The Impact on the Family of Young Onset Dementia

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Abstract

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Young onset dementia (YOD) is a contemporary phenomenon and refers to people under the age of 65 with dementia. There are currently 44,000 people living with YOD in the UK and rates are projected to continue rising. Specialist age-appropriate services for people with YOD are scarce, although it is known that they have different needs due to their age and life stage. YOD affects the whole family unit and it is this aspect that the current research focuses on.

The research question posed was: 'What is the impact of young onset dementia on the family?' The study applied a qualitative thematic analysis using Framework to systematically analysis the data collected from a convenience sample of families recruited from dementia cafes. Data were collected through semi-structured interviews with the family unit and individual participants. A total of six families, comprising of 16 participants in total, were recruited. The data generated were analysed to identify three main themes, namely: the Uncertain World; the Changing World; and the Shrinking World.

These themes informed the development of a 'three stage model of the subjective experience of families living with young onset dementia'. The model highlights the optimum stage for families to change and adapt promoting and extending the time they live well with dementia.

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This thesis is dedicated to all those affected by young onset dementia.

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List of Abbreviations

PwD	Person with Dementia
YOD	Young Onset Dementia
LOD	Late Onset Dementia
AD	Alzheimer's Dementia
FTD	Frontal Temporal Dementia
VD	Vascular Dementia
PCA	Posterior Cortical Atrophy
MCI	Mild Cognitive Impairment
CST	Cognitive Stimulation Therapy
GP	General Practitioner
NHS	National Health Service
MCA	Mental Capacity Act
NMC	Nursing & Midwifery Council
PIP	Personal Independence Payment

Preface

The researcher's interest in dementia started with early career care positions in dementia services and, on qualifying as a nurse, developing skills in person-centered approaches working with people with learning disabilities and their families. Practicing in the field of learning disabilities provided a solid skill base with which to support people with impairment as individuals to deliver person-centered care within a family context. These skills transferred into dementia services on returning to work with PwD as a Nurse Consultant for learning disabilities and dementia. This return highlighted person-centered approaches for people with dementia and their families as vital to delivering meaningful care.

Within practice I witnessed people with YOD and their families experiencing difficulties accessing the help and support they needed due to the inappropriacy of the services. With no specific YOD services available, they would be seen either by older adult services or mainstream adult mental health services, both of which could only provide part of the skills and experience required to support them. People with YOD became lost in one or other of these services, either receiving specialist dementia services that failed to provide the appropriate age-related care needs, or specialist mental health services for their age needs without the specific dementia element. Staff working in these services struggled to meet their needs, with adverse consequences for the PwD and their family. The person and their family appeared to ricochet between the services and their GP before reaching a diagnosis, during which time they experienced a significant impact, due to the financial implications and changes within the family roles. Witnessing families struggle to get the help and information required at a time when they were frightened and confused, led to an interest in the impact of YOD on the person and their family unit.

Chapter 1: Introduction

This chapter will provide an introduction to and overview of the research topic, setting the scene in order to explain the development and importance of the research study. The reader will be introduced to the researcher, while the relevance of involving people with lived experience as participants will also be outlined.

Young Onset Dementia

Young Onset Dementia (YOD) is defined as dementia that is diagnosed before the age of 65 years old and is often referred to as Early Onset Dementia or YOD (Alzheimer's Society, 2021a; Dementia UK, 2020). For consistency, the term YOD will be applied to refer to people who experience the onset of dementia before the age of 65 years old and the term Late Onset Dementia (LOD) will refer to the onset of dementia after 65 years old. There are many different types and causes of dementia (NHS, 2020) and the risk increases with age (Alzheimer's Society, 2021a; NHS, 2020), resulting in it being thought of as a disease of older people. However, although it is less common, dementia also affects younger people.

Society attaches many stigmas to dementia which are further exacerbated in the case of a younger person. Terry Pratchett was diagnosed with YOD at 57 and spoke publicly about the difficulties he experienced. He believed that a contributory factor to the stigma was that dementia is thought of and treated as a mental illness, although it is a physical disease, and highlighted that people feel shame which prevents them talking about it (Pratchett, 2008a). The impact of YOD is different to that of LOD due

to the life stage at which it occurs, with its corresponding commitments and responsibilities such as financial obligations, employment and dependent children, along with the loss of current and expected future plans (Roach et al., 2016; van Vliet et al., 2010a). Combined with the fact that there are few appropriate support services available, this results in younger people with dementia and their families having unmet needs (Kobiske et al., 2019; Cations et al., 2017; Millenaar et al., 2017a).

An overview of YOD will now be provided to set the scene for this study.

Overview of Young Onset Dementia

Dementia describes symptoms that occur when disease damages the brain (Alzheimer's Society, 2021b; Ahmed et al., 2016). It is commonly referred to as an 'umbrella' term for organic brain disease characterised by irreversible decline that is progressive, affecting intellectual functioning, communication, and behaviour, and impacting on activities of daily living (Alzheimer's Disease International, 2016; Robinson et al., 2015). Dementia is defined as:

> *"…a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing."*
>
> (World Health Organisation, 2021, para 2)

Dementia symptoms are wide and varied with no single set of symptoms, which makes it a clinical syndrome (World Health Organisation, 2021; Robinson et al., 2015). Therefore, diagnosis requires the identification of a cluster of symptoms,

meaning that each person's experience of dementia is individual, depending upon the presenting symptoms (Alzheimer's Society, 2021c; Werner et al., 2009). Combined with the fact that there are many different types of dementia, and it is an unexpected diagnosis for younger people, this presents challenges with making the diagnosis and delivering effective care pathways (Samsi, 2015). Symptoms can include memory loss, difficulties with thinking and processing information, communication, orientation, anxiety, depression and frustration with the loss of memory and skills (NHS Choices, 2018).

The beginning of the 20th Century saw the first documentation of these symptoms with the case of Auguste D, aged 51 years old, presented by Alois Alzheimer in 1906 (Alzheimer, 1906, cited in Maurer et al, 1997). Auguste herself was central to the recognition of Alzheimer's disease, although the importance of her case was not considered until after her death due to the culture (Page and Fletcher, 2006) at that time. Kitwood and Benson (1996, cited in Page and Fletcher, 2006) referred to the 'old culture' as a time where the person's history was not considered, resulting in the loss of the person's individuality behind the illness.

Similar symptoms, in people under 65 years old, recognised around this time included, identification of changes in the case of Johann F to the neurofibrillary tangles (Kraepelin, 1910, cited in Maurer et al, 1997). These cases were significant to the recognition of Alzheimer's disease which was referred to as a '*serious form of senile dementia',* and subsequently led to Kraepelin identifying the condition as Alzheimer's disease in 1910 (Kraeplin 1910, cited in Maurer et al, 1997).

It is curios that Alzheimer's disease was first distinguished from Senility as a younger person's disease, with older people experiencing the same symptoms being diagnosed with *senile dementia.* This remained unchallenged until the 1970s, when Katzman (cited in Lock, 2013) recognised senility in older people was in fact Alzheimer's disease. The irony being that it was first associated with illness that affected younger people, but now it is recognised that the risk of dementia increases with age and predominantly affects the older population (Alzheimer's Society, 2017). Since the recognition of AD many different types of dementia have been recognised and identified, although AD remains the most common type (National Institute for Health Research, 2017; Alzheimer's Association, 2017).

Recent years have seen considerable developments in dementia research, resulting in a significant amount of literature. However, gaps in the literature remain in relation to the impact of YOD on the person's family, and specifically in terms of studies that include people with YOD as participants, which led to my interest in this area. The impact of YOD for younger people and their families is different, because it occurs during a life stage where people are generally more active with plans for retirement and beyond (Young Dementia UK, 2020a; Rabanal et al, 2018). There is also a widely reported experience of increased stigma, with the loss of social networks due to dementia being an invisible illness, and unexpected in the case of younger people. Gloria Sterin (2002), who was diagnosed with dementia, believed that people can cope with dementia, but they need more time in which to adjust. Terry Pratchett (2008a) also spoke about the power attached to the label 'dementia', but claimed that speaking about it enables us to have power over it. He also expressed how alone he felt and compared the experience to cancer, suggesting that if he had

cancer there would be a treatment pathway with support available, and he would be seen differently by society:

> *'When you have cancer you are a brave battler against the disease, but when you have dementia you are an old fart, and that's how society seems to see it'* (Pratchett, 2008b)

This captures the experience of people with YOD and highlights how isolating it can be. By ensuring that the experience of dementia is better understood, we can start to address some of the challenges and barriers that people face. This demonstrates the need for more understanding about YOD and its impact on the family, so they can be supported to cope, with less stigma attached to it, and have more time to live well with dementia.

In recent years, there has been a growth of autobiographies written by experts by experience including younger people with dementia. Works include Christen Bryden (Bryden, 2015; 2012; 2005), diagnosed with dementia at 46 with two young children, who shared her story about living with dementia and the changes and challenges she and her family have faced. Bryden's work has been powerful in challenging stereotypes and stigma attached to dementia.

Overall, dementia has attracted considerable interest in recent years, becoming the leading cause of death in England and Wales in 2015, overtaking circulatory diseases including heart disease and stroke (Office for National Statistic, 2016). This pattern is also reflected in the US, with Alzheimer's Disease as a current leading

causes of death (Centre for Disease Control and Prevention, 2017). As well as a growing population of people living with dementia, there is substantial under-diagnosis (Parkin & Baker, 2018) demonstrated by the fact that only 44% of people with dementia in the UK received a diagnosis prior to death (Alzheimer's Society, 2015). Dementia is a growing issue with wide-ranging implications for the person, their family, society, health care and social care.

Having defined YOD and outlined the social context in which it occurs, the prevalence of YOD will be now be explored to demonstrate the importance of this issue.

Prevalence

Dementia is a major health problem on a global scale (Prince et al., 2016; Robinson et al., 2015). It currently affects 46.8 million people worldwide which is expected to double over the next 20 years (Alzheimer's Disease International, 2016), further increasing to a staggering 135 million by 2050, according to predictions (BMJ, 2017; Werner et al., 2009). This highlights the importance of improving support and treatment for people with dementia (PwD) and their families, especially considering that dementia touches most families in the UK in some way (Pratchett, 2008c).

The current estimated total number of people with dementia in the UK is 850,000, and this figure is expected to rise to 1 million by 2025 (Alzheimer's Society, 2017). There are currently 44,000 people in the UK with YOD (Alzheimer's Society, 2021a;

Dementia UK, 2020; Burns et al., 2017), highlighting how YOD can be overshadowed due to the majority of people affected by dementia being in the later stages of life. This explains why dementia is unexpected in younger people. The current and projected impact of dementia is significant enough that the International G8 meeting in 2013 specified dementia as a major disease burden (Department of Health and Social Care, 2013), instigating a global need for all countries to manage the projected socio-economic impact of dementia through public health agendas (World Health Organisation, 2015). This was further supported in the UK by the Prime Minister's challenge (Department of Health, 2012) that aimed to improve dementia care and research by 2015. Although YOD was recognised within this government policy, it is often not considered on its own receiving less attention than LOD.

In many ways dementia is indiscriminate and affects people regardless of ethnicity and gender. However, some groups are at a higher risk, such as people with Down's syndrome, people with a history of strokes and/or cardiovascular issues. People with Down's Syndrome are the largest group of people with dementia under 50 (Ballard et al., 2016). At least 10% of people with dementia will be diagnosed within a year following a stroke (Moulin et al., 2016), and there is evidence of a detrimental link between hypertension and dementia (Perrotta et al., 2016) which is considered responsible for the increased risk of dementia among the African-Caribbean and South Asian populations (Social Care Institute for Excellence, 2015).

This section has drawn attention to the scale of dementia and the breadth of its impact. The next section will look at the types of dementia that affect people with YOD.

Types of Dementia

There are many types of dementia, including some rarer types of disease that lead to dementia or mild cognitive impairment (MCI). Mild cognitive impairment involves persistent memory issues and impaired cognition that is more than the expected decline for someone's age, but not to the extent of dementia (Mayo Clinic, 2017). It is estimated that between 5% and 20% of people over 65 years of age have MCI, and although the risks of dementia increase with MCI, not everyone with MCI will get dementia (Alzheimer's Society, 2015). The most common types of dementia in the general population of PwD are: Alzheimer's Disease (AD), which affects 50-75% of PwD; Vascular dementia (VD), which is the second most common type, affecting 20-30% of PwD; Dementia with Lewy bodies, which affects 10-15% of PwD; and lastly Frontotemporal dementia (FTD), accounting for approximately 5% of cases (National Institute for Health Research, 2017; Alzheimer's Association, 2017).

Prevalent types of dementia among younger people are similar to those for the general population of PwD and include AD, VD, Frontotemporal dementia, Korsakoff's syndrome and Lewy bodies, although they have an increased risk of rarer forms of dementia, including conditions such as Parkinson's disease, Creutzfeld-Jakob disease and Huntington's disease (Young Dementia UK, 2020b). These rarer types of dementia increase the likelihood of misdiagnosis, further

compounded by dementia being unexpected in younger people. The next section focuses on the diagnostic categories.

Diagnostic Categories

The International Classification of Disease (ICD-10) is a commonly used diagnostic tool, with 117 countries currently using it to report health data (World Health Organisation, 2016). The Diagnostic and Statistical Manual (DSM-5) is the American diagnostic coding tool and is also used internationally. There is no single test that can be used to diagnose dementia, and diagnosis involves taking a medical history, and conducting a physical examination, as well as cognitive assessment, blood testing, brain imaging and symptom reporting. This process takes time and it is not always possible to identify a specific type of dementia (National Institutes of Health, 2017). Furthermore, people with YOD have more varied presentations than people with LOD (Drape & Withall, 2016), meaning that the former are often misdiagnosed and experience delays in reaching diagnosis (Ahmed et al., 2016; Roach et al., 2016; Robinson et al., 2015; Werner et al., 2009), which will be explored in the following section.

Diagnostic Rates

Although the aforementioned diagnostic categories are used internationally to promote consistency of diagnosis, the emerging picture is that there has been underestimation of the numbers of people with dementia in several world regions, but at present it is difficult to know if this is a result of changing diagnostic criteria or changes in actual prevalence (Alzheimer's Disease International, 2016). Currently, 9.9 million people are newly diagnosed with dementia worldwide annually, which

equates to one new case every 3.2 seconds (Alzheimer's Disease International, 2016). This has increased by 30% from the figure specified in a previous report in 2012 which estimated a new case every 4.2 seconds (Alzheimer's Disease International, 2012). The impact of the increasing rates is associated with huge economic costs and, in the UK, the costs are estimated to surpass those of cancer, heart disease and stroke combined (NHS England, 2017). Consequently, it has become a key priority in England to improve access to diagnosis, improve the GP's role, provide better care after diagnosis and more effective training for NHS staff about dementia (NHS England, 2017). The progress of diagnosis rates is being monitored by NHS England (2017) to measure the success of local arrangements designed to increase access to dementia diagnosis.

In relation to YOD this picture is further complicated by the unrecorded cases of the disease, which has been estimated to be three times higher for people of working age (Care Quality Commission, 2013) compared to LOD. Together with the stigma and difficulties they face in accessing support, this constitutes a difficult landscape for people with YOD and their families. The next section provides an overview of health and social care provision followed by the lived experience of YOD.

Overview of Health and Social Care

UK policy over the last decade has focused on improving dementia care and services, starting with the first National Dementia Strategy (Department of Health, 2009). It aimed to improve the quality of life for PwD and carers by setting three objectives: to raise awareness of dementia and reduce stigma; to increase diagnosis; and to develop services. The Prime Minister's Challenge (Department of

Health, 2012) aimed to improve dementia care and services, develop dementia-friendly communities, and increase dementia research by 2015. In response, Public Health England (2014) and Alzheimer's Society launched "Dementia Friends" with the campaign to increase overall awareness of dementia. A commitment to dementia continued with 'The Challenge on Dementia 2020' (Department of Health, 2015) and the implementation plan (Department of Health, 2016). The NHS Long Term Plan continued this commitment but included it as part of their "healthy ageing" agenda. Meanwhile, the NHS Implementation Plan (NHS England, 2019) failed to mention dementia specifically. Sadly, this indicates that dementia may now receive less attention than it has done during the past decade. Grouping dementia with healthy ageing demonstrates how YOD can get lost among the dementia services, adding to the difficulties that people encounter reaching a diagnosis of YOD.

Lived Experience of Young Onset Dementia

Due to dementia occurring predominantly in older age, it is often represented as a disease of old age, however the picture of dementia is wider than age related with many types and presentations, including people of younger ages. Although less people under 65 years old experience dementia, it is naive to exclude younger people. The assumption of dementia only affecting older people, amplifies the shock and difficulties that younger people experience in accessing help and support when they have dementia. Receiving a dementia diagnosis as a young person can be devastating, as expectations of life leading into older age with retirement plans are suddenly impacted. This is specific to being in the midst of adult life, often with dependent children and mortgages, and the expectation to continue working, resulting in far-reaching financial implications as well as shock. People experience a

disconnection from society and it is not uncommon for people with YOD to become isolated as they withdraw, due to finding it difficult to function as expected, while they also commonly describe feeling too ashamed to explain their difficulties (Johannessen et al., 2018; Pratchett, 2008a). A '*process of becoming invisible'* (Sterin, 2002, p. 8.) occurs as the label of dementia transforms their roles and relationships within their family and community (Sterin, 2002).

The invisible diagnosis sees key roles that have given meaning to the person disappear and networks withdraw, leaving physically fit and able younger people disempowered to venture outside their home or take the everyday risks that make life worth living (Social Care Institute for Excellence, 2020). The impact that is felt across the person's life, and that of their family, is significant as a result of the stigma associated with dementia that leads to exclusion and isolation. This experience is reflected in the belief that including someone with dementia in research would cause them distress (Keady, 2017a), and has resulted in people with YOD often being excluded and a heavy reliance on carer participation to try to understand the PwD's experience. The persistence of this view continues to alienate PwD from participating, and restricts the impact of research, whilst allowing the stigma to continue.

Approximately two thirds of people with dementia live in the community, with most of these living in their own homes (Keady 2017b). However, Werner et al. (2009) found a significant number of people residing in care homes had YOD, reflecting the challenges of YOD faced by the person and their family. Although this may be

connected to the higher prevalence of behavioural changes that often occur with the types of dementia that younger people tend to experience (Cook et al., 2020; van Vliet et al., 2010b), it provides clear evidence of the need to shed more light on the impact of YOD on the family unit, in order to support and enable them to maximise living well with dementia and prevent the phenomenon of becoming invisible (Sterin, 2002) and separated from society. The importance of including PwD in research and allowing their voices to be heard cannot be underestimated and was fundamental to the researcher when she commenced this journey, as discussed below.

People with Young Onset Dementia as Research Participants

Kitwood (1997) challenged attitudes and beliefs about dementia by placing emphasis on identifying the person as opposed to the dementia, which informed the movement towards person-centered work, such as that by Brooker (2004) and NICE guidance (National Institute for Health and Care Excellence, 2016) identifying person-centered care as best practice. Person-centered care played a significant role in expanding the possibilities for supporting PwD to be involved in research and, together with the Mental Capacity Act (2005, amended 2019), provides a clear framework with which to work. There are extra considerations to take into account when designing research for participants with dementia including additional time, tools and scales being made available in accessible formats, additional resources, and funding (Morbey et al., 2019). However, having dementia should not imply that the person lacks capacity to consent (Higgins, 2013).

The six ‘core principles for involving people with dementia in research’ (Scottish Dementia Working Group, 2013) identifies six areas for researchers to concentrate on and draws attention to the fact that PwD experience dementia all day and every day, but do not often get the opportunity to answer research questions or advise on the best ways to involve them in research. This is an area that the researcher was committed to holding as a focus throughout the study and the following section draws on my own experience that led me to consider this as a fundamental element of YOD research.

Research Aims

This study developed from the researcher’s background of working with PwD and their families and seeing them face challenges during an extended wait for a diagnosis. From the outset it was decided that the person with YOD would be involved in the research with their family unit. The fundamental aim was to give PwD a voice in this study in order to respect their personhood (Kitwood,1997) and gain a deeper understanding of the experience of dementia to inform future services about the specific needs of the family unit when one member has YOD. More specifically, the objectives were to: explore the areas of impact of a YOD diagnosis for the person and their family; describe the changes that occur in family relationships and dynamics; identify coping strategies used by families to deal with a diagnosis of YOD; and describe the sources of help and support used after diagnosis. Keady (2017b) emphasised the need for researchers to adapt the way they work in order to facilitate the participation of PwD in research. This study sets out to provide an insight into the lived experience of YOD and the impact on the person and their

family. Strategies applied to support the person with YOD to participate in this study are explained in the Methodology section in Chapter 3.

Structure of the Thesis

Having explained my interest in YOD and the impact for the person and their family in Chapter One, a review of the current literature will be presented in Chapter Two. This commences by reviewing the largest current studies on YOD and then moves on to examining the remaining literature according to the methodology used, including quantitative, qualitative and mixed-methods studies. Following this, the remaining part of this chapter sets out the key areas identified within the literature to inform the research study. Chapter Three builds on this by setting out the design of my research questions and the methodology used.

Chapter Four presents the key research findings that emerged from the data, which are set out under three sections relating to the over-arching themes of: The Uncertain World; The Changing World; and The Shrinking World. Chapter Five presents a model that developed from the findings and identified the three themes as stages of impact that families experience. The model shows how families move between the stages emphasising an opportunity to change services in order to maintain families in the Changing World stage during which they can adapt and adjust to live well with dementia. Lastly, in Chapter Six I review my primary findings addressing the research questions, and discuss how this relates to previous research. This is followed with the limitations and problems that arose in the study identifying the implications and recommendations for practice, finally closing with my autobiographical reflections.

Chapter 2: Literature Review

This chapter presents a review of the current literature available relating to YOD, and the experience of it and impact for the family. The review will ascertain gaps in current literature and inform the development of research questions. Starting with an overview of relevant policies in a health and social care context, it moves on to summarise the themes within the literature, thereby setting the scene for the reader. It finishes with a review of the literature according to the methodology used, highlighting gaps to inform the development of research questions and study design.

Search Strategy

A narrative review of the literature was conducted using date limiters, 2009 to 2021, to identify available literature and explore areas relating to YOD, and its impact on the person and their family, including their experiences of living with YOD. The review identified the literature available in order to provide an overview of the current relevant research, offer background information about the study, and to support the study design.

The literature review was conducted by searching sources of literature through EBSCOhost Research Databases, including, CINAHL Complete; E-journals; MEDLINE with full text; PsycARTICLES; and PsycINFO. Google Scholar and literature accessible to the researcher in her current clinical role was included to ensure that relevant literature was captured. Exclusion criteria were applied to all literature and where relevant grey literature was included.

Various combinations of terms were applied to the search using the following keywords: Dementia, young onset, carer, experience, family, and impact (see literature search table - Figure 1). Manual searches and snowballing from reference lists of relevant literature were also undertaken. International studies were included where available in English so as to ensure the inclusion of relevant literature.

Table 2.1: Literature Search Table

Search	**Term**	**Results**	**Total**
Search 1	“young onset dementia” OR “Early onset dementia	1,703	
Search 2	famil* OR children	5,721,199	
Search 3	experienc* OR impact* OR perception* OR view*	7,550,137	
Search 4	Search 1 + 2 + 3 Search with AND	189	189
Search 5	Search 4 with date limiters 2009>	141	141
Search 6	Search 5 with Peer Reviewed	72	72
Following Review	72 reviewed, 32 discarded = 40 included	72	40
Final Total	(Summary in Literature Table - Appendix 1)	40	40

A total of 72 research papers were identified and extracted from searching the databases with an additional 12 found from other sources, as described above. The papers were then reviewed in detail, applying exclusion criteria that removed

research solely related to LOD and research conducted before 2009 unless it was specifically significant or relevant to the study. This resulted in 40 primary and secondary papers relating to the impact of YOD, using a range of methodologies, comprising 28 qualitative, 10 quantitative, and two mixed method studies, as shown in the literature table (Appendix 1). The papers were critically appraised using CASP checklists (Critical Appraisal Skills Programme, 2017) ensuring the consistency of the review process. Grey literature was used in addition to the 40 research papers.

Summary of Literature

Defining Young Onset Dementia

YOD is the onset of dementia before the age of 65 years old (Alzheimer's Society, 2021a ; Young Dementia UK, 2020a). Younger people experience the same types of dementia; however, some types are more prevalent (NHS England, 2015) than they are in the older population and the table below shows how the most common types vary between YOD and the general population. There are many different types of dementia, such as AD, FTD and VD, but there are also rarer types of dementia which occur more often in YOD, resulting from neurodegenerative disease such as AD, FTD and dementia with Lewy bodies (Kelly et al., 2008, cited in Hayo, 2015). People with YOD are therefore more likely to present with rarer types of dementia, as reflected in the table below. AD and VD is more common in people with LOD whereas FTD is more common in people with YOD. There are mixed findings regarding alcohol-related dementia (Alzheimer's Society, 2021a), and Alzheimer's Research UK (2018) claims that over 57% of people with YOD have had a previous hospital admission related to alcohol.

The literature is not definitive, which explains why the table shows percentile ranges as opposed to a single figure.

