the possibility of linking personal details to anonymised data. I also took further precautions to maintain confidentiality and data storage safety by turning off the cloud function in Microsoft Teams prior to the interview to ensure that information was not stored on external servers.

2.6.3. Potential Distress

The University of East London risk assessment form was completed for the study to identify potential risks to the participants. This assessment identified that the overall risk to participants was low, however individuals may experience distress from discussing sensitive or emotive issues relating to young-onset dementia. This was discussed with the individuals taking part and support information was provided in the participant information sheet.

I acknowledged the potential for distress to arise from discussing sensitive or emotive issues with the participant both during and after the interview. To minimise the likelihood of harm, the interview was approached in a sensitive way, I remained mindful and watchful for any distress that arose. Breaks were offered to help reduce distress and I reminded the participants that they could choose not to speak about areas that were potentially upsetting for them. Participants were also given a list of available services and online resources both before and after the interview and were directed to these when required. I reminded the individuals throughout that their participation was voluntary, and they could terminate the interview or withdraw from the study without consequence. A full debrief was facilitated at the end of each interview.

2.6.4. Debriefing

At the end of each interview, a debrief space was created for the participant to reflect on their involvement and ask any questions. A written participant debrief sheet was sent to their email immediately after the interview. The debrief sheet reminded them of how their data would be managed, what will happen to the results of the research, and included services and online resources to access. The research team's details were also included to allow the participant to withdraw or ask further questions.

2.7. Analytic Approach: Thematic Analysis

2.7.1. Justification

This study used Thematic Analysis (TA) to analyse the data (Braun & Clarke, 2012) as this fit with the qualitative and theoretical frameworks underpinning the research questions and aims. Alternate methods of analysis were considered, such as interpretative phenomenological analysis (IPA: Smith et al., 2009). IPA can be useful for exploring under researched areas and considers the researcher as part of the meaning making process, which aligns with the present study. However, it has an idiographic focus which is incompatible with the present study’s aim of producing transferable findings to support many individuals with young-onset dementia in employment.

2.7.2. Reflexivity

Wiling (2008) states that personal reflexivity is the researcher’s reflection and acknowledgement of how one’s own experiences, assumptions and values may shape the research and findings. To encourage the reader to consider my influence on the research project, an exploration of relevant aspects of my identity and experience is presented next.

Firstly, my professional experience of caring for those with dementia, and how this impacted me personally, was relevant throughout the research process. I have witnessed the inadequacies within dementia care, including the lack of resources, time, and consideration given both to individuals with dementia and the services designed to support them. I felt compelled to give my time to hear individual stories, thus influencing the choice of interviews when designing the research. My experience caring for individuals with dementia also influenced my existing knowledge of the research area. The culmination of the factors mentioned may have potentially affected the ideas that were attended to and which were not during the design, execution, and the analysis of the data (Kelly, 2017).

My experience of coming from a working-class background, where financial struggles were common, influenced my desire to research employment matters. At times, I felt closely aligned to the participants fear of financial implications resulting from employment loss. Many individuals with similar backgrounds to my own have not been as fortunate as I have to progress to higher education. I feel as though this results from the lack of support and high levels of social inequality experienced by those in less privileged positions, which I believe mirrors the experience of some individuals with young-onset dementia in employment. The consideration of social inequality may shape the way in which I interpret responses during the interviews, which could have an impact on the resulting analysis.

Training as a clinical psychologist at the University of East London moulded my critical approach to research, thus influencing my choice to adopt a critical realist epistemological position. This critical lens also encouraged me to question my own assumptions about the research and how this may shape the knowledge produced. Finally, I have previously been described as having a strong sense of justice and feel strongly about promoting equality for marginalised groups. These values have been the driving force and guiding principles for the research.

2.7.3. Phases of Thematic Analysis

Braun and Clarke (2006) initially developed a six-phase approach to TA which offers guidelines for the process of analysis. This study will utilise the newest guidance for TA, using the most up to date processes and language (Braun & Clarke, 2012). More recent forms of TA are described as a progressive but recursive process whereby an individual moves between each phase in a non-linear manner, sometimes moving in circles between earlier and later phases before finishing the process (Braun & Clarke, 2012). A description of my engagement with the six phases is described below.

1. Familiarisation with the data: Through a process of immersion, I became familiar with the content of the data by conducting the interviews, transcribing the data, and by repeatedly reading the transcripts whilst making analytic notes about observations or ideas that arose.

2. Coding: Codes are ‘pithy, analytically meaningful’ descriptions of segments of the data which relate to the research question (Braun & Clarke, 2022). I systematically coded the data manually using Microsoft Word, whilst considering both semantic and latent meaning within the data. The codes and relevant segments of data were then collated using Microsoft Excel. Initial codes and an example transcript from the interview with participant three’s professional carer can be found in Appendix H.

3. Generating initial themes: I compiled clusters of codes which shared patterned meaning across the data which could provide meaningful ‘answers’ to the research questions. My knowledge of the area, the research questions, and the content of the data was central in influencing the provisional theme development.

4. Developing and reviewing themes: The provisional themes were reviewed alongside the entire dataset to assess the initial fit, and to ensure that the provisional themes made sense in relation to both the coded extracts and full dataset. During this phase, certain provisional themes were collapsed together, split, or discarded from the analysis to ensure that the remaining themes reflected the most important and convincing patterns across the dataset.

5. Refining, defining, and naming themes: I reviewed each theme to ensure that it was clearly demarcated and was built around a strong concept. Concise but informative names were given to each theme during this phase and a brief synopsis of each theme was also developed.

6. Writing up: I used a formal and an informal approach when writing up the research project. In the formal writing of the report, I developed a coherent and persuasive story using extracts from the data whilst addressing the research questions at hand. Alongside this, I used several Informal analytic writing techniques, such as a reflexive journal (See Appendix G) and familiarisation notes in phase one of the analysis.

3. RESULTS

3.1. Overview

In TA, it is considered appropriate to either combine the results and discussion section of a report, or to separate them by treating the results section in a more descriptive way, and expanding on the literature within the discussion (Braun & Clarke, 2022). It is recommended to separate the results and discussion section if a key goal of the research is to produce accessible implications or recommendations for the reader. Therefore, I chose to separate the results and discussion section, as the present study aims to provide recommendations regarding possible adaptations to better support individuals with young-onset dementia in the workplace. Accordingly, this chapter presents a more descriptive account of the overarching themes, themes, and subthemes which emerged from the data.

3.2. Demographics

A total of six carers took part in the semi-structured interviews, four of which were informal carers and the remaining two were professional carers who worked in dementia services. Of the individuals with young-onset dementia who were the focus of the interviews, five were male and one female. These details, along with their young-onset dementia subtype, employment type, and age at the time of the interview can be found in Table 1. It is important to note that during the interviews, professional carers were encouraged to speak of the experience of one individual in which they worked with. Nevertheless, often professional carers enriched their responses by drawing upon the experience of multiple individuals with young-onset dementia which they had previously worked with. This is evident throughout the analysis, with some of the excerpts from carers P1 and P3 switching between drawing upon their varied experience and discussing the individual with young-onset dementia described in Table 1.

Table 1

Demographic Information for Individuals with Dementia and Their Carers

Carer			Individual with Dementia			
Pseudonym	**Carer Status**	**Mini Vignette**	**Age**	**Sex**	**Diagnosis**	**Employment Type**
P1	Professional carer	P1 is a dementia specialist who took on the role of offering advice and support post diagnosis.	62	Male	Young-onset mixed dementia	Hospital porter
P2	Informal carer	P2 is married to the individual with YOD, she often liaises with his employer to support him at work.	61	Male	Young-onset semantic dementia and frontotemporal lobe dementia	Academic lecturer
P3	Professional carer	P3 is an Admiral nurse who offers support to the individual with YOD and his family.	55	Male	Young-onset Alzheimer's disease	General manager - retail
P4	Informal carer	P4 is married to the individual with YOD, offering both practical and emotional support.	56	Male	Young-onset posterior cortical atrophy	Rail worker
P5	Informal carer	P5 is married to the individual with YOD, she identifies as his 'personal assistant' instead of carer.	67	Male	Young-onset Alzheimer's disease	Police community support officer
P6	Informal carer	P6 is married to the individual with YOD, he supports her to live a fulfilled life and to maintain previous endeavours.	73	Female	Young-onset Lewy-body dementia	Nanny

3.3. Description of Themes

Through the use of themes, the analysis presents a story describing the barriers and facilitators to employment from the initial recognition of dementia symptoms and the prospect of a diagnosis, through to the employers' approach and response to this. The story ends by exploring how a formal dementia diagnosis can either lead to better employment outcomes or can guide an individual to transition to alternative meaningful occupation. Potential workplace adaptations, and the impact of employment loss are identified and explored throughout the themes. When analysing the data, one overarching theme, three themes and five subthemes were developed. Their hierarchical structure is presented visually in Table 2, which also separates them into barriers or facilitators to employment.

Table 2

A Breakdown of the Overarching theme, Themes, and Subthemes

Overarching Theme	Themes	Subthemes	Barrier or Facilitator to Employment
	The Nature of Dementia as a Barrier to Employment	The Restrictiveness of Dementia Symptoms	Barrier
		Diagnostic Process as a Barrier	Barrier
Employer’s Approach and Response to Dementia	Employers’ Unhelpful Approach and Response to Dementia		Barrier
	Employers’ Helpful Approach and Response to Dementia		Facilitator
	Diagnosis as an Opportunity	Renewed Understanding of Difficulties	Facilitator
		Diagnosis as a Ticket for Support	Facilitator
		Diagnosis as a Path Forward	Facilitator

3.4. Theme: The Nature of Dementia as a Barrier to Employment

This theme explores how the unique difficulties presented by having young-onset dementia may be a barrier to employment. For example, carers describe how an individual’s symptoms, dementia type, and the diagnostic process that they endure intrinsically have implications for the individual and act as a barrier to retaining employment. An individual’s dementia symptoms, such as memory or communication difficulties, can be considered a barrier to employment as they are debilitating and often lead to them not being able to fulfil their job role as before. When one is limited in their ability to work, they are often left with little choice but to leave employment. Furthermore, the process of diagnosis in itself acts as a barrier to employment. Carers shared the nature of the diagnostic process as time-consuming and stressful, resulting in individuals being asked to take long-term sick leave. The implications on the individual and their employment is discussed throughout each subtheme.

3.4.1. Subtheme: The Restrictiveness of Dementia Symptoms

This subtheme captures several barriers to employment for those with young-onset dementia. Firstly, this subtheme explores the carers description of how the symptoms of young-onset dementia can impact an individual's ability to carry out their job role, sometimes resulting in job loss. Secondly, the subtheme describes the experience of other individuals with young-onset dementia who attempted to compensate for their symptoms by working longer hours or throughout the night, resulting in a worsening of one's symptoms, further impacting their ability to carry out their role. Finally, the different adaptations made by employers are considered in relation to how these can be interpreted as a barrier to employment, whilst highlighting financial and psychological consequences of these adaptations.

Firstly, a common pattern noted in the interviews was that the symptoms of dementia, such as forgetting things or becoming disorientated, could impact the individual's ability to carry out crucial aspects of their job. For example, in the following excerpts, one carer described her husband's memory decline impacting his ability to participate in meetings, another carer discussed the visual changes associated with Posterior Cortical Atrophy (PCA), and how this impacted her husband's ability to carry out a variety of jobs, and a final carer shared the disorientation felt by an individual with young-onset dementia working a range of different shifts.

> *"So socially in a board meeting or in an academic meeting, he is going to have difficulties because he can't remember words, he can't remember faces" P2*
>
> *"With that type of dementia [Posterior Cortical Atrophy], it's always gonna be problems with vision. So, they see things differently and look differently like space wise so that would never have worked out. For example, driving a van and helping or whether it be in like a stock room or at a warehouse. It just wasn't it wasn't feasible" P4*
>
> *"Things became very disorientating for him, and the times that he was up wasn't helping with how his dementia was because, very often they [employer] swapped nights and days and things like that, so it was totally disorientating for him" P1*

Other carers gave further descriptions of how an individual's symptoms can act as a barrier to retaining their employment. Both carers in the following excerpts described the communication difficulties experienced by those with young-onset dementia at work, which were particularly detrimental to their ability to maintain their employment in public-facing roles where communication and punctuality were paramount.

> *"I think at the beginning, but they adapted his role by taking away a lot of what they perceived as to be stresses that he was really struggling with… The kind of struggle he had particularly was around being in the shop with the public because he struggled with the words." P3*

> *"He'd been put on sick, sick leave. Because he'd started to make, he knew he'd started to make mistakes. He would go to the wrong school for an appointment. Or if it wasn't the wrong school, it would be the wrong day, or it would be the wrong house... The little things that he knew wasn't right and he'd never made those mistakes before" P5*

Dementia is a progressive disease, impacting an individual's level of autonomy, liberty, and freedom of choice (Ward & Sandberg, 2023). It could be assumed that in the following excerpt, the carers description of the progression of dementia symptoms acting as a barrier to retaining employment mirrors the restrictive and debilitating nature of the disease. The progression of dementia has damning consequences for employment, as currently there is no cure (Patil et al. 2023), thus potentially contributing to the feeling that there is little opportunity to intervene to maintain one's employment.

> *"Knowing you're never going to get better with Alzheimer's and knowing that some people can progress quicker than others. I don't really think they [employer] could have kept him on. If there had been a way I think they would have tried it" P5*

Unfortunately, some individuals sacrificed their wellbeing to maintain their employment. In the following excerpts, carers stated that individuals with dementia were working extra hours throughout the night to meet deadlines, with some feeling increasingly fatigued whilst exerting extra energy to carry out the same work-related tasks that they used to.

> *"Yeah, he is also taking a longer to do things... he is still meeting deadlines, but he has to work into the night and early hours of the morning to do it" P2*

> *"One day he overbooked himself and he'd given himself three zoom calls. When he got through them, he just said I'm so tired because the concentration of that to stay alert all day, it just drained him" P5*

It can be understood that working harder to complete one's job role whilst experiencing dementia symptoms could act as a barrier to maintaining one's employment in the long run, particularly due to the fatigue and cognitive strain caused. Over time, these consequences could potentially lead to burn out and employment loss.

The following excerpts describe times where individuals with young-onset dementia were unable to maintain their employment. One carer shared the journey that their partner faced when he, began to experience problems with his memory and visuospatial skills[4]. This impacted his quality of driving and ability to remember familiar routes. His employer was obliged to take away his company van to ensure the individual's safety, however, the individual was unable to carry out his job role without a van and was told that he was no longer able to work.