Table 2.2: Types of Dementia

YOD	**General Population with Dementia**
AD - 30%	AD - 50-75%
VD - 15%	VD - 20-30%
Dementia with Lewy bodies 4%	Dementia with Lewy bodies 10-15%
FTD - 13%	FTD - 5%
Alcohol related dementia - 12%	Alcohol related dementia – Unable to identify rate
Other - 25%	Other 25%

(National Institute for Health Research, 2017; Alzheimer's Association, 2017)

Presentation

The presentation of YOD is challenging due to its wide range of features and possible symptoms, and is further complicated by the fact that the symptoms and features can easily be attributed to common age and life-stage related issues (Ahmed et al., 2016; Robinson et al., 2015) including stress, work-related issues or depression (Hayo, 2015). Symptoms are broad including changes in behaviour, cognition, and neurological and psychological function, leading to frequent misdiagnosis (Ahmed et al., 2016; Robinson et al., 2015; Werner et al., 2009).

Diagnosis

YOD is not a typical disease for younger people so symptoms are often thought to be caused by stress, depression or anxiety connected to age and life-stage. These assumptions can cause delays in diagnosis, leading to dementia being explored much later in the presentation than would be the case for an older person presenting with the same symptoms (Flynn & Mulcahy, 2013; Lockeridge and Simpson, 2013). Further complicating the picture, metabolic causes like thyroid disease and diabetes are more common among younger people (Kelley et al., 2008, cited in Hayo, 2015), adding to the likelihood of diagnostic overshadowing. It is particularly difficult to diagnose when there is a history of psychiatric disorder (Werner et al., 2009). Van Vliet et al. (2011) found that over a third of participants received a psychological diagnosis before a dementia diagnosis.

Although early identification and referral is recognised as a key area (Department of Health, 2015; Armari et al., 2012), the literature identifies that lengthy and delayed diagnosis is common (Ahmed et al., 2016; Baptista et al., 2016). Research found long time lapses between the first symptom and diagnosis (Werner et al., 2009), in some cases up to 10 years (Armari et al., 2012), with other studies reporting an average of 2 to 3 years (Draper et al., 2016; Wawrziczny, 2016; Hayo, 2015), while van Vliet (2011) identified an average time of 4.6 years.

Younger people take longer to seek consultation from the time when they experience their first symptom than LOD (Hoppe, 2019; Draper et al., 2016) which is likely to be connected with the assumption that symptoms are related to life stage stressors

rather than dementia due to their age. Denial plays a role in the delay in seeking help, and sometimes unconsciously, changes occur within the family to compensate for symptoms, such as other family members providing increased support to enable the person to cope (Robinson et al., 2015). Although diagnosis takes longer than for LOD, Draper et al. (2016) found that it was quicker to reach a final diagnosis with a specific type of dementia than in the older population (Draper et al., 2016).

Difficulties in Diagnosis

A presenting difficulty with diagnosis is that families sometimes delay seeking help (Hoppe, 2019), often seen further along the dementia journey than older people. However, LoBue et al. (2016) identified as a causal factor the fact that changes may be present before they are classifiable as a clinical manifestation, resulting in dementia being present for some years before it is clinically recognisable. People can experience high anxiety when changes occur without explanation (Roach et al., 2014) and Baptista et al. (2016) found that these presenting needs are unmet, resulting in a difficult time for the person and the family, being described as a negative experience (van Vliet et al., 2010a; van Vliet et al., 2010b).

Hayo (2015) pointed out that not all people with YOD present with memory issues as the predominant symptom, which makes it more difficult for YOD to be recognised. Generally, there is a higher prevalence of behavioural issues, mostly connected to the types of dementia that are more common in YOD, such as FTD, which typically presents with behavioural issues (van Vliet et al., 2010b). This situation is reflected in the UK by Cook et al.'s (2020) audit confirming that people with YOD are more

likely to receive a diagnosis of VD, FTD, alcohol-related dementia and ‘other dementia’ than members of the older population. Furthermore, this audit found that only 23% of patients under 65 years old were diagnosed with dementia, compared to 67% of patients over 65 (Cook et al., 2020). Whilst it is not possible to make a direct comparison, this gives an insight into the limited specialist dementia services available and reflects the different types of dementia that younger people experience compared with the older population. The literature clearly points to people with YOD and their families requiring specific services to support them.

Dementia Services

Dementia services are provided by statutory and non-statutory bodies like the Alzheimer’s Society in the UK. In 2015 the government set a target to improve diagnosis, care and increase participation in research by 2020 (Department of Health, 2015). However, Cook et al.’s (2020) audit of memory services showed that just 53% of services had an identified lead for YOD, confirming the literature findings that services for YOD are patchy, generally lacking, and inappropriate for younger people (Kobiske et al., 2019; Cations et al., 2017; Millenaar et al., 2017a).

Whilst non-statutory services like the Alzheimer’s Society provide YOD services, overall the picture of YOD services in the UK is characterised by gaps between age-related needs and specialist dementia needs, and barriers to access. This is a fundamental factor in the delays in reaching diagnosis, leading to misdiagnosis (Draper et al., 2016; Flynn & Mulcahy, 2013; Werner et al., 2009), and often makes the screening process distressing (Robinson et al., 2015). In addition to this, Roach

et al. (2016) found that professionals are generally reluctant to investigate dementia because of a person's age.

Many areas offer diagnostic and treatment services for people with YOD within mainstream services aimed at older people. However, services for the older population have been found to lack the family focus required (Hayo, 2015; Nichols et al., 2013) to support people with YOD who often have a young family with dependents. This life stage often entails financial commitments relating to employment, mortgages and family costs (Roach et al., 2016; van Vliet et al., 2010b) that older people generally no longer have. These specific support issues related to the younger person with dementia leaves people feeling disconnected from services (Nichols et al., 2013).

Specific YOD services are sporadic in their availability (van Vliet et al., 2011; van Vliet et al., 2010b; Werner et al., 2009), leaving deficits in services for people with YOD and their families (van Vliet et al., 2010a). Services geared towards older people have been reported to be inappropriate (Werner et al., 2009; Lockeridge & Simpson, 2013), and those accessing generic mental health services have found that, although they could support people of their age group, professionals often lacked knowledge and experience of YOD, which impacts on diagnosis and treatment (Werner et al., 2009). Therefore, it is not surprising that Werner et al. (2009) identified that less than 40% of people with YOD use services when there is a *"disconnect between disease and services available"* (Flynn & Mulcahy, 2013, p. 600).

Werner et al. (2009) found a significant number of people with YOD receiving services in residential and nursing care homes, which could be connected to the types of dementia that younger people are more likely to have, often involving behavioural changes (Cook et al., 2020; van Vliet et al., 2010b). It is believed that this reflects the deficit in dedicated YOD services to support the person and their family to remain living at home in the community. People with YOD often find barriers to access services required, unable to access them until a diagnosis is made (van Vliet et al., 2010b). It is known that early diagnosis enables people to take control and plan ahead (Stokes et al., 2014). When the right support is provided, people develop positive strategies (Hayo, 2015) and positive strategies require adequate information to be available, something which is often missing in the management of YOD. Furthermore Lockeridge and Simpson (2013) found that carers felt that although the decisions were made by services, they were left to explain those decisions to the person with dementia, sometimes resulting in conflict.

The literature highlighted a gap in services for children with a parent with YOD, despite the fact that early diagnosis and disclosure is believed to be preferable (Nichols et al., 2013; Allen et al., 2009). Extra help at home, respite and befriending services (Svanberg et al., 2010), along with having access to someone with knowledge of YOD (Millenaar et al, 2014) were highlighted as being helpful. Nichols et al.'s (2013) study found a preference for online support forums for children living with someone with dementia.

Management of Young Onset Dementia

The timing of information is crucial for developing positive management plans, taking into account individual preferences (Stokes et al., 2014). Flynn and Mulcahy (2013) found that people want more information at the point of diagnosis about the progression of the disease and what to expect, while Stokes et al. (2014) reported that people generally want two types of information: on the manifestations of dementia, and on practical support, both of which would enable them to prepare for the future.

Services need to provide continuity in care throughout the YOD journey, which includes carers receiving *confirmation* of the choices they have made for the person with YOD (Bakker et al., 2010). By recognising the burden that making decisions places on family members, professionals can ease the difficulties by reassuring carers and acknowledging the validity of those decisions. An example of this would be a professional reminding the family carer that looking after themselves enables them to look after the person with YOD more effectively (Bakker et al., 2010).

Stigma

The stigma attached to dementia is a barrier to seeking help and can mean that the person with YOD might hide their difficulties, with over a third reported to use denial when the symptoms affected their daily lives (van Vliet et al., 2011). Furthermore, if family and friends lack understanding of the condition, that makes it more difficult to seek medical help (van Vliet et al., 2011). Stigma not only serves to restrict the extent to which YOD is spoken about, but also impacts on the children in the family,

with feelings of loss, shame and embarrassment (Hayo, 2015; Nichols et al., 2013) reported as leading to social isolation (Hayo, 2015; Johannessen et al., 2015).

Further evidence of the stigma was shown in Lockeridge and Simpson's (2013) study in which carers explained that they *'Clutched at straws'* in the hope of a diagnosis that was not dementia, and on receiving a diagnosis of dementia they described feeling like they had been *'hit by a ten ton truck'* (Lockeridge and Simpson, 2013, p. 641). Often spouses spend a long time searching for alternative causes for the symptoms because they find the idea of dementia difficult to accept and, when the diagnosis is finally reached, they react with shock (Ducharme et al., 2013).

Caregiving

Taking on the role of caregiver to the family member with YOD changes their relationship, and Werner et al. (2009) identified that carers' emotional well-being can suffer as a result of the physical and emotional burden of caring for someone with YOD. Financial obligations often add to the burden within the family, as it is likely that the family carer will be of an age where they need to work, despite having concerns about the PwD's safety when they are at home alone (Roach et al., 2016). On the other hand, some carers choose to keep working as a way to alleviate and gain respite from the daily stress of the disease (Wawrziczny, 2016).

There were mixed findings regarding the differences between carers of people with YOD and those with LOD. Although van Vliet et al. (2010a) found no difference in the carer burden between YOD and LOD, Ahmed et al. (2016) found that the burden

was more onerous for carers of people with YOD. Van Vliet et al. (2010a) suggested that the higher prevalence of behavioural problems in people with YOD is responsible for the greater burden. Ahmed et al. (2016) identified a correlation between the PwD having less insight into the disease, and an increased carer burden. Female carers appear to experience higher levels of stress than male carers (van Vliet et al., 2010a) and evidence suggests an overall higher prevalence of depression in all carers of people with YOD (Werner et al., 2009).

Partner and Spouse Carers

Partners and spouses were predominantly represented as family carers within the literature. The literature demonstrates the link between the PwD having unmet needs and the carer's quality of life (Bakker et al., 2014), and the negative attitudes towards and lack of understanding of YOD within social situations, leading to a reduction in social activities (Lockeridge & Simpson, 2013). This shows the partner or spouse's experience is closely linked to the PwD and, as their skills decline, so do the carer's, resulting in a reduced social network and activities (Wawrzicny, 2016)

Families find themselves faced with a sudden loss of earnings at a time when they have mortgages, university fees and other costs associated with a family (Roach et al., 2016). This results in the carer having to keep working, but experiencing high levels of anxiety regarding the safety of the person with YOD at home whilst they are at work (Roach et al., 2016; Roach & Drummond, 2014). Carers describe comforting their partner or spouse with YOD, whilst also having to pick up financial

responsibilities and, in some situations, liaising with the PwD's employer (van Vliet et al., 2011).

Children within the Family

Young carers often experience emotional chaos (Johannessen et al., 2015), describing trauma and feeling very different to their peers. Alongside this, young people report that they miss '*them being a parent'* (Millenaar et al., 2014, p. 2004) as the YOD impacts on their relationship and a process occurs whereby they become a parent to their parent (Johannessen et al., 2015). Furthermore, this study depicted that the parent slipped away from the child and became lost in a 'world' that the child cannot enter. In addition, the balance between childhood and caring for their parent changes (Nicholas et al., 2013). Young people also report that they experience a loss of financial support with the onset of YOD (Allen et al., 2009). Although children reported negative and stressful experiences of caring for a parent with YOD, they also mentioned positive aspects such as feeling closer to their family and deriving satisfaction from being able to care for their parent (Flynn & Mulcahy, 2013; Nichols et al., 2013).

Some young carers experience feelings of shame, resulting in self-isolation (Hutchinson et al., 2016; Svanberg et al., 2010), which can have an adverse impact on their education (Svanberg et al., 2010; Allen et al., 2009). They describe using detachment as a coping mechanism in order to meet their own needs and cope emotionally (Johannessen et al., 2016; Svanberg et al., 2010). The same study

highlighted the importance of social relationships and having people to confide in (Barca et al., 2014).

As the parent's dementia progresses children report feelings of losing their parent and a sense that the parent loses interest in them (Johannessen et al., 2015), leading to a grieving process (Hayo, 2015). Conflict between the parent with dementia and their children is not uncommon (Johannessen et al., 2015; Flynn & Mulcahy, 2013). Furthermore, children experience difficulties in expressing their feelings about the situation for fear of burdening the parent who does not have dementia (Hayo, 2015; Millenaar et al., 2014).

Person with Dementia

PwD do not always disclose their diagnosis immediately to their family and Draper et al. (2016) found that the younger the PwD is, the longer it takes for the family to become aware of the diagnosis. This was supported by Wawrziczny's (2016) study that found the person with YOD may try to hide the changes and avoid talking about it in an attempt to protect their partner.

The PwD's experience changes in relation to their employment, status and role within the family as the YOD progresses. Rabanal et al. (2018) identified that the workplace may be the first place where changes in the PwD are noticed. Diagnosis is a key transition for people with YOD and their families, and Roach & Drummond (2014) and Roach et al. (2016) found that employment usually ceases following

diagnosis, as people with YOD either leave their employment, are sacked or made redundant.

People with YOD generally experience changes in ability, especially with regard to their ability to perform day to day tasks (van Vliet, 2011), which can result in employment ending abruptly (Roach & Drummond, 2014). This results in not only a sudden loss of earnings (Roach et al, 2016) but also a loss of activity. The PwD becomes dependent upon their partner, spouse or other family member financially and a progression towards the carer making decisions occurs, which results in a change in reciprocity within these relationships (Bakker et al., 2010). Dourado et al. (2016) found that people with YOD rate their quality of life as higher than that of their caregivers, reflecting a change in the PwD's level of awareness.

Presenting the key themes from the literature has set the scene for the reader by highlighting the unique difficulties associated with YOD because of the earlier stage of life at which it occurs. The literature will now be reviewed according to the methodology used, before concluding the chapter by identifying the gaps in current literature and developing the research questions for this study.

Overview of Papers by Methodology

The Table of Literature (Appendix 1) provides a summary of papers that were included by methodology, with a brief overview of each study to support the literature review. The literature is presented below in terms of individual studies and

methodology used, ending with an overview of the main themes observed from the literature review.

Evaluation of Literature

Of the 42 research papers identified, 11 focused on three studies, thus demonstrating the paucity of enquiry into YOD. The three studies with multiple papers will be reviewed first followed by the remaining single study papers according to their methodology.

The NeedYD Study

The NeedYD study was the largest study identified among the literature searched. It was a prospective cohort follow-up study conducted in the Netherlands, focusing on people with YOD and their carers who were followed-up every two years and measured on a six monthly basis using qualitative and quantitative data collection tools such as interviews, questionnaires and cognitive tests. This study also published a literature review (van Vliet et al., 2010b) and a research protocol (van Vliet et al., 2010a) supporting the overall validity of the study. Millenaar et al.'s (2016) study was included for the purpose of the literature review as it used baseline data from two cohort studies, one being the NeedYD study. Eight papers from this study (Millenaar et al., 2017a; Millenaar et al., 2017b; Millenaar et al., 2016; Millenaar et al., 2014; Bakker et al., 2014; van Vliet et al., 2012; van Vliet et al., 2011; Bakker et al., 2010;) were included in the literature search. They applied a range of methodologies comprising qualitative (Millenaar et al., 2017a; Millenaar et al., 2014; van Vliet et al., 2011; Bakker et al., 2010), quantitative (Millenaar et al., 2016; Bakker et al., 2014; van Vliet et al., 2012) and a single case study (Bakker et

al., 2010). Although not explicitly stated in the papers, it was observed that the studies followed the themes identified in the initial case study (Bakker et al., 2010), such as lengthy delays in reaching a diagnosis, which was identified in the single case study, a larger qualitative study (van Vliet et al., 2011), and supported in the quantitative study (van Vliet et al., 2012). The theme of difficulties experienced by carers was also reflected across the qualitative papers and was evident in the quantitative studies (Millenaar et al., 2016; Bakker et al., 2014). It was identified that the carer's health-related quality of life is closely linked to the unmet needs of the person with YOD. The application of different methodologies reinforces the findings of this study. The papers are discussed below in date order.

The first paper (Bakker et al., 2010), published in the same year as the protocol (van Vliet et al., 2010b), applied a qualitative single case study to explore the unmet needs of a person with YOD and their carer along with experiences of transitions in care. Overall, it found three themes that can be categorised as: choices, conditions for using care, and involvement in care, illustrating the need for services specifically tailored to YOD. Although the single case study is not generalisable, the validity of its findings is strengthened by the fact that the themes are reflected in the other studies, providing opportunities for triangulation of the findings across the studies. There is an evident overlap in the findings of the other NeedYD studies, particularly those connected to carers across both the qualitative studies (Milleanaar et al., 2014; van Vliet, 2011) and the quantitative study (Bakker et al., 2014). Relationships are emphasised in the findings, implying that the main themes common to the studies are weighted towards the carers, with minimal attention paid to the person with YOD. The overall NeedYD study has a weakness in that it does not capture the firsthand

experience of the person with YOD. Although people with YOD participated in two of the qualitative studies (Bakker, 2014; van Vliet et al., 2012), there is a gap in terms of data directly collected from people with YOD in the qualitative studies, meaning that data on the lived experience of people with YOD are in short supply. The single case study also reflects this gap as the data about the person with YOD's experience were collected from the carer.

The next two papers employed similar research teams with the same lead author (van Vliet et al., 2012; van Vliet et al., 2011), exploring the process and time to reach diagnosis. The earlier paper (van Vliet et al., 2011) applied qualitative methodology, focusing on the carer's view of the period leading up to diagnosis through secondary data analysis, by selecting excerpts from semi-structured interviews relevant to this theme. Seven main areas were identified, namely: changes in the person with YOD, family disruption, misattribution of the symptoms, denial, lack of confirmation from a social context, GPs' lack of responsiveness, and wrong diagnosis. The research team used a framework to complete the data analysis, applying a rigorous process of verification of the themes and codes, although the study had missing data together with incorrect diagnosis/co-morbid diagnosis, which were likely limitations of the research findings.

The latter paper (van Vliet et al., 2012), a quantitative comparative study, focused on the time taken to diagnose YOD compared to LOD. Differences were identified between the samples and dementia types, which could have skewed the findings. Diagnosing FTD took longer regardless of age, which may have caused the findings to be misleading, as it is more common in YOD than LOD. The findings could have been related to dementia type opposed the age related. They showed that it took an

average of 1.6 years longer to diagnose YOD than LOD, but surprisingly the living situation of the person or a family history of dementia did not predict the time taken to diagnose.

Bakker et al. (2014) conducted a quantitative cross-sectional study to identify unmet needs and assess quality of life. Inclusion and exclusion criteria were applied to manage bias. However, this inadvertently excluded rarer complex types of dementia that often present in YOD (Dementia UK, 2020), such as PCA, thus limiting their generalisability. They recruited from the health service which is likely to have caused people earlier in their dementia journey or people who prefer not to use statutory agencies to be under-represented. The exclusion criteria applied is also likely to have excluded types of dementia most often presenting with a behavioural element. People with these types of dementia and their carers often report higher levels of both physical and psychological distress (Dementia UK, 2020). Therefore, this study is representative of younger people with some types of dementia, but not people with YOD per se. However, this study adds to the literature by offering greater insight into the connection between YOD and quality of life. It was found that people with YOD reported a higher quality of life than their carer, reflecting a change in awareness for the person with YOD. Interestingly, there was a correlation between the unmet needs of the person with YOD and poorer general health, not only for the person with YOD, but also for the carer. These findings add to the overall picture of YOD and the impact on their carers by capturing how dementia impacts on physical health and mental health, along with the social restrictions that families experience at a time when they need increased support.

Using qualitative methods, Millenaar et al. (2014) collected children's experiences of having a parent with YOD through semi-structured interviews. The children, aged between 15 and 27 years, discussed the following three themes: *impact of dementia on daily living; coping with dementia; and the need for care and support*. The researchers acknowledged they may have missed children experiencing the highest levels of stress due to the high refusal rate. Nonetheless, the findings make a useful contribution to the available literature.

A qualitative method study (Millennar et al., 2016) was conducted to identify the determinants of quality of life for people with AD and FTD, recruited from the NeedYD study and the Nordic YOD-study. It found depression and unmet needs were related to a lower quality of life, although the severity of dementia did not have any effect on quality of life. These findings are significant to help understand factors impacting on quality of life.

Building on this study, Millenaar et al. (2017a) used qualitative content analysis to explore high and low unmet needs of carers for people with YOD. 18 interviews revealed that the number of services being used did not indicate unmet needs; however, there is a correlation between the availability of social support and unmet needs. Similarly to the above study, it was found that the PwD's awareness of the diagnosis had a positive impact on arranging care. It should be noted that participants in this study were all spouses, so it did not capture the views of other family carers.

Whilst the size of the NeedYD study and number of papers give gravitas to the study, it is important to take into account the possibility of bias and the impact of using the same sample pool recruited in the same areas. The locality of the study presents some generalisability issues as the services and systems that the sample accessed are specific to the Netherlands.

A Longitudinal Study

The next largest study was a longitudinal study carried out over two years that explored children's experiences of having a parent with YOD through a qualitative follow-up study producing three papers. The first paper presented findings from the first interview (Johannessen et al., 2015) while the second reported the findings of another interview conducted during the study (Johannessen et al., 2016), and the final one was written after five follow-up interviews (Johannessen et al, 2018). Being qualitative, the sample was small compared with the NeedYD study, but it is significant in terms of the experience captured over a period of time. This study explored the phenomena through open-ended questions during all the phases, although questions were added at follow-up interviews in response to earlier interviews. The research team analysed the data for metaphors to capture the experience of having a parent with YOD. This study demonstrated the changes that occur within the family after diagnosis using the unique method of analysing metaphors. The first phase of data analysis highlighted the following themes which demonstrated the impact YOD has on the family unit: *"My parent is sliding away"; Emotional chaos; Becoming a parent to my parent; Provision of public services: a battle* (Johannessen et al., 2015). The second interview, a year later, showed that a process of detachment had occurred in order to cope with the impact of having a

parent with YOD. This identified *Detachment* as the main theme, with sub-themes of *Moving apart; Greater personal space; Calmer emotional reactions;* and *Resilience* (Johannessen et al., 2016). The latest paper (Johannessen et al., 2018) identified changes in identity over time with increasing isolation and difficulties maintaining previous roles and habits. Being conducted over a substantial period of time using qualitative approaches it enabled the experience of having a parent with YOD to be captured in a way that quantitative approaches could not, showing how the children adapted by developing strategies that involved detaching themselves from the parent with YOD. Although this study was Norwegian, the authors argue that the findings are transferable.

A Family Follow-up Study

Another key qualitative study produced two papers (Roach et al., 2016; Roach & Drummond, 2014), applying a follow-up interview approach which provided a longer perspective as opposed to a snapshot view, thereby strengthening the validity of the findings. This study interviewed the families as a whole unit. The initial interview (Roach and Drummond, 2014) explored the transition that occurs within the family unit when the person with YOD leaves employment/voluntary work and, in doing so, identified the following four transition themes: *diagnosis, finances, relationships* and *meaningful activity*. The later study (Roach et al., 2016) conducted follow-up interviews focusing on the post-diagnosis process of adjustment for the family using sub-themes taken from the initial interviews. They found that meaningful activity for the person with YOD positively influenced their ability to cope with transitions along the dementia pathway, whilst providing a continuing biography and sense of self. Both studies had some limitations, the main one being that the participants with YOD

were all male, thus making it gender specific. Recruitment was from NHS services, missing those using voluntary services. However, these papers are significant, being directly relevant to the YOD family unit.

Remaining Literature

In addition to these three larger studies, the literature review identified a further 29 papers. Four (Roach et al., 2016; Roach & Drummond, 2014; Roach et al., 2014; Roach et al., 2012), had a specific focus on the experience of people with YOD and their families, with all of them using a qualitative methodology. However, one study (Roach et al., 20014) stood out due to its adoption of a narrative approach to create a biography for the families. This creative approach captured how families make storylines about the YOD that can agree, collude, conflict, protect and be fabricated. Capturing how families create storylines shows how they cope with the impact of dementia in a different way to the other studies that use similar data collection tools. Two of the remaining three papers from the same study conducted follow-up interviews using the same sample of nine families. The findings highlighted diagnosis, finances, relationships and meaningful activity as key themes. Limitations were noted, primarily the fact that the people with YOD were all male and family members were female, which is likely to have led to some gender bias. All the families, with one exception, consisted of the person with YOD and their spouse, which may have affected the findings. However, a family unit composed of the person and their spouse appears to be common within YOD research, indicating that

it is representative of the population, but further research regarding the family unit and their participation in research could be warranted.