> *"He's always had a van. And so, they would send them to places that he'd been like many, many times and he was forgetting where these places where, or he was forgetting what they do when they get there and just coming back.. They had to take the van from him" P4*

In another example illustrating the link between one's dementia symptoms acting as a barrier to employment, the carer described that the individual with dementia was struggling with their memory and was asked to take medical retirement as they were unable to stay in their current job role. However, the carer felt that if their job responsibilities were different, they may have been able to stay in employment.

> *"He couldn't work anymore. If he had been working in a different job he might have been able to take a desk job and just sort of type up reports or something, but because it was still dealing with public the public, and sensitive information, and retaining information. It couldn't be done. So, they said you'll have to take like a medical retirement" P5*

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[4] Visuospatial skills allow us to perceive our position in relation to objects around us, and to recognise how movement can impact that. It is an important skill required for driving safely (Schott & Crutch, 2019).

The impact of losing one's employment was explored in the interviews. In the following excerpts, both informal and professional carers describe the psychosocial consequences of employment loss, with some individuals struggling with a loss of independence, purpose, and routine, which negatively impacted the progression of their dementia.

> *"And he is still struggling a bit because it doesn't have anything to do. So, he doesn't have any hobbies" P4*

> *"It's dismissing them. Because that is the worst thing. As soon as they are dismissed, they progress rapidly because it's been their whole life, they enter into depression and the families have to pick that up. Their dementia gets worse… So, they have no routine, that routine, going to work, absolutely held them together." P1*

Although some individuals in the previous excerpts were unable to continue in employment, other individuals discussed in the interviews were offered work-place adaptations. In the following excerpts, carers described some of these adaptations, such as the reduction of working hours and the use of sick leave to alleviate some of the challenges that individuals faced at work.

> *"The other thing that they looked at doing and that was I suppose more recently was they did reduce his hours. Because he was finding it really tiring to work full time hours" P3*

> *"So, they just kept putting him on sick leave and then sick leave run out. So, he got moved into another position which was easier. So, it might be Inside or working with someone. But then that got too much" P5*

Some of the suggestions made by employers may initially appear to be a facilitator to employment. For example, some employers recommended a reduction in work hours, a move which can be seen as facilitating some form of employment by reducing the stress associated with working longer hours. However, the reduction in work hours ultimately is a barrier to employment, reducing one's time spent at work. Furthermore, other suggestions from employers may act as a barrier to employment, such as the use of continual sick leave.

In the following excerpts, carers discussed the financial consequences when changing an individual's job to a lower-paid role or reducing their working hours. This was particularly challenging for those with young families and mortgages to pay for. Carers also described the impact of losing employment at a young age, with some individuals not eligible for their pensions, instead having no choice but to live on benefits.

> *"There was a drop in pay, I think, because he gone from that general manager level to tea shop worker level, if you like." P3*

> *"Because you lot of a lot of people aren't ready to give up their work so early, they'll expect to continue until they're 65 or 67 and then claim pension or whatever. If you're dropped early, you didn't get a chance to get to that pension poll. You're existing on benefits for many years unless we can negotiate with pension providers to release that. And they might have mortgages. We might even have younger children or teenagers living at home, people, children at university, that they're paying for." P1*

It is important to consider the financial impact of adapting one's job role or working hours, with these adaptations not being an option for those from lower socio-economic backgrounds who are unable to accept a reduction in their pay as this will impact their ability to pay for their family or mortgage. A professional carer described the experience of one family that she had worked with, whereby the wife wanted her husband to continue working to maintain their finances, despite his dementia symptoms impacting his ability to carry out his job.

> *"She [wife] said, I need him [individual with dementia] to carry on working to pay our mortgage. Otherwise, we're going to have to sell out and move. She was living, I guess not. Well, yeah, I suppose it was living in fear, actually, that their financial situation would be dramatically changed. And so, she wanted him to carry on working." P3*

It could be considered that an individual's financial commitments, and the pressure this places on both the individual and the carer could be considered as a facilitator to employment. However, this may have psychological consequences for the individual with dementia, with the pressure to work alongside their dementia symptoms increasing their levels of distress.

When exploring potential undertones to the interview responses, it could be hypothesised that employers are faced with systemic and structural barriers, inhibiting their ability to support an individual with young-onset dementia to remain in employment. For example, if an individual's dementia symptoms do not heavily impact their job role, often they are able to be supported to remain in employment with few adjustments. However, when speaking to the carers in the study, this is frequently not the case for all, with individuals often losing their employment or being placed on sick leave as there are no structures in place for employers to support individuals in these positions. This demonstrates a need for radical structural reform in the approach taken to support those with young-onset dementia in employment, one which does not disadvantage an individual based on their dementia, employment type, or socioeconomic status.

Overall, this subtheme demonstrated that the particularities of one's symptoms and how this relates to the nature of their job role can act as a barrier to employment, with some individuals exerting extra energy to maintain their employment, whilst others feeling no choice but to terminate their employment. Some individuals were not afforded the same luxury to adapt their job role to manage their dementia symptoms due to the financial implications of a drop in salary. These factors can have psychosocial consequences for both the individual with dementia and their family, leading to financial concerns, a lack of routine, and loss of one's purpose.

3.4.2. Subtheme: Diagnostic Process as a Barrier

Carers recounted the diagnostic process and explained the impact that this had on an individual's employment. In the following excerpt, a carer noted that obtaining a diagnosis of young-onset dementia is a lengthy and complex process, sometimes taking twice as long as obtaining a standard dementia diagnosis. During this wait, individuals are left struggling to carry out tasks at work.

> *"I mean, so it's really hard as well because it can take so long getting a young-onset diagnosis. So, you know the stats say it's often twice as long as an older person… It could take so long to tease apart what's going on for that person" P3*

In the following excerpts, carers also described the difficulty of diagnosing young-onset dementia, with individuals under several lines of investigation. This could be interpreted as a barrier to employment as employers were unable to keep the individual in their job role whilst they were under investigation, often losing patience with the process.

> *"Like I said before, was much more difficult to pick up initially and to diagnose. So very often, families are struggling for that amount of time and employers, you know, get up. Losing patience" P1*

> *"They obviously couldn't let him back to work under investigations you know, I mean, so a lot of that was to do with why he couldn't go back to work… It was beginning to get like go on and on and on and on" P4*

Carers shared that many different conditions are often diagnosed initially before discovering the root of the problem. In the following excerpts, carers gave examples of some individuals receiving a diagnosis of depression, and other changes were attributed to a midlife crisis or menopause. This could lead to the delay in the true diagnosis of dementia, extending the amount of time that individuals are left struggling.

> *"And you know the chat, the challenges with young-onset dementia particularly for women, things like menopause, and as I say, there's the typical kind of having a midlife crisis." P3*

> *"He had just seen the doctor and they thought was just depression and maybe overtired or you're overthinking or. But no one thought of anything serious" P5*

As demonstrated in the following excerpts, the delay in receiving a diagnosis of young-onset dementia led to some individuals taking many bouts of sick leave due to the collective struggle faced by the individual, employer, and healthcare professional to understand the changes. Whilst unaware of the true underlying diagnosis, some individuals experienced hope that their health concerns would resolve and that they could return to work if they were to adhere to the GPs treatment plan.

> *"We got to the doctor. And he said ohh, you're just depressed and suffering from anxiety, so take these antidepressants and take a few weeks off and you'll be fine. But it never got fine" P5*

> *"We thought it was NPH [normal pressure hydrocephalus] …. So, we thought that he would get back to work" P4*

The complexity of diagnosing young-onset dementia, coupled with the length of time to obtain a correct diagnosis can invertedly act as a barrier to employment. In the following excerpt, a professional carer drawing upon their previous experience of working with individuals with young-onset dementia shared an example of an employer terminating one's employment when an individual was making unexplained mistakes, with employers suggesting this was due to gross misconduct. These decisions were made prior to the individual receiving a diagnosis of young-onset dementia.

> *"You hear of situations that haven't gone so well so often where people have been sacked before their company knows what's going on, you know they don't necessarily know that it's dementia, but the person's been sacked, gross misconduct." P3*

Overall, it appears as the lengthy diagnostic process, and frequent misdiagnosis of other conditions before obtaining a diagnosis of young-onset dementia fosters an air of uncertainty. This leads to a number of barriers to employment, including employers suggesting that individuals with young-onset dementia should take periods of sick leave whilst their symptoms are investigated, whilst others are sacked due to mistakes made whilst working.

3.5. Overarching Theme: Employers' Approach and Response to Dementia

This overarching theme tells a story about how the attitudes that an employer has, and the way in which they respond to an employee with dementia, can act as a barrier or can support an individual to remain in employment.

3.5.1. Theme: Employers' Unhelpful Approach and Response to Dementia

Carers described several unhelpful attitudes that employers held about dementia generally. Firstly, carers described some employers as having a poor awareness of dementia, with some not recognising it as a concern for younger individuals. Some employers also demonstrated a lack of awareness regarding the unique needs that younger individuals with dementia face.

> *"I felt that they didn't really understand the dementia enough, I mean most people have heard about older age adults getting dementia, but younger people, they have no idea and the needs for young people are very, very different" P1*

An employer’s lack of awareness of young-onset dementia in the workplace may shape the lens to which they view and make sense of an individual’s struggles at work. The following excerpt describes some of the things that employers would consider as the reason for one’s difficulties, such as additional caring responsibilities or marital difficulties. However, carers felt that employers did not consider the idea young-onset dementia as a potential explanation for one’s difficulties.

> *“I think work could often jump to the conclusion that there is obviously something going on, and we I think as human beings we think of what reasons they might be before we've even asked the person. So, we might think, well, maybe there's marital difficulties because of their age. Maybe they're going through a midlife crisis. Maybe they've got other stuff going on in their life. Maybe they're caring for a parent and it's difficult” P3*

Viewing the challenges that one faces through a narrow lens which fails to consider young-onset dementia may lead employers to make negative or unhelpful assumptions about one’s difficulties at work. A carer gave a particular example of the negative assumptions made by an employer about an individual with young-onset dementia in the workplace, with the employer suggesting that he was “mucking around”.

> *“But his new [employer] said he is just mucking about. You just can't be bothered… Why would he suddenly act like he can't be bothered anymore. You’d just leave if you're hated the job that much, you leave. You wouldn't pretend you were ill” P5*

> *“She [employer] said he just didn’t want to do the work” P5*

In this example, the carer felt as though the employer was undermining, leaving him confused, overwhelmed, and questioning himself.

> *“He would just cry and become overwhelmed because he didn't know what he'd done. You know when it's like what have I done? What? How have I got it so wrong.” P5*

It could be interpreted that some employers exhibit unconscious incompetence, displaying both a lack of awareness, and ignorance towards the concept of young-onset dementia in the workplace.

This may leave employers feeling deskilled or unable to respond effectively to an individual with dementia.

> *"They struggled with knowing what to do and how they should support him moving forward" P3*

This lack of awareness may also influence the quality of the actions that employers took to manage dementia symptoms in the workplace. Carers described some employers not taking a proactive stance in managing dementia in the workplace, instead reacting to changes in ability. This reactionary response could be considered as a barrier to employment as it left room for individuals with dementia to struggle in the workplace, both with the work but also with their mental health and wellbeing.

> *"It was like, this isn't working now, and we have to change this type of thing. It was always like a knee jerk reaction" P1*

> *"They realised that he wasn't able to engage with the public very well and he was, as I said, struggling and really that was impacting on his mental state" P3*

> *"He couldn't do it. They had to bring him home, and that's when they said, well you can't work like this. You just go on sick" P5*

Eventually, carers described the frustration felt by employers when struggling to understand an individual's difficulties in the workplace. This lack of understanding led to concerning employment outcomes for the individual with dementia, with employers responding unhelpfully by dismissing the individual. The following excerpt demonstrates how unhelpful responses to individuals struggling with dementia at work can act as a barrier to retaining employment as ultimately, it can lead to employment loss.

> *"You can understand in some respects why employers get frustrated with dealing with somebody. Not knowing what's going on, thinking it's something to do with capabilities to do the job, etcetera. And actually, you know, by the time they do get their diagnosis, they've already been dismissed." P3*

During the interviews, carers explained the implications of employment loss for those with young-onset dementia. A common experience described by carers was that individuals with dementia felt like a burden and had lost their sense of purpose following the loss of their employment. This had negative psychosocial consequences on their mood and productivity.

> *“Because like he said, I don't have a purpose. I was the breadwinner, but I'm not anymore. I'm a burden. I'm going to end up like this. I'm going to end up like that” P5*

> *“I think his mood dropped a little because he doesn't have that [employment]. So that has definitely been the biggest impact on him, that he can't work, and can't go back to work.” P4*

Overall, carers described several factors which act as a barrier to maintaining one’s employment. Employers who exhibited a lack of awareness of young-onset dementia often responded unhelpfully when managing difficulties in the workplace, with some generating their own conclusions to explain one’s difficulties which fail to consider young-onset dementia, such as a midlife crisis, depression, or gross misconduct. This lack of understanding and awareness of young-onset dementia led to some employers feeling as though dismissal was an appropriate course of action, resulting in devastating psychosocial consequences such as loss of one’s purpose and routine.

3.5.2. Theme: Employers’ Helpful Approach and Response to Dementia

On the contrary, carers were also able to share some of the more helpful approaches and responses from employers when working with an individual with young-onset dementia that facilitated employment. Carers described some employers as great sources of support during the diagnostic process, whilst noting that this is not always the case.

> *“He [person with dementia] told them [employer] all the way through actually that he was undergoing tests and they were actually really supportive all the way through. Which was really nice to hear because it it's sometimes a story that you don't hear, but they were supportive” P3*

It appears as though close working relationships were beneficial between the employer and the individual experiencing dementia symptoms, as employers could often be the first to notice a decline. In the following excerpt, carers note that colleagues and employers are likely to notice changes in an individual due to the large amount of time spent at work.

> *"I think particularly work colleagues are often the first people to notice that there are issues and pick up that there are issues. I think most of our time is with our work colleague's… and they're probably likely to see changes. So, for his, for his employers, they noticed the changes" P3*

When noticing a decline, carers shared that some employers responded by setting up a time and space to sensitively discuss this with the individual, whilst adopting an open and non-judgemental attitude.

> *"His manager, and sensitively as he could, spoke to him about the changes and I think that's when he first went to the GP, but really not having a clue what was going on" P3*
>
> *"His boss asked to see him one morning before starting the shift…there were concerns about his work, he had noticed it for about six weeks. They've been really good with him" P4*

After discussing an individual's difficulties with them, some employers took the initiative to seek support from occupational health to understand one's difficulties, and for advice regarding employment support. In the following excerpts, one carer shares her husband's experience of speaking to occupational health about his difficulties and being offered diagnostic support. Another carer shared an example where the employer responded to an individual's diagnosis by discussing a plan of action to move forward in employment with support from occupational therapists. It appears as though these initiatives to seek support from internal structures within the system acted as a facilitator to employment, by supporting those struggling to receive extra support.