The family focus of the aforementioned four papers place them at the top of the hierarchy of available research on the experience of YOD families. They represent the research studies most closely aligned with my research question, demonstrating gaps in research and the importance of the current research study. The gaps in research on this subject reflects the contemporary nature of the problem along with the stigma attached to YOD, thereby emphasising the importance of conducting further research into the impact of YOD for families.

Three papers (Gelman & Rhames, 2020; Aslett et al., 2017; Sikes & Hall, 2017) that could have been classed as having a family focus, excluded the person with dementia, so they have been categorised as family carer focused instead. The remaining 16 papers were a mix of single studies using two mixed methods, 11 quantitative and 10 qualitative studies which are reviewed below according to their methodology.

Mixed Methods

Of the two mixed method studies, the largest one (Cations et al., 2017), which had 86 participants, conducted quantitative interviews and qualitative focus groups, and discovered that people with YOD often find services inaccessible due to age barriers and financial constraints. The strength of this study was that it applied the quantitative results to inform the qualitative data collection, although it should be

noted that this study had a small sample and lacked diversity. Nonetheless, the findings are relevant to service design.

The second mixed method study (Svanberg et al., 2010), which had 12 participants aged 11-18 years old, aimed to gain insight into children's experience of having a parent with YOD and the *impact of* diagnosis. Using a grounded theory approach that took the form of in-depth interviews supplemented by quantitative measures on mood, carer burden and resilience, supported analysis using data triangulation. The findings were grouped under four headings: discovering dementia, developing a new relationship, learning to live with it, and going through it together. A pilot study refined the qualitative semi-structured interview tool and undertook third party credibility checks of the data analysis and verification with the participants, which added to its rigour and validity. These findings contribute to the literature by identifying the impact of YOD on children.

Quantitative Studies

11 quantitative studies were included, three of which have been reviewed as part of the NeedYD study. This section will review the remaining eight. There were some similarities in the methodologies used, with clinical assessments, questionnaires and scales applied as measurement tools, all of which are appropriate to quantitative research. Each study applied a mix of data collection methods, which will be discussed below in more detail, although questionnaires were commonly used (Dourado et al., 2016; Armari et al., 2012). Two of these combined scales within the questionnaires, and one applied scales separately from the questionnaire (Dourado et al., 2016).

Most appeared to used a 22-item version of the Zarit Burden Interview (Zarit et al., 1980), a self-report scale designed to measure the perceived carer burden. It was not possible to compare on these due to a lack of detail on specific findings and variations within the scale itself. Although the instrument has been criticised for its unclear factor structure (Branger et al., 2014; Knight et al., 2000), it has the advantage of enabling analysis and comparison of results (Bedard et al., 2011) and remains popular in dementia research (American Psychological Association, 2017; Branger et al., 2014). A different approach was applied by Hvidsten et al. (2019) who assessed the carer burden using the Relatives' Stress Scale combined with the Montgomery-Asberg Depression Rating Scale, whilst Kobiske et al. (2019) used three scales including the Perceived Stress Scale.

Sample sizes varied with the largest study involving 678 participants and the remainder between 44 and 104 participants. The largest study (LoBue et al., 2016) recruited from a data set and asked participants three standard questions with a three-way choice rating scale. Although this can be seen as a simplistic approach to data collection, it enabled a larger sample to be managed, and met the aim of exploring the association between brain injury and FTD. Two studies recruited participants from clinical services, one of which (Dourado et al., 2016) applied a consecutive approach to outpatients. However Hvidsten et al.'s (2019) paper was unclear about whether the assessments were in addition to existing clinic appointments. Draper et al. (2016) recruited from a broad spectrum of services, including health services and the voluntary sector. Kobiske et al. (2019) used flyers with a link to an online platform to recruit participants through a variety of dementia

related services, whilst Armari et al. (2012) held a public symposium, publicised via flyers and information, to clinic practices, universities and the voluntary sector. Following this general review of the quantitative studies, each study will now be individually reviewed below.

Armari et al. (2012) used a questionnaire to collect data on demographics, dementia pathway, needs, services and areas for improvement from people with YOD and caregivers. This highlighted a difference between the perceived needs of the person with dementia and the carers. The participants were female dominated and the composition of the carers may have affected the findings as they included health professionals.

An Australian study conducted by Draper et al. (2016), recruited participants from an epidemiological study via health professionals who completed an initial survey and passed on information to their patients who then self-referred. Clear inclusion criteria applied so that only people with YOD and their carers were included. Data relied on participants' memories which were not always accurate and there was also limited GP information.

Dourado et al. (2016) conducted a comparative study exploring potential differences between YOD and LOD regarding whether functional status is a predictor of awareness. Quantitative data collected from a diagnostic workup, and scans and detailed information from the carers were used from a larger sample than in the other studies, with 207 participants. Although there was some disproportion in the sample sizes with only 52 people having YOD, which may have affected the findings. It is

important to consider the implications, given that the study was conducted in Brazil and all the participants were recruited from an Alzheimer's Disease outpatient service.

A two-year prospective cohort study (Hvidsten et al., 2019) recruited dyads of PwD and their families. The researchers trained clinic staff to administer the scales and questionnaires, most of which were part of the standard assessments. There was some variation between carers who lived with the PwD and visiting family carers which with the gender differences in the follow-up may have impacted on the results.

Kobiske et al. (2019) applied a cross-sectional, correlational design that measured the effect of resourcefulness on pre-death grief and the perceived stress experienced by carers. An online survey was used and participants received a gift voucher on completion. Three instruments were applied, all of which were existing validated measures. The convenience sampling and need for participants to be computer literate may have caused some bias. In addition being a survey only provided a snapshot at the moment it was completed.

LoBue et al.'s (2016) study researched the link between traumatic brain injury and young onset FTD using data collected by asking participants three standard questions at an initial visit and then a year later, or earlier if they required treatment, to establish if they had a traumatic brain injury, and a subsequent neurological deficit. There were wide variations among the participants in terms of time between the injury and the study, and falls were not factored in, making it impossible to tell if

the traumatic brain injury had occurred after the onset of the dementia when the risk of falls is higher.

Qualitative Studies

Of the 28 qualitative studies, nine have been reviewed as part of the larger studies above, so this section reviews the remaining 17 qualitative studies. In keeping with qualitative methodology they all applied a semi-structured approach to the data collection. Eight studies collected data through semi-structured interviews and one (Nichols et al., 2013) used semi-structured focus groups. One study combined *co-construction of family biography* (Roach et al., 2014) with semi-structured interviews to collect data, thus providing the content for narrative analysis. This study presented the findings from a unique stance of *storylines* which will be explored further below.

Expected participant numbers were smaller than those of the quantitative studies, thus enabling a focus on lived experience. Sample sizes varied from 41 (Hoppe, 2019; Hoppe, 2018) to 5 (Aslett et al., 2017; Roach et al., 2012), with the largest including PwD and family members, while the smallest recruited children of a parent with YOD.

Two papers failed to detail the ethics approval process (Lockeridge & Simpson, 2013; Nichols et al., 2013) and a further two did not provide details of the consent processes (Lockeridge & Simpson, 2013; Roach et al., 2012). However, the remaining seven papers explain both the ethical and consent processes followed.

All the papers detailed the data analysis process, with all but one adopting thematic analysis, although this one used a similar approach, namely narrative analysis. Seven papers identified specific thematic analysis frameworks, indicating a good level of rigour in the analytical process.

Allen et al. (2009) collected data via semi-structured interviews from 12 young people aged 13 to 24 years old with a father with YOD. Participants consisted of slightly more females than males from seven families, and some participants were siblings. There was wide variation in the life stages of the participants, ranging from preadolescent to young adult, which is likely to have affected the findings.

A study by Aslett et al. (2017) recruited five participants, both males and females, aged 23 to 36 years old, who had a parent with YOD. The small sample size lent itself to in-depth interviews, although the findings should be treated with caution given the sample size. The research team recognised the rural locality of the study as a limitation and the participants were dependent on the parent sharing information about the study with them. Given distress varies at points along the dementia journey, a longitudinal approach may be helpful in terms of providing a more complete picture of the lived experience.

Three qualitative studies applied grounded theory approach with Van Vliet et al.'s (2011) previously reviewed as part of the NeedYD study, and the remaining two being Barca et al. (2014) and Harris & Keady, (2009). The earlier one (Harris & Keady, 2009) collected data via interviews from two countries focused on selfhood and identity of the PwD and carers. The approach on interviewing PwD in the US

and carers in the UK may have affected the findings, however this is acknowledged by the authors. It is unclear as to the gender mix of carers in the UK participants, however people with YOD who participated in the US represented a balanced gender and age range, being 41 to 63 years old at diagnosis. The later study, Barca et al. (2014), was a Norwegian study that used semi-structured interviews to collect data from participants recruited from a variety of services. The response rate was also unknown and the participants were all female except two family members who were sons. The female dominant composition of the participants may have affected the findings.

Ducharme et al. (2013) interviewed 12 spouse carers recruited from memory clinics in Canada. Selection criteria was applied for consistency and recruitment was sequential, with data collected through semi-structured interviews. The majority of PwD that they cared for had dementia type AD, which may have impacted on the findings. However, it is also representative of the commonality of the types of dementia.

Descriptive qualitative methodology was used by Flynn and Mulcahy (2013) to collect data from semi-structured interviews to research the impact of YOD on family carers. A small convenience sample was used, and the findings were similar to those of other studies regarding the difficulties in obtaining a diagnosis, the lack of support and the change in relationships. They applied a care-giver burden model which may have restricted the findings.

Gelman & Rhames (2020) used a small sample comprising four families living in one geographical area, which may have restricted the findings. However, the study incorporated children aged 13 to 20 years old, thus capturing data not included in other studies. All the parents with YOD were fathers, while the caring parents were all mothers. The team acknowledged that their study missed divorced or separated families. However, overall the findings make a positive contribution to the literature, highlighting the impact on the caring parent and the role reversal in the case of children from families with a parent with YOD.

Two studies by Hoppe (2019; 2018) drew on the same data source collected from PwD and family members but applied different research questions. It is not clear if this was the original aim, or if the latter paper was developed after the completion of the initial study. However, the studies used data produced from interviews with PwD and family members, either with a single participant or two or more people together, conducted in a variety of environments. Each study focuses on a different element of the data and both add to the pool of literature by providing insight into the role of empathy in supporting carers and the uncertainty that they face during the pre-diagnostic stage. Limitations included recruitment from the Alzheimer's Society in the Netherlands may have overlooked other members of the population, and its retrospective nature which relied on participants' memories.

12 young people aged 8 to 24 years who had a parent with YOD took part in semi-structured interviews in Hutchinson et al.'s (2016) study, which used a purposive sample of participants to explore their emotional well-being. Gender bias was evident with 11 of the participants being female, while the wide age range indicates there are

likely to be issues with the generalisability of the findings. In addition it was an Australian study, so there may be differences with services in other countries.

Kilty et al. (2019) interviewed nine health professionals using semi-structured interviews and established that they faced challenges in terms of barriers to services, age-related issues with the approaches to care, and rigid criteria for accessing services. This created frustration for health professionals who felt ethically compromised by delivering services that did not meet the needs of the PwD or their family due to the lack of services specifically tailored towards YOD. The small sample size used in this study and an absence of senior professionals led to the researchers acknowledging that the findings may not be transferable.

Semi-structured interviews were conducted with six participants by Lockeridge & Simpson (2013) who collected data to understand more about the experience of caring for a partner with YOD. Although the sample was small it was also gender balanced. The participants were in a variety of situations as some of their partners with YOD had died and it is not known how this affected their views and the information they provided for the study. Additionally, the participants were recruited from a voluntary sector service. However, the themes showed similarities in terms of the lack of support and difficulties with the diagnosis.

Another study by Mohsen et al. (2020) recruited participants through purposive sampling, and conducted semi-structured interviews with PwD to understand the difficulties faced by people with YOD with regard to being embarrassed, feeling like a burden and fears about the future. The limitations of this study included the use of

purposive sampling combined with variations in the participant interviews, with seven PwD being supported by their partner and two not. The interviews were conversational, which also resulted in question variations that could have impacted on the data. Despite these weaknesses, the strength of the study lay in the fact that the data were collected directly from people with YOD, as opposed to carers, unlike in many YOD studies.

Nichols et al.'s (2013) study applied a different data collection approach, namely using Skype to conduct semi-structured focus groups with 14 young carers between 11 and 18 years of age. Like some of the other studies, there was a gender imbalance as females were over-represented. It should be borne in mind that this study had a flaw in the ethical approach it adopted towards the data collection, as the focus group leader was a carer to someone with dementia and her two children were in both focus groups, raising questions about how this influenced the focus groups and the direction in which they were led during the data collection. This is regrettable, as the study attempted to address a clear research gap. However, given the ethical implications of the data collection, the findings should be viewed with caution.

Recruitment of 14 people with YOD by Rabanal et al. (2018) captured themes relating to the diagnosis, the impact of YOD, the needs of PwD, and living well with YOD. The mixed approach to interviews, with some participants supported by their carer and others not, may have influenced the data generated. Geographical considerations also need to be taken into account as the study was conducted in a city in the north of the UK which is often associated with deprivation.

Van Rickstall et al.'s (2019) study conducted in Belgium interviewed 15 caregivers and applied a constant comparative method of analysis. The relationship of the caregivers to the PwD varied and there was a weighty discussion on euthanasia only relevant in certain countries. However, the findings relating to gaps in advanced care planning added to the literature but the geographical location needs to be considered, as does the fact that the data were collected from the perspective of caregivers' perceptions of YOD.

Five family biographies created and anyalsed by Roach et al. (2014) identified family storylines in relation to YOD. Like the other qualitative studies, they conducted a semi-structured interview at the first meeting with the families, followed by an unstructured interview. Uniquely the families were then given an empty scrapbook in which to create their biography. This differed from the other studies which all used semi-structured interviews to collect the data. The families mainly consisted of married couples, however this consistent with other studies.

A larger study by Sikes & Hall (2017) was conducted using 22 participants with a parent with YOD who self-selected to participate through online advertising. The study identified changes in relationships caused by YOD resulting in the experience of pre-death grief. Services proved hard to find and, where they were available, did not have much experience in providing specialist grief support and therapies. The recruitment approach would only have identified those actively looking at dementia-related social media or dementia organisations online.

Wawrziczny (2016) conducted semi-structured interviews to collect data on couples' experiences of YOD using an interpretative phenomenological analysis method. 16 couples (thirty-two participants) were recruited from a University Hospital in France using inclusion criteria. The experiences reported would have been reflective of French services, which may make transferability of the findings to other countries/areas difficult. In addition, the researchers identified that their own skills lay in the field of dementia and not necessarily couples, which may have restricted the exploration of some areas like intimacy and sexuality.

Reviewing the literature highlighted the difficulties that people with YOD and their families experience with delayed diagnosis, often combined with misdiagnosis, due to the fact that the person is at an earlier stage of life. Across the literature, it was uncommon for the PwD to be included as participants in the research, and commonly represented by their family carer. There was limited representation of PwDs across the papers and only a handful explored the family as a whole unit (Roach et al., 2016; Roach and Drummond, 2014; Roach et al., 2012), highlighting that there is scope for greater insight into and understanding of the lived experience of the impact of YOD on the family unit. The research questions will now be presented, together with the aims and objective.

Research Question with the Aims and Objectives

From the outset the researcher had a keen interest in the impact of YOD on the family and the desire to ensure that the voices of PwDs were present in the research. This directed the aims and objectives of the study, which were then

informed by the literature review. The literature review highlighted an area that required further exploration and posed the following research question: ‘What is the impact of young onset dementia on the family?’. Within this overarching question there were further specific questions which formed the aims and objectives of the study, as follows:

- What is the impact of a diagnosis of young onset dementia on the family unit?
- What changes occur in the family relationships and dynamics?
- What coping strategies are used by families to deal with the diagnosis of young onset dementia?
- What sources of help and support do families use leading up to and after diagnosis?
- Are there additional needs (and services)?

Summary

This chapter has reviewed the literature, highlighting the importance of gaining more insight into the unique experience of people with YOD and their families, and presented the research question, together with the aims and objectives. Chapter Three will present the chosen methodology that was deemed appropriate to answer the research question, setting out the recruitment processes and the sample, data collection and approach to data analysis that were used. It will conclude by addressing any ethical issues.

Chapter 3: Methodology

This chapter sets out the methodology used within the research study. Firstly, it looks at the research question and design, outlining the theoretical framework underpinning the research methods. A discussion of the research sample will follow, after which the interview schedule will be explored. Lastly, the method of analysis will be presented and discussed, followed by the ethical issues.

Research Question

The overarching research question posed was: 'What is the impact of young onset dementia on the family?'

Within this, the following sub-questions were addressed:

- What is the impact of diagnosis of young onset dementia on the family unit?
- What changes occur in the family relationships and dynamics?
- What coping strategies are used by families to deal with the diagnosis of young onset dementia?
- What sources of help and support do families use leading up to and after diagnosis?
- Are there additional needs (and services)?

Posing the research question is important as it sets out the research study aims which direct the research. However, it is equally important to ensure the methods are appropriately applied to answer the research question, whilst facilitating access to the relevant data. This is an important consideration as the ability to answer the question relies on using methods that match the aims of the study, thereby providing

credibility to the research. Addressing the aforementioned questions drew on the family's experience of what it was like to have a member of the family diagnosed with YOD, what changes they experienced and how this impacted on the family, which was only accessible by listening to the families telling their stories. Such information has to be sought directly from people involved in that experience, thus making it primary data. This type of enquiry can be categorised as qualitative research that aims to *'explain, as well as illuminate, people's attitudes, experiences and behavior'* (Ritchie & Spence, 1994, p. 191) gaining insight into a particular phenomenon (Gray, 2014).

Research Design

Each type of methodology has strengths and weaknesses, but the main strength of both types lies in applying the methodology most appropriate to answer the research question. For example, any attempt to answer the research question using quantitative methods would mean quantifying individual experiences to produce statistical data, using standardised statements can act to disconnect the person from their reality (Gray, 2014). Whilst this approach may be feasible, it is unlikely to produce the depth of enquiry required to gain meaningful insight into the full story of the families' experiences of the impact of YOD.

This study intended to uncover the impact of dementia on the entire family unit, including the PwD, when one member has YOD. This objective was further informed by the literature review to develop the research question: 'What is the impact of young onset dementia on the family?'. Qualitative approaches are most suited to

addressing this type of issue, due to its sensitive, complex nature (Bowling, 2014), whilst providing tools to explore complex phenomena with participants in their own environment (Baxter and Jack, 2008). It is important for PwD to feel connected and safe (Keady, 2017b), so facilitating interviews in the family home promoted the production of rich data. Semi-structured interviews are the most appropriate tool with which to collect primary data, in order to generate an authentic view of people's experience (Silvermann, 2011, cited in Saks and Allsop, 2013). Although time consuming, semi-structured interviews are a well-established approach providing the opportunity to collect rich data, providing credibility to the research methods (Shenton et al., 2004) and demonstrating application of the correct measures for the area under investigation (Yin, 2014).

Conducting research as a nurse practitioner requires careful consideration of how pre-existing clinical skills and experiences can affect the research. Fox et al. (2007) argued the boundaries between practitioner and researcher can be unclear and that practitioners should develop *'Strategies for managing practitioner research'* (Fox et al., 2007, pp. 85). Included in these strategies is reflectivity and reflexivity where the relationship between the clinical role and researcher role is considered. For this study, the researcher established a reflective diary combined with regular supervision and discussion with peers supporting a process of 'check-in' with thoughts, assumptions and perspectives as a clinician and a researcher. This ensured a continuous system of engagement and exploration of the researchers' place within the research providing reflexivity (Barrett et al., 2020).

Acknowledgement of researcher bias, as a product of the researcher's philosophy and perspective, manages potential impact on the study. The researcher needs to consider how this fits with the methodology and method of data analysis in order to provide credibility to the research. Credibility refers to how the participants' views are represented by the researcher and how these 'fit' together (Tobin and Bengley, 2004, cited in Nowell et al., 2017), so it is imperative to recognise the researcher's beliefs about how reality is formed. Credibility also plays an important role in establishing trustworthiness (Lincoln & Guba, 1985, cited in Gurreiri and Drenten, 2019). The next section will consider the researcher's position and discuss views on epistemology and ontology.

Ontology and Epistemology

Ontology and epistemology are both concerned with the philosophy of knowledge and overlap to some extent. However, epistemology focuses on the way we know things while ontology is concerned with what things are. Thus, ontology and epistemology are relevant to this study in order to understand the participants' reality of the experience of YOD for the family unit. When exploring the family's reality and structure of their world, consideration must also be given to how the researcher's reality interacts with the interview process and the experiences shared. Therefore, it is important to explore how the research fits within a research paradigm in order to interpret and explain the concepts associated with the phenomena (Gray, 2014) within the research findings. The researcher subscribes to the following view which sees:

> *"reality as a product of human intelligence interacting with experience in the real world. As soon as you include human mental activity in the process of knowing reality, you have accepted constructivism."*
>
> (Elkind, cited in Business Research Methodology, 2019)

Constructivism argues that *'truth and meaning are … created by the subject's interactions with the world',* resulting in multiple accounts of the world (Gray, 2014, p. 20). YOD being multifaceted in its presentation and how it impacts on the PwD, means the family members' experiences are intertwined with how they interpret their lives, within the 'structures of their world' (Siegle, 2019). If we accept that reality is constructed in the mind, then reality is internal and there are multiple realities. It should be kept in mind that it is not just the participants' realities that inform the research, but the researcher's too. This should be acknowledged in the research, as the qualitative approach enables the reality of YOD to be constructed by the researcher and the participants together (Kara, 2012). The researcher's experience of working with and interviewing PwD and their families in previous roles benefited the study. Combined with steps that were taken in the development of the research material, in collaboration with people with YOD, this aided participants' understanding. Explaining and discussing the research material with PwD helped to establish a shared language about the research in the interviews, which facilitated deeper access to the participants' experiences of their reality.

The process of exploring the thoughts and feelings of the participants through semi-structured interviews enabled their reality to be brought out and identified. As there are so many variables involved in this process, it is important to understand

experiences are dependent on the families' realities which are grounded in the concept of ontology, the science of being (Mclaughlin, 2009).

In ontological terms, this study is concerned with understanding how YOD affects the family unit as a whole. To fulfil the research aim, the study explores what has occurred and how it relates to the YOD. The other important element of the philosophy of knowledge is epistemology, which is about discovering the nature and limits of knowledge. Epistemology is relevant to this study through the aim of seeking to understand the families' experiences of YOD by eliciting their knowledge about YOD and its impact on them. Therefore the sample would need to represent the population so the next section looks at how the sample criteria promoted population representativeness.

Sample

Sample Criteria

As well as recruiting individuals I looked to recruit family units in order to capture the data required to explore the impact of YOD on families. Due to the diversity of family membership, this was defined as immediate family, one member of whom had been diagnosed with YOD. This decision was based on modern families often not conforming to the traditional definition of a family, for example:

> *'a group of people who are related to each other, such as a mother, a father, and their children.'* (Cambridge University Press, 2020)

Families are diverse in nature, comprising a variety of different relationships, and one family may look quite different to another. This led to the application of Bowen's family systems theory, as this views the family as an emotional unit in which the members share an intense emotional connection. This connection affects the family members' thoughts, feelings and actions; each member needs attention, approval and support from the family unit whilst reacting to each other's needs, expectations and upsets. The fact that family members are connected and reactive to each other makes the family unit interdependent; therefore, a change in one member's function typically changes the function of the other members too (Bowen, cited by Hewitt, 2019). It is this interdependence that underpins the study's exploration of the impact on the family, as changes in the PwD affect the other family members. Therefore, the family unit was defined as the people whom the PwD considered to be their family.

The study aimed for the family unit to consist of three people, which was considered the ideal number. However, it was recognised that the number of family members was likely to fluctuate according to each family's situation. Inclusion and exclusion criteria were applied and all participating families met these.

Inclusion criteria

- Both male and female participants.
- 18 years or older.
- One family member having received a diagnosis of dementia before they reached 65 years of age.
- Diagnosis was received more than six months prior to participating in this study.
- Family units made up of adults (18 years and over) residing within the same home environment as the person with a YOD diagnosis.
- A minimum of two members per family unit including the person with dementia.
- The person is able and willing to give informed consent.

Exclusion criteria

- Children under 18 years old due to the possibility of emotional distress.
- Diagnosis of YOD received in last six months as, due to the likelihood of emotional distress, it may affect the quality of the data and could be unethical.
- People with advanced dementia as it would be unethical.
- Families who require an interpreter due to the lack of resources to fund interpreters.
- People with behaviours that challenge and require residential or in-patient care (it would be unethical to include someone in distress, and would also affect the quality of the data).
- People who require a Consultee (MCA, 2005) to be appointed due to a lack of capacity.

Access to Participants

The research was conducted in a county with a mixed rural and urban population, where according to local authority figures, approximately 7.5% of the population known to have dementia were under the age of 65. As a specific population of people with YOD was required, and the population was relatively small, it was appropriate to use convenience sampling to access families with knowledge and experience of living with YOD (Cresswell & Planto Clark, 2011). Therefore, the Alzheimer's Society was contacted as a third sector provider of support groups for people with dementia, which included some specific support groups for people with YOD and their carers. The Alzheimer's Society supported the research and played a crucial role in facilitating the recruitment of participants from their Dementia Cafés.

Participants were recruited from Dementia Cafés which are 'a safe, comfortable and supportive environment for people with dementia and their carers to socialise' (Alzheimer's Society, 2021d). They provide support, information and advice on dementia along with the opportunity for social activities. They are run by a variety of services in the voluntary sector and sometimes by the NHS. However, the majority in the local area are run by the Alzheimer's Society. The cafés were chosen as people attended them voluntarily, as opposed to a health clinic which people attend for health input, advice or interventions. Cafés were more likely to offer access to people in a relaxed environment where they could freely decide whether to participate or not. It is acknowledged that this approach may not represent the diversity of people with YOD, being unable to recruit some groups of people. An example of this is representation from the BAME community, where there is a recognised under

representation in dementia services, where people often use services they know such as religious groups (Baghirathan et al., 2018; Parveen et al., 2017).

This approach is recognised as beneficial for a small population, but convenience sampling is also particularly suited to studying complex issues as it promotes access to people who meet the inclusion criteria (Bowling, 2014). In addition, snowballing was used as a recruitment technique, whereby participants were asked if they knew other families with YOD who may be interested in participating. Providing material about the study is an important part of the recruitment process in order to ensure that people have relevant information so that they can make informed decisions about participation.

Development of Materials

To support recruitment and meet ethical standards, material was developed with a focus on enabling participants to understand the study information. In order to do this, two versions of the study information were designed: one version for family members; and one version for PwD. This approach was taken as difficulties with vision and reading are common among people with dementia (Alzheimer's Association, 2020; Alzheimer's Society, 2016), which made it particularly important to consider how to provide clear information about the study to PwD. Advice was sought from the Alzheimer's Society Service User Reference Group, a group of PwD who provided feedback on designing the study information in a format most suitable for PwD.

Access to the group was obtained via the facilitator who worked for the Alzheimer's Society. Copies of the draft information were provided, following which the researcher attended the group and discussed the appropriateness of the information for PwD. The group consisted of five people with dementia, four of whom had YOD and two of whom were Alzheimer's Society staff with experience of supporting people with YOD. The group were consulted about the Poster (Appendix 2), Participation Information Leaflet (Appendix 3), Expression of Interest Form Person with YOD (Appendix 4), Consent Form Person with YOD (Appendix 5), and Further Support and Advice Leaflet for post interview (Appendix 6).

Feedback was collected and the group approved the poster. The Participant Information Leaflet was discussed at greater length due to the large amount of information it contained. It was explained that a certain amount of information was a requirement of a research study to ensure that participants knew what was being asked of them, and it was then agreed that the researcher would discuss the content of the leaflet with the PwD prior to the interview and provide an opportunity to answer any queries and check that they understood what they were being asked to do.

The format of the Expression of Interest Form Person with YOD needed adjusting as the text was too busy for people to read easily. Some questions were raised about the confidentiality statement, as it was stated on the Consent Form Person with YOD that the study could be published. This highlighted the importance of holding a discussion about the study to provide an opportunity for potential participants to ask questions and raise concerns. The group approved the Further Support and Advice Leaflet for post interview, reporting that they found it clear and helpful.

Although not discussed, the Expression of Interest Form Family Member (Appendix 7) and the Consent Form Family Member (Appendix 8) were revised based on comments from the Reference Group (Appendix 9). to make them as clear as possible. Developing the material in conjunction with PwD strengthened the integrity of the study by making it as easy as possible to understand the purpose of the study and what participation would involve. It also supported positive ethical approaches, as discussed later in this chapter.

Following ethical approval (Appendix10) on the 27th September 2016, permission was granted by the Alzheimer's Society Research Team to access the Dementia Cafés within the county (Appendix11). The research team shared information about my research with the Dementia Cafés, following which I contacted each café to arrange a convenient time to attend. The Dementia Cafés varied across the county, as some were specific to YOD, some were generic (not YOD specific) and some were run in conjunction with other organisations. The latter were discounted to avoid potential conflict or ethical issues as these had not been included in the ethics proposal. Attending six cafés in all, three of which were specifically for YOD, enabled me to recruit a total of six families. Half of the participating families were recruited from the YOD Cafés and the other half from generic Dementia Cafés.

The YOD Cafés reflected the needs of this group (employment and physically active) with regard to the times at which they were held and the venues, taking the form of evening cafes and walking groups to enable younger people and their families to attend. I attended one YOD Café on two occasions as the first time there was low attendance due to snow, so I was subsequently invited to return, as a result of which

I recruited two families. The YOD walking café involved talking about my study on a walk and resulted in the recruitment of one family. The remaining three families were recruited at generic dementia cafés. Some families who expressed an interest were excluded due to their age at diagnosis not meeting the inclusion criteria, and another family was excluded as the adult son declined to be involved. All the families received the participant information, completed the Expression of Interest forms, and made arrangements to meet me the following week. Interviews took place between April and September 2017. No participants withdrew, but some potential participants who had initially discussed taking part, took information away to read and then contacted me to say they did not wish to participate, while others withdrew when I contacted them to arrange an interview.

The Sample

The sample, as shown in Table 3.1 below, comprised of 16 study participants from six family units of varying sizes and relationships, thus being representative of contemporary families. There was an even gender mix of PwD, with three females and three males. All the family units contained a couple apart from one that was made up of a mother, son and daughter-in-law. Another family consisted of the PwD, his wife and sister-in-law. Five families consisted of couples and three families had three or more members. One family consisted of the PwD's parents together with the PwD and his same-sex partner, neither of which had been specifically considered prior to recruitment. The variety in the composition of the participating families was considered representative of the population, which aided the data collection process.

Table 3.1: Family Codes and Pseudonyms

Family Code	Participant Code	Pseudonym	Age at Interview	Sex	Type of Dementia	Relationship to PwD	Date of interview
F1	Family 1 Interview – 2 members/participants						April 2017
	PwD1	Mary	61	F	Vascular Dementia	PwD	May 2017
	F1P	Nigel	56	M	-	Husband	May 2017
F2	Family 2 Interview – 4 members/participants						May 2017
	PwD2	Steven	58	M	Mixed Dementia with Alzheimer's	PwD	May 2017
	F2P	Matthew	56	M	-	Husband	May 2017
	F2M	Ann	77	F	-	Mother	May 2017
	F2F	George	80	M	-	Father	May 2017
F3	Family 3 Interview – 2 members/participants						May 2017
	PwD3	Karen	61	F	Primary Progressive Aphasia (PPA)	PwD	May 2017
	F3P	Jerry	61	M	-	Husband	May 2017
F4	Family 4 Interview – 3 members/participants						June 2017
	PwD4	Jane	69	F	-	PwD	June 2017
	F4S	Bill	49	M	-	Son	June 2017
	F4D	Sharon	40	F	-	Daughter in Law	June 2017
F5	Family 5 Interview – 2 members/participants						June 2017
	PwD5	John	63	M	Alzheimer's Disease	PwD	June 2017
	F5P	Clare	61	F	-	Wife	June 2017
F6	Family 6 Interview – 3 members/participants						Sep 2017
	PwD6	Michael	54	M	Posterior Cortical Atrophy (PCA)	PwD	-
	F6P	Beryl	50	F	-	Wife	-
	F6S	Kate	51	F	-	Sister in Law	-

Data Collection

Data were collected via semi-structured interviews with the family unit, followed by semi-structured individual interviews. The family interview provided an opportunity to draw on the social interactions between family members whilst allowing spontaneous statements that occurred within the group interview to be captured, thus providing rich data at both a factual and a meaningful level (Kvale, 1996), which supported exploration of their experience of YOD as a family. The individual interviews allowed

individual family members to explore themes on an individual basis without influence from other family members, thus providing an opportunity to discuss issues that they may prefer not to talk about in front of other family members.

Interview Process

Conducting two interviews provided an opportunity for families to engage in a reflexive process of critical reflection, exploring the family's experience as a whole, as well as each participant's experience of YOD, thereby enhancing the connection between experience and theoretical knowledge. Using semi-structured interviews provided both structure and flexibility to the data collection process, facilitating extensive interpersonal communication to establish an environment in which participants felt able to share details of their own experiences and shed light on the families' experiences. The interview conversation sought to gather the views and perspectives of the family members relating to their lived experience of the diagnosis of YOD as a family. Semi-structured interviews were conducted with both the family and individual members to facilitate the collection of the participants' experiences, thoughts and feelings.

A research diary was kept during the study, providing a written record of the researcher's thought process to support reflexivity (Gary, 2014), enabling recognition of the practitioner role within the research. Following each interview, I recorded notes about the interview, the experience, my feelings and thoughts, and any initial hunches. For example following the initial interview with Family one, through documenting thoughts and feelings, the researcher was able to identify a desire to respond to participant's challenges and deficits of services as a clinician.

Recognition enabled the researcher to differentiate between the role of clinician and researcher identifying the remit and outcome was different to previous clinician interviews. This process enabled reflection and reflexivity to maintain the role of researcher, without which it may have been easy to move into practitioner as opposed to researcher.

Lone worker arrangements were made prior to each interview, with the researcher informing a peer when and where an interview was to take place. It was agreed that the researcher would phone after the interview to confirm it had finished. Had the researcher failed to 'phone in', the colleague was to call the researcher's mobile and home to check they were safe. This process was followed each time to ensure the researcher's wellbeing.

Family Interviews

All the families chose to be interviewed within their own homes. The interviews were supported by Interview Schedules (Appendix 12 and 13) to aid consistency and act as a reminder to cover specific topics, whilst also allowing new ideas to be included. In addition to following the interview schedule, previously acquired skills in interviewing and building rapport helped to facilitate flexibility whilst keeping the interview on track (Robson, 2011). The interview schedule also acted as a practical prompt for the researcher to remember the introductory part, thus ensuring that all participants were given the same information. It explained how confidentiality would be ensured and emphasised that the interviewees were participating of their own

free will and would be able to withdraw at any time, both of which are important elements in promoting the trustworthiness of a study (Shenton, 2004).

The family interviews were arranged via telephone, after the receipt of completed Expression of Interest Forms from all family members. All the family members had received Information Leaflets, including a specific one for the person with YOD, during the recruitment process. These were used to open conversations before the interview commenced and incorporated discussion about consent, voluntary participation, interview recording, and confidentiality processes, and provided an opportunity for participants to ask any questions. When it had been established that all the family members understood the purpose of the study and what it would involve, and demonstrated they were participating of their own free will, they each completed the Consent forms. The recording process, handling and storage of the recordings, including how they would be destroyed on completion of typing up, was explained. If a family member had shown signs of not understanding or feeling pressured to participate, the interviews would have been stopped. A total of six family interviews were recorded, ranging from 45 to 90 minutes in duration, and were then transcribed verbatim. Transcripts used pseudonyms and were typed up by the researcher, applying a process multiple checking for accuracy, before deleting the recordings. This involved typing, reading and re-reading whilst listening to the recordings multiple times until they were accurate.

Individual Interviews

Individual interviews were conducted following the family interview. Family One (F1) asked if I could return at another time as the person with YOD was tired from the

group interview and Family Six declined the individual interviews as they felt that they had spoken freely and did not have anything else to add to what had already been shared in the family interview. I repeated the opening discussion and revisited the information leaflet on return to conduct F1's individual interviews ensuring that they were still happy to consent to the interviews. The process of recording with storage, typing up and deletion of recordings was explained again prior to commencing the interview. A total of 13 individual interviews were conducted, lasting between 10 and 15 minutes except three that were less than 10 minutes. Individual interviews provided opportunity for additional data to be collected on experiences that participants did not feel comfortable sharing within the family interviews. These interviews were shorter, which was partly connected to less time being required to prepare the participants with all families apart from Family One continuing after the family interview. On their own, the data would have been limited, but overall with the family interviews they added to the data and particularly for some topics such as employment and finances. Without the individual interviews, the data would not have included experiences related to employment and finances in such detail, limiting the richness of the data.

They were all recorded and transcribed verbatim by the researcher in the same manner as the family interviews. Recordings were deleted once the transcripts had been checked for accuracy multiple times. At the end of the interviews I explained that, if anyone should feel distressed following the interviews, they could seek help and support and provided a Further Support and Advice Leaflet containing advice and support options. I repeated this process twice for F1 due to the break between the family interview and the individual interviews.

Data Analysis

Both the family and individual interviews were transcribed, checked for accuracy via a process of listening and re-listening to the recordings whilst reading the transcripts to remove any inaccuracies and ensure the completeness of each interview in preparation for the data analysis.

The clean transcripts were loaded on to MAXQDA software to support the management of the data which enabled the transcripts to be explored in detail. Framework (Ritchie and Spence, 1994) is a data analysis approach suitable for use in thematic analysis (Smith and Firth, 2011) and was applied to facilitate a systematic process of data analysis that ensured rigour and integrity. Thematic analysis is an interpretative process in which data are systematically searched for patterns to provide an illuminating description of the phenomenon being investigated (Tesch, 1990) cited in Smith & Firth, 2011)), and Framework provided a structure for the process by means of the following five stages:

- familiarisation with the data
- identifying thematic framework
- indexing the data
- charting and mapping themes
- interpretation of the themes.

Familiarisation

Familiarisation of the data commenced during the ‘clean-up’ stage with the listening to and re-reading of the transcripts. The software MAXQDA was used to support the

qualitative analysis by holding the transcripts and enabling movement between them whilst making notes and memos across the data to support familiarisation. As I became familiar with the data, a natural progression towards the next stage of identifying a thematic framework occurred, during which similarities and differences started to become apparent and the initial themes emerged from the data. Memos and notes were made during this process, which were used in the following stage to construct a thematic framework.

Construction of Thematic Framework

As explained previously, areas of interest were marked with memos and notes made during the familiarisation stage whilst identifying emerging issues of importance to the participants across the transcripts (Ritchie & Spencer, 1994). Reference was made to memos in my research diary during this stage as part of the reflective process on the data collection. This process produced recurrent themes and topics which were reviewed to form a thematic framework designed to support the filtration and organisation of the data.

Indexing the Data

This lengthy process required a multitude of skills involving logic, intuition, and making judgements combined with revisiting initial notes and memos in my research diary to identify and refine initial themes (Ritchie & Spencer, 1994). This process was complex and my supervisors played an important role in being able to guide and challenge my logic and judgements with identifying the themes. Initial themes identified were: Loss; Information; Work; Services; Changes; Diagnosis; Emotional;

Age; and Finances. These themes formed the thematic framework and all the data were read and annotated against this framework and indexed accordingly.

Charting and Mapping Themes

The next stage involved charting and mapping the themes from the data that had been removed from the transcripts and grouped according to themes. A 'chart' for each theme was created using Excel (an example can be seen in Appendix 14), thereby producing a table from which it was possible to identify the participant and/or family against each piece of selected data within each theme. This approach was effective in terms of charting and mapping the data whilst providing a way of moving between and immersing myself in the data, that allowed the experiences of YOD to be explored in relation to the impact they had on the family along with any patterns.

Interpretation of Themes

Through the process of charting and mapping the data, some overarching themes emerged which then led onto the next stage of analysis, namely interpretation. Charting the data against the themes revealed some of the key dimensions of the experience of YOD for the families, and these became evident through comparing and contrasting the data within each theme and across the themes. This process is fundamental to identifying the *'the form and nature of the phenomenon'* (Ritchie & Spencer, 1994, p. 188). The Findings chapter (Chapter 4) and Discussion chapter (Chapter 5) will expand on the data analysis.

Ethical Considerations

Ethical approval was obtained on the 27th September 2016 through the University of Essex as the research was conducted outside of the health services. Participants were recruited from the Alzheimer's Society Dementia Cafés, excluding any cafés run with partner organisations. Steps were taken to ensure that there was no contact with health services during the research. Ethical considerations were paramount in the study, not only to ensure the quality of the study but also to protect the participants who included people with YOD. The core principles listed in the guidance, 'Involving people with dementia in research' (The Scottish Dementia Working Group, 2013), were applied to this study as they are specific to involving people with dementia in research. The inclusion of the PwD is significant, recognising and respecting the importance of their role, rather than excluding them from research, as discussed in Chapter One. The emphasis of this study was on the encapsulation of the whole family in order to discover new information about the impact of YOD with the aim of benefitting the population affected by YOD in the future.

This study followed the six Core Principles set out by the Scottish Dementia Working Group for involving people with dementia in research. These are based on ethical research principles such as avoiding harm to participants, ensuring informed consent, respecting the participants' privacy, avoiding any deception and promoting trustworthiness throughout the study (Gray, 2014). The study development reflected each step, with the primary consideration being '*the dignity, rights, safety and well-being of participants*' (Department of Health Research Governance Framework, 2005, p. 7).

Avoiding Harm

Participants were anonymised to protect them from psychological harm, as well as from any social harm, by ensuring they could not be identified within the research. Recruiting them from the Dementia Cafés prevented any repercussions on their health service provision, regardless of whether they chose to participate or not. This acted as another layer of protection as there was no link between health services and the research data, thus ensuring the data could not be affected in any way. There were multiple opportunities for questions and concerns to be raised during the talk that I gave at the cafés, on the Expression of Interest form, the Consent form, and before each interview.

All the interviews were held in the suitable, safe environment of the participants' homes, which met their needs in terms of convenience, comfort, access for those with disabilities, and any sensory issues. A suitable alternative venue would have been identified if required; however, all the families chose to be interviewed in their own homes. At the end of the interview all the participants were provided with a Support leaflet containing contact details of where support could be sought if they felt distressed following the interview. These contacts included local and national support agencies.

Confidentiality

Assurances of confidentiality, anonymity and privacy were provided through the introductory talk, the Information Leaflet and in the discussion prior to the interview. The participants were advised that the data would be kept on a password-protected computer and any data recorded on paper would be kept at home and would only be

accessible to the researcher. Assurances were also provided that no identifiable data would be used in the reports. The Information Leaflet explicitly stated that all information provided by the participants was confidential and would not be shared with the Dementia Cafés or Dementia services, with the only caveat being a disclosure of harm to self/others or criminal activity. This issue was also discussed before the interview to ensure the participants understood that my obligation to prevent harm was paramount, and check that they were happy to go ahead with the interview.

As a nurse, I was also bound by Professional standards of practice and behaviour for nurses, as set out in the Code of practice (NMC, 2018). My clinical role was in a local NHS service but involved no direct responsibility for the clinical care of patients with dementia; instead, it was more concerned with staff guidance and supervision. Although this issue did not arise during the recruitment stage, it was decided that in the unlikely event that I had been involved in the clinical care of a potential participant, they would not be included in the research.

Consent Procedures

Only people who were able and willing to give informed consent were included in the study and this applied to all family members. Dementia does not automatically imply that the person lacks capacity to consent (Higgins, 2013; McKeown et al., 2010). Capacity to consent is mostly situational (Mental Capacity Act, 2005) and depends on what each decision involves and the complexity of the decision. The Mental Capacity Act (2005) ensures that assumptions about capacity based on diagnosis are no longer made, so capacity is assumed unless there is evidence to the contrary.

Nonetheless, it was important to recognise the potential vulnerabilities of people with YOD and particular attention was paid to ensuring that participants were safeguarded and able to consent willingly, which involved the following strategies:

Firstly, self-referral of all participants to the study using the contact details provided on the poster or by attending the information sessions. Checks were carried out to ensure that all participants met the inclusion and exclusion criteria and potential participants had to complete an Expression of Interest form as part of the consent process. Following this, the researcher made contact with them and explained the purpose of the research and ensured the family agreed. Arrangements were then made to conduct an interview. Information Leaflets, Consent forms and Expression of Interest forms were provided to all participants with versions both for family members and the person with YOD. These had been produced in an easy to read format that provided clear and concise information, in consultation with people with dementia, to encourage people to participate voluntarily.

The second opportunity to detect capacity issues occurred during the discussion that took place prior to each interview about the purpose of the research, confidentiality, etc., mentioned previously, whereby participants were encouraged to raise any questions or concerns. During this discussion, the researcher's previously acquired nursing skills were utilised to identify any consent issues. No consent or capacity issues arose at this time, and the families all chose to continue with the interview.

During the interview, there were times when participants showed signs of sadness and frustration while they were sharing their experiences. However, the family

members supported each other and it was not necessary to stop the interview, but experience played an important role in recognising the limits of distress. If participants had become intensely distressed, over and above expressing emotions related to their experience, the interviews would have been stopped and support offered.

Conclusion

This chapter has explained the methodology applied within the study and explored the theoretical framework underpinning the research methods. The methods and approaches taken to recruitment, data collection and analysis have been outlined, whilst identifying the actions taken to ensure the ethical involvement of PwD in the study. The next Chapter presents the findings from the data.

Chapter 4: Findings

This chapter presents the key findings that emerged from the data on an ‘Uncertain World’, a ‘Changing world’ and a ‘Shrinking World’. These themes reflect the stages that the family moves through in their YOD journey as the symptoms impact on them. The process of data analysis led to three distinct stages becoming visible: firstly, an ‘Uncertain World’ as symptoms appear; secondly, a ‘Changing World’ when the diagnosis is confirmed; and finally, a ‘Shrinking World’ as the symptoms increase and reduce activities and change roles within and outside the family.

To ensure confidentiality, pseudonyms are used throughout. To help the reader relate the participants to the data, each family and individual member were allocated a number and code, as shown in Table 3.1.

Theme 1: An Uncertain World

This theme reflects the period during which families begin to recognise changes in the PwD but are ‘uncertain’ of the cause. Experiences shared in the interviews highlighted that they found this a very uncertain time, with symptoms affecting the PwD, their daily routines, employment and family roles. The changes noticed by families led them to seek help to understand what was happening. Seeking help was a significant step in response to the level of uncertainties they experienced; however, they often encountered lengthy delays in obtaining a diagnosis, thus intensifying the uncertainty.

Emerging Symptoms

The start of the 'Uncertain World' was characterised by families recognising the symptoms of dementia but being unsure of the cause. Symptoms often not noticed by the PwD were recognised by family members or the PwD's employer. Family members reported that, *'there's something not quite* right' (Clare F5P) for some time, and in some cases for years, before concluding that the symptoms were significant enough to cause concern. This meant that families had often been living in an 'Uncertain World' for a protracted period prior to seeking help or a diagnosis. Symptoms often presented with a change in the PwD's established role within the family, usually involving household tasks not being done or deviation from established family routines.

Overall, the families described the PwD's behaviour as becoming unpredictable and no longer being able to rely on them as they had done previously. They conveyed an overwhelming sense of their worlds shifting, due to changes outside of their control, which had a significant impact on the family, and of huge uncertainty about where their worlds were shifting to.

Recognising the Symptoms

Often the PwD did not notice the changes and relied on family members to do so, as Mary (PwD1) explained:

> *"He* [F1P] *was the one that pointed it out to me; that I was getting very forgetful and I didn't notice…he did, and my daughter."* (Mary PwD1)

George (F2F) highlighted the protracted time families can sometimes spend in the 'Uncertain World', unsure of the cause of the symptoms:

> *"Gradually we were aware that his memory was getting worse. We thought almost immediately it was dementia, but from there it took 6 years to get a psychiatrist to say, 'Yes it is dementia'."* (George F2F)

Although Family 2 recognised the symptoms early on, other families took much longer. Jerry (F3P) reflected on the importance of other family members in detecting the changes in the PwD as well as the difficulties in getting a diagnosis:

> *"It seemed quite difficult for them to diagnose it for some while really. When we saw the older consultant they did a brain scan and that's when they said she had vascular dementia and we went back in 6 or 9 months' time. They did some tests and then sent her on you know?"* (Jerry F3P)

Jerry (F3P) acknowledged that it was not always the family members living with the PwD who detected the changes or symptoms, or, if they did, attributed the changes to another cause, such as hearing loss. Changes in the PwD's communication were often recognised first, prompting families to seek health advice, as illustrated below:

> *"It started very slowly and, in fact, our son noticed because he was living here at the time. We used to say, you need to get your hearing tested because it didn't seem like you could hear."* (Jerry F3P)

Changes can occur slowly, resulting in the signs and symptoms being missed. Beryl (F6P) reflected that she did not notice Michael's (PWD6) symptoms, but his colleagues did:

> *"Because you see it day to day you don't notice it* [the changes in the PwD] *so much, but they did notice at work."* (Beryl F6P)

Michael's (PWD6) symptoms presented at work; however, as he worked in engineering, there were specific policies regarding risk management that entailed routine health checks. It is therefore likely that the type of work he did expedited the diagnosis, but Beryl (F6P) felt that if his employer had not identified it, the problem may gone unrecognised for much longer.

> *"But nobody knew what was wrong! But he was putting the pass in the security machine, so when you* [Michael] *went in the turnstile you… kept putting it in the wrong place, and things like that…it might have been a year on but lots of things were noticed at work, more than me."* (Beryl F6P)

This shows how the symptoms of YOD trigger many uncertainties in the family unit that lead them to seek help and/or a diagnosis.