> *"The Police force got a new occupational health doctor… Within 10 minutes, she said to him. You're not depressed, I think you've got Alzheimer's. And then the police paid for the MRI scan because they wanted to know what was wrong with him, because, you know, he'd had, like 10 years clean record. Perfect basically. And now all this suddenly." P5*

> *"His supervisor didn't want him to leave. You know, they wanted to make it work. And you know, being a health authority and you know, having, you know, discussions with occupational therapists and stuff, you know, they, they have to plan to help him." P1*

In the following examples, it appears as though a proactive response to support an individual in the workplace was more likely when the individual with dementia was a valued member of the team. Both carers gave examples of employers seeking to support an individual to remain in employment as they had been a valued employee for many years.

> *"He said, well, we're going to be fully supportive of [name]. There's no way I'm going to sack him… He is one of my best lecturers, he's been here for over 30 years. There is no way I want to lose [name]. I value him" P2.*

> *"They accommodated him, and they kept him on. They loved him because he'd been there for 16 years. So, they looked after him and because he's a nice guy you know, he got on with everyone there and they had a good team" P1*

Carers also suggested that a positive relationship between employers and carers was crucial for sharing information to aid the diagnosis and to highlight available support. Some carers felt that this open communication style was reassuring and led to positive action to support the individual on their journey.

> *"He got a lot of support from the company that he was working with. And they knew his wife as well. So, it meant that they, you know, could have conversations about the challenges that they were seeing within work, which I think then gradually led to him visiting his GP" P3*

> *"Every step of the way they've told me [carer] what they've been doing and, and obviously I've been reassured, they've been outstanding" P4*

In the following excerpts, carers described the benefits of communication between the employer and carer as it allowed for a space to discuss the individual's difficulties and share information about how to support an individual with dementia in the workplace. This open communication style had positive outcomes for the individual by strengthening their support network and facilitating them to remain in employment.

> *"I think because it was somebody they [employer] knew really well and they knew the wife well, they were able to have those conversations even though they were really challenging." P3*

> *"With the head, he said to me, we will support, and he's seen the rare dementia fact sheet because he wanted to know… and read about it because I highlighted all in green and I told him those are what you need to see" P2*

Overall, carers described the significant role that employers play in recognising the individuals decline, communicating their concerns with the individual in a sensitive way, and seeking help from occupational health to better understand their concerns. Seeking support from occupational health facilitated a speedier diagnosis as they could skip long NHS waiting times and also helped employers to put measures in place to support the individual at work sooner. Carers also noted that a positive working relationship was beneficial for supporting an individual to remain in employment as this fostered open communication between the employer and family. Carers described sharing relevant information about any changes or decline in an individual's ability, leaving them feeling reassured that the employers would use this information to make adaptations to suit their needs.

3.6. Theme: Diagnosis as an Opportunity

Carers often described receiving a diagnosis of young-onset dementia as the catalyst to developing a new understanding of one's difficulties, receiving support in an employment context, and choosing a path to move forward. This process acted as a facilitator for the individual with young-onset dementia to remain in employment and afforded them the opportunity to choose a different occupational interest if they wished.

3.6.1. Subtheme: Renewed Understanding of Difficulties

This subtheme explores the transition from struggling to understand one's difficulties, and the impact this has at work, to gaining a new understanding of one's difficulties through the diagnosis of young-onset dementia. In the interviews, carers described the initial difficulty that professionals, such as GPs, face in recognising young-onset dementia, with some suggesting that one's difficulties could be due to depression.

> *“Particularly when your younger, it’s not often recognized. Even by GPs or other professionals, they don't... Dementia is not the first thing that they think of” P3*

Carers shared the experience of an individual with young-onset dementia who was struggling to deal with the uncertainty of unexplained symptoms. This person was experiencing recurrent headaches which was impacting his ability to follow instructions. This lack of understanding one’s difficulties initially acted as a barrier to employment, as he was unable to remain at work.

> *“He was having to take time off because the headaches were quite bad. He didn't quite know… understand where the headaches were coming from, and nobody did. So, he was struggling, and he wasn't able to follow instructions” P1*

However, some carers shared alternative narratives, where individuals with dementia who sought further support from professionals could share their concerns and have these investigated further. In the following excerpt, a carer described an example of their husband seeking support from the GP who was able to recognise a memory impairment and refer him for further investigation and support with the local memory services. This acted as the catalyst to gaining a better understanding of one’s difficulties.

> *“I think the GP noticed that there were some issues around memory as well… so he was referred to the local memory service for initial tests. And then, because of his age, because he was under 65 and very, very early 50s, they decided to refer him on to neurology.” P3*

When obtaining the diagnosis of young-onset dementia, carers shared that some employers began to consider adjustments that could be made for the individual in the workplace. It could be understood that the diagnosis provided a renewed understanding of one’s difficulties, and an opportunity for all to think differently about the challenges and barriers in place, including the potential to remove social barriers to employment and move forward. In the following excerpts, carers give examples of times where individuals with a diagnosis of young-onset dementia were able to continue working for longer. This is potentially because their employers were better able to understand their needs and consider workplace adjustments to facilitate them to reach their full potential.

> *“Probably he could carry on working a bit longer because they understood some of the needs that he had” P3*

> *“You have to adjust their work accordingly... with dementia… you have to make adaptations to help them to carry on their life here as full as what they can, you know, so yeah” P6*

> *“With his diagnosis and he needs very simple breakdowns, very simple tasks. And you know, you can't go into a big descriptive and orientated task because he will just forget it” P1*

When discussing the utility of a dementia diagnosis, one carer considered that the employers shift in approach from feeling unable to support an individual at work towards considering support options could be attributed to the diagnosis providing a framework to understand one’s difficulties in the context of a disability.

> *“Once that diagnosis, it was in place. It made things easier then to kind of work within the legal framework of dementia being a disability and support, support the gentleman” P3*

This shift in understanding one’s difficulties in the context of a disability may have acted as a facilitator to employment, as it could have supported employers to consider the legal framework around supporting individuals with a disability at work, such as legal protection from disability discrimination or unfair dismissal under the Equality Act (2010).

In summary, carers noted a change in employment support opportunities for individuals with young-onset dementia prior to receiving a diagnosis, whilst under investigation, and once receiving a formal diagnosis. Moving from a period of uncertainty and distress regarding the nature of an individual’s symptoms and employment prospects towards a renewed understanding of their difficulties when receiving a diagnosis. The formality of a diagnosis appeared to promote a more supportive and understanding context at work, with employers better positioned to understand the nature of their difficulties and facilitate employment support to assist an individual.

3.6.2. Subtheme: Diagnosis as a Ticket for Support

When discussing the support available for an individual, carers noted that at the point of diagnosis, dementia specific support services were made available for the whole family. In the following excerpt, a professional carer described her role when meeting a family for the first time, including listening to the family's story, sharing local resources, and developing a collaborative and robust support plan.

> *"Well, I [professional carer] bring in the memory nurse or other resources. So, I will go to the families, and I will sit, and I'll talk to them …I'll listen to their story and then we'll create a plan with what resources there are out there locally to support them all" P1*

In the following excerpt, it appears as though the involvement of a professional carer acted as a facilitator to employment, as their role involved supporting an individual to tell their employer of their diagnosis and to create a plan going forward, particularly when the individual was fearful of their employer's reaction.

> *"He was scared [to tell his employer of his diagnosis]. He was scared of the reaction, and I said we'll work through this together. So together we did that. We created a plan, and he was at ease with the with what they presented to him" P1*

The following excerpts provide examples of employers formalising support for the individual with young-onset dementia *after* receiving a diagnosis. However, this was despite employers recognising unmet needs *prior* to the diagnosis. As noted in previous themes, it appears as though the formal nature of receiving a diagnosis acted as a catalyst to prompt action from employers to better support the individual. This suggests a gap in the structures and frameworks required to support those struggling prior to a formal diagnosis.

> *"When they got the diagnosis, they did speak to the employers, and they [employers] knew that things weren't right before the diagnosis actually formalised everything" P3*

> *"Once he had the diagnosis and it was dementia, then they made things more formal. They were able to see that dementia was a disability and they're able to kind of formalize reasonable adjustments for him" P3*

An example of another professional carer providing employment support was noted within one of the interviews. This carer described facilitating group sessions which involved information sharing, and a space for employers, colleagues, and the family to ask questions.

> *"With the person with dementia's consent and his wife's consent. We did some work, a couple of sessions with them [employer and colleagues] sort of question-and-answer sessions with everybody there" P3*

Alongside external support services helping at the point of diagnosis, some employers offered workplace adjustments that were tailored to the individual's needs. The following excerpt emphasises the professional carer's role in providing employment support, with them offering employers information about one's diagnosis and making suggestions about an individual's needs.

> *"They did accommodate him, and they helped him with his with his tasks. But I [professional carer] had to be the one to, to tell them what had happened, his, his diagnosis and his needs" P1*

Other adaptations and adjustments were made by employers to support the individual with dementia to remain in employment for longer, including a buddy-style system where individuals with dementia were paired with another colleague who could assist them with their difficulties, and ensure that their work was completed to an appropriate standard.

> *"And they did make allowances and put things in place that he could have additional helpers to help him. Like a buddy worker. Because obviously, when you're working in a [operating] theatre, the standard of cleanliness has to be top. And I from what I can gather, it started to slip" P1*

When discussing the implementation of adjustments at work in the following excerpts, carers described the need to collaborate with the individual with young-onset dementia, and cater to their strengths, by simplifying their job role, providing extra assistance, and changing their working hours to suit their needs. Although not said explicitly, it appears as though carers recognised the utility of seeing the individual behind the dementia diagnosis and collaborating with them when planning workplace adaptations.

> *"They changed his hours to a daytime ending at 11:00pm instead of 3:00am because he got disorientated in the hospital, couldn't find his way out and panicked, had to call his brother to come out and find him. So, they changed his hours to a slightly earlier finishing time" P1*

> *"You have to find something that works for the person with dementia and have those conversations with them about what they want" P3*

Overall, carers described the involvement of services after the individual receives a diagnosis of young-onset dementia. This support paved the way for professional carers to assist the individual with telling their employer of their difficulties, and to work with the employer to enable them to make workplace adjustments. Although unsaid by the carers in the interviews, it could be interpreted that the lack of support structures for those *prior* to a diagnosis to remain in employment was evident, with employers appearing to take a passive approach when faced with challenges prior to a formal diagnosis of young-onset dementia.

3.6.3. Subtheme: Diagnosis as a Path Forward

This subtheme conceptualises the facilitation of meaningful occupation as an alternative to employment, particularly for those with a diagnosis of young-onset dementia who were told their current employment was no longer possible. This subtheme presents the carers descriptions of the experience faced by individuals with young-onset dementia when they are told that remaining in employment is no longer an option. It then explores the several paths forward for individuals in this position to maintain some meaningful occupation, whether this be in the form of alternative paid employment, volunteering, or recreational activity. The positive impact of facilitating meaningful occupation is considered whilst describing the actions that employers can take to minimise the financial and psychosocial consequences of leaving employment, for example by providing pension or retirement support.

In the following excerpts, at the point of receiving a diagnosis, carers described an emotional experience where some individuals with young-onset dementia recognised changes to their ability to carry out work related tasks. With the added context of understanding their diagnosis, individuals could recognise that they were not going to improve in their functioning. This led to some individuals leaving employment without provisions in place to support them financially or psychologically.

> *"He knew himself that he would have to stop working. He knew that he wouldn't. He couldn't read it. He couldn't remember. I think his memory was. Yeah, impacted I suppose." P1*

> *"Whatever I [professional carer] could, I was gonna try and negotiate for him. But that didn't happen because of the way that he decided, just he just jacked in. He just said that's it one day and I'm just gonna leave. I've had enough. And that was a really sad day." P1*

Some individuals with young-onset dementia were told by their employers that they were unable to continue working after receiving a diagnosis. Their carers explained that this decision was often out of their control and was particularly distressing.

> *"Yeah, he was basically told you you wouldn't be able to work again, and he was quite upset about that" P4*

> *"They [employer] had to get all his paperwork together and get the notes from the specialist, then have a panel and decide that yes, there is no way in this job that you can continue" P5*

Some carers noted that individuals with young-onset dementia continued to enjoy working despite the additional challenges posed by their symptoms at work. The following excerpt provides an example of an employer putting measures in place and making allowances to facilitate employment for the individual with dementia.

> *"Well, they [employer] basically they said they had an idea that could be it [dementia]. And I [carer] said, you know, we need to work with him, he doesn't want to give up work he really enjoys, enjoys his work. And you know, we want to, we want to work with the dementia rather than just like cutting them off. And they were happy to do that. And they did make allowances and put things in place." P1*

Other carers described that once receiving a diagnosis of young-onset dementia, some individuals decided to leave their employment. However, it appears as though individuals in more fortunate positions were supported to make a choice about their path moving forward in a person-centred way. For example, some individuals with young-onset dementia were supported to take early retirement or negotiate an exit package with their employer to assist them whilst waiting for retirement.

> *"I [professional carer] am looking at sorting a settlement package because he is going to take early retirement." P4*

> *"I think it's just being very person centred and recognizing that we're all different and that we want to approach things differently. So it might be that you want to hand your notice in and retire and you might be in a position to do that, but it might be that you do want to carry on working and you need some support around that. So, it's just thinking I guess outside the box about how to do that. What is the best way to support people." P3*

Carers shared some examples of alternative opportunities to keep occupied when an individual with young-onset dementia is no longer working, with one individual waiting for an opportunity to join dementia friendly groups, and another signed up to volunteer with a dementia charity to support others through their diagnostic journey. In the following example, the individual volunteering with the dementia charity treated it as his work and felt better in himself for being involved.

> *"We've got someone coming out tomorrow and she's the person that helps the young-onset dementia team like maybe get him into some things like football and a man shed or you know, some things like that" P4*

> *"Once he started to get involved with [the dementia charity], he would come and say, well, we do this group, or we do this group... He sort of felt better, and the more he does for [the charity], he sees it like a second job. He treats it as work" P5*

In summary, carers shared a similar experience whereby individuals with a diagnosis of young-onset dementia are faced with inevitable changes to their working lives due to a decline in their function. Carers described some of the approaches taken by employers to manage this decline. For example, some individuals experienced employment loss without provisions in place to support them financially or psychologically, whilst others could choose their path moving forward, by remaining in employment with reasonable adjustments, or taking opportunities outside of the employment arena such as volunteering or attending young-onset dementia specific groups. Overall, an important thread throughout the interviews demonstrated the benefits of supporting those with young-onset dementia to have the opportunity to maintain a sense of purpose and occupation, whether this be in the form of paid employment or recreational activity.