Diagnosis

Seeking a Diagnosis

Families sought a diagnosis when the uncertainty became overwhelming and impacted on all areas of their life, such as employment and finances, and family roles and relationships. Usually, whilst they waited for an explanation, the PwD continued to deteriorate requiring more support. They experienced competing concerns, such as between the PwD's needs and maintaining the household finances. Most commonly, families sought help from their General Practitioner (GP).

General Practitioner's Role

The GP was the first person families turned to when they realised they needed help: all the families except Family 6, whose employer referred the PwD for a medical examination, presented themselves to the GP. Contact with the GP was often made after a lengthy period of time living with the changes and symptoms. When families realised the changes were significant or had become permanent, the GP played a vital role in referring them on for assessment and diagnosis, and remained pivotal to families throughout their YOD journey. They also returned to the GP each time there were changes in needs or symptoms, and problems with referrals, or assessments.

The GP was a fundamental part of the dementia service pathway, although it could be difficult to secure an appointment:

> *"I phoned up and said, "Can we get an appointment?" They said, "No, you can't get one for three days." I wasn't very happy and put a few swear words down the phone and I said, "Right I need one, he's got dementia and I need an appointment." Then she said, "I'll see what I can do and phone you back in half an hour." She phoned back in about 25 minutes and said… you've got to be here in 10 minutes."* (Matthew F2P)

Difficulties in obtaining timely appointments added to the delay in receiving a diagnosis. However, the GP's role was important for accessing support and acting as a gateway to statutory specialist services:

> *"At the mental health bit and she made the diagnosis, but we've had no contact with her ever since. Not, 'How you getting on?', you know…it seems that we have to go back to the GP rather than go anywhere else."* (Mary PwD1)

Lack of follow-up contact from services left families feeling isolated, thus adding to the difficulties and uncertainties they experienced, highlighting the GP as a consistent presence through the YOD journey.

Delay in Diagnosis

Another source of uncertainty frequently mentioned was the fact that families knew something was wrong long before they received a diagnosis, which, combined with the time taken to obtain a diagnosis, meant they experienced an extended period of uncertainty. Jerry (F3P) and Clare (F5P) described the symptoms gradually increasing whilst waiting for a diagnosis:

> *"…we always knew there was something wrong … because it was slowly getting worse, and it's only the last year it's got really worse. Up until a year or so it wasn't much of a problem."* (Jerry F3P)

> *"I've been saying for years, there's something not quite right about John* [PwD5]*, saying to the kids, 'Your dad's not quite right, he does things that were out of sync for him.' …you* [John PwD5] *went with Lyn* [daughter] *to the Chinese restaurant. She said you were laughing at people, and that's not like John* [PwD5] *at all. That…was one of the first things. Lyn was quite shocked because she'd never known her Dad do anything like that before."* (Clare F5P)

Despite his employer identifying relatively early that Michael (PwD6) had an issue, the family still experienced difficulties in obtaining a diagnosis. Both they and Michael's employer grappled with uncertainty during this time, with the latter becoming frustrated and wrongly attributing the symptoms to laziness:

> *"It was them that really pushed it and they weren't particularly nice with it, well one man wasn't particularly nice with it, they can have a positive assessment but it was falling short…they just thought he was lazy and that wasn't very nice for you was it?"* (Beryl F6P)

"Oh yeah and what I know now, it wasn't very nice." (Michael PwD6)

Even when families expected a dementia diagnosis, the process was no quicker. When the diagnosis was finally received, although relieved, it also caused anxiety as they were forced to contemplate the reality of living with dementia. However, establishing the cause with certainty enabled adaptation to occur, signifying a shift from an Uncertain World to a Changing World. Family 2 shared how the diagnosis moved them to a different stage in the dementia journey, which they knew would involve changes:

> *"It was a bit of a relief because in one way you've got the diagnosis, and then you think, God what have we got to face now?"* (Matthew F2P)

> *"But also as a relief we began to realise the other implications and learn more about dementia…And of course it becomes more worrying…You're hoping that different medications can delay the effects… It's becoming more of a problem as we go along, because really we feel if anyone should have dementia* [laughs] *it's Ann* [F2M] *and I. And I'm not sure if we haven't already got it, you know at our age. I'm only partly joking about that…We have bad memories now…which probably amuses Steven* [PwD2] *you know thinking, 'I know where I get that from'."* (George F2F)

George (F2F) discussed how the implications of YOD impacted on the family's expected future. He described himself and his wife struggling to accept that their son had dementia, as they associated dementia with ageing and thought themselves far more likely to develop it than Steven (PWD2). They also spoke about the increasing difficulties in supporting Steven (PWD2) whilst meeting their own needs connected to ageing.

Diagnostic Tests

The system did not appear to support a swift diagnosis and test results took longer than expected. Some families 'knew' it was dementia but, as discussed previously, this did not expedite the diagnosis and all reported a protracted wait:

> "W*e went, got all excited…then they told us…it would take three weeks to get the results back and after three weeks I phoned for the results, should have been told it's more like seven."* (Clare F5P)

Families described multiple tests being undertaken, including verbal, mental and scans. Often they felt clinicians were unsure what the problem was being sent back and forth between services, as described below:

> *"He sort of 'ummed' and 'ahhed' a little bit whether to send you, didn't he?... It was only when they'd done these longer tests and things that I think they came up with that."* (Jerry F3P)

> *"… we knew there was something wrong but to get the diagnosis was a nightmare. Backwards and forwards, backwards and forwards. Nobody could help. It was frustrating, because you've got all this going on and nobody's saying anything… not getting the help we needed."* (Bill F4S)

Family 5 were the exceptions with a quick diagnosis, which was most likely due to the specific consultant who recognised the symptoms and selected a different test due to the person's age. This indicates that the speed of diagnosis may depend upon the professional's skills and experience in identifying the correct test:

> *"We saw a Mr. X* [Consultant] *and he said he wouldn't worry about anything else, and went straight for the lumbar puncture, because of his age."* (Clare F5P)

Having private health insurance did not hasten the diagnosis or treatment for Family 6. Their experience of being caught between services and departments was similar to the other participants'. They felt there were additional barriers between private and NHS provisions, further delaying the process:

> *"We were back to the GP, work then got involved and made him do a cognitive assessment… Then they referred us again because we'd done that bit private and that didn't link up with NHS. We had to go back to the neurologist in the NHS. I was annoyed with myself… didn't know at the time, but had we gone to a neurologist in the NHS I don't think that would have held us up as much. Then another neurologist seemed to think it was just that you go into yourself, part of anxiety*." (Beryl F6P)

Most participants reported similar experiences of having to attend repeated appointments and long waits for test results. Family 2 felt that they only obtained a diagnosis by 'pushing' for it:

> *"It was…through his brother's persistence that we got a diagnosis. Otherwise he still probably wouldn't have had one now."* (Matthew F2P)

The families found this process exhausting and became frustrated with waiting. The excerpts below capture the repeated difficulties and inconsistencies they experienced during this period:

> *"We waited for those results and didn't hear anything so about March I was so fed up, I rung them and got an appointment. We went back… through all the same things that we'd done the first time…a total waste of time."* (Clare F5P)

> *"They* [Steven, PwD2] *were initially seeing different doctors each time he went and that can't be right, even if they read the same computer scripts…he saw different doctors and then what with the upheaval in the National Health Service the other doctor at the clinic here said, "It's alright Steven you'll see me every time now so it will be alright." Next time he went, he'd moved, so he never saw him and it took some time to get to the final diagnosis."* (George F2F)

Some PwD were misdiagnosed, thus delaying the final diagnosis. Family 6 experienced diagnostic overshadowing with alcohol dependency, following which they were told it was disassociation with anxiety. Each misdiagnosis resulted in them returning to the GP to be referred to another specialist. When a diagnosis was eventually made, aftercare and information was lacking, as Beryl (F6P) explained:

> *"They put radioactive stuff in you, so it showed up. We had to…have that done, and then he said, 'Yes, I was right, you've got PCA but it's a very rare form. I don't know anything about it, all I can tell you is, Terry Pratchett had it and you have to cope with it.' That was the diagnosis after waiting for two years."* (Beryl F6P)

Families felt it took too long to reach a diagnosis, with repetitive tests that delayed treatment. Family 2 explained how they had been sent back and forth between different departments and felt they should have been given the diagnosis from the outset, enabling treatment to start earlier:

> *"I can't remember which doctor gave us the diagnosis … going in all different departments in the hospital trying to find different things. Is it this? Is it that? Rather than get down to the nitty gritty right from the start… if they would have told us five years ago and put him on the tablets that he's on now… he would have been a lot better than now what he is. Because since he's been on the tablets it's levelled out."* (Matthew F2P)

Families wondered if earlier treatment would have delayed the decline or improved the situation. Some suspected that tests might have been lost, and, as Matthew (F2P) explained, when they did get the results they thought the scans had been mixed up as they could not find anything wrong:

> *"They kept saying no, there's no problem, there's no problem. I don't know if they got the wrong scan at some point, because obviously something was wrong wasn't it? I think we all knew what it was."* (Matthew F2P)

After being given the diagnosis, families thought they would get the help and support they needed, but this was not always the case, as shown in the next section.

Post Diagnosis

Families found that services offered limited information at the point of diagnosis and a lack of support following diagnosis. In particular, the PwD was not given diagnosis or management information. Some were not even directly spoken to about the diagnosis and what it meant for them. Families found that statutory services generally were not very helpful with regard to information and support; instead, most of their support and information came from the Alzheimer's Society and peers at Dementia Cafés.

Problems with Services

Families felt let down by statutory services that discharged them after each contact, resulting in their GP having to re-refer them each time their needs changed. They felt isolated, unsupported and concerned that they were not getting the right medical support:

> *"They know whether I am worse by looking and talking to me right? They should have a follow up appointment, make me feel that I am here and haven't forgotten about me, but as far as I am concerned they have…once your illness has been diagnosed… they wash their hands… but you are still a patient, you are still ill."* (Mary PwD1)

Mary (PwD1) described her experience as leaving her feeling like she did not exist, losing her sense of self, and receiving no acknowledgement of the difficulties she

encountered due to YOD. The PwD was often left with uncertainties about their health care and health needs. The families' only certainty was the diagnosis, but with little post-diagnostic support. Additionally, the services offered were not always appropriate for their age or needs, for example being referred to a seated physical exercise group despite being fit and healthy:

> *"They sat me there with people who were worse off than me all in a, in a half thingy* [hand gesture for semi-circle] *wanting us to exercise as we were in a care home… I didn't go the following week. She rang me and I said to her, 'look I'm sorry I'm not going anymore'… I'm 60 years old. I don't see myself in a home and having to do those exercises."* (Mary PwD1)

Derek (PWD6) reported a similar experience of attending a group for people with dementia, who were older and had more advanced dementia than himself, with whom he felt he had little in common:

> *"Then you go and … you think 'Oh gawd blimey, I don't want to do all that', because …we've still got … our marbles."* (PWD6)

Person with Dementia's Experience

Some participants with YOD recognised the symptoms and decline in their abilities. Mary (PwD1) shared how she remained positive most of the time, but sometimes the knowledge that the symptoms would lead to a continuing decline resulted in low moods, thus illustrating the PwD's experience of an uncertain world:

> *"For me maybe it didn't sink in… there are people worse off than me, that's my attitude, still is until I get low. That's when it hits me. I live each day as happily as I can. Tomorrow, God knows because once I start going, I won't notice, you know? It's not that I won't notice but my memory will be worse. I won't remember much of the day before. Little by little, my memory gets worse."* (Mary PwD1)

Mary's (PWD1) insight demonstrates the huge impact that YOD can have on the PwD, yet they are generally not given sufficient information to help them prepare and plan to make choices in advance.

The PwD does not always share their concerns about their symptoms, as Steven (PwD2) explained:

> *"My worst problem…is my memory it's nearly completely gone… I might think about it* [memory] *if I'm on my own, but I wouldn't tell them* [the family]." (Steven, PwD2)

This demonstrates the importance of ensuring the PwD is provided with information and support as an individual.

Lack of Information for Person with Dementia

It was notable that the PwD was not given specific information or support either pre-diagnosis, at diagnosis or post diagnosis:

> *"That didn't help in the whole scheme of things…we couldn't really talk to anybody about it either, but still today – nobody's really spoken to Michael about the whole thing."* (Beryl F6P)

This indicated that YOD differed from other diagnoses, following which the person would be given as much information as possible, and it appeared that the PwD was treated as separate from the assessment. There was less evidence of patient-led care for PwD, further contributing to the difficulties that they and their families experienced. The unforeseen consequence of this was that families lacked

confidence and were unsure how to talk to the person about their diagnosis, again demonstrating the uncertain world they inhabited.

Families seemed to be left to deal with the unknown aspects of YOD themselves, and were unsure how to support or share information about YOD with the PwD:

> *"The thing about Steven* [PwD2] *getting the diagnosis is that we hadn't known what to say to Steven, or what Steven thinks. I think we've rather been avoiding it and Steven* [PwD2] *doesn't say much about it himself."* (George F2F)

Lack of Information for Families

The general lack of information provided whilst waiting for a diagnosis combined with the slow response from services added to families' uncertainty. The need for them to keep asking services for diagnosis, support and information meant that they were repeatedly making additional efforts to get help and information. Information about support was lacking before and after diagnosis, but when the families came into contact with the Dementia Cafés it was very different: suddenly they had a source of information and shared experiences. However, families often did not contact the cafés until after diagnosis, meaning it was late in their journey and past the time when information would have helped.

Nonetheless, the families found peers at the Dementia Cafés were the best source of information, particularly partners sharing experiences of difficulties they encountered. For example, despite being seen by a Neurologist, Family 6 were not informed that epilepsy was a common experience for PwD, which left them unprepared and uncertain about what to expect from the dementia journey or what was outside of the 'normal' experience, as expressed by Beryl (F6P):

> *"We're early on in that journey, but I still haven't really had anyone explain what's likely to happen, what's next... there must be something out there for people … He's not the only one that's had this, is he? There must be some sort of information out there that would help others, Google and stuff…we've read some things. It's very vague and it just says 'later stages it's like cancer', so it doesn't really help. Then you read one thing that says "things are faster because you're younger."* (Beryl F6P)

This made an already difficult time for families even more challenging. The lack of support from services left them feeling unsupported and unclear about how best to help the PwD.

Support

In many cases, professionals also appeared unsure about where to signpost people for support, as Family 6's experience demonstrates:

> *"During that time I did speak to the GP, who was very supportive, because Michael suffered with anxiety and depression prior to that. She was great all the way through, but her hands were tied because where she had to refer us. I asked for help and support and she said, 'I can't point you in any direction for support because we don't know what it is you've got and I don't want to send you off to a support group and it be the wrong."* (Beryl F6P)

Although the GP was concerned about giving inappropriate information, in fact the family would have been grateful for details of any dementia support services in the area at that time. This shows how difficult it could be to obtain a correct diagnosis, along with relevant support and information. It left families feeling unsupported during a very uncertain time when support, information and help would have alleviated some of these uncertainties.

The age of their members impacted on how support groups were used and how supportive peers were. Support groups were often held during the day and aimed at older, retired people. Consequently, they were either inaccessible to younger people, due to employment, or inappropriate due to the age difference. George (F2F) described his family's experience of being unable to integrate at the Dementia Cafés:

> *"We started going to bowls once and the Dementia Cafés, but we found Steven* [PwD2], *and I found, that we went and there's tables, and the people there all know each other and sit at the same tables. Me and Steven* [PwD2] *were usually on a table on our own and we could do that anywhere."* (George F2F)

Alzheimer's Society

Family 2's experience notwithstanding, the families consistently reported that the Alzheimer's Society was a positive source of support and information. It provided various types of support and information, including Dementia Cafés for all age groups and in some areas specifically for YOD. During time of crisis the Society was able to put families in touch with statutory services. The responsiveness and support provided by the Alzheimer's Society gave families a sense of support and certainty during an uncertain stage. Family 6 provided an example of the support they received after Michael (PwD6) had gone missing during the night and the family did not know what to do:

> *"I rang Hannah* [staff member] *from the Alzheimer's Society because it was the only number that I had, I didn't know what to do. She came round the next day and got in touch with the dementia crisis team. I didn't even know they existed. They were there the next day and they've been with me ever since, they're the ones that've really helped."* (Beryl F6P)

This shows the contrast between the information and support provided by the statutory services and the voluntary sector. The voluntary sector (Alzheimer's Society) was key to connecting families to the right statutory service and, once referred to the appropriate specialist dementia service, it was usually a positive experience. However, the problem lay in finding out about the service and knowing how to access it. Family 2 described a similar experience:

> *"We've had more contact with them* [statutory services] *since Kay* [Alzheimer's Society staff member], *stirred them up… they've actually phoned this morning and someone's coming to see us this week."* (George F2F)

These experiences highlight that, as a voluntary organisation, the Alzheimer's Society was key to providing an access route to statutory services. This stands in contrast to the inadequate information and support families reported receiving from the GP, indicating that the voluntary sector is 'plugging' a gap in the pathway to accessing statutory services.

Dementia Cafés

Dementia Cafés used by the participants, including young onset Dementia Cafés, were all described as a positive source of support and information. Although age differences with people at generic Dementia cafés was mentioned as problematic (see section 1.7 on Support), all other references highlighted how supportive they were. Participants reported feeling accepted and understood as well as being able to form friendships at the YOD cafés:

> *"The support groups are the people I call my friends. They understand me and I understand them. For example this lady Jane, her husband Mark, I've known*

> *him since day one and we get on great. We can have banter, and if he's not too good, I can cheer him up… the people are not on their last legs and you can have a laugh, and the thing is their partners…and I can still relate with some of them because I'm not that bad...so I can have a laugh. I bake for them as well.… It's the social side, I can get out every 2 weeks."* (Mary PwD1)

Families valued having somewhere they could go to have regular contact with people of similar ages and with similar experiences. Families sometimes found the Alzheimer's Society through word-of-mouth, by talking to people about their situation, and Family 6 described it favourably after finding it by chance:

> *"We joined the Conservative Club …we thought we could just socialise with them. A lady… said, 'Oh there's a Dementia café that's held there every Friday' It's actually run by the Alzheimer's Society, so we went there. Got welcomed…it was lovely, really nice… Albeit everybody in there are in their seventies, lovely people and the two girls that run it, you know were really good and helpful with information…"* (Beryl F6P)

Theme 2: A Changing World

The 'Uncertain World' did not end at diagnosis and families continued to experience uncertainties as the dementia developed. However, receiving a diagnosis acted as a gateway to enable families to move between the 'Uncertain World' and the 'Changing world' stage, during which they could make changes that enabled them to adapt to the dementia and apply strategies for living well with it. For example, uncertainties pertaining to employment continued before and after the diagnosis, but once the diagnosis was confirmed, the families knew the cause and nature of the changes and were thus able to adapt more easily in order to manage them.

Employment

Person with Dementia

A major change resulting from the impact of YOD was related to employment and family finances, with the PwD often losing the ability to manage finances. This had the effect of reducing the PwD's exposure to everyday activities, while their social network dwindled when employment ceased.

The loss of their career was particularly significant for the PwD, reducing their contribution to the family. An example was given by Karen (PwD3) who had been a childminder for many years and planned to provide childcare for her grandchildren, but was prevented from doing so by the dementia. She felt great disappointment, not only about the loss of employment and earnings, but also the loss of her perceived role in the family as a parent and grandparent:

> *"I did it* [childminding] *for another year* [after diagnosis] *and that's the worst thing about this. I've had all those children and loved them all. I had a good job and my baby* [son] *I can't do it for him."* (Karen PwD3)

The onset of dementia made it increasingly difficult to work and all the participants with YOD stopped working due to the impact of dementia. Families were unable to apply for financial help until the diagnosis was confirmed, but simultaneously struggled to work. Some tried to maintain employment by changing jobs before they could be dismissed, but this only offered a temporary solution until the dementia made employment too difficult for the PwD:

> *"He did get some work at a light shop for a while to do with computers and things and that became a strain…with memory loss and things....the financial*

> *bit, we hadn't got the diagnosis, so couldn't get any support until you got it. That's been the problem right up until you got it."* (George F2F)

PwD who were working when they received diagnosis had to deal with disclosing the diagnosis to their employer. They experienced sorrow at the unimagined loss of future plans to continue working and eventually retire. This aspect of the changing world meant confronting a future without employment, which affected their routine, role and purpose, leaving them suddenly unoccupied during the daytime. Clare (F5P) and John (PwD5) ran a business from home and Clare spoke about the dilemma posed by John being unable to work like he used to, but also unable to be left upstairs, unoccupied, whilst she worked, making neither option feasible:

> *"He wants to do all the things that he used to do* [work role], *it really doesn't work… You just make yourself work and yet on the other hand, he can't sit up here* [in the flat] *and sleep all day."* (Clare F5P)

One PwD who wanted to continue working found it difficult being on sick leave whilst waiting for tests to be completed. He struggled to cope with the loss of activity and became bored, resulting in him turning to alcohol, which caused additional issues:

> *"Michael* [PWD6] *was at home on his own, the only thing he could do was drink…which was like a vicious circle… They had to take him off working, he couldn't drive because he had an accident… had his licence* [Driver's Licence] *taken off him… it's left him at a very low edge, and of course once he did get that diagnosis I think he just thought, well I might as well just carry on drinking."* (Beryl F6P)

Losses connected to employment, daily routine, and having to stop driving were hard for the PwD to accept but also impacted on the family. They had to cope with

changes in family roles, such as caring for the PwD, and becoming the sole earner in the household, which are explored next.

Family Carer

Employment-related changes impacted directly on family finances. Most of the carers became the sole earner, making their employment more vital to maintaining the family finances. This put added pressure on the carer, as they became aware of the potential for their caring role to interfere with their employment. Carers described feeling a loss of control as their world changed and they found themselves caught between their work and caring responsibilities.

Loss of the PwD's employment had multifaceted implications for the whole family. Not only did the PwD experience a loss of their role, loss of control and loss of financial status, but also of daily activity and routine. Carers described difficulties associated with juggling work and caring responsibilities, which were magnified by trying to keep the PwD, who would otherwise be unoccupied, safe and engaged in something. Carers faced the added responsibility of the family finances and ensuring secure employment. Thus, carers were caught between meeting the care needs of the PwD and being able to meet the household's financial needs. Attempts to resolve this dilemma involved making changes to working hours, working locally to reduce travel time, and regularly telephoning the PwD from work:

> *"I went part time to support Karen* [(PwD3)]…*I had to give some areas away, so I generally work local."* (Jerry F3P)
>
> *"Juggling everything all the time trying to think what you're going to do. I mean I'm on call 24 hours every day of the week aren't I? Sometimes I phone Steven in the morning, and if he's having a bad morning I have to come out of*

> *work…my company are pretty good…But work's having a funny time at the moment, so if I carry on losing my work, they might turn round and say you can't go, and where would we be?"* (Matthew F2P)

The changing world of dementia presented challenges for family carers in terms of meeting the PwD's needs as well as the need to deliver in the work environment. They battled with worries about losing their job if they took too much time off, and the perceived pressure to be seen as performing well in the work environment:

> *"I can't keep having time off. I can't afford to do it for one, and two…if I have too much time off, they might say, "Well we don't need you". Then we really would be in trouble, because we've still got to pay the mortgage…It's a hard one isn't it? The pressure of needing to be seen to be doing it?"* (Matthew F2P)

Working family carers also faced other challenges, such as the PwD becoming anxious if they forgot the carer was at work and, in some cases, leaving the family home to look for them. Equally, this caused the carer anxiety when working as they worried about the PwD's safety:

> *"She'll go round to a neighbours' or outside if the neighbours aren't there. She'll be like – 'they've left me – they've left me'. You know you've just gone to work or something."* (Bill F4S)

Family carers were unable to control the changing situation presented by the challenges of caring and paid employment. Some acknowledged that it would be easier if they did not have to work, but in the absence of other help, they had no alternative, as Clare (F5P) explained:

> *"I honestly don't know what else I can do…the system's not there. You know it would be so much easier if I didn't have to work, in lots of ways."* (Clare F5P)

Some carers explored respite care as an option for enabling the PwD to be cared for whilst they worked. However, the period of respite available was too short to cover working hours and travel time. This limited the types of work they could do and ultimately prevented them pursuing work, which was frustrating for those who wished to work.

However, despite the challenges associated with employment, it was often crucial to the carer's identity and in terms of providing a role within the wider community:

> *"I don't feel that I exist, I feel that I'm just here* [laugh]*, I don't exist anywhere on paper. I don't earn any money... Really, bearing in mind I worked since I was 16. I haven't had children so I've not had time off, it's horrible and I hate that."* (Beryl F6P)

The 'Changing world' stage provided an opportunity for adjustments to be made, but lack of financial support and information hampered the adjustment process, leading to anxiety about the future and feeling trapped, unable to change or control the situation:

> *"If I make myself unemployed by giving up the shop, they're not going to give me anything… I don't see me getting Job Seekers at my age. I haven't got a qualification to my name, and I couldn't work – go out and leave John anyway! So do we just hobble on for the next so many years? Ideally we should be getting out and about and doing things before it's too blinking late! Doing the things we thought we would when we're retired… financially we can't afford to and if we lose this place then we lose our home... Goes round and round and round..."* (Clare F5P)

Families found that support groups were often held during the week, making them inaccessible to working carers. Although many employers were flexible, carers often felt unable to ask for time out from the working day to attend support groups. The main barrier was the additional travel time necessary to collect the PwD and drop them back home:

> *"If it's an hour group, it's not just an hour, its half hour to come and get Steven and half hour bringing him back home, so that's two hours and it's not fair… on the company, but also on the people I work with..."* (Matthew F2P)

Work commitments therefore resulted in both the carer and the PwD abstaining from support groups. Worries about work were closely connected with the need to maintain the family finances, which families reported had been impacted by YOD, a theme which is further explored below.

Finances

It was noted that families spoke about difficulties relating to finances and claiming benefits in the family unit interviews, but less about employment. Experiences concerning finances were predominantly shared by the families through the family interviews rather than the individual interviews. However, the reverse was true regarding employment: the topic was largely addressed in the individual interviews. This may reflect the fact that an individual is employed, but finances belong to the whole family.

As the PwD's dementia progressed, their ability to understand the value of money reduced, adversely affecting their capacity to manage finances. Being unable to

manage without support caused a loss of confidence and feelings of vulnerability, thus increasing their dependency on other family members, as Mary (PwD1) explained:

> *"They ask me £50 for a packet of crisps I would pay £50. I don't have the value; I don't check the change, nothing like that."* (Mary PwD1)

The PwD's loss of control over their finances resulted in the family carer taking on this responsibility instead. However, while the PwD realised they needed help, this left them vulnerable to others taking advantage of them, as described in the following excerpt:

> *"I always had control over my own accounts, and now he has control, not that he has 'control' of them, I don't go without you know? I only need to open my mouth and I've got it. Before… I knew where my money was… to be honest most of the days, I don't care. But when I'm low, that is one of the things that affects me."* (Mary PwD1)

Family carers, in turn, often appreciated how difficult it could be for the PwD to lose control of their accounts and finances. The PwD did not always remember what they had spent money on or the amounts in their accounts, and consequently needed support from the carer to keep track of their finances, which could be frustrating for the PwD, as Nigel (F1P) divulged:

> *"She hates asking for money, because she had control of her own money."* (Nigel F1P)

Families employed coping mechanisms to help balance the PwD's need for access to money with protecting the family finances:

> *“We’ve always shared our money; I was worried about her losing her card... I opened another bank account and put most of our money in that.”* (Jerry F3P)

Benefits helped the financial situation, but negotiating the benefit system and securing payment often proved difficult, as the next section shows.

Barriers to Benefits

Benefits

The ‘Changing world’ brought a loss of earnings and increasing support needs, leading families to turn to the benefit system for financial assistance. They encountered many barriers in trying to access financial support, including difficulties finding information about benefits and with the application process. Information about what benefits they were entitled to and how to apply was often lacking. In addition, families encountered difficulties in identifying the right department to contact, often to then be told in that their age and unconfirmed diagnosis made them ineligible.

The fact that people with YOD are, by definition, not old prevented them from claiming pensions. In conjunction with the extended time taken to reach diagnosis, this left families in a difficult predicament if they did not meet the basic requirements. It was during this time that they really needed financial help to alleviate the pressures of trying to earn enough to support the family with meeting the PwD’s increasing needs, yet they were often unable to claim.

Contacts and Information on Benefits

The benefit system was a source of great concern to families, as information and support on how to access any type of financial help seemed almost non-existent. When families did find information and tried to contact the Work and Pensions Department, they experienced other barriers such as incorrect information.

Often the telephone numbers provided did not work or automated messages directed the families in circles from department to department, thus resulting in delays. This was frustrating for the families and caused additional stress. Not only did the families have to cope with living in a changing world due to the impact of dementia, they also had additional pressure of trying to navigate a confusing and complex process without clear information. At a time when families needed the stability of receiving regular benefits, the benefit system appeared to fail them, through a lack of support and unnecessary delays in the process. Additionally, it was noted that families seeking diagnosis were not provided with information about benefits or financial support, leaving them to search for help and support themselves, as Clare (F5P) explained:

> *"…they give you one number and the first thing it says is this number has been changed and you now need this number. I tried that, still couldn't get anyone to answer and there's another number on the back, tried that one and that also, funnily enough, has been changed to the same number that you would ring on the front of the first one! I felt I was going round and round in circles and not getting anywhere, so I thought Citizens' Advice."* (Clare F5P)

When they eventually managed to contact them, families found the Work and Pensions Department helpful, but they still faced what seemed an almost impossible

task of trying to find the right person or department to help. They struggled to navigate the application forms and identify which forms were required:

> *"The PIP* [Personal Independence Payment] *isn't means tested is it, so we didn't have so much trouble getting that once I'd sorted the reams and reams of paperwork out. No one makes it easy! No one tells you… All our lives, we've never claimed for anything and it's so difficult, they make people work so hard. I don't think I'm stupid but… you have to know the right way of filling them out.".* (Clare F5P)

The difficulties Clare (F5P) related in identifying which form to complete and then trying to complete it added to the families' stress. When they reached breaking point, they often sought advice from the Citizen's Advice Bureau.

Citizens Advice

Families were not informed about the Citizens Advice Bureau, but sometimes turned to them as a last resort to help with financial support. They found Citizens Advice to be a positive source of support and information regarding benefits and help with completing forms. However, families were often quite distressed by the time they approached them for help. Families reported varying degrees of support from Citizens Advice in different locations, but all contact with them was related to obtaining information, signposting or help completing forms. Generally, they found Citizens Advice accessible and helpful, as Bill (F4S) and Clare (F5P) both attested:

> *"This woman come and said she'd get somebody… because they sent us all the paperwork… get somebody from Citizens Advice to help you fill the forms in."* (Bill F4S)
>
> *"I phoned up Citizens Advice… they said, "There's hardly anyone here at the moment, is it okay if you come down?", so I went straight down… I had left*

> *John in the shop and I was over two hours... The women got in front of the computer and Googled a few things and said, "We could do that for you but we haven't got time today. You'll have to come back next week". I was so fed up. I phoned the clinic* [GP] *and they've got someone on a Thursday, he's been really good. He helped with the PIP form initially. I just thought I'd get it in the post quicker if I got to Citizens Advice and be a couple of days ahead. He sorted it out."* (Clare F5P)

The lack of clarity about where help and support could be accessed, led to families going from service to service and often only finding someone who could help them by chance. Some families reported getting help through their GP's surgery.

General Practitioner

It was identified that some GP surgeries have a designated person to support people with completing forms. It was not clear if this service was available at all surgeries, but where it was available, the families were particularly positive about it:

> *"We actually got someone from the Works & Pensions to come and help me initially with the PIP people, and she knew how to fill it out properly because she was from Works & Pensions. Calvin at the clinic* [GP], *he is quite good now I know he's there."* (Clare F5P)

Families were not told that this support was available, and often discovered it by chance. The process of trying to obtain financial support presented challenges which further complicated the situation for families, resulting in them viewing the benefit system as unhelpful and adding to their distress. This was not solely due to eligibility issues, but also with regard to completing forms and accessing advice, as Clare (F5P) confirmed:

> *"… they'd sent this back* [benefit application form] *saying that I had to make a … mandatory re-request if you like. You can't just appeal, you have to do this first and I didn't even know what it was.*" (Clare F5P)

This demonstrates the difficulties families faced in accessing support: even if they found the right forms and managed to submit them, they faced long waits, forms returned with requests for more information, or being told to appeal against the outcome. In addition, age was found to be a barrier to accessing benefits.

Age

Family carers were too young to claim a pension, but not eligible for other benefits that would help to support the family unit financially. Access to pensions whilst waiting for the diagnosis would have helped families adapt more easily to meeting the care and support needs of the PwD. The impact on finances at this time left families caught in a 'waiting game', wondering how long they could manage, whilst also being unable to plan for the future because they did not know how the dementia would progress. This made them feel vulnerable and disempowered by the situation, at a time of great change and need, as articulated by Beryl (F6P):

> *"I'm stuck. Obviously the priority is to look after Michael while we can afford, but if I don't get help and we need more respite or more services. If I don't get financial support then I'll probably have to go to work. That's going to put a whole other pressure on that I don't have now. You know it's difficult because I'm 50 and I'm not going to get a pension till … 65, is it for women?"* (Beryl F6P)

Thus, the PwD and their partner were trapped waiting for a diagnosis to allow them to apply for disability benefits, because they were not old enough to access their pensions which would have helped alleviate some of their financial difficulties.

Benefit Delay due to Diagnosis

Once the diagnosis was confirmed, receiving benefits provided some help but did not always fully resolve the difficulties, because families still had to pay for additional things like prescriptions and chiropodists, as described below:

> *"She doesn't get that money it goes straight to them… they're giving it in one hand and taking it out in the other."* (Bill F4S)

> *"got a card and pay monthly because that's cheaper. Its £8.60 a prescription now… He's on 8 a week which if you start paying that out it's a lot of money."* (Matthew F2P)

This demonstrates how the families fluctuated between the 'Changing' and the 'Uncertain' world, particularly in relation to receiving a diagnosis and claiming benefits.

Theme 3: A Shrinking World

Families recognised that the impact of YOD resulted in them living in a 'Shrinking World' through the loss of activities, roles outside the family home and their community network. This 'Shrinking World' was also experienced within the family unit, characterised by a reduction in hobbies, activities and communication as the dementia progressed.

The data provided an overwhelming sense of the family's world shrinking following the onset of dementia. This shrinking world was evident across many areas of family life and for individuals within the family. A significant area of impact was communication, particularly in relation to family roles and relationships within the family unit.

Communication

As the dementia progresses the PwD's communication deteriorates, impacting on roles within and outside the family unit and thereby 'shrinking' their world. Reduced communication is partly due to the PwD's loss of skills, but also to the limitations on the carer communicating with the PwD. As a result, roles and responsibilities within the family unit altered, with the balance of everyday responsibilities gradually being tipped away from the PwD and towards the carers.

Impact on Family Roles

As the PwD's communication skills changed, the families described trying to maintain their roles as far as possible by altering the ways they communicated and employing coping mechanisms. One example was shared by Mary (PwD1) who used written instructions in an attempt to maintain her role and responsibilities within the family unit. However, this approach involved challenges for both the PwD and the family members. Written instructions were generally helpful for the PwD, unless they became distracted, as explained in the following excerpt:

> *"I'm very set in my ways. I do this first, I do this second, I do this third and I've got this all written down. When I've got somebody* [paid carers] *in the kitchen talking, it distracts and… I start forgetting things."* (Mary PwD1)

Leaving instructions helped the PwD to continue to perform household tasks, although they did not always know when to do them. This could cause anxiety, so the need for support remained even with the written instructions. For the carer, although the instructions meant they could still share some household tasks and keep the PwD occupied when they were at work, they did not alleviate their concerns about the PwD's safety, as Matthew (F2P) explained:

> *"If I leave instructions, he will do the vegetables, but I normally do them myself…you know it's a safety thing cos I don't want him to cut himself. We got a white board and Jane* [friend] *had an idea to write instructions on it… and that really helps because he'll look at that and do it. I used to put it on the settee but one night he sat there and said, 'Have I got to do that now?'"* (Matthew F2P)

Dementia changes how family members communicate with each other as the PwD's decreasing abilities impact on their roles, causing them to shift as they try to maintain responsibilities and roles within the family unit. The PwD's hearing, sight and perception were affected and these changes were noticed by family members, impacting on the PwD's ability to perform tasks and maintain roles as well as on communication within the family:

> *"Your vision is not so good. His perception of things isn't how it should be. That's part of it, altered perception. He has got the start of cataracts and …macular degeneration."*(Clare F5P)

The changes in John's (PwD5) eyesight limited his activities as he became unable to judge distances accurately or see clearly, thus illustrating the 'shrinking' range of activities and tasks the PwD could participate in. This in turn changed roles and activities within the family unit, as carers picked up more responsibilities or supported the PwD to continue doing them with reminders and instructions. In both cases, the outcome was the same. Family members' responsibilities increased as the PwD's skills decreased.

Some families described a rapid loss of skills (F3 and F4) whilst one (F6) reported symptoms coming in clusters, following which the PwD would recover. These differences were likely to be connected with the specific types of YOD which varied between the participants (see Table 5).

As the PwD's skills and independence decreased, the caring role within the family expanded in response to the PwD's symptoms. Meanwhile, the growing burden of the caring role impacted on the carer's 'world', causing it to 'shrink' as their everyday activities and social network diminished. The whole family experienced a sense of their world shrinking as they progressed along the dementia pathway. The PwD's individual activities within and outside the family, such as socialising and hobbies, and performing household tasks, reduced with their loss of communication skills and general abilities. In tandem, the other family members experienced a reduction in everyday activities as more of their time was occupied with supporting the PwD to maintain their interests.

Conversation

Another startling illustration of the families' 'Shrinking World' was the loss of conversation with the PwD due to difficulties with communication, memory, interest and the ability to participate in activities they had once shared. Family members found it increasingly difficult to converse about topics they had regularly discussed throughout their relationship. The PwD found it difficult to understand these subjects, while the family member struggled to explain them. This resulted in the loss of a sense of the 'sharing' process within the conversation, appearing to become unbalanced, impacting on relationships both within and outside the family unit.

Impact on Relationships

The loss of conversation was often regarded by carers as directly responsible for the loss of their relationship, as exemplified by Clare (F5P):

> *"We can't really have a normal conversation… anymore. We can't just chit chat. We can sit in the car and I can say something to him… but he's not there, or it takes so long to get through to him – it's gone! So we've totally lost, well our relationship to a certain extent isn't there any more…"* (Clare F5P)

Carers described how conversation dwindled with the increasing loss of language and understanding, as it became harder to explain things to the PwD. Consequently, the carer often withdrew and stopped conversing with the PwD in the way that they would have done previously, to avoid the frustration and effort associated with having to support the PwD to share a conversation. The carer found discussions could become difficult and stressful, as expressed by Jerry (F3P) in the following excerpt:

> *"I realised this a year or two ago. The three of you start chatting away and she doesn't understand what's going on, unless you speak to her directly she doesn't join in. I get frustrated now because I don't tell her a lot of things, I don't speak to her about things because she doesn't understand it and you can't be bothered to try and explain it. You just think oh I'm not going to bother telling her now."* (Jerry F3P)

Another key element of the 'Shrinking World' was the loss of social activities as conversations with friends became increasingly difficult. Social activities with friends that had previously been enjoyed became challenging and their continuation depended upon friends' ability to understand dementia and assist the PwD to participate in conversations. Both Jerry (F3P) and George (F2F) appreciated friends who understood dementia and supported the PwD to engage socially:

> *"….it is getting quite difficult now and we're going on holiday with friends to Madrid. We went to Cyprus with them last year. His mum's got dementia so he knew when to stop talking and let her. The biggest problem we have is when there's four of you she can't get in on the conversation."* (Jerry F3P)

> *"Jane* [friend] *comes round he looks at her and she says "You don't know who I am?", and he says, "No". She says, "You know me, but you don't". She knows how to speak to him and she's pretty good…as she makes him laugh."* (George F2F)

Friends' ability to understand and support the PwD to converse within their abilities was fundamental to social activities continuing. It was regarded as important that the PwD could contribute to conversation and rely on friends and family to do so. Another factor that impacted on conversations, and contributed to the sense of a shrinking world, was the PwD's memory.

Memory

As the PwD's memory declined, and in some cases affected their ability to recognise family members, both their world and that of their family members shrunk further. Sharon (F4D) captured the distressing nature of this experience:

> *"They go around to your brother's on a Friday night, when Jane is there for dinner. The kids* [grandchildren] *see her there but… last time it was a bit heart breaking for them… she didn't recognise them."* (Sharon F4D)

Memory symptoms also presented challenges in relation to losing and forgetting things which families found frustrating. The PwD's support needs put pressure on family relationships, as the discussion below between a couple (Clare and John, Family 5) illustrates:

> *"It was your keys that really drove me to distraction – always been pretty bad with keys. The day that you knew where your keys were… in the end I got so fed up with it, I wouldn't look for them anymore. I refused to look for them. Thing is, I couldn't cope with it any more. It sounds a silly thing, losing my keys all the time, but it nearly drove me round the twist. Our daughter got us a key finder … that was quite good on occasion. He'd lose the van keys, he'd lose the house keys, you know he'd lose it."* (Clare F5P)
>
> *"But that plays an important part of my life…….the keys, because of the job I used to have a small van."* (John PwD5)
>
> *"Important enough to lose your marriage* [laughs]*? Enough to send you round the twist……* [laugh] *But where would I go?"* (Clare F5P)

The changing relationship between John (PwD5) and Clare (F5P) demonstrates the shift that the PwD goes through, from independence to dependence. This shift does not go unnoticed by the PwD, as illustrated by Mary's (PwD1) description of feeling a loss of 'self' that undermined her confidence:

> *"I said to him you know the person I used to be I'm not anymore. My confidence has gone completely. I don't trust myself."* (Mary PwD1)

Nigel (F1P) responded by reassuring Mary that he understood that her behaviour was simply due to the dementia:

> *"I know you're ill and… make mistakes, but that's just all part of the illness. I don't want to make a song and dance of it saying you stupid fool, you should have looked."* (Nigel F1P)

As she grew increasingly reliant on Nigel, Mary reported feeling closer to him, but also acknowledged she needed his help to 'control' the impact of the dementia:

> *"Nigel is there and Nigel controls me. Because you see with me, I have a short temper. I think that's how the dementia affects me, I get frustration and he pulls the reins. He goes* [puts finger over lips - shush sign] *like that. Tells me to be quiet… If not, I open my mouth and away I go*." (Mary PwD1)

In this case, the carer's support made the PwD feel safe in the knowledge that he would contain her emotions and reactions. She acknowledged that she needed his support and that it helped her maintain good relationships with her extended family.

The impact of the dementia symptoms on the PwD resulted in changes in relationships within the family, which could be distressing. The preceding discussion captures the impact of these changes, both in terms of the PwD's needs and the additional responsibilities that fall to the carer as a result. The balance within the relationship shifts, as the PwD becomes more dependent on the family member. These changes also impacted on family activities, as discussed next.

Activities

The interviews gave an impression of the carer increasingly entering the PwD's world in an attempt to maintain their independence and previously shared activities; however, the effort required to do so resulted in the carer needing to withdraw, as described above. Mary (PWD1) found this frustrating but at the same time acknowledged that it was necessary:

> *"He's the only person here so I have a go at him. I blame him that he's taken over my life, that I haven't got a life anymore, that everything is decided for me. You know things like that, it really gets to me… I feel like he's taking over my life… makes all the decisions for me, but then again I think if I didn't have him, who is going to make those decisions for me? I would have to make them and most probably they would be the wrong decisions."* (Mary PwD1)

This provides another example of how the world 'shrinks' as the dementia progresses and the PwD becomes increasingly dependent. Meanwhile, the carers felt sadness about the loss of shared and personal activities associated with the shrinking world of the family unit.

Families shared their experiences of how changes in activities impacted on them. Ann (F2M) referred to reaching a point where she had to accept the changes and acknowledge that she had done everything possible to fight the dementia and support Steven (PwD2):

> *"I've noticed he's losing interest… used to play Scrabble, and … Sequence. We played regular so I thought yesterday I'd get them out. Well, Sequence was a loss and so was Scrabble. I felt so sorry because only me and him used to play it. I thought that's a shame as he was quite bright before, but not now. I can't fight, we've done everything we possibly can…. He loved walking,*

> *but he's not keen now. I took the dog out last night and he didn't even want to do the short walk. He's lost a lot since we started…"* (Ann F2M)

The PwD's loss of skills and abilities are also experienced as family losses. The loss of familiar activities reduces options available for shared activity contributing to the 'Shrinking World' that they find themselves inhabiting. Awareness of these losses and the increasing challenges that they faced was difficult for them to deal with. There was a sense of loss in relation to the future they had envisaged. The knowledge that dementia is a progressive disease made the future appear bleaker and led to feelings of entrapment, as described by two carers below:

> *"It's like a life sentence isn't it really?"* (Clare F5P)

> *"For her it's… well I don't know what it's like to get up every day knowing you're getting worse. I had prostate cancer several years ago but at least you have a chance of getting better. I got over that and got through it. Whereas with this she knows every day she's getting a bit worse. It would be quite difficult you know. It's difficult for me, so it must be even worse for her now. I think it's going to go the other way and she will probably not know what's happening and at some time and I'm going to have to try and live with that you know."* (Jerry F3P)

The fact that Clare refers to YOD as a life sentence indicates an acceptance of its permanence and irreversibility. Both quotes acknowledge that, once the 'Shrinking World' stage is reached, there is no going back because of the progressive nature of dementia.

It was a common experience among PwD's for friends to stop inviting them out. Even if they were invited, they felt unable to accept for fear of not receiving the necessary support:

> *"Because I used to go out with them, now they don't even bother to tell me. Not that I'm going to go, because I wouldn't go… they go to London to the shows and all that… I wouldn't go. I would go with him and as the care he gives me my friends wouldn't give it to me. They would expect me to keep up with them and I wouldn't be able to… I would get lost in London and I would panic. Even here I would get lost."* (Mary PwD1)

Mary continued by explaining why even going out locally was difficult. A lack of confidence and the fear of getting lost were serious concerns for the PwD. The effects of the dementia hampered the PwD's ability to go out independently, another feature of the 'Shrinking World' in which they were living:

> *"There's many mornings that I'm by myself here… I've thought of going out but I'm afraid of going out by myself… because I'm thinking I might get lost. I do think of these things, but… I just think I'll just stay here."* (Mary PwD1)

Being unable to work or participate in activities left the PwD with little to do. They had to stay at home with nothing to occupy them when the carer was working, resulting in feelings of boredom, yet engaging in activities outside of the home was also difficult due to the impact of the YOD. Families reported PwD's lost confidence to participate in social activities which prevented them from doing things that they used to enjoy:

> *"I've always been very active…. I used to go away with my friends at the weekends. I don't get to do those things anymore… I used to travel a lot by myself going to Europe. I don't do that anymore. Well I wouldn't go by myself now."* (Mary PwD1)

This shows how difficult the losses can be for the PwD to deal with. As their abilities and confidence to engage in activities independently diminish, their world and experiences shrink. Families suggested that, if transport was available, it would offer more opportunities for the PwD to access groups whilst the carers were at work:

> *"It would be nice if there was more clubs for them to go to and get picked up, because obviously with us both working that's hard."* (Sharon F4D)

Family 3 appreciated transport being provided, but noted that having to plan ahead made it more difficult:

> *"The only down side with that is you have to book it quite early on but if you've forgotten, it gets a day or two before, they can't always do it… you have to really plan ahead with that, which is difficult because I don't always know until the day or two before whether I can do it for her."* (Jerry F3P)

The examples relayed by the families highlight how the carer's time became increasingly consumed with caring, impacting on the activities and interests they had previously enjoyed. The PwD's interests often took precedence over their own, as Nigel (F1P) explained:

> *"My weekends now are mostly at home supervising Mary when she's doing the cooking and baking and stuff like that."* (Nigel F1P)

At the same time, Mary (PwD1) also felt restricted as she loved cooking and crafts but was now limited to doing these when Nigel or paid carers were with her. This highlights that the shrinking process is a gradual one that affects the whole family. Carers slowly reduce their own outside activities in order to support the PwD to continue pursuing their interests for as long as possible.

However, at some point, the worsening dementia symptoms mean that most PwD lose the interest and ability to engage in hobbies and pastimes, or it becomes unsafe for them. John (PwD5) was a keen cyclist but on one occasion he forgot to tell anyone he was going out and got lost, resulting in his wife (F5P) reporting him missing to the police. He was found late at night lost, dehydrated and injured, but unable to recall any details of the day.

Family 6 described a similar experience whereby Michael (PwD6) left the house during the night and walked to another family member's house, unaware of the risks to himself. The fact that the PwD would put themselves at risk was concerning for the family. Consequently, working members of the family spent more time when not at work supporting the PwD to safely maintain their interests and hobbies, at the expense of their own. Families had to think about safety considerations in their own homes to keep the PwD safe, which was unexpected at their time of life:

> *"I just couldn't keep him from going out, in and out, in and out, and then he'd just gone and that was it."* (Clare F5P)

Particular difficulties were encountered when the PwD forgot where their carer was and became upset, often going to look for them if they were not where they expected them to be. This level of dependence impacted significantly on the family unit:

> *"Dressing and it's just that I have to be there all the time or you get worried don't you? When I have a shower in the morning you don't know where I am. He thinks I've gone out, thinks I've left him - so it's being there all the time. They've talked about respite but we have to get Social Services to refer him and I've got an appointment tomorrow, so that's nine weeks from when he first got referred."* (Beryl F6P)

Families found different ways of supporting the PwD to meet their everyday needs and keep active. Paid carers were key and all the families used them to support the PwD in some way.