4. DISCUSSION

4.1. Overview

In this chapter, I summarise the findings from the research, whilst relating the results to the research questions, existing literature, and make recommendations to address the implications of the findings. I then describe the quality control measures used in the research, before discussing the limitations and suggestions for further research. I conclude this chapter by sharing my final reflections.

4.2. Summary of Research and Findings

Six carers of individuals with young-onset dementia were interviewed to understand the barriers and facilitators to employment, with the aim of identifying potential adaptations which could be made to support them to remain in employment. This study contributes to the lack of available research into employment experiences for those with young-onset dementia and is clinically relevant by describing some of the psychological implications experienced by a lack of meaningful occupation.

The interviews were analysed using Thematic Analysis. A number of barriers and facilitators to employment were identified and have been arranged into a series of overarching themes, themes, and subthemes. Themes pertaining to the barriers include the following: The restrictiveness of dementia symptoms, Employers’ unhelpful approach and response to dementia, The nature of dementia as a barrier to employment, and Diagnostic process as a barrier. Themes pertaining to the facilitators include the following: Employers’ helpful approach and response to dementia, Renewed understanding of difficulties, Diagnosis as a ticket for support, and Diagnosis as a path forward.

4.3. Research Question 1

This section discusses how the findings relate to the previous literature and research question one, “What are the barriers to employment for those with young onset dementia?”. Each section is organised with reference to the relevant themes. A summary of the findings is presented, and resulting implications at an individual, organisational and policy level are considered further.

4.3.1. The Restrictiveness of Dementia Symptoms

Overall, this theme suggests that the nature of one's dementia type, and the progression of their symptoms can negatively impact their ability to carry out their job role, thus acting as a barrier to employment. Carers gave examples to describe this interaction, for example, an individual experiencing visuospatial difficulties was unable to drive their van for work, leaving them no choice but to leave their job. Another individual experiencing word finding difficulties was unable to continue with customer service aspects of their role and was supported to refocus their job role away from these difficulties. Whilst some individuals were fortunate enough to continue working with adaptations, carers stated that others continued to struggle at work and became increasingly stressed and fatigued. This is in keeping with previous literature which describes the increased stress felt by those with young-onset dementia at work, with individuals linking it to worsening cognitive abilities (McCulloch et al., 2016). The worsening of one's cognitive abilities may further act as a barrier to retaining one's employment, as it impacts an individual's ability to carry out aspects of their job role.

When an individual's symptoms would impact their work, some employers responded by reducing their working hours, or by changing an individual's job role. However, carers noted the drop in pay associated with this, and the resulting fear and worry about one's financial stability. Previous literature has also reported the financial impact of employment changes or loss, particularly for individuals with young-onset dementia who may still have financial commitments that they are required to maintain, such as mortgages and household bills (Carter et al., 2018; Chaplin & Davidson, 2016). The literature comments further on the employment loss for partners of those with young-onset dementia who find themselves with increased caring responsibilities (Bayly et al., 2021; Couzner et al., 2022). This leads to further financial strain which was not touched upon in the present study.

It appears as though the type of job that an individual with young-onset dementia had, and the responsibilities involved could act as a barrier to employment. Some carers in the study felt as though the individual had no choice but to leave their job due to safety concerns, with some feeling as though they still had remaining abilities that would be suited to a different job role. This is in keeping with previous research suggesting that many individuals with young-onset dementia were required to leave work due to their workplace's inability to adapt with the progression of their symptoms (Silvaggi et al., 2020), with other research highlighting that individuals felt unsupported by their employer to find alternative roles within their workplace when they were unable to maintain their current role (McCulloch et al., 2016). It is possible that some employers who feel unable to change inaccessible working environments to support an individual to remain in employment are not considering the disabling nature of certain structural barriers in the workplace, as considered in the social model of disability (Oliver, 1983). Instead, viewing the situation through a biomedical lens, positioning dementia as the problem (Priestley, 2003) and failing to recognise the changes that can be made to one's environment.

4.3.2. Diagnostic Process as a Barrier

The findings from this study suggest that the process that an individual must go through to obtain a diagnosis of young-onset dementia can act as a barrier to retaining one's employment. Carers shared that obtaining a diagnosis was a lengthy process. Some individuals were misdiagnosed with other conditions, such as depression and menopause, before discovering that their difficulties were due to young-onset dementia. A large proportion of the literature researching young-onset dementia supports the findings in the current research project, focusing both on the challenges experienced by diagnosing professionals, and the individuals experiencing young-onset dementia. Research has shown that a large proportion of individuals with young-onset dementia are misdiagnosed with persistent depression (Rosness et al., 2010). This misattribution of symptoms can lead to a delay in diagnosis and access to help (O'Malley et al., 2021). The attitudes and awareness levels of healthcare professionals explored in the literature may explain the delay in diagnosis found in the present study, with many professionals exhibiting a low expectation that young-onset dementia may be the underlying cause of one's difficulties (Vliet et al., 2013).

Carers shared that employers often struggled to manage the uncertainty associated with the diagnostic process and responded by placing the struggling individuals on sick leave or sacking them due to misunderstandings attributed to misconduct. Previous research has found similar findings, whereby individuals with young-onset dementia were dismissed from work without being offered reasonable adjustments (Brechin, 2004). Other individuals felt abandoned by their employer whilst on sick leave and were sacked (Harris, 2004). The lack of support for the employer, the individual, and the family during the diagnostic process acts a barrier to them retaining their employment. Previous research suggests that increased support can mitigate the risk of one being required to take early retirement (kasl et al., 2021). This suggests that employers require specific guidelines to support individuals struggling through the diagnostic process, especially when considering the examples of employment loss in the present study alongside previous research which claims that this can be avoided.

4.3.3. Employers' Unhelpful Approach and Response to Dementia

Within the study, carers described several unhelpful approaches and responses towards employees with young-onset dementia in the workplace. Carers shared that employers demonstrated a lack of awareness of young-onset dementia both generally, and with how to support an individual with young-onset dementia in the workplace. This is in line with previous research into employer attitudes, which suggested that many employers feel as though dementia is not a workplace concern as they have a relatively young workforce (Egdell et al., 2021), demonstrating a lack of insight of dementia presenting in younger individuals. These findings emphasise a need to raise awareness of young-onset dementia to allow employers to consider how it can present in the workplace.

Carers shared the incorrect assumptions made by employers about an individual's struggles at work, attributing changes as the result of caring responsibilities or marital difficulties. One carer gave an example of an individual's employer taking a harsh approach, accusing the individual of pretending that they were unwell. When discussing the management of dementia symptoms in the workplace, some carers stated that employers were not proactive, instead, only reacting to changes once an individual had begun to struggle. Previous research has highlighted the lack of policy and guidance in the workplace to support an individual with young-onset dementia, with findings from a recent survey suggesting there are no policies in place to support individuals with young-onset dementia at work (Egdell et al., 2021).

This lack of guidance could explain why employers have not taken a proactive approach to support individuals in the workplace in the current study, with this having devastating consequences for the individual, including struggling with their workload, mental state, and being placed on sick leave or having their employment terminated. Carers shared the psychosocial consequences of losing one's employment, including a loss of independence, lack of purpose, and poor routine. Much of the literature commenting on the consequence of employment loss mirror this finding, with those experiencing social exclusion, mental health challenges, disempowerment (Greenwood & Smith, 2016), poor sleep, lower self-esteem and lower mood (Richardson et al., 2016), following the loss of their occupation. The poor psychosocial consequences identified following the loss of meaningful occupation may be explained by Kitwood's (1997) theory of personhood in dementia, which states that psychosocial distress arises if one of an individual's basic needs, such as meaningful occupation, is not met.

4.3.4. Diagnosis as a Ticket for Support

Whilst the subtheme 'diagnosis as a ticket for support' has been considered a facilitator to employment, there were some undertones which highlighted certain barriers to employment. The influx of employment support experienced by some individuals in the interviews after receiving a diagnosis highlighted the lack of available support *prior* to a diagnosis. Like the present study, previous research also states that it can take a long time to receive a diagnosis of young-onset dementia (Loi et al., 2022). During this time, individuals are left with no formal employment support, often leading to them attempting to make their own adaptations and adjustments to remain in employment (Chaplin & Davidson, 2016). In keeping with the findings from the present study, other research noted that individual's often experienced increased stress at work due to their symptoms and felt unable to approach their employer to discuss their difficulties (McCulloch et al., 2016). This emphasises the lack of structures to support individuals prior to a diagnosis and can have devastating implications, such as the traumatic cessation of employment, financial concerns, and psychological concerns (Roach & Drummond, 2014).

4.3.5. Summary of the Findings

In summary, the study identified a number of barriers to employment for those with young-onset dementia. Firstly, the nature of one's difficulties impacting their ability to carry out their job role can act as a barrier to employment. However, with structured support, this should not act as a limiter. Therefore, whilst considering the social model of disability (Oliver, 1983) it could be suggested that it is not the individual's dementia that is a barrier to employment, instead it is the structures in society, such as poor employment support, which are disabling the individual.

It was identified in the present study that employers often felt unable to support the individual to remain in employment for a number of reasons. For example, long diagnostic processes with frequent misdiagnosis meant that employers were faced with uncertainty regarding the individual's health status. Furthermore, the study considered the employers lack of awareness of young-onset dementia symptoms both generally and in the workplace, leading to unhelpful assumptions made about the nature of one's difficulties. Often employers would place an individual on sick leave, or sack individuals due to misunderstandings regarding misconduct. This would leave the individual with young-onset dementia facing many more challenges, including financial and psychosocial consequences.

4.3.6. Implications and Recommendations

Firstly, the results from the study suggest that some employers exhibit a lack of awareness of the symptoms of young-onset dementia and how this can impact an individual in the workplace. Although attempts to educate the public about dementia have been made through health promotion initiatives, it is recommended that workplace education programmes include information specific to young-onset dementia, whilst promoting inclusivity and acceptability of reasonable adaptations to support individuals to live well and thrive at work. Awareness raising in the workplace could help to improve social connectedness through the maintenance of employment, and reduce the stigma faced by individuals with young-onset dementia and their families.

Intervening at an organisational and policy level would further support individuals with young-onset dementia to remain in employment. The findings from this study imply that currently, employers struggle to access guidance to support individuals with young-onset dementia in the workplace. It is important that professionals are supported to remove the current barriers in place, such as poor awareness of young-onset dementia, and an absence of guidance and policy, which limit an individual’s ability to maintain employment. Therefore, the development of policy specific to supporting those with young-onset dementia to remain in the workplace is required for employers to refer to. Due to the range of different barriers found across different job roles, the policy must be specific to each organisation and include reference to the dementia related symptoms that one might experience, the particular barriers they may face in their job role, and the actions that an employer must take to mitigate the impact of this.

It is hoped that organisations will embed the policy specific to supporting those with young-onset dementia in the workplace, so employers are aware of it and better positioned to recognise potential barriers and intervene where necessary. In addition to this, the study considers the consequences experienced by those who have their job roles changed, working hours reduced, or employment terminated, such as financial strain and a loss of independence and purpose. This indicates a need to incorporate information into the proposed policy to highlight these consequences, and to encourage employers to take an individualised and collaborative approach, involving the individual with dementia and their carers in any decisions made about adapting one's job. The development of structured policy, and the collaboration with individuals with young-onset dementia and their carers could reduce the likelihood of unintended consequences arising from a lack of support, such as increased stress at work, a lack of understanding of one's difficulties, and employment loss. Further research with those with young-onset dementia would be useful ascertain their insight and perspectives regarding the content and development of policy and guidance for employers.

4.4. Research Questions 2 and 3

The research questions explored within this section are: "What are the facilitators to employment for those with young-onset dementia?", and "What adaptations could employers make to support those living with young-onset dementia to remain in employment?". This section addresses both research questions together as the themes identified within the research relating to the facilitators to employment are intertwined with different adaptations which could be made by employers to support an individual with young-onset dementia to remain in employment.

4.4.1 Employers Approach and Response to Dementia

The findings from the study suggest that the approach and response employers take when working with an individual who is struggling prior to a diagnosis can influence if an individual retains their employment. Carers noted that individuals with young-onset dementia felt better supported to retain their employment when their employer took an open and non-judgemental approach to discussing their difficulties. For example, carers reported that employers who had positive relationships with the individual with dementia were often the first to notice a decline in the individual, a finding also demonstrated in the literature (Roach & Drummond, 2014). Supportive employers would seek support from occupational health, collaborate with the carers to share information, and encourage the individual to seek support from their GP. In some cases, this proactive stance from the employer led to the individual receiving an earlier diagnosis, as the employer was able to seek private healthcare and skip long NHS waiting times. Carers felt this led to the employer better understanding the individuals' difficulties and enabled them to make adaptations to support the individual at work.

The findings from the study regarding employers taking an open and non-judgemental approach when discussing one's difficulties prior to a diagnosis has positive implications for the individual with young-onset dementia, such as receiving an earlier diagnosis and adaptations to manage their role in the workplace. Previous literature suggests that gaining an earlier diagnosis of dementia can allow for better planning of disease management (Jackson et al., 2022) and can improve one's quality of life (Martyr et al., 2018; Robinson et al., 2015). The combination of employers approaching individuals to discuss their difficulties at work in an open and non-judgmental way, whilst seeking support from occupational health, has demonstrated to be an effective way to help an individual with young-onset dementia to feel supported at work, and employers should be encouraged to take this empathic approach to improve one's quality of life and level of social engagement (Martyr et al., 2018).

4.4.2. Diagnosis as an Opportunity

Further findings from this study suggest that receiving a diagnosis of young-onset dementia can act as a catalyst for an individual to gain a true understanding of their difficulties. Previous research into the reactions of those receiving a diagnosis of young-onset dementia echoed the carers accounts in the present study, suggesting that individuals felt relieved that their symptoms had an explanation (O'Malley et al., 2021). Carers describe the importance of this renewed understanding after experiencing many years of uncertainty and misdiagnosis, with professionals and employers not recognising one's difficulties as young-onset dementia. This is in keeping with previous research suggesting that delays in diagnosis may be attributed to professionals misdiagnosing individuals, and associating symptoms to other conditions such as depression (Mendez, 2006; O'Malley et al., 2021; Rosness et al., 2010).