Paid Carers

Paid carers supported families to cope with their changing needs and to maintain the PwD's routine and interests. Some carers helped them with hobbies and going out which worked particularly well when there was an established relationship with the PwD, although sometimes there were communication issues between the carers and other family members. One PwD felt her relationship with her regular carers was good but refused to accept replacement carers if they were on leave:

> *"I've got two* [paid carers] *and one phoned in sick and the other one couldn't come, and they* [the care agency] *say well you've got to go singing. But it doesn't matter I won't go singing. Don't send me anybody else, I don't want anybody else. I said to Nigel that when they run out I don't want anyone else. I don't! Because for me, even though my girls* [paid carers] *are lovely. It's an invasion of privacy."* (Mary PwD1)

Sometimes the PwD forgot they had paid carers or told them they were not needed. When this happened the care company would often call the family carer who then had to try to manage the situation. Alternatively, the care company might not tell the family carer that the PwD had sent them away and they only found out when they got home, leaving them to contact the agency to see why the carers had not provided care as agreed. Matthew (F2P) found a phone app used by the agency helpful as it enabled him to see when the carers had been in and read about what they had been

doing with Steven (PwD2). This also provided topics for discussion when he got home.

Paid care presented challenges for both the PwD and family members. However, when it worked well, it helped maintain the PwD's confidence to continue engaging in activities they enjoyed, and kept them active, which reduced the carers' concerns about the PwD when they were at work.

Summary

This chapter presented the study findings, demonstrating the impact of YOD for the family and the three clear stages experienced. Beginning with the uncertainty experienced before the diagnosis is confirmed, followed by the 'Changing World' families find themselves in once they receive a diagnosis, during which time they adapt and change. Finally, they undergo a shift towards the 'Shrinking World', with fewer opportunities for the PwD to participate in activities within and outside the family. These stages are experienced by the whole family unit with roles, relationships, activities, employment and interests all impacted by the YOD. The 'Uncertain World' sees the family experiencing a period of uncertainty about the cause and nature of the changes occurring, together with long delays in reaching diagnosis, while a lack of information and support for both the PwD and their family members make it worse. Consistent support and information was provided by the Alzheimer's Society and Dementia Cafés, although they often only found out about these accidentally.

Confirmation of the diagnosis gave the families some certainty, as they then entered a ‘Changing World’ in which they adapted to living with the YOD. During this period there were impacts on employment and finances and most family carers had to make employment-related changes in order to balance family finances and care for the PwD. Families encountered barriers when applying for benefits, relating to their age and eligibility. Families moved in and out of the ‘Uncertain’ and ‘Changing’ worlds as the YOD symptoms progressed. During this time, the changes and adaptations they made in response to the impact of YOD resulted in a reduction in activities and altered roles within and outside the family unit. It was not only the PwD who experienced a reduction in activities and interests as their skills deteriorated, but also family members, whose activities and interests took second place to the PwD’ s needs. The declining ability to participate in activities, employment and socialising reduced the role of the individual with dementia within the family, while the whole family experienced a reduction in activities that they used to do. Thus, the world of the individual with dementia and the whole family appeared to shrink. The data revealed that, whilst the families could fluctuate and move between the ‘Uncertain World’ and the ‘Changing World’, once they entered the ‘Shrinking World’, there was no going back. The next chapter will discuss this in more detail using a model to demonstrate the process of movement between these ‘worlds’.

Chapter 5: Discussion

Introduction

This chapter is concerned with the findings from the analysis that identified three stages of impact that the family with YOD experience. These findings have informed the development of a model of the impact of YOD the families experience using the three stages identified from the data, which will be explored and discussed in relation to the literature paying specific consideration to the movement between the Uncertain World, Changing World and Shrinking World.

The aim of this research was to examine the impact of YOD experienced by the family unit to gain a better understanding of their needs and describe how the family adapted to the diagnosis of YOD. It aimed to document the changes that occurred within the family, exploring how the roles are affected both within and outside the family. Overall the research focus was to enhance the current understanding of how a diagnosis of YOD impacts on the family as a whole to inform services of their support needs.

A brief summary of the research findings from the previous chapter will be provided prior to presenting the *'Three stage model of the subjective experience of families living with young onset dementia'*.

Uncertain World

The Uncertain World stage was described by the families before a diagnosis was given, but where changes occurred causing uncertainties to ripple throughout the family. The PwD's role within the family was impacted where household chores, hobbies, social activities and employment were affected. Family members recognise changes and support the PwD in ways they had not done previously. Health advice was sought and time to reach diagnosis was extensive. During this stage the family experience great uncertainties that touch all areas of their lives.

Changing World

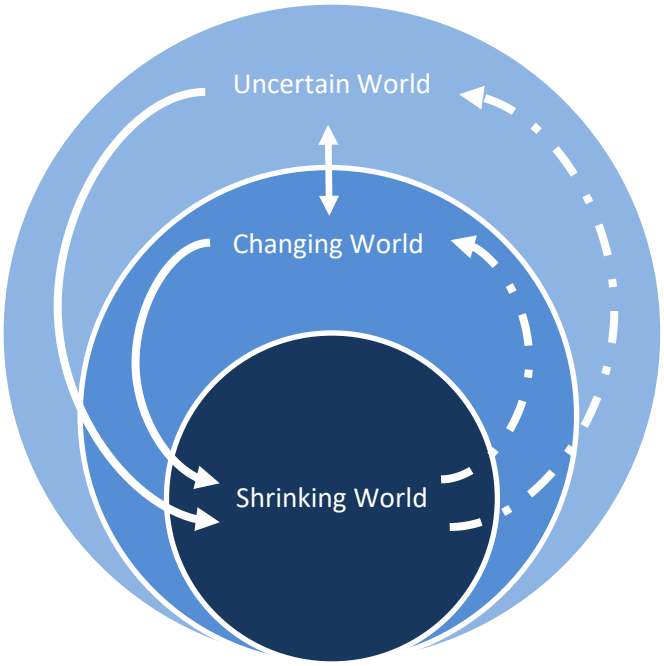
The Changing World was the stage where the diagnosis of YOD provided some certainty to the changes. Although some families expressed relief receiving the diagnosis, they also experienced it as a shock and confirmation of permanent change in their lives. During this stage the families make changes to maintain the PwD activities and role, however this impacts on the family members by having their own hobbies, activities and roles replaced with supporting the PwD to maintain theirs.

Shrinking World

The Shrinking World represented a stage described by the families where YOD impacted on roles within the family, community and as a family unit finding hobbies, employment and social activities became increasingly difficult to the point where families were unable to continue many activities, entering a shrinking world. The

stage was described as a one way process not fluctuating as in previous stages where families moved between the Uncertain and Changing World.

Figure 5.1: Three stage model of the subjective experience of families living with young onset dementia



Three Stage Model

The data analysis process identified the three-stage model summarising the impact of YOD on the family. The family as a whole unit move through the stages described above in the dementia journey. Movement occurs between stages and they overlap, however once the Shrinking World is reached movement back out of this stage becomes significantly reduced. Hoppe (2019) argues there are three clear patterns in how uncertainty shifts pre-diagnosis being *'Accepting and maintaining uncertainty,*

Finding explanations and Taking action', which has similarities to this study's findings, being three stages of YOD that impact on the family unit, supporting my model of movement and overlap between the stages of impact. Hoppe (2019) recognised three patterns can overlap with the person with dementia and their family shifting between them, reflecting my findings of movement between the stages of impact with a continual shift towards the Shrinking World where movement between stages is severely restricted or ceases. I liken this to the tide with the families shifting between each wave with movement between the waves representing the overlap of stages, but all the time moving towards the Shrinking World where the tide of YOD restricts movement and the families become stuck in the Shrinking World.

Discussion

The over-arching themes of 'Uncertain World', 'Changing World' and the 'Shrinking World' will be used to present the discussion followed by the impact of the model. In each section the impact of the YOD will be discussed and the challenges that families encountered.

Uncertain World

Diagnosis

This study found diagnosis was protracted leaving families in limbo for long periods where uncertainty became the only certainty and families found this a challenging stage. Campbell et al, (2016) identified people live with uncertainty as they *'transition from pre-diagnosis to a diagnosis of dementia'*, and recognised four phases of

transition to reach diagnosis. It is argued that living with uncertainty can have advantages due to families still having hope and continuing to live their lives (Hoppe, 2019). This study found families with the most recent diagnosis displayed levels of distress supporting the stages identified in the model with transition occurring from the Uncertain World to the Changing World. In addition Millenaar et al (2017b) argued that the severity of dementia does not impact on the quality of life similar this study where families with recent diagnosis presented with less severe dementia but showed higher levels of distress. This suggests that as families move through the model stages from the Uncertain World to the Changing World there is an acceptance and changes including strategies to manage the difficulties. All families reported the period leading up to diagnosis as stressful which has been seen in other studies (Sweeney et al, 2015; van Vliet et al, 2011). Symptoms of YOD often attributed to age-related issues such as stress, work or depression which make diagnosis difficult (Hayo, 2015), also indicated by my findings showing diagnosis was problematic for the families (van Vliet et al, 2011). Although there are similarities for people with LOD (van Vliet et al, 2012), the challenges are emphasised by the life stage younger people are in with employment and financial responsibilities such as mortgages that older people do not have.

Many studies recommended that early diagnosis would alleviate uncertainties experienced (Kilty et al, 2019; Armari et al, 2013). Being able to replace the uncertainty experienced with certainty is identified by Campbell et al's, (2016) four phases of transition to diagnosis being, *becoming self-aware, being referred, undergoing tests, and adjusting to the diagnosis.* These phases, focused on the period to diagnosis, are reflected in this study with the families moving through the

Uncertain World into the Changing World and the need to expedite the diagnosis process. Giebel et al (2020) identified that professionals wanted to achieve a quick diagnosis to support families, but were reluctant to rush and misdiagnose. This is especially important considering the limited treatment to offer. Families often had repetitive tests and Novek et al (2016) found that people with YOD waited for a diagnosis three times longer than people with LOD. Additionally, services are challenged by the features of YOD being wide ranging, making misdiagnosis common (Ahmed et al, 2016; Roach et al, 2016; Robinson et al, 2015). For example not all people have memory issues which would be expected as a predominant symptom of dementia (Hayo, 2015).

Delayed Diagnosis

Contrary to my study that found once the symptoms had been recognised as problematic families sought help, Hoppe (2019) identified that families can avoid seeking help extending the pre-diagnosis phase. Flynn and Mulcay (2013) and Lockeridge and Simspon (2013) identified difficulties with diagnosis and a lack of support for the PwD and their families as factors in the delay in diagnosis which reflects my findings. Families reported lengthy wait for diagnosis and multiple referrals to different specialists, and following each referral, the family end up back at the GP causing further delay to the whole process and leaving the families cycling between the GP and services. This study identified disjointed communication and sharing of information, with issues between services. For example, statutory services had to verify the diagnosis made by a private health provider for Family 6 to move along the diagnosis pathway demonstrating the common delays experienced. Lack

of services has been recognised in previous studies (Kobiske et al, 2019; Millenaar et al, 2017a) or that services were not appropriate for younger people (Cations et al, 2017) leading to missed opportunities for early support (Kilty et al, 2019). Hoppe (2019) points out that services only become available after diagnosis has been made, leaving families without access to specialist services in the Uncertain World stage.

Draper et al (2016) suggests that the time difference for younger people to be diagnosed with dementia is delayed, with almost half receiving a non-dementia diagnosis with psychiatric disorders being most common, especially depression, before receiving the dementia diagnosis. Reluctance from professionals to investigate dementia due to the person's age was found (Roach et al, 2016), however once YOD is ascertained they reach final diagnosis quicker than LOD (Draper et al, 2016). Waiting for diagnosis was difficult for the whole family experiencing anxiety due to the uncertainties supported by studies identifying it as a negative experience (van Vliet et al, 2010a; van Vliet et al 2010b) with unmet needs (Baptista et al, 2016). Campbell et al's (2016) recommendation for provision of transparent information regarding assessments including the time diagnostic processes take would help prepare families at this uncertain time of what to expect.

This study recognised after diagnosis that participants reported symptoms had been present for some years, describing something had not right and LoBue et al (2016) found similarities with changes occurring but not being significant enough to be classed as clinical manifestation of dementia. The uncertainties stretch across many

areas of the families' life, experienced by the family as a whole unit. They are uncertain of the cause of symptoms, uncertain of where to get help and advice and experience uncertainty with employment.

Seeking Help

Seeking help was also detected as a delaying factor, described as a time lapse between first symptom and diagnosis (Werner et al, 2009). Families commonly do not recognise symptoms with the gradual nature and often it was people outside the family home that detected changes. Robinson et al (2015) connected this to family members compensating for the PwD's symptoms and this is an example of where uncertainty crosses over into the Changing World. However this study identified lack of services as a major factor in seeking help. Families were confused with little awareness of YOD combined with lacking information, pathway and support available, which was a common theme across the literature (van Rickstal et al, 2019; Rodda & Carter, 2016; Ducharme et al 2013). Barca et al (2014) identified similar findings with insufficient information for the PwD and their carer, along with the general population lacking awareness.

Information

My study found that PwD are not given information about YOD and do not have the diagnosis explained directly to them. Family carers felt that their loved one had been let down by services not being told about dementia or given information and support to understand. Whilst not a new finding (Millenaar et al, 2017a; Millenaar et al,

2017b), it demonstrates the gap in PwD being involved in the process pre and post diagnosis, which only serves to disconnect the PwD from the situation reducing their voice and opportunity for informed decisions.

Changing World

Work

Employment changes feature in the Changing World impacting on everyone within the family. The PwD's employment often ceases resulting in loss of occupation whilst impacting on family members with increased financial responsibilities and caring role for the PwD.

People with Dementia

Entry into the Changing World is seen for PwD with employment ceasing if it has not already done so. Rabanal et al (2018) found similar identifying employers were often first to notice signs and symptoms. My study found changes at work for PwD were early signs and symptoms of YOD. For example Family 6 experienced work triggering the medical examination due to the presentation at work and Family 2 saw the PwD change jobs as the symptoms started to impact on his role at work. Loss of employment sees their role as an employee end along with daily routine and income. The response to this is twofold with a need for activities and safety concerns for the person being at home alone.

The issue of wandering was raised participants where the PwD forgets their family member is at work and they wander looking for them. The families found it challenging to balance the PwD's safety whilst maintaining their independence. One example was encouraging the PwD to prepare dinner to help maintain skills, promote independence and provide activity during the day, balanced with the individual's safety with not cutting themselves or forgetting the cooker is on. This dilemma results in the safety becoming paramount to the PwD's need for activity and independence, showing a correlation between employment ceasing and meaningful activity during the daytime. This study identified that paid carers were an important part of supporting PwD to continue activities, however they also reported they were intrusive. Roach et al (2016) found that meaningful activity for the PwD was key to positively impacting on the family unit's ability to cope with changes within the dementia pathway whilst maintaining '*continued biography and sense of self*', and yet Carter et al (2018) found that people with YOD are more likely to have unmet needs in 'important areas of life' as reflected my study.

Main Family Carer

The Changing World coincides with the main carer making changes to their employment to adapt to the increasing care needs. Coping mechanisms employed took various forms such as changes to work patterns, reducing working hours or working closer to home. This finding is supported by Bakker et al (2010) who found carers commitment to the PwD replace their own interest and activities. Losses are experienced such as long standing relationships with previous customers and co-workers, reduction in earnings, daily routine whilst impacting on their perception of

their role in the community. This demonstrates how YOD impacts on the family as a whole unit with changes for all members.

My study showed those who gave up work to care for the PwD experience loss of self and role in the community. The working role is perceived to validate membership of society and being a ‘real person’. Loss of a work role impacts on the carer’s perception of self-worth and value in society. The unexpected nature of supporting someone with YOD added to the challenges, as families were unable to see their plans for later life. Rabanal et al (2018) recognised the needs of people with YOD was different to those with LOD and recommend people with YOD should be defined as a group in their own right, with their own characteristics to support the development of specific YOD services. Carter et al (2018) found that carers of people with YOD are more likely to use informal care systems than statutory services due to not wanting to be within ‘dementia’ services, although families in my study reported activities were not suitable in formal services due to being fit and more active reflecting Cations et al’s (2017) findings.

Sikes and Hall (2017) related the loses experienced in relationships, roles and the perceived future of the disease was experienced as ‘pre-death grief’, which my findings relate to with the families description of their experience of moving through the stages from the Uncertain World to the Shrinking World. Losses appeared to be experienced more by family members than the PwD within the data, which may be due to the symptoms of dementia, although this could be in line with Millenaar et al (2017b) who recognised a link between the PwD awareness of the dementia and

higher quality of life with being able to have some control and choice over adaptations and acceptance.

Barca et al (2009) identified gender differences in the roles and responsibilities that family members took on, however this study did not highlight specific gender related differences within the family roles which may be due to the number and diversity of the families that participated.

Family Unit

The families in my study highlighted the difficulties in maintaining social activities and friendships due to the changes in communication, and that ultimately there was a reduction in social activities. Wawrzicny et al (2016) identified reduction in social network serves to impact further loss of communication skills. This study found that the social activities became harder as the PwD would be left out of conversations leaving the family carer feeling guilty showing the impact on the family unit. Similarly the reducing activities within the home reduce as the safety of the PwD takes priority, a finding also captured by Johannessen et al's (2018).

Shrinking World

Duggan et al, (2008) identified a *'shrinking world'* occurs for PwD with a reduction in independent activities outside of the home feeling safer to stay closer to home. Similarly, this study found the whole family experienced a shrinking world as the dementia progresses with the carer's activities, interests and social network also decreasing where they replaced these with the PwD's needs. Bakker et al (2014)

recognised the carers' quality of life and unmet needs of the PwD were correlated. This is reflected in this study with the carer's interests shrinking being replaced by maintaining the PwD's interests and hobbies. This also supports my findings of the impact on the whole family unit. Examples can be seen in Family 4 where the son cared for his parent with YOD, also the parents in Family 2 where they felt they should be slowing down but having to continue to support their son because of the YOD. This study found family members described their own interests and activities gradually replaced by the PwD's interests and activities similar to that of a parent-child relationship. Similar changes in relationships between family members and subsequent difficulties have been identified in other studies (Busted et al, 2020; Flynn & Mulcahy, 2013; Barca et al, 2009). My study identified changes in all relationships within the family as the dementia progressed.

Services

Services lack specialist skills and awareness of the signs and symptoms of YOD (Hayo, 2015; Bokberg et al, 2014) which leaves people without adequate support (Flynn & Mulchay, 2013; van Vliet et al, 2010a). Flynn & Mulcahy (2013) also found that the younger the person is the less support they receive, which is reflected in my study findings with families not being able to find respite care to enable the main carer to continue to work and services offered during working hours preventing those in employment or supporting the PwD to access them.

Families find specialist YOD statutory services valuable, but cannot access them easily. Barriers include GPs lacking knowledge of what is available and the younger

age. Services are often available through non-statutory services like the Alzheimer's Society but without signposting they are not know about. This highlights the lack of awareness of specialist services and supports the finding that specialist YOD services are lacking and sporadic in availability (van Vliet et al, 2010a; Werner et al, 2009). This leaves families accessing mainstream dementia services not geared up for younger people and their specific needs (Werner et al, 2009).

The quality of services available is an issue, as Millenaar et al (2017a) points out the number of services does not indicate the level of unmet need, although unmet need relates to the availability of services. This supports my findings where families reported difficulties in the PwD having activities or access to respite services to enable the family member to work. It is argued by Kilty et al (2019) that the lack of appropriate services is difficult for professionals too, as they are constrained by what they can offer people with YOD and their families.

Information

Families found that there was a lack of information, also identified by Campbell et al, (2016) and Flynn & Mulchay (2013). Families specifically recognised the PwD were not provided information or spoken to individually by professionals in statutory services which was a gap identified by this study. In contrast to this study, Lockeridge & Simpson (2013) found carers felt that there was no benefit for the PwD knowing about their diagnosis and chose not to discuss it with them. This is not reflected in my study, and furthermore Millenaar et al (2017b) found that people with YOD who have an awareness of the dementia have a higher quality of life where

they can have some control over care choices and adaptations. Campbell et al (2016) recommended that people would benefit from specific information related to the assessment process with timeframes to help alleviate some anxiety whilst waiting for diagnosis. Stokes et al (2014) makes an important point that the timing of information for PwD at diagnosis, on progression and what is ahead, is needed with particular attention to the manifestations of dementia and ways of coping with dementia.

Summary

The chapter has discussed the findings from the data analysis in relation to the literature paying attention to the development of the model and movement between the stages. The next Chapter explores how the research questions were addressed, discusses the limitations and outlining the implications and recommendation from the study.

Chapter 6: Recommendations and Conclusion

This chapter will present a brief overview of the findings and the three-stage model, followed by an exploration of the research questions, summarising how the study addressed them. It will then discuss how this related to previous research, followed by the limitations, the sample and any problems that arose in the study. Lastly, the implications of the findings will then be discussed along with recommendations for practice.

Overview

The key findings of this study led to a three-stage model that emerged from the three over-arching themes identified in the data, namely, the Uncertain World, the Changing World, and the Shrinking World. The *'three-stage model of the subjective experience of families living with YOD'* describes the stages of impact that families go through when a family member has YOD. The significance of the model is that it identifies the middle stage, the Changing World, as the optimum time for families to adjust and adapt in order to live well with dementia for as long as possible. If services make it their key objective to extend the time that families spend in this stage and maintain it for as long as possible, then it will give families greater potential to maximise their ability to live well with dementia and delay the 'shrinkage' experienced when they move into the Shrinking World stage.

Research Questions

The overarching research question posed by this study was: ‘What is the impact of young onset dementia on the family?’ This was divided into five specific sub-questions, and a summary of how each of these was addressed in the study follows.

What is the impact of young onset dementia on the family unit?

Diagnosis was seen as a critical point for the families as it represented the first certainty that they had experienced since embarking on a quest to identify the cause of the symptoms and marked the point at which they entered the Changing World stage. However, this was by no means the start of the journey. The data identified a stage that families experienced before receiving the diagnosis that was characterised by uncertainties, a lack of information and support, and which often extended over a long period of time. During the Uncertain stage, the families experienced the impact of YOD before knowing that it was YOD, with changes in employment, family roles and responsibilities. The uncertainty had a significant impact on the whole family because they did not know the cause of the changes they were witnessing or whether they were permanent in nature.

Diagnosis signified entry to a stage where families were able to employ coping strategies now that they knew what they were dealing with. By this stage, the PwD had ceased employment, and having a diagnosis enabled them to apply for benefits to help ease the financial strain on the families. It also meant they could seek help from support groups, and this was often when they came into contact with the

Alzheimer's Society, the Citizen's Advice Bureau and GP benefit support workers, where available. Diagnosis removed barriers to support and financial help in the form of benefits, although signposting to such help and support was limited. Family roles shifted to accommodate the symptoms of YOD, most notably through changes in employment, such as working location and hours, whilst the PwD experienced a loss of daily occupation.

During the YOD journey, relationships within and outside the family changed. The PwD experienced a loss of their former roles and social network, while family members increasingly found their own interests and activities being replaced with those of the PwD.

What changes occur in the family relationships and dynamics?

The first significant shift resulted from changes in employment whereby the PwD ceased paid employment due to the symptoms of YOD (often before diagnosis), while the family carer often made adjustments to their working hours or work location in order to support the PwD. This marked a significant change in terms of roles within the family and a shift from independence to greater dependency for the PwD. As a consequence of losing their employment role as well as that of financial contributor to the family, the PwD no longer had a regular daily routine and lacked meaningful activity, which often left a void in their day to day life. Family members responded by supporting the PwD to continue doing some form of activities using prompts for household chores, organising paid carers, calling the PwD during the day, and making adjustments to their own employment so they could provide more support,

for example by changing their working hours and work location so they could be nearer the PwD.

Often these changes had already started to occur gradually, during the Uncertain stage, before the family recognised the symptoms of YOD. The balance of roles and responsibilities within the family unit changed, as the decline in skills and abilities experienced by the PwD was compensated by increasing support from other family members, resulting in the PwD becoming more dependent on them. Similarly, family members' independence reduced in terms of their capacity to maintain their hobbies, interests and pastimes as they were required to provide a growing level of support to help the PwD continue with their own activities.

A decreased ability on the part of the PwD to communicate and hold a conversation as they would previously have done had a significant impact on family relationships. Family members described not sharing things in the way they used to, due to the PwD being unable to understand or needing things explained, which could make the family carer feel that the effort of having to explain something outweighed the benefit of trying to converse. Additionally, the PwD's ability to participate in social situations diminished, ultimately leading to a reduction in social activities with friends.

What coping strategies are used by families to deal with the diagnosis of young onset dementia?

The study identified the following coping strategies employed by families to deal with the YOD diagnosis: applying for benefits to help ease the financial burden; organising paid carers; making changes to the activities undertaken by both the PwD and family members; and making contact with support groups. Strategies used by families to remind the PwD to do specific tasks included the use of notes, telephone calls and prompts for household chores, although this reduced over time as concerns about the PwD's safety increased. When this happened, family members' own interests and activities were gradually replaced by the need to provide more extensive support to allow the PwD to continue their activities.

The significance of the research findings in this respect lay in identifying the model and recognising that the optimum stage for families to adapt and employ coping strategies was during the Changing World stage. Adjustments and adaptions made at this time promoted living well with dementia, and therefore the aim is to extend this stage to increase the use of positive coping strategies. This is particularly relevant to health professionals and services to allow them to focus their efforts on ways to extend this stage and maximise the impact of positive coping strategies, thereby delaying entry to the Shrinking World stage.

What sources of help and support do families use leading up to and after diagnosis?