Despite long waiting times and frequent misdiagnosis, the notion of gaining an understanding of one's difficulties through a diagnosis of young-onset dementia acted as a facilitator to retaining employment. This is because employers were better informed of ones needs and positioned to work with the individual to adjust and adapt their job role accordingly. The importance of formalising the diagnosis of young-onset dementia could be better understood when considering carers descriptions of employers changing their stance towards a more supportive approach after being informed of the diagnosis, potentially as they could understand an individual's difficulties in the context of a disability. The formality of a diagnosis may have led to employers considering the Equality Act

(2010), which protects individuals with a disability and entitles them to reasonable adjustments in the workplace.

When considering the social model of disability (Oliver, 1983), it could be interpreted that the reframing of one’s difficulties into the context of a disability allowed for the employer to consider ways to support an individual with dementia in the workplace, by removing the structural barriers in place and by reframing their attitudes towards a more optimistic view that an individual can function at work with dementia. This new understanding of one’s difficulties may have led to practical changes in the workplace, such as incorporating a buddy system and restructuring ones working hours to accommodate their needs. Despite this positive experience for some in the interviews, previous research recognises a need for clearer and more specific guidance relating to employment rights for those with young-onset dementia (Kilty et al., 2023).

The findings from the study suggest that receiving a diagnosis of young-onset dementia led to both the carers and the individual with young-onset dementia receiving further support from professionals, something which is not explored in the limited literature base currently. Carers noted that the support offered came in the form of emotional and practical assistance, with some also receiving guidance to help the individual with young-onset dementia to navigate their diagnosis alongside employment. Some carers stated that professionals could support the individual with young-onset dementia to develop a plan to tell their employer of their diagnosis, and to facilitate information sharing sessions with the employer to inform them of how they can support an individual to remain in employment.

Whilst the influx of support and workplace adjustments was experienced by some of the individuals discussed in the interviews, and acted as a facilitator to employment, this is not in keeping with previous literature which often finds that individuals are not supported well in the workplace. Individuals with young-onset dementia in other research studies often feel unsupported in the workplace, under extra scrutiny, are not offered reasonable adjustments (Chaplin & Davidson, 2016), and feel abandoned by their employer (Harris, 2004). This is despite prior research advocating for the use of reasonable adjustments to support an individual to retain their employment post diagnosis (Sakata & Okumura, 2017). Therefore, the findings in the current study regarding the benefits of professionals offering employment support should have positive implications for service development, by advocating the importance of developing young-onset dementia specific employment support roles or services to target the needs of individuals with a diagnosis. Further thought and research is required to understand how to provide employment support for those prior to a diagnosis.

4.4.3. Diagnosis as a Path Forward

The subtheme ‘diagnosis as a path forward’, does not specifically relate solely to employment. Instead, it explores the occupational path chosen by individuals with young-onset dementia after receiving a diagnosis. It will be discussed whilst considering the facilitators to any meaningful occupation, such as volunteering or attending social groups, rather than just formal employment. Carers described the changes an individual faces regarding their employment after receiving a diagnosis of young-onset dementia. Initially, individuals realise that they are going to, or already are, experiencing irreversible changes in their ability to carry out their job role. At this stage, carers gave examples of individuals with young-onset dementia choosing to remain in employment for as long as possible with adaptations, whilst others negotiated an exit package, or took early retirement. Some individuals were supported to volunteer or attend dementia related groups and found that this had a number of psychosocial benefits, such as maintaining a sense of purpose and meaningful occupation, whilst improving one’s mindset from uncertainty and fear to a more hopeful outlook.

The findings within the present study regarding the notion of improving one’s psychosocial outcomes by supporting them to maintain any form of meaningful occupation are in line with the ideas presented around personhood for individuals with dementia (Kitwood, 1997). It is possible that the present study demonstrated a practical example of facilitating the initiation of a “virtuous circle”, whereby supporting an individual to engage in one of the five needs identified for individuals with dementia (occupation) can positively enhance the other identified needs (identity, inclusion, attachment, and comfort). As acknowledged previously, this can have positive implications for an individual’s overall wellbeing and can reduce feelings of fear about one’s decline in ability, demonstrating the practical utility and clinical relevance of the findings from the present research project.

Unfortunately, there is not a wealth of existing literature to consider alongside this study’s findings regarding the utility of maintaining any form of meaningful occupation. However, findings from workplace initiatives in other countries to help individuals retain employment after a diagnosis demonstrate the practicality of such initiatives, with one study able to support all seven participants to remain in employment with workplace adaptations. This had positive psychological benefits, including increased life satisfaction and self-esteem of the individuals involved, with authors advocating for the use of supportive frameworks to help individuals with young-onset dementia to maintain their employment (Robertson et al., 2013). The psychological benefits of maintaining meaningful occupation presented in the current study contributes to the limited literature in the UK and should be considered in the development of employment initiatives to support those with young-onset dementia in the UK.

4.4.4. Summary of the Findings

Overall, the findings of the study suggest several things that employers can do to support individuals to remain in employment both during the diagnostic process and after a formal diagnosis. Carers described employers facilitating the diagnostic process by adopting an open and non-judgemental stance when noticing one's difficulties at work. Employers who adopted this stance could better understand one's difficulties by discussing them with the individual and their families, and by seeking support from organisational structures such as human resources or occupational health. This allows for employers to consider reasonable adjustments to support the individual to remain in employment both through the diagnostic process and after a formal diagnosis was obtained.

4.4.5. Implications and Recommendations

There are a number of recommendations that employers can consider to best support an individual with young-onset dementia in the workplace at different stages of their dementia. Firstly, the research noted the lack of support available for those going through the diagnostic process, with examples of employers responding unhelpfully by terminating one's employment due to the assumption of misconduct, rather than exploring the underlying problems. Therefore, it is recommended that employers seek support from organisational structures that already exist, including occupational health, and collaborate with the family to share information about the individuals' difficulties with their consent. This recommendation can be easily implemented within most workplaces who have such organisational structures already and encourages the employer to collaborate with carers to support the individual to remain in employment from the onset of their difficulties, and whilst they are going through the diagnostic process.

After the individual receives a diagnosis of young-onset dementia, it is recommended that employers inform themselves of the challenges associated with this diagnosis and use this information to collaboratively plan how to adapt one's role to best support them in the workplace. A range of practical recommendations that employers could carefully consider to support an individual in the workplace were identified within the study. These included the following: implementing a buddy system at work, adjusting one's job role, adjusting one's working hours, and providing practical assistance to manage one's difficulties using technological prompts and reminders. These strategies and adjustments are most effective when discussed with the individual with young-onset dementia and their carers to ensure that the adjustments are tailored to their specific needs and do not lead to financial or psychosocial consequences.

A number of strategies from external sources, such as professional carers and dementia services, also served to support an individual to remain in employment and should be recommended as a key component of the professional's job role. These strategies included the facilitation of information sharing sessions with colleagues and employers to raise awareness of young-onset dementia, and the provision of emotional support for both the individual and their family to come to terms with the diagnosis and changes to ability. Whilst the findings from the present study considers the benefits of professional carers taking an active role to support an individual with dementia with their employment concerns, it is recommended that other healthcare professionals working with individuals with young-onset dementia, such as psychologists and occupational therapists, also consider employment support as a key component of their role. This is because the present study has demonstrated the psychological benefits of this, such as improved self-esteem and sense of purpose, and is key to maintaining a sense of personhood (Roach, 2017).

Although the findings demonstrate the benefits of professional intervention, it is often the case that services to support individuals are inconsistent, funded only on an ad-hoc basis (Francis & Hanna, 2022). Therefore, it is imperative that services, and professionals such as clinical psychologists, campaign at the government level for more funding to ensure the continued and consistent provision of support for those with young-onset dementia to improve their psychological wellbeing and occupational functioning.

4.5. Quality Checking

Several quality insurance practices can be used within the thematic analysis framework to ensure the validity of data, such as participant validation or member checking (Varpio et al., 2017). Member checking involves asking participants whether the resulting analysis fairly represents their experience and can help control for subjective bias or misinterpretation (Smith & McGannon, 2018). This method of quality control was not used within the present study as it does not sit comfortably within TA framework, as member checking holds underlying assumptions that a researchers experience and influence may be removed, something which TA embraces as part of the process. Instead, a 15-point checklist for good TA was considered throughout the research project to enhance the quality of the research (Braun & Clarke, 2022).

This checklist focuses on a number of processes involved in thematic analysis, including ensuring that transcription is checked against original recordings for accuracy, codes are given thorough and repeated attention, themes are internally coherent, consistent, and contain a well-defined central organising concept. The checklist also extends to ensuring quality in the analysis and report, with particular emphasis on analysis taking an interpretive approach instead of simply describing the data. The checklist stipulates that the written report should tell a convincing overall story and the researcher should be active in the research process. These ideas were regularly explored in supervision to ensure that these factors were considered, and to ensure the overall quality of the research project. To ensure researcher reflexivity, a reflexive diary was kept throughout the project, this will be discussed at the end of this chapter.

4.6 Critical Review

This section will detail the main limitations of the research, whilst making suggestions for further research avenues to address these limitations.

4.6.1. Recruitment Considerations

Initially, I aimed to recruit participants who were living with young-onset dementia to hear their experiences first hand. However, when contacting young-onset dementia specific community groups and dementia charities to advertise my study, and whilst consulting my research project supervisor at the time, it was advised that this approach may not be feasible when considering several practical aspects of the research project. The aspects to be considered included time constraints of the project, the availability of the target population, and multiple complexities of the pandemic impacting research practices. Whilst it would have been considered best practice to spend more time attempting to recruit individuals with young-onset dementia, this was not possible due to the lengthy processes required to gain approval to advertise the study via charities and organisations who had access to individuals with young-onset dementia.

Further attempts to advertise the study independently were unsuccessful. When discussing this challenge with local young-onset dementia groups, I was advised to consider that whilst not all, many individuals with lived experience of losing employment due to their young-onset dementia diagnosis are often in more advanced stages of the disease, with the extent of the dementia symptoms making it difficult to ascertain their perspective and participate in research. Therefore, to combat the multiple challenges to the research, whilst maintaining the integrity of the project, it was decided that the employment experience of those with young-onset dementia could be heard by interviewing their carers. Carers can provide unique insights into the preferences and needs of those living with dementia, whilst advocating for the highest quality care (Beardon et al., 2018). Whilst recruitment was still challenging, I was able to recruit enough carers to take part in the research project. The decision to interview carers instead of individuals with young-onset dementia will have ultimately impacted the research findings, as the carers accounts will be slightly different to the perspective of the individual with young-onset dementia.

4.6.2. Participant Characteristics

Of the six individuals with young-onset dementia who were the focus of the interviews, all where white British, five were men and one was female. This is an unrepresentative demographic, which is particularly important to note as the rates of young-onset dementia are higher for those from minority ethnic backgrounds, and for those with a learning disability (Dementia UK, 2022). This may restrict the transferability of the research findings, as they do not represent the experience of those from other gender or ethnic groups. There was difficulty recruiting individuals from other ethnic groups despite attempts made, including a refocusing of the study advertisement to explicitly state that the voices of other ethnic groups would be valued, and by approaching community centres used predominantly by individuals from other ethnic backgrounds.

Furthermore, it was previously noted that the professional carers recruited in the study were encouraged to describe the experience of one individual with young-onset dementia in which they knew well and had worked with. However, often professional carers would enrich their discussion in the interview by drawing upon a wide range of experiences of individuals with young-onset dementia that they had previously worked with. This led to particular challenges when analysing the interviews with professional carers. I attempted to separate the experience of the individual who was the focus of the interview to honour their story, whilst paying attention to, and avoiding the dismissal of rich information arising from the more general comments made about the experience of young-onset dementia and employment more widely.

4.6.3. Choice of Analysis

Initially, it felt appropriate to approach the research using a thematic analysis framework in order to ascertain the experiences of employment for those with young-onset dementia, an under researched area in the field of dementia. However, after some reflection, I realised that the nature of my research questions which attempt to understand practical aspects of employment may have limited my ability to provide latent and speculative analysis. Furthermore, much of the research aimed to provide practical, wide reaching, and concrete recommendations to best support an individual with young-onset dementia to remain in employment. Such recommendations are not fully in line with a thematic analysis framework and with the small sample size adopted in the study. It may have been more appropriate to scale down the study to firstly consider the experiences of individuals with young-onset dementia in employment, with the view of developing a follow up study, using a quantitative analytical approach with a larger sample size to develop practical, generalisable recommendations to support those with young-onset dementia to remain in employment.

4.6.4. Future Research Avenues

Further research exploring the experiences of individuals with young-onset dementia in employment is warranted. This research could elaborate on or corroborate the current findings by specifically including those with young-onset dementia and individuals from other ethnic and gender groups. This would contribute to the extremely limited literature in this topic area, whilst narrowing the gap between the amount of research conducted on young-onset dementia compared to older age dementia. To elaborate on the current research, further work could seek to implement some of the recommendations made in the present project, by consulting with employers and individuals with young-onset dementia to co-create policy specific to supporting those with young-onset dementia in the workplace. To take this even further, the implementation of such policy could be explored in an audit style project, aimed at ensuring that the policy is embedded within the organisation and is used in a facilitatory manner. Such policy could then be used to inform policy within other employing organisations.

Further research could also seek to replicate some of the global initiatives which have demonstrated the psychosocial benefits of developing and implementing employment initiatives for those with young-onset dementia. This would further the overall goal of enabling individuals with young-onset dementia to continue to work, meeting some of the five psychosocial needs identified for those with dementia, such as social inclusion and meaningful occupation (Kitwood, 1997).

4.7. Reflexivity

This section explores my final reflections as a researcher. I consider the process of research and engagement with participants, whilst interrogating how my values and experiences have shaped this.

As mentioned previously, I have been described as having a strong sense of justice and feel strongly about promoting equality for marginalised groups. I have valued the opportunity to develop a research project to support those with young-onset dementia, who have been the victim of exclusion from the wider discourses around dementia more generally. I recognise that I am a practical person, who values supporting individuals and organisations to make meaningful change as part of my job role. During the interviews and analysis, I noticed my tendency to attend to the practical implications of the research which can act as the catalyst for such changes. I attempted to remain aware of this tendency, as it may have drawn my attention away from rich information relating to the experience of employment concerns for those with young-onset dementia and may have influenced the questions asked during the interviews and the information I attended to during analysis.

When reflecting upon participant involvement within my research, I felt as though the inclusion of individuals with young-onset dementia and those from other ethnic backgrounds was hampered by several practical barriers which have been discussed. The lack of inclusion of those affected by the research is not in line with my values, or ways of working with individuals in a clinical setting. It felt counterproductive to interview carers when considering my original research aims of understanding the experiences of those with a diagnosis of young-onset dementia. Thankfully, the carers involved in the interviews were in very good, informed positions to share the barriers and facilitators to employment, and I valued their commitment to authentically share the experiences of those with young-onset dementia in the workplace. However, I do remain critical of what information was missed and the implications of using carers perspectives to inform the recommendations for individuals with young-onset dementia.

Finally, I am particularly taken aback by the high level of commitment from the participants in the research, and the frequent comments by those hearing of my research on the utility and value of it for the dementia community. This has strengthened my commitment to further this work as a qualified clinical psychologist both in research and clinical practice, to improve the lives and experiences of those with young-onset dementia.

4.8. Conclusion

This study explored the barriers and facilitators to employment for those with young-onset dementia through the perspective of their carers, whilst identifying potential adaptations that could be made to support an individual to remain in employment and reduce psychological consequences of employment loss. The research findings suggest the need for further investigation, consultation, and political action to begin the journey of developing robust intervention at several levels. Firstly, support is required at the individual level, by providing emotional and practical assistance at work. Secondly, at the organisational and service level, by increasing service provision and funding. Finally, at the policy level, by developing clear policy and guidance specifically tailored to support those with young-onset dementia in the workplace.

It is recommended that professionals working with those with young-onset dementia, including clinical psychologists, consider employment support as a key component of their role, and should support the campaign for increased funding to ensure consistent service provision specific to those with young-onset dementia. Research to further the proposed interventions should involve the perspectives and insight of those living with young-onset dementia. I would like to thank those who have taken the time to take part in this research, and to read this report, and would hope that this research offers some guidance regarding compassionate employment support for those with young-onset dementia.

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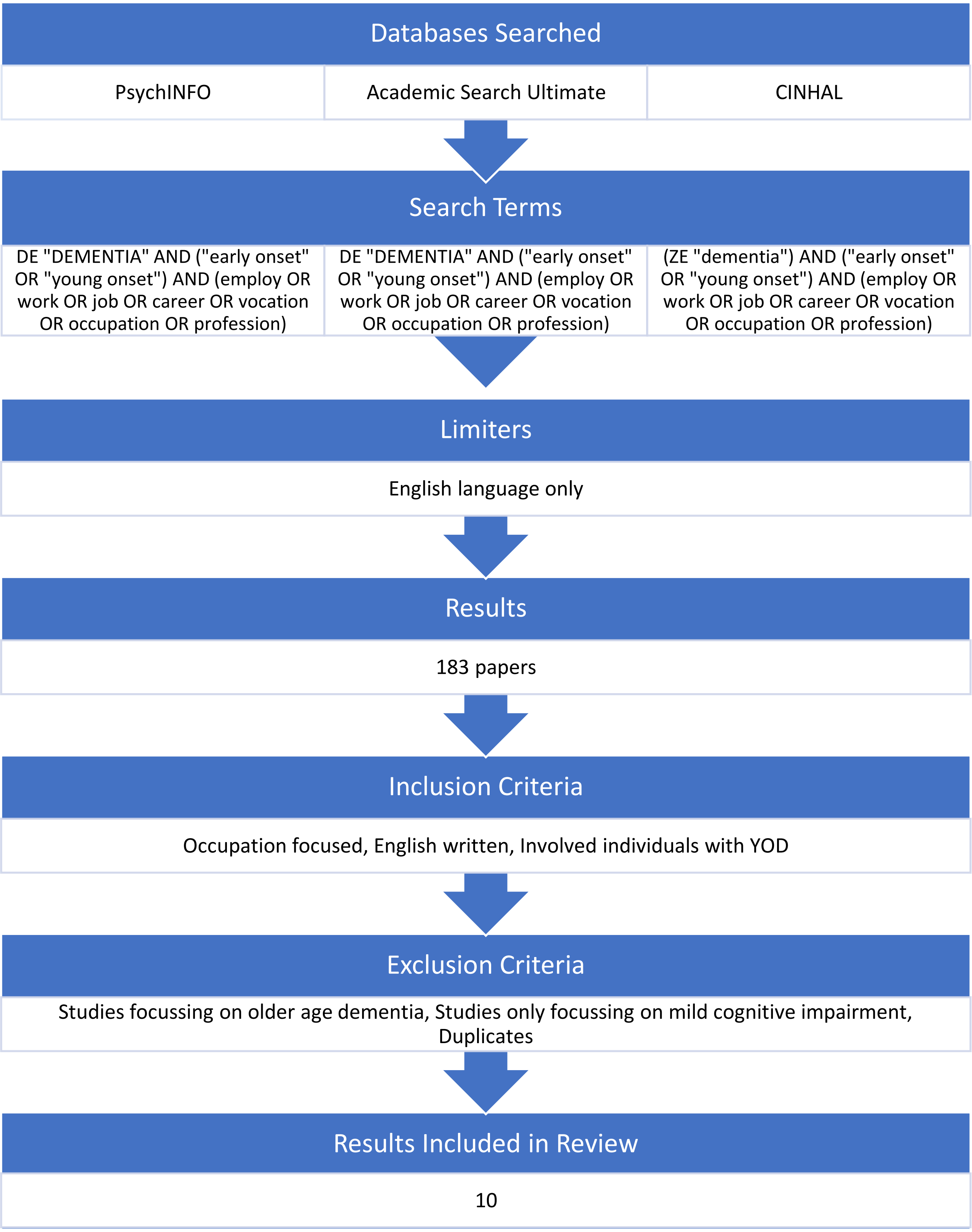
Yassine, H. N., & Schneider, L. S. (2017). Lessons from the Multidomain Alzheimer Preventive Trial. *The Lancet Neurology*, *16*(8), 585–586. https://doi.org/10.1016/S1474-4422(17)30227-2

APPENDIX A: Literature Search Strategy



APPENDIX B: Study Advertisement

Participants required

Hello, my name is Rebecca Lee, and I am a Trainee Clinical Psychologist studying at the University of East London. I am looking to speak to carers about their loved one's experience of employment following a diagnosis of young onset dementia.

Previous research has shown that those with young onset dementia are likely to leave their jobs or retire early due to the difficulties associated with dementia. This can lead to many challenges, including financial difficulty. Unfortunately, there is limited research exploring reasonable adjustments and employment opportunities to help those with young onset dementia remain in employment.

Do you know someone with young onset dementia? Would you be able to help share their experience of employment?

Do you know someone with young onset dementia?

I am interested in finding out more about the experiece of employment for those with young onset dementia.

If you would like to take part in this research and share their experience in a **short online interview** please contact Rebecca via email at: **U2075211@UEL.AC.UK**

If you would like to take part in a short online interview to share the experience of your loved one, please contact Rebecca Lee via email at: U2075211@UEL.AC.UK. Please also drop me an email if you would like more information.

APPENDIX C: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Barriers and Facilitators to Employment in Those with Young Onset Dementia

Contact person: Ms Rebecca Lee
Email: u2075211@uel.ac.uk

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on my email.

Who am I?

My name is Rebecca. I am a student in the School of Psychology at the University of East London (UEL) studying for a doctorate in clinical psychology. As part of my studies, I am conducting the research that you are being invited to participate in.

What is the purpose of the research?

I am studying what barriers there are to people with young onset dementia keeping their jobs and what factors support them staying in work. I aim to share the study findings with different groups to promote positive change.

Why have I been invited to take part?

As a carer, you have been invited to take part to share your experience of supporting your loved one who may have lost their job because of the impact of dementia or, alternatively, might have been able to continue work for some time at least despite their dementia.

What will I be asked to do if I agree to take part?

If you agree to take part, you will be asked to attend one online interview, lasting up to an hour. During this interview, I will ask you about the experience your loved one has had in relation to their employment. This will be via the Microsoft Teams software (you do not need to download this). So that I do not miss anything I will record the interview but neither you nor your loved one will be identifiable when I write the research up (see below).

Can I change my mind?

Yes, you can change your mind and withdraw without explanation, disadvantage, or consequence. If you would like to withdraw from the research, please contact me within three weeks of the interview so your data can be removed from the study. After this time, I will have begun to analyse the data and so will need to retain the right to use it in my research but neither you nor your loved one will be identifiable.

Are there any disadvantages to taking part?
Sometimes it can be difficult to discuss challenges around young onset dementia. If you feel distressed as a result of taking part in the study, you can take a break or speak to Rebecca about this and you will be directed to some useful resources and support agencies if needed (which can also be found at the bottom of this leaflet).

How will the information I provide be kept secure and confidential?
When I type up a transcript of the interview I will change any identifiable information (such as names and place names) to protect your identities. The information you provide will be kept securely, only the research team and examiners will have access to the anonymised interview transcript. In the unlikely event that there is any risk identified, we may need to share this information to keep you and your loved one safe. However, this will be discussed with you where possible.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

What will happen to the results of the research?
The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on the university's online Repository.. This is a good way of sharing the results of the research more widely. Findings may also be shared with a range of audiences, such as the public or other professionals through journal articles, conference presentations, talks, magazine articles, blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.
Anonymised research data will be securely stored by the university for a maximum of 5 years, following which all data will be deleted.

Who has reviewed the research?
My research has been approved by the School of Psychology Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Ms Rebecca Lee
U2075211@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor: Professor David Harper, School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: D.Harper@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

Thank you for taking the time to read this information sheet

Support information:

1) A website that allows you to type in your address to find local support organisations:
https://www.dementiauk.org/about-dementia/young-onset-dementia/find-support/

2) A website with many information leaflets to read for carers and individuals with young onset dementia
https://www.dementiauk.org/get-support/our-leaflets/

3) Anyone with a question or concern about young onset dementia can call the Dementia Helpline for free on 0800 888 6678 or send an email to helpline@dementiauk.org

APPENDIX D: Consent Form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Barriers and Facilitators to Employment in Those with Young Onset Dementia

Contact person: Ms Rebecca Lee

Email: u2075211@uel.ac.uk

	Initial
I confirm that I have read the participant information sheet dated 11/04/2022 (version 2) for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage.	
I understand that if I withdraw during the interview, my data will not be used.	
I understand that I have three weeks from the date of the interview to withdraw my data from the study.	
I understand that the interview will be recorded using Ms teams.	
I understand that my personal information and data, including audio/video recordings from the research will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from the interview may be used when writing the thesis and in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me.	
I am aware that the thesis will be made publicly available online	
I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I agree to take part in the above study.	

Participant’s Name (BLOCK CAPITALS):
Participant’s Signature:
Researcher’s Name (BLOCK CAPITALS):
Researcher’s Signature:
Date:

APPENDIX E: Interview Schedule

1) Demographic information

- Age
- Sex
- Dementia type / progression
- Age of YOD diagnosis
- How do you know the person with YOD?

2) Employment history

- What was X’s job role?
- Tell me about their duties
- How long were they employed / are they still employed?
- Did they tell employer about their diagnosis? / What did you think their experience was of disclosing their diagnosis? / What was their experience of not telling their employer? / Why did they not tell their employer?
- How long did they retain the employment since difficulties started?
- How long did they retain the employment since diagnosis?

3) Barriers to employment

- What made it difficult / what were the challenges to maintain employment?
- What did employers do that didn’t support them / was unhelpful?
- How did this impact the individual with YOD?

4) Facilitators to employment

- What helped X to maintain employment for longer?
- What adaptions did X make to help them stay at work for longer?
- How did you or other people who are important to X help them stay at work?
- How did the employer support X to stay at work?

5) Adaptions you think would be helpful

- What would you like employers to know about what is unhelpful for someone with YOD in the workplace?
- What adaptions would be helpful to support someone with YOD in employment?
  - *Adaption prompts (memory aids/ assisted technology (Alerts), extra support from manager / colleagues, regular breaks to support concentration and tiredness, reduced workload, change in role, stigma / discrimination).*

APPENDIX F: Debrief Sheet

University of East London

PARTICIPANT DEBRIEF SHEET

What are the Barriers and Facilitators to Employment for Those with Young Onset Dementia?

Thank you for participating in my research study looking at barriers and facilitators to retaining employment for those with young onset dementia. This document offers information that may be relevant in light of you having now taken part.

How will my data be managed?

The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research. Please remember, if you would like to withdraw from this research, please contact Rebecca within three weeks of finishing the interview. You may not be able to withdraw after this time as data analysis may have begun.

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository (where all thesis reports are kept). Findings may also be shared with a range of audiences (e.g., academics, clinicians, public, etc.) through journal articles, conference presentations, talks, magazine articles, and blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally as this information will be removed.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by my supervisor for a maximum of 5 years, following which all data will be deleted.

What if I been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise distress or harm of any kind. Nevertheless, it is possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways, you may find the following resources/services helpful in relation to obtaining information and support:

1) A website that allows you to type in your address to find local support organisations:

https://www.dementiauk.org/about-dementia/young-onset-dementia/find-support/

2) A website with many information leaflets to read for carers and individuals with young onset dementia

https://www.dementiauk.org/get-support/our-leaflets/

3) Anyone with a question or concern relating to young onset dementia can call the Dementia Helpline for free on 0800 888 6678 or send an email to helpline@dementiauk.org

Who can I contact if I have any questions/concerns?
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Contact person: Ms Rebecca Lee
Email: u2075211@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Professor David Harper. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: D.Harper@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

Thank you for taking part in my study

APPENDIX G: Reflexive Journal Excerpt

Reflecting on my first interview

I was feeling very nervous before my interview. I was wondering if my interview schedule would be enough to prompt discussion. I was worrying about remembering to discuss confidentiality / right to withdraw etc. I was also worrying about only interviewing the carer and not the individual with young onset dementia. Luckily the interview ran smoothly and was very enjoyable.

Reflecting on recruitment

I feel like I have stumbled across so many barriers when trying to recruit, I feel like time is running out and I have barely got going. I wonder if this is what people with dementia face on a daily basis, a range of structural barriers stopping them from fulfilling their potential, all whilst facing a ticking clock. This is the reason I am doing this research.

Reflecting on coding and theme development

Coding has been a really long process. I am however enjoying reliving the interviews and remembering the conversations and stories that I heard from my participants. I feel like I am on a roll now that I have a useful strategy. It is really technical, but I am getting there. I showed some of my coding and initial themes to my supervisor and we noticed that I am neglecting latent meaning within the text. It has made me realise that I see things through a pragmatic lens. I need to take a step back to make sure that I can do the analysis justice.

Reflecting on writing

I've had to use a chunk of my annual leave to give me enough time to write the thesis without placing too much stress on myself. I keep thinking about the participants in my study reading the report, I am hopeful that I have captured their thoughts and experiences well. The process of writing has helped me to develop a thread in my mind about the theory and methods that underpin the work that I am doing. It is taking me a very long time, and every time I read over something, I see a million other ways that I could write or structure it. I think I am approaching the thesis differently after reading more into the theories underpinning dementia. I wish I had done this part earlier, as this information would have been useful to guide the development of my project. So much has changed since the start of the project, hindsight is a wonderful thing.

APPENDIX H: Transcript Excerpt and Initial Codes

Transcript	Initial Coding
P3: The other thing that they looked at doing and that was I suppose more recently was they did reduce his hours. Because he was finding it really tiring to work full time hours, so they reduced his hours. And I think he worked four days a week, but he could fit that over 5 days. Say he be working 5 days, but the reduced hours so be working about 30 hours a week. He found it working with the [removed for anonymity purposes] was fine, but actually he still struggled with engaging with the public and he said, look, actually, it's really tiring for him because he he's very aware, he's got dementia. He says my brain has to work, you know, really hard to do what anyone else does because of the damage to it. So actually, at the end of the day, I'm really tired. And when I'm really tired, it makes things worse. It makes me my thinking worse. It makes my memory worse.	Working hours adjusted to support employment Awareness of symptoms impacting employment
P3: He found that if he was able to do short hours, that made things a lot easier for him, and he often took quite a long lunch break. But again, his employers were very, very supportive of that. I think because they had known him such a long time and they had a good relationship with him, actually, and his wife. That that's why they were able to kind of accommodate him, but it doesn't always work out in such a nice way for people I'm aware of that.	Good working relationships as support
P3: But as I say before you had the diagnosis, because they knew him so well, I think they were able to adapt, but then once he had the diagnosis, they were able to look at things more formally and work with it more formally. And it's worked really well for him and his partner. I think the partner really worries about money because obviously there's been a drop in money over the years and she's worried about his hours dropping and his salary being reduced. That does concern her, and obviously thinking about how that will impact in the future as well in terms of pensions and finances.	Formalisation of employment adjustments when under investigation / diagnosis Family distress Financial impact of loss of employment
P3: So yeah. Hopefully that explains it.	

APPENDIX I: Full Ethics Application and Approval Letter

UNIVERSITY OF EAST LONDON

School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL

FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

(Updated October 2021)

PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL PSYCHOLOGY

Section 1 – Guidance on Completing the Application Form (please read carefully)	
1.1	Before completing this application, please familiarise yourself with: British Psychological Society's Code of Ethics and Conduct UEL's Code of Practice for Research Ethics UEL's Research Data Management Policy UEL's Data Backup Policy
1.2	Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will look over your application and provide feedback.
1.3	When your application demonstrates a sound ethical protocol, your supervisor will submit it for review.
1.4	Your supervisor will let you know the outcome of your application. Recruitment and data collection must **NOT** commence until your ethics application has been approved, along with other approvals that may be necessary (see section 7).
1.5	Research in the NHS: If your research involves patients or service users of the NHS, their relatives or carers, as well as those in receipt of services provided under contract to the NHS, you will need to

	apply for HRA approval/NHS permission (through IRAS). You DO NOT need to apply to the School of Psychology for ethical clearance. Useful websites: https://www.myresearchproject.org.uk/Signin.aspx https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/hra-approval/ If recruitment involves NHS staff via the NHS, an application will need to be submitted to the HRA in order to obtain R&D approval. This is in addition to separate approval via the R&D department of the NHS Trust involved in the research. UEL ethical approval will also be required. HRA/R&D approval is not required for research when NHS employees are not recruited directly through NHS lines of communication (UEL ethical approval is required). This means that NHS staff can participate in research without HRA approval when a student recruits via their own social/professional networks or through a professional body such as the BPS, for example. The School strongly discourages BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
1.6	If you require Disclosure Barring Service (DBS) clearance (see section 6), please request a DBS clearance form from the Hub, complete it fully, and return it to applicantchecks@uel.ac.uk. Once the form has been approved, you will be registered with GBG Online Disclosures and a registration email will be sent to you. Guidance for completing the online form is provided on the GBG website: https://fadv.onlinedisclosures.co.uk/Authentication/Login You may also find the following website to be a useful resource: https://www.gov.uk/government/organisations/disclosure-and-barring-service
1.7	Checklist, the following attachments should be included if appropriate: Study advertisement Participant Information Sheet (PIS) Participant Consent Form Participant Debrief Sheet Risk Assessment Form/Country-Specific Risk Assessment Form (see section 5) Permission from an external organisation (see section 7) Original and/or pre-existing questionnaire(s) and test(s) you intend to use

	Interview guide for qualitative studies Visual material(s) you intend showing participants

Section 2 – Your Details		
2.1	**Your name:**	**Ms Rebecca Kerry Lee**
2.2	**Your supervisor's name:**	**Professor David Harper**
2.3	**Name(s) of additional UEL supervisors:**	2nd supervisor
		3rd supervisor (if applicable)
2.4	**Title of your programme:**	**Professional Doctorate in Clinical Psychology**
2.5	**UEL assignment submission date:**	Initial submission date
		Re-sit date (if applicable)

Section 3 – Project Details		
Please give as much detail as necessary for a reviewer to be able to fully understand the nature and purpose of your research.		
3.1	**Study title:** Please note - If your study requires registration, the title inserted here must be the same as that on PhD Manager	**What are the Barriers and Facilitators to Retaining Employment for Those with Young Onset Dementia?**
3.2	**Summary of study background and aims (using lay language):**	**The study will interview up to 10 carers of those with young onset dementia with the aim of finding out the barriers and facilitators to retaining employment after a diagnosis of young onset dementia (YOD).**
3.3	**Research question(s):**	**What are the barriers to retaining employment for those with young onset dementia? What are the facilitators to retaining employment for those with young onset dementia?**
3.4	**Research design:**	**Qualitative analysis**
3.5	**Participants:** Include all relevant information including inclusion and exclusion criteria	**Carers of those with a diagnosis of YOD will be recruited for the interviews. Inclusion criteria: the person with young onset dementia must have been in employment or still be in employment. Carers may be relatives,**

		friends or professionals involved in supporting a person with young onset dementia.	
3.6	**Recruitment strategy:** Provide as much detail as possible and include a backup plan if relevant	**I will ask relevant charities to distribute details about the study and I will also recruit via social media and other online forums as well as via word of mouth.**	
3.7	**Measures, materials or equipment:** Provide detailed information, e.g., for measures, include scoring instructions, psychometric properties, if freely available, permissions required, etc.	**An interview schedule – see Appendix E**	
3.8	**Data collection:** Provide information on how data will be collected from the point of consent to debrief	**The interviews will be conducted on Microsoft teams which will be recorded and saved to the live stream. These will be moved to password protected folders on the laptop and deleted from the live stream.**	
3.9	**Will you be engaging in deception?**	**YES** ☐	**NO** ☒
	If yes, what will participants be told about the nature of the research, and how/when will you inform them about its real nature?	If you selected yes, please provide more information here	
3.10	**Will participants be reimbursed?**	**YES** ☐	**NO** ☒
	If yes, please detail why it is necessary.	If you selected yes, please provide more information here	
	How much will you offer? Please note - This must be in the form of vouchers, not cash.	Please state the value of vouchers	

3.11	**Data analysis:**	**Data will be analysed qualitatively.**

Section 4 – Confidentiality, Security and Data Retention			
It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations. If a Research Data Management Plan (RDMP) has been completed and reviewed, information from this document can be inserted here.			
4.1	**Will the participants be anonymised at source?**	**YES** ☐	**NO** ☒
	If yes, please provide details of how the data will be anonymised.		
4.2	**Are participants' responses anonymised or are an anonymised sample?**	**YES** ☒	**NO** ☐
	If yes, please provide details of how data will be anonymised (e.g., all identifying information will be removed during transcription, pseudonyms used, etc.).	**Personally identifying information will be changed during transcription (e.g. all place names and names of people will be changed).**	
4.3	**How will you ensure participant details will be kept confidential?**	**Anonymised transcripts, participant contact details, demographic information and consent forms will be stored in password protected files on the encrypted personal UEL OneDrive.**	
4.4	**How will data be securely stored and backed up during the research?** Please include details of how you will manage access, sharing and security	**Data will be stored on an encrypted personal UEL OneDrive. It will be backed up on an encrypted hard drive. Only the research team and examiners will have access to the data which will be stored in password protected files on the encrypted personal UEL OneDrive.**	
4.5	**Who will have access to the data and in what form?**	**In normal circumstances only the researcher will have access to the raw audio files. The anonymised**	

	(e.g., raw data, anonymised data)	**transcripts will be available to the DoS and examiners on request.**	
4.6	**Which data are of long-term value and will be retained?** (e.g., anonymised interview transcripts, anonymised databases)	**Anonymised interview transcripts will be retained for 5 years.**	
4.7	**What is the long-term retention plan for this data?**	**Data will be shared with the DOS to save on OneDrive upon completion of the research project and will be securely stored until publication. Any other records of the data will be deleted upon completion of the research study.**	
4.8	**Will anonymised data be made available for use in future research by other researchers?**	**YES** ☐	**NO** ☒
	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐
4.9	**Will personal contact details be retained to contact participants in the future for other research studies?**	**YES** ☐	**NO** ☒
	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐

Section 5 – Risk Assessment			
If you have serious concerns about the safety of a participant, or others, during the course of your research please speak with your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g., a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.			
5.1	**Are there any potential physical or psychological risks to participants related to taking part?** (e.g., potential adverse effects, pain, discomfort, emotional distress, intrusion, etc.)	**YES** ☒	**NO** ☐

	If yes, what are these, and how will they be minimised?	**The researcher will monitor distress and allow participants to take a break if needed. My supervisor will be contacted for further support if needed.**		
5.2	**Are there any potential physical or psychological risks to you as a researcher?**	**YES** ☐	**NO** ☒	
	If yes, what are these, and how will they be minimised?			
5.3	**If you answered yes to either 5.1 and/or 5.2, you will need to complete and include a General Risk Assessment (GRA) form (signed by your supervisor). Please confirm that you have attached a GRA form as an appendix:**	**YES** ☒		
5.4	**If necessary, have appropriate support services been identified in material provided to participants?**	**YES** ☒	**NO** ☐	**N/A** ☐
5.5	**Does the research take place outside the UEL campus?**	**YES** ☒	**NO** ☐	
	If yes, where?	**Online**		
5.6	**Does the research take place outside the UK?**	**YES** ☐	**NO** ☒	
	If yes, where?	Please state the country and other relevant details		
	If yes, in addition to the General Risk Assessment form, a Country-Specific Risk Assessment form must also be completed and included (available in the Ethics folder in the Psychology Noticeboard). Please confirm a Country-Specific Risk Assessment form has been attached as an appendix.	**YES** ☐		

	Please note - A Country-Specific Risk Assessment form is not needed if the research is online only (e.g., Qualtrics survey), regardless of the location of the researcher or the participants.	
5.7	**Additional guidance:** For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on 'sign in' and then 'register here' using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance. For on campus students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Director of Impact and Innovation, Professor Ian Tucker (who may escalate it up to the Vice Chancellor). For distance learning students conducting research abroad in the country where they currently reside, a risk assessment must also be carried out. To minimise risk, it is recommended that such students only conduct data collection online. If the project is deemed low risk, then it is not necessary for the risk assessment to be signed by the Director of Impact and Innovation. However, if not deemed low risk, it must be signed by the Director of Impact and Innovation (or potentially the Vice Chancellor). Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.	

Section 6 – Disclosure and Barring Service (DBS) Clearance			
6.1	**Does your research involve working with children (aged 16 or under) or vulnerable adults (see below for definition)?** If yes, you will require Disclosure Barring Service (DBS) or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project	**YES** ☒	**NO** ☐

	You are required to have DBS or equivalent clearance if your participant group involves: (1) Children and young people who are 16 years of age or under, or (2) 'Vulnerable' people aged 16 and over with particular psychiatric diagnoses, cognitive difficulties, receiving domestic care, in nursing homes, in palliative care, living in institutions or sheltered accommodation, or involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak with your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible.		
6.2	**Do you have DBS or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project?**	**YES** ☒	**NO** ☐
6.3	**Is your DBS or equivalent (for those residing in countries outside of the UK) clearance valid for the duration of the research project?**	**YES** ☒	**NO** ☐
6.4	**If you have current DBS clearance, please provide your DBS certificate number:**	**001704225120 – Enhanced DBS check**	
	If residing outside of the UK, please detail the type of clearance and/or provide certificate number.	Please provide details of the type of clearance, including any identification information such as a certificate number	
6.5	**Additional guidance:** If participants are aged 16 or under, you will need two separate information sheets, consent forms, and debrief forms (one for the participant, and one for their parent/guardian). For younger participants, their information sheets, consent form, and debrief form need to be written in age-appropriate language.		

Section 7 – Other Permissions

7.1	**Does the research involve other organisations (e.g., a school, charity, workplace, local authority, care home, etc.)?**	**YES** ☐	**NO** ☒
	If yes, please provide their details.	**I will ask charities like Dementiaresearch.org and Mindcare.org.uk to advertise my study but I will not be asking them to supply me names of potential participants.**	
	If yes, written permission is needed from such organisations (i.e., if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation). Please confirm that you have attached written permission as an appendix.	**YES** ☒ **Ethical approval needed before permission can be granted – email attached in appendix 1.**	
7.2	**Additional guidance:** Before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application or approval letter. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as 'my' or 'I' with 'our organisation' or with the title of the organisation. This organisational consent form must be signed before the research can commence. If the organisation has their own ethics committee and review process, a SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s.		

Section 8 – Declarations

8.1	**Declaration by student. I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor:**	**YES** ☒
8.2	**Student's name:** (Typed name acts as a signature)	**Ms Rebecca Lee**
8.3	**Student's number:**	**2075211**
8.4	**Date:**	**11/04/2022**
Supervisor's declaration of support is given upon their electronic submission of the application		

Appendix A: Participant Information Sheet (PIS) template

Version: 2

Date: 11/4/22

University of East London

PARTICIPANT INFORMATION SHEET

Barriers and Facilitators to Employment in Those with Young Onset Dementia

Contact person: Ms Rebecca Lee

Email: u2075211@uel.ac.uk

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on my email.

Who am I?

My name is Rebecca. I am a student in the School of Psychology at the University of East London (UEL) studying for a doctorate in clinical psychology. As part of my studies, I am conducting the research that you are being invited to participate in.

What is the purpose of the research?

I am studying what barriers there are to people with young onset dementia keeping their jobs and what factors support them staying in work. I aim to share the study findings with different groups to promote positive change.

Why have I been invited to take part?

As a carer, you have been invited to take part to share your experience of supporting your loved one who may have lost their job because of the impact of dementia or, alternatively, might have been able to continue work for some time at least despite their dementia.

What will I be asked to do if I agree to take part?

If you agree to take part, you will be asked to attend one online interview, lasting up to an hour. During this interview, I will ask you about the experience your loved one has had in relation to their employment. This will be via the Microsoft Teams software (you do not need to download this). So that I do not miss anything I will record the interview but neither you nor your loved one will be identifiable when I write the research up (see below).

Can I change my mind?

Yes, you can change your mind and withdraw without explanation, disadvantage, or consequence. If you would like to withdraw from the research, please contact me within three weeks of the interview so your data can be removed from the study. After this time I will have begun to analyse the data and so will need to retain the right to use it in my research but neither you nor your loved one will be identifiable.

Are there any disadvantages to taking part?

Sometimes it can be difficult to discuss challenges around young onset dementia. If you feel distressed as a result of taking part in the study, you can take a break or speak to Rebecca about this and you will be directed to some useful resources and support agencies if needed (which can also be found at the bottom of this leaflet).

How will the information I provide be kept secure and confidential?

When I type up a transcript of the interview I will change any identifiable information (such as names and place names) to protect your identities. The information you provide will be kept securely, only the research team and examiners will have access to the anonymised interview transcript. In the unlikely event that there is any risk identified, we may need to share this information to keep you and your loved one safe. However, this will be discussed with you where possible.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on the university's online Repository.. This is a good way of sharing the results of the research more widely. Findings may also be shared with a range of audiences, such as the public or other professionals through journal articles, conference presentations, talks, magazine articles, blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by the university for a maximum of 5 years, following which all data will be deleted.

Who has reviewed the research?

My research has been approved by the School of Psychology Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Ms Rebecca Lee
U2075211@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor: Professor David Harper, School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: D.Harper@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.patel@uel.ac.uk)

Thank you for taking the time to read this information sheet

Support information:

A website that allows you to type in your address to find local support organisations:

https://www.dementiauk.org/about-dementia/young-onset-dementia/find-support/

A website with many information leaflets to read for carers and individuals with young onset dementia https://www.dementiauk.org/get-support/our-leaflets/

Anyone with a question or concern about young onset dementia can call the Dementia Helpline for free on 0800 888 6678 or send an email to helpline@dementiauk.org

Appendix B: Consent Form template

University of East London

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Barriers and Facilitators to Employment in Those with Young Onset Dementia

Contact person: Ms Rebecca Lee

Email: u2075211@uel.ac.uk

	Please initial
I confirm that I have read the participant information sheet dated 11/04/2022 (version 2) for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage.	
I understand that if I withdraw during the interview, my data will not be used.	
I understand that I have three weeks from the date of the interview to withdraw my data from the study.	
I understand that the interview will be recorded using Ms teams.	

I understand that my personal information and data, including audio/video recordings from the research will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from the interview may be used when writing the thesis and in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me.	
I am aware that the thesis will be made publicly available online	
I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I agree to take part in the above study.	

Participant’s Name (BLOCK CAPITALS)

………

Participant’s Signature

………

Researcher’s Name (BLOCK CAPITALS)

………

Researcher’s Signature

………

Date

………

Appendix C: Participant Debrief Sheet template

PARTICIPANT DEBRIEF SHEET

Barriers and Facilitators to Employment in Those with Young Onset Dementia

Thank you for participating in my research study looking at barriers and facilitators to retaining employment for those with young onset dementia. This document offers information that may be relevant in light of you having now taken part.

How will my data be managed?

The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research. Please remember, if you would like to withdraw from this research, please contact Rebecca within three weeks of finishing the interview. You may not be able to withdraw after this time as data analysis may have begun.

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository (where all thesis reports are kept). Findings may also be shared with a range of audiences (e.g., academics, clinicians, public, etc.) through journal articles, conference presentations, talks, magazine articles, and blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally as this information will be removed.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by my supervisor for a maximum of 5 years, following which all data will be deleted.

What if I been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise distress or harm of any kind. Nevertheless, it is possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways, you may find the following resources/services helpful in relation to obtaining information and support:

A website that allows you to type in your address to find local support organisations:

https://www.dementiauk.org/about-dementia/young-onset-dementia/find-support/

A website with many information leaflets to read for carers and individuals with young onset dementia

https://www.dementiauk.org/get-support/our-leaflets/

Anyone with a question or concern relating to young onset dementia can call the Dementia Helpline for free on 0800 888 6678 or send an email to helpline@dementiauk.org

Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Contact person: Ms Rebecca Lee
Email: u2075211@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Professor David Harper. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: D.Harper@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Email: t.patel@uel.ac.uk)

Appendix D: General Risk Assessment Form

UEL Risk Assessment Form

Name of Assessor:	**Rebecca Lee**	**Date of Assessment:**	**26/01/2022**
Activity title:	**Barriers and Facilitators to Employment in Those with Young Onset Dementia**	**Location of activity:**	**UEL Campus at Stratford**
Signed off by Manager: (Print Name)	**David Harper**	**Date and time: (if applicable)**	**30 May 2022**

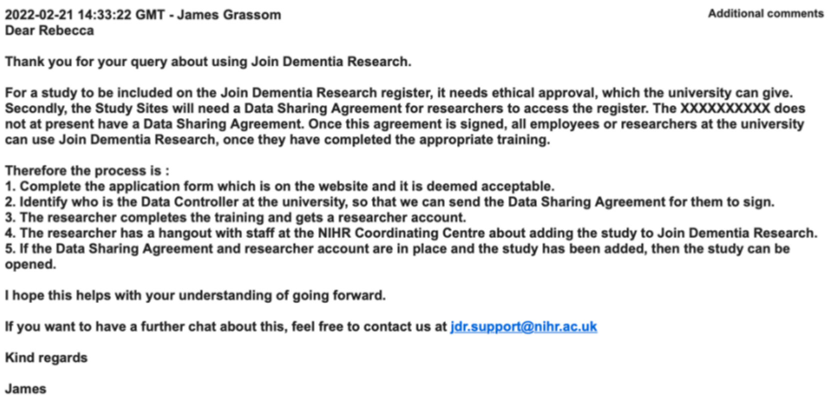
Please describe the activity/event in as much detail as possible (include nature of activity, estimated number of participants, etc.). If the activity to be assessed is part of a fieldtrip or event please add an overview of this below:
One Interview via Ms Teams with up to 10 carers of those with Young onset dementia.
Overview of FIELD TRIP or EVENT:
One interview with up to 10 carers via Ms Teams.

Likelihood of Risk	**Hazard Severity**	**Risk Rating (a x b = c)**
1 = Low (Unlikely)	1 = Slight (Minor / less than 3 days off work)	1-2 = Minor (No further action required)

Likelihood of Risk	Hazard Severity	Risk Rating (a x b = c)
2 = Moderate (Quite likely)	2= Serious (Over 3 days off work)	3-4 = Medium (May require further control measures)
3 = High (Very likely or certain)	3 = Major (Over 7 days off work, specified injury or death)	6/9 = High (Further control measures essential)

Hazards attached to the activity							
Hazards identified	**Who is at risk?**	**Existing Controls**	**Likelihood**	**Severity**	**Residual Risk Rating (Likelihood x Severity)**	**Additional control measures required (if any)**	**Final risk rating**
Distress resulting from taking part in the interview.	Carers	Provide an opportunity for a break or to leave the discussion if the distress is more pronounced. Create an open space to share and talk through concerns. Researcher to take it to supervision if there are remaining concerns	1	1	1	Direct individuals to extra support via charities / organisations.	1

Appendix E: Contact with dementia research



2022-02-21 14:33:22 GMT - James Grassom

Additional comments

Dear Rebecca

Thank you for your query about using Join Dementia Research.

For a study to be included on the Join Dementia Research register, it needs ethical approval, which the university can give. Secondly, the Study Sites will need a Data Sharing Agreement for researchers to access the register. The XXXXXXXXXX does not at present have a Data Sharing Agreement. Once this agreement is signed, all employees or researchers at the university can use Join Dementia Research, once they have completed the appropriate training.

Therefore the process is :
1. Complete the application form which is on the website and it is deemed acceptable.
2. Identify who is the Data Controller at the university, so that we can send the Data Sharing Agreement for them to sign.
3. The researcher completes the training and gets a researcher account.
4. The researcher has a hangout with staff at the NIHR Coordinating Centre about adding the study to Join Dementia Research.
5. If the Data Sharing Agreement and researcher account are in place and the study has been added, then the study can be opened.

I hope this helps with your understanding of going forward.

If you want to have a further chat about this, feel free to contact us at jdr.support@nihr.ac.uk

Kind regards

James

Appendix F: Interview schedule

Interview schedule

Demographic information

Age / DOB (of carer and of person with YOD)

Sex (of carer and of person with YOD)

Education level

Marital status

Housing (rented, owned)

Dementia info

Dementia type / progression

Age of YOD diagnosis

Relationship to the person with YOD?

Employment history

What job was it?

What did the job role look like initially?

How long were they employed / are they still employed?

Did they tell employer about their diagnosis?

How long did they retain the employment since difficulties started (possibly pre diagnosis)?

How long did they remain in their job following diagnosis?

Barriers to employment

What made it difficult to maintain employment?

What did employers do that didn't support them?

How did this impact the individual with YOD?

Facilitators to employment

What helped to maintain employment for longer?

Did they personally make any adaptions to stay at work longer?

Did the employer make any adaptions to support employment?

Did the family or others besides the employer support? If so how?

Adaptions you think would be helpful

What would you like employers to know about what is unhelpful for someone with YOD in the workplace?

What adaptions would be helpful to support someone with YOD in employment?

Adaption prompts (memory aids/ assisted technology (Alerts), extra support from manager / colleagues, regular breaks to support concentration and tiredness, reduced workload, change in role)

Appendix G: Study Advertisement

UEL
University of East London

Do you know someone with young onset dementia?

I am interested in finding out more about the experiece of employment for those with young onset dementia.

If you would like to take part in this research and share their experience in a **short online interview** please contact Rebecca via email at:
U2075211@UEL.AC.UK

School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in **blue** | **Student:** Please complete/read sections in **orange**

Details

Reviewer:	**Paul Penn**
Supervisor:	**David Harper**
Student:	**Rebecca Kerry Lee**
Course:	**Prof Doc Clinical Psychology**
Title of proposed study:	**What are the Barriers and Facilitators to Retaining Employment for Those with Young Onset Dementia?**

Checklist

(Optional)

	YES	**NO**	**N/A**
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	☐	☐	☐
Detailed account of participants, including inclusion and exclusion criteria	☐	☐	☐
Concerns regarding participants/target sample	☐	☐	☐
Detailed account of recruitment strategy	☐	☐	☐
Concerns regarding recruitment strategy	☐	☐	☐
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	☐	☐	☐
Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	☐	☐	☐
Clear and detailed outline of data collection	☐	☐	☐
Data collection appropriate for target sample	☐	☐	☐
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	☐	☐	☐

If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	☐	☐	☐
Concerns regarding data storage (e.g., location, type of data, etc.)	☐	☐	☐
Concerns regarding data sharing (e.g., who will have access and how)	☐	☐	☐
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	☐	☐	☐
If required, General Risk Assessment form attached	☐	☐	☐
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
If required, Country-Specific Risk Assessment form attached	☐	☐	☐
If required, a DBS or equivalent certificate number/information provided	☐	☐	☐
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	☐	☐	☐
All relevant information included in the participant information sheet (PIS)	☐	☐	☐
Information in the PIS is study specific	☐	☐	☐
Language used in the PIS is appropriate for the target audience	☐	☐	☐
All issues specific to the study are covered in the consent form	☐	☐	☐
Language used in the consent form is appropriate for the target audience	☐	☐	☐
All necessary information included in the participant debrief sheet	☐	☐	☐
Language used in the debrief sheet is appropriate for the target audience	☐	☐	☐
Study advertisement included	☐	☐	☐
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)	☐	☐	☐

Decision options

APPROVED	Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment.
APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made **before** the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records. **Minor amendments guidance:** typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.
NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED	In this circumstance, a revised ethics application **must** be submitted and approved **before** any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

	Major amendments guidance: typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate's ability to ethically, safely and sensitively execute the study.

Decision on the above-named proposed research study

Please indicate the decision:	**APPROVED**

Minor amendments

Please clearly detail the amendments the student is required to make

Major amendments

Please clearly detail the amendments the student is required to make

Assessment of risk to researcher

Has an adequate risk assessment been offered in the application form?	**YES** ☒	**NO** ☐
	If no, please request resubmission with an **adequate risk assessment.**	
If the proposed research could expose the researcher to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:		
HIGH	Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	☐
MEDIUM	Approve but include appropriate recommendations in the below box.	☐

LOW	Approve and if necessary, include any recommendations in the below box.	☒
Reviewer recommendations in relation to risk (if any):	Please insert any recommendations	

Reviewer's signature

Reviewer: (Typed name to act as signature)	**Paul Penn**
Date:	**20/06/2022**

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee

RESEARCHER PLEASE NOTE

For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

Confirmation of minor amendments

(Student to complete)

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data

Student name: (Typed name to act as signature)	Please type your full name
Student number:	Please type your student number
Date:	Click or tap to enter a date

Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required

APPENDIX J: Title Change Form (Post Viva)

School of Psychology Ethics Committee

REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for a proposed title change to an ethics application that has been approved by the School of Psychology

By applying for a change of title request, you confirm that in doing so, the process by which you have collected your data/conducted your research has not changed or deviated from your original ethics approval. If either of these have changed, then you are required to complete an 'Ethics Application Amendment Form'.

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	Using your UEL email address, email the completed request form along with associated documents to Dr Jérémy Lemoine (School Ethics Committee Member): j.lemoine@uel.ac.uk
4	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.

Required documents

A copy of the approval of your initial ethics application.	YES ☒

Details

Name of applicant:	Rebecca Kerry Lee

Programme of study:	Professional doctorate in Clinical Psychology
Title of research:	What are the Barriers and Facilitators to Retaining Employment for Those with Young Onset Dementia?
Name of supervisor:	Nimisha Patel

Proposed title change

Briefly outline the nature of your proposed title change in the boxes below

Old title:	What are the Barriers and Facilitators to Retaining Employment for Those with Young Onset Dementia?
New title:	‘On The Scrap Heap’: Exploring Carers’ Perspectives on the Barriers and Facilitators of Employment for People with Young Onset Dementia
Rationale:	Better describes my original aim and is more punchy – it was agreed in the Viva

Confirmation

Is your supervisor aware of your proposed change of title and in agreement with it?	YES ☒	NO ☐
Does your change of title impact the process of how you collected your data/conducted your research?	YES ☐	NO ☒

Student’s signature

Student: (Typed name to act as signature)	Rebecca Kerry Lee
Date:	20/08/2024

Reviewer’s decision

Title change approved:	YES ☒	NO ☐
Comments:	Please enter any further comments here	
Reviewer: (Typed name to act as signature)	Miles Thomas	
Date:	20/08/2024	