Families reported that there was very little help and support available before diagnosis, and that the diagnosis was vital to enable them to access information and support services. It was noted that health professionals lacked awareness of the support services available, which, in many cases, meant that families were often left to seek support on their own. Families consistently referred to the Alzheimer's Society as providing valuable help and support, including Dementia Cafés, information, advice, activities and a social network.

Waiting for diagnosis was described as a difficult time for families, characterised by uncertainty and exacerbated by a lack of information, awareness from medical professionals, and support that would help them to manage the symptoms and uncertainties more effectively. During this time the GP appeared to play a pivotal role, as families returned to their GP pre- and post-diagnosis. Information was inadequate and most families reported that health professionals did not appear to think dementia could be an option until a late stage in the investigations. The relatively young age of the PwD resulted in other causes such as stress-related conditions being considered first, leading to misdiagnosis and delaying the point at which a dementia diagnosis was reached.

Are there additional needs (and services)?

The families clearly identified additional needs such as the need for greater awareness of dementia affecting younger people, information and signposting to support groups. A speedier diagnosis process would reduce the time families spend in the Uncertain World stage, and enable them to implement positive coping strategies to adapt to the YOD. Families would welcome suitable respite services that allowed the family carer to continue in paid employment or seek employment, in addition to more consistency in relation to paid carers. They identified a strong need for more information at the pre-diagnosis stage as well as at diagnosis and afterwards. The GP played a pivotal role in enabling the families to access further statutory services and was well placed to provide this vital information, implying that GP practices would be well suited to acting as a hub for information on YOD, as well as local services and support available for families, including benefit information.

In the next section the relationship between my study and the existing research will be discussed, as well as the study's limitations.

Relationship to Previous Research

The main strength of the study's findings lies in the formulation of the three-stage model. However, the findings also support previously identified needs and gaps in services for people with YOD and their family members. The study findings contribute to the literature by focusing on the impact of YOD on the family as a whole unit, including ensuring that the voice of the PwD is heard, which has not always

been the case in other studies within the existing literature. The identification of the *'three-stage model of the subjective experience of families living with YOD'* offers another lens through which to view the needs of the family and provides a focal point that services can use to maximise their effectiveness in terms of supporting families to live well for as long as possible with YOD. This model could also help families to identify the stage at which they can make changes that best support their needs and enable them to plan ahead in their YOD journey. The insight offered by the study into the three stages that families experience provides an opportunity to reduce the time they spend in the Uncertain World stage by expediting the diagnosis and then delaying entry to the Shrinking World by making the most appropriate adaptions and adjustments that will enable them to live well for longer with dementia in the optimal Changing World stage.

Limitations

It is important to recognise that there are a number of limitations to the study. Qualitative research by nature has some limitations in terms of generalisability, sample size, a lack of rigour (Anderson, 2010), the researcher's role and how the data are interpreted, as well as the time taken to conduct the research (Gray, 2014). It is important to address the limitations caused by the development and design of qualitative research.

Qualitative semi-structured interviews using a Framework (Ritchie and Spence, 1994) design were selected as the most appropriate method with which to uncover rich data about the lived experience of YOD for the families. This approach was time

consuming and required skills in managing large quantities of data, whilst continually analysing and consistently verifying the data. The extensive time resources necessary to apply Framework has previously been acknowledged, along with the complicated nature of charting and summarising data (Hackett and Strickland, 2018). However, it was worth the effort required to overcome these challenges as doing so enabled me, as a novice researcher, to navigate and manage the data in a systematic way that facilitated the discovery of the three-stage model. In addition to this, the support and expertise of my supervisors during the charting and summarising stage was vital in ensuring the reasoning for and verification of decisions made. This process supported reflexivity in the data analysis stage by encouraging discussion of the interpretation and charting of themes, as well as challenging me to justify decisions.

The Sample

The sample, although small by quantitative standards, was an acceptable size for qualitative research, consisting of 16 participants who adequately reflected the diverse nature of families. They represented a variety of relationships, including spousal, sibling, child-parent, parent-child and in-law relationships, which is considered a strength of this study because it added to the breadth and richness of the data. The sample did not include representation from the Black, Asian or Ethnic Minority population and although they were not excluded, it was noted that people from these communities were not seen during my visits to the Dementia Cafés. Future research should therefore consider recruitment approaches that could ensure

representation of this population, as well as the types of support and services accessed by this population with YOD.

Participants were recruited from a single county and, although it encompassed both urban and rural areas, it is important to consider that service provision and funding is often specific to geographical areas. Convenience sampling is known to risk both the omission of some characteristics and bias (Gray, 2014), and the decision to recruit from Alzheimer's Society Dementia Cafés may have excluded those families who only accessed statutory services, those who were naturally less sociable, and those who preferred not to use the Alzheimer's Society. However, it was appropriate to recruit participants in this way because the study was seeking those with experience of having a family member with YOD. In addition, recruiting from the Alzheimer's Society Dementia Cafés constituted an intentional step in the development of the study that was designed to address potential ethical issues arising from the researcher's employment role within an organisation that provided statutory dementia services across the county. It reduced the likelihood of coming into contact with, or potentially recruiting, people who may have been accessing dementia services within the researcher's organisation. Although this situation did not arise, it was important to consider what steps could be taken to prepare for it in the development stage. Firstly, the researcher ensured she did not engage in the direct provision of dementia services during the research period. Secondly, recruitment was only from Dementia Cafés run by the Alzheimer's Society as opposed to the NHS, and lastly, if she had previously encountered a family through her work, they would not have been included in the study.

Presenting information about the study at Dementia Cafés benefited the recruitment process and provided an opportunity to discuss inclusion and exclusion criteria, enabling the researcher to explore capacity issues at an early stage. This made it possible to hold early discussions with the interested parties and, where capacity was an issue, it was mutually agreed that they would not meet the inclusion criteria.

Problems that Arose

The inclusion and exclusion criteria set for the research resulted in some families expressing an interest but subsequently being excluded as one member declined to participate. It was noted that, in both cases where this happened, it was the adult children who were university students who declined, resulting in the whole family being excluded. On reflection, the inclusion criteria could have accommodated inclusion of the remaining family members, which would have facilitated representation of families with university aged children. Excluding them resulted in families with young adult children not being represented in the findings, and therefore it is worth considering including them in future research.

The desire to ensure that the voice of the PwD was represented led to the decision to hold family unit interviews followed by individual interviews, which generated data that were inclusive of the PwD's experiences and views. To enable PwD's voices to be heard, steps were taken within the research design, such as consultation with the Alzheimer's Society Service User Reference Group, which ensured that input was

provided by people with YOD and that they were able to verify the format and content of the research information. This process also gave the researcher greater insight into and knowledge of PwD and their needs, which was important as Keady identified that there is usually a power imbalance between participants and researchers, due to the type of language generally used in research (Keady, 2017b). By involving people with YOD during the research design stage, the study was therefore able to support reflexivity by helping to establish a shared language that promoted the participants' understanding of the research and thus redressed the power balance between participants and researcher (Keady, 2017b). This process also proved valuable and informative for the researcher when interviewing PwD and their families by providing background information about the issues they faced. An additional step intended to encourage the PwD to participate was to consider the responsibility that I had as a researcher to recognise the environments where people feel connected and safe (Keady, 20017b), which led me to attend the Dementia Cafés to discuss the study and to conduct the interviews within the family home. However, despite these steps, it was recognised that the PwD's voice is less distinct within the larger family units. This may be due to the difficulties that the PwD experienced in terms of participating in conversations with multiple people, as highlighted by Family 3 in the findings, which could constitute a possible area for further research.

At times, the families showed appropriate emotions in response to sharing their experiences and feelings during the interviews. Although the levels of distress did not warrant stopping the interviews, it was noted that the two families who were tearful at times were those who had most recently received a diagnosis. The

possibility of emotional distress had been considered in the development of the study and, as a result, the decision was made to exclude families whose diagnosis was confirmed less than six months ago. However, families' emotional coping responses to diagnosis during the initial period following diagnosis could constitute a potential area for further research.

Implications of the Findings

The findings identified that the timing of provision of support and services is key, in order to enable families to make changes and adaptions that can be most effective in terms of helping them to live well with dementia. The model demonstrated the stages of impact of YOD that families experience and highlighted the need to reduce the Uncertain Stage and extend the Changing World stage. In order to achieve this, the diagnosis would need to be made at the earliest point possible, and the support, information and signposting provided by the GP and services would need to be increased, so that families could implement positive adaptive coping strategies to best effect during the Changing World stage. In turn, this would postpone the 'shrinkage' experienced by families and would thus delay their entry to the Shrinking World stage at which point adjustments and adaptions become more limited and less effective, as family members' roles and relationships within the family, community, and wider society are adversely affected.

Recommendations for Change

The most significant finding was the identification of the three-stage model, which, if used by services, could serve to focus attention on the most beneficial point for families to adapt in order to enable them to live well with dementia. Targeting the Changing World stage would maximise the efficiency of the input from services, thus supporting families to prepare for the future and reduce the impact of YOD on the family. The specific recommendations outlined below aim to address this by supporting families to prepare for the future and live well with YOD.

1. Dementia Nurse Practitioners

The first recommendation is to establish Dementia Nurse Practitioners, with specialist YOD skills and knowledge of local services, in GP practices to bolster support at the pivotal point for the PwD and their family. This role would support the GP practices in providing quicker access to appropriate advice, support and information, enabling families to make changes and adaptations thus minimising time spent in the Uncertain and Shrinking World stages. This would act to support the findings of the study to maximise the time spent in the Changing World where adaptions enable families to live well with YOD.

2. Access to Information on YOD

Families need quick access to relevant information on YOD. The study findings identified that the uncertainty of being passed from one service to the next without receiving information could be reduced if adequate information was provided. It is

therefore recommended, that all dementia services could provide information on their services including symptoms, assessment process, types of assessment and possible outcomes. Furthermore, it is recommended that the Dementia Nurse Practitioner could facilitate this by requesting services make information available to provide to the PwD and families at the point of referral from the GP practice. Families would benefit from this early responsive role throughout all stages and ultimately it could serve to increase the time younger people living with dementia and their families are in the Changing World stage promoting new avenues of interactions and activities to break out of the Shrinking World.

3. Involvement of the Person with Dementia

The study found an absence of information and support provided by professionals directly to the PwD. Families reported that the person with YOD was often not spoken to directly about YOD or offered time with professionals to discuss their own diagnosis. This leads to the third recommendation relating to the Nurse Practitioner role including the provision of specific information and direct involvement of the PwD to promote their engagement in diagnosis and beyond, ensuring receipt of information and provide opportunities to discuss the diagnosis, treatment and support throughout the pathway. This role could act to ensure the PwD is central to initial and subsequent contact resulting in a person centred approach through the pivotal point that people with YOD and their families return to throughout the pathway.

4. Access to Specialist YOD Support

The study identified a gap between initial referral to diagnosis and the pathway of support after diagnosis. For example, families reported they often found non-statutory services, such as the Alzheimer's Society, by accident or through word of mouth, suggesting families require an earlier link to these services at the initial referral stage. In addition, families found services were not always adequate to support the specific needs of people with YOD and their families. Therefore, two actions have been identified being, an increase in services with specific skills to support people with YOD and their families, and secondly to increase access to information available on these services.

As outlined in Recommendation 2, the role of the Nurse Practitioner is essential to provide the information, but additionally has potential to provide a link between statutory and non-statutory services including local commissioning teams, thus increasing access to appropriate YOD services. On order to achieve this the role of the Nurse Practitioner could extend beyond the GP practice in order to provide a two-way information loop between people with YOD and local services. The Nurse Practitioner could feed into service development with the commissioning team, supporting the establishment of services to meet the specific need of people with YOD and their families. Development of appropriate services requires statutory, non-statutory and commissioning bodies to work together to review current provision in each local area. Inclusion within the remit of the Dementia Nurse Practitioner would provide a link between people with YOD, their families, services, and commissioning creating the platform to develop appropriate service provision for PwD and their families in each local geographical area.

The above recommendations address the main finding of the study, being the *Three stage model of the subjective experience of families living with young onset dementia* (Figure 5.1), by seeking to maintain the person and their family in the most adaptive stage, the Changing World, for as long as possible. Establishing a Dementia Nurse Practitioner with the GP practice would enable people with YOD and their families to receive quicker access to person centred assessment, information and appropriate services. This role could offer a combination of specialist skills and knowledge of YOD, the services available, and act a link between service development and improvement with the families, thus reducing the impact on the family of YOD.

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Appendix 1:
Table of Literature

Appendix 1 – Table of Literature

Summary of Quantitative Studies

Author	Title	Sample / Location	Method	Key Findings	Strengths	Weaknesses
Hvidsten et al (2019)	Quality of life of family carers of persons with young-onset dementia: A Nordic two-year observational multicenter study	88dyads of people with AD and FTD and their carer from Nordic memory clinics	2 year prospective cohort study using QOL questionnaires and burden scale	QOL for all family carers decline and explained due to deterioration in people with AD, whilst QOL of carers of people with FTD remained stable. Depression in carers and make carers associated with lower QOL – at baseline there was not a difference between FTD and AD.	Recognised and used scales and questionnaire.	Limitation in sample size and follow up. Lost more men with YOD in follow up than women. Mixed population of spouses and other family carers
Kobiske et al (2019)	Pre-death Grief, Resourcefulness, and Perceived Stress Among Caregivers of Partners With Young-Onset Dementia	104 caregiving partners to people with YOD in USA	Cross sectional correlational design with convenience sample. On-line survey	Correlation between pre-death grief and perceived stress. Pre-death grief is linked to many losses – financial, social network and relationships. As resourcefulness and self-help increased so did relationship between pre-death grief and perceived stress.	Sample size Flexibility for participant to complete survey in own time Recognised scales used. First study to focus on effect of resourceful ness and pre-death grief/perceived stress for YOD caregivers.	Convenience sample Reliant on access and ability to use online platform. Cross-sectional design is one moment in time. Dementia stage, period of time partner caring, access and use of resources were not addressed
Millenaar et al (2017b)	Determinants of quality of life in young onset dementia – results from a European multicenter assessment	248 participants with AD and FTD NeedYD study Netherlands and Nordic	Used baseline data from 2 prospective cohort studies	QOL score related to disease awareness. People with AD lower on memory but higher of friend scale that people with FTD. Depression correlated with QOL – more depressed less QOL. Needs being met or unmet still associated with lower QOL – number of hours of care does not impact on QOL	Large sample and recognised study that data were taken from.	Varied nationalities unlikely to have comparable services and social networks. Only AD and FTD so excluded other dementias – reduced generalizability.

Millenaar et al (2016)	The impact of young onset dementia on informal caregivers compared to late onset dementia	220 YOD & 108 YOD PwD and Caregiver dyads NeedYD study Dutch	Prospective cohort follow-up study Questionnaires and scales to describe caregiver burden analysed with linear mixed models.	High levels of physical & psychological burden and poor health and quality of life for both groups, however carers of people with YOD were found to have lower quality of life for physical/mental health and perceive more difficulties due to the dementia.	Large sample with repeated measures every 6 months over 2 years provided data over period of time opposed to a snap shot.	Caregivers views and not PwD. Difference in time since diagnosis in 2 groups. Length of time longer for YOD group which could be why they reported lower mental and physical health. The measures may have been influenced by differing ages.
Dourado et al (2016)	Functional Status Predicts Awareness in Late-Onset but not in Early-Onset Alzheimer Disease	207 people with AD (52 YOD and 155 LOD from specific AD service Brazil	Cross-sectional Questionnaires Clinical diagnostic interviews, cognitive screening, laboratory tests and scans.	Q of L higher in people with YOD & LOD than their carers. No significant difference in burden between LOD/YOD carers. Functioning impairment predicts awareness in LOD but not in YOD.	Descriptive statistics used to illustrate sample characteristics. Stepwise regression models calculated awareness/clinical variables. Educational differences between YOD and LOD Good design to support person with dementia to participate - verbal and large visual display of choices	Small YOD sample may have led to being underpowered. Only assessed neuropsychiatric symptoms of depression, not other psychiatric conditions
Draper et al (2016)	Time to diagnosis in young-onset dementia and its determinants: the INSPIRED study	88 participants with YOD Professionals involved in another study recruited participants. Australia	Part recruited from an epidemiological study. Interviews	median time symptom to first consultation was 2.3 years and to dementia diagnosis was 3.2 years and family awareness 3.5 years and final dementia type diagnosis 4.7 years. Non-diagnosis included depression and MCI. Time to dementia diagnosis significantly longer if MCI or depression presented or if not AD or FTD type. Scans higher time to diagnosis.	Regression analysis used. Discrepancies in data checked with clinical reports. Independent dementia diagnosis was made by 2 experts not involved in the person's care. Findings relevant.	Family reports reliant of memory and dating onset of symptoms was imprecise. Gaps in GP information on initial assessment. Australian pathway Mixed recruitment - 2/3 from an epidemiological study, some self and some clinician recruited.
LoBue et al (2016)	Traumatic Brain Injury History is Associated with Earlier Age of Onset in Frontotemporal Dementia	678 selected from data set USA	Follow-up study Data set and 2 x Interviews with 3 questions	signs of decline in less than year of TBI and possible association of TBI and FTD.	Inclusion/exclusion criteria applied. Analysis of covariance used for age of symptom and diagnosis.	Missing data regarding age at time of injury - estimated age of symptom onset Unknown YOD/falls connection.

Bakker et al (2014)	The relationship between unmet care needs in young-onset dementia and the course of neuropsychiatric symptoms: a two-year follow-up study	209 dyad - patient/carer Netherlands NeedYD Study	Cross-sectional Structured interviews and questionnaires	Unmet needs in activities and tasks requiring eyesight, hearing or memory. Carers had unmet psychological needs. The person with YOD reported a higher quality of life than their carers. Carers reduced social functioning and physical health then general population. Correlation between social activities and mental health.	Large sample and Multiple regression analyses used. Inclusion/exclusion criteria applied. Multiple linear regression used Unmet needs in health-related quality of life is an important prerequisite for personalising care in YOD, which is key to enhancing quality of life. Part of larger study with independent literature review and protocol. Research team attended a training day for data collection.	Recruited through existing healthcare services probably missed uncommon types of dementia. Carers age range 18-89 Non-completers likely to have higher disease severity more likely female. Excluded some types of dementia.
Van Vliet et al (2012)	Time to diagnosis in young-onset dementia as compared with late-onset dementia	235 YOD & 167 LOD participants and carers Consecutive referrals Netherlands - NeedYD	Interview with carer and person with dementia and interview with just carer on signs, symptoms and onset. Demographic data collected and a scale of deterioration (GSD) applied.	Onset age for YOD 54.8 yrs and for LOD 75.8 yrs. Dementia more severe in YOD group. Spouses often carer in YOD but LOD children carers.	Large sample and comparison study. Findings useful between YOD & LOD. FTD longer regardless of age. Family history or living situation not a predictor of diagnosis time. Regression analysis with adjustments for variance.	Sample differences in carer and gender. Sample size unclear as change through paper. Differences in recruitment sites. MMSE unreliable FTD as numbers too small to analyse.
Armari et al (2012)	The Needs of Patients With Early Onset Dementia	57 - 18 people with YOD (10 female/8 male) 39 Caregivers Australia	Cross-sectional Team developed Questionnaire based on clinical experience. Public symposium to recruit.	Principle area for improvement - early recognition and referral along with diagnosis and treatment. people with YOD and carers had different priority areas.	Balanced YOD gender and carer type. Both person with YOD and carer participated. Chi-square used for statistical trends	Imbalance of family carer type and unclear definition of carer as 4 carers were health professionals. Predominantly spouse carers. Questionnaire not used before and not piloted. No discussion of limitations or ethical process in paper.

Figure 3 - Summary of Qualitative Studies

Author		Sample/ Location	Method	Key Findings	Strengths	Weaknesses

Busted et al (2020)	"Sometimes it feels like thinking in syrup" – the experience of losing sense of self in those with young onset dementia	9 PwD recruited by dementia consultants Denmark	Purposive sampling. Interviewed 2 PwD on own and 7 with their partner. Conversational interviews	Changes in family relationships PwD consider themselves a burden Need to involve whole family	PwD involved in the study. Reflexivity discussion in paper.	Varying interview setup with and without support. Conversational interviews would be impacted by partner or not.
Gelman & Rhames (2020)	"I have to be both mother and father": The impact of Young-onset dementia on the partner's parenting and the children's experience	12 participants - 4 mothers and 8 children of PwD (16-20 yrs old) USA	Semi-structured interviews analysed for core concepts and sub-themes using thematic narrative analysis	Not wanting to overwhelm mother - muting of child's experience Divergent perspectives of YOD Changing family structure. Difference in mothers and child's perceptions in support roles and impact on childhood.	2 people verified and checked the analysis until agreement reached.	3 phone interviews and 1 from notes as recorder malfunctioned Small sample from one geographical area.
Hoppe (2019)	Shifting uncertainties in the pre-diagnostic trajectory of early-onset dementia	41 participants 7 PwD and 39 family members Netherlands	Semi-structured interviews (27 individual and14 with 2 or more)	Accepting/maintaining uncertainty Finding explanations Taking Action 3 stage pattern	Included PwD	Recruitment from one organisation Mix of interview attendee number from individual to 2 or more.
Kilty et al (2019)	Constraints and ethical tensions in the area of young-onset dementia	9 Health care professionals from public, voluntary and private services9 Health care professionals from public, voluntary and private services Republic of Ireland	IPA convenience sampling semi-structure interviews	HCP - uncertainty, frustration and concern for PwD and family wellbeing. Barriers to timely diagnosis. Missed opportunities for early support. Lack of age appropriate post-diagnosis models. Rigid service eligibility. Professional tension	Implications for future practice changes regarding practice education and awareness of YOD	Small sample Transferability and generalizability.
Van Rickstal et al (2019)	Limited engagement in, yet clear preferences for advance care planning in young-onset dementia: An exploratory interview-study with family carers	15 Caregivers of People with YOD Belgium	Face to face semi-structured interviews - constant comparative method of qualitative data analysis and comprehensive coding of open-ended data.	2 overarching themes - engagement & planning for future and Preferences how to engage in advance care planning Lack of info on trajectory. Cares find it difficult to communicate in front of PwD. Guilt, protective inhibits ability to advance care plan.	Saturation achieved supporting analysis Independent review of transcripts conducted.	Specific to Belgium with focus on euthanasia not applicable in other countries.

Rabanal et al (2018)	Understanding the needs and experience of people with young onset dementia: a qualitative study	14 people with YOD	IPA with cross sectional analysis Semi-structured interviews Recruited from YOD support organisations and neurological NHS unit in Northern UK City	Four themes Process of diagnosis, impact of living with YOD, needs of people with YOD and living well with YOD. Need more information and awareness of YOD. Professionals need to deliver in a tailored way to meet the person with YOD needs.	Sample represented socioeconomic status, age and gender in the population. Identified areas for further research	Recruitment strategy likely skewed towards socially active people engaged in services. Regional impact of where study held. Small sample size (fair for qualitative)
Hoppe (2018)	A Sorrow Shared is a Sorrow Halved: The Search for Empathic Understanding of Family Members of a Person with Early-Onset Dementia	41 participants 7 PwD and 39 family members Netherlands	Semi-structured interview over period of 1 year	Empathy required for support not just dementia but loss of a parent. Difference between LOD and YOD is to big	Included PwD. Participants could choose where to be interviewed and family members	All in home except 2 in office
Aslett et al (2017)	'This is killing me inside': The Impact of Having a Parent with Young-Onset Dementia	5 children of parent with YOD 23-26yrs old UK	IPA semi-structured interviews	Relationship changes, shifts in roles and responsibilities, support for non-affected parent, support for self and the impact of living with own potential risk of dementia	Participants reporting own experience	Rural location of study Retrospective on childhood memories.
Johannessen et al (2018)	"To be, or not to be": experiencing deterioration among people with young-onset dementia living alone	10 PwD recruited from 6 memory clinics Norway	Longitudinal explorative descriptive study over 2 years. Individual qualitative interviews conducted 5 times with 6 month intervals.	Changes of identity. Carer reduce activities and replace with persons interests and need to maintain a 'normal life'	Longitudinal study and they argue it is transferable. Informs better understanding	Small sample in one country.
Millenaar et al (2017a)	Exploring perspectives of young onset dementia caregivers with high versus low unmet needs	20 caregiver Netherlands NeedYD study	Inductive content analysis – 18 transcripts reached saturation.	6 themes acceptance, perception of relationships, role adaptation, availability of services, social support and awareness in PwD No of services no indication of unmet need. Accepting diagnosis needs adjusted expectations. Availability of social support relates to unmet need. Important to communicate difficulties faced. Arranging the fight care easier	Perspective from caregivers experience – identified difference to needs of LOD	Spousal carers sample so not all carers.

				when PwD is aware of the diagnosis.		
Sikes & Hall (2017)	'Every time I see him he's the worst he's ever been and the best he'll ever be': grief and sadness in children and young people who have a parent with dementia	22 participants aged 6 -31 UK	Life history and narrative approach Self-selecting through online recruitment and snowballing for 2.	Younger relatives experienced pre-death grief associated with changes in the relationships. Services are patchy and few specialized in grief and bereavement counselling	Perspectives form children of PwD	Age range Gender make up.
Johannessen et al (2016)	Coping efforts and resilience among adult children who grew up with a parent with young-onset dementia: A qualitative follow-up study	14 (18-30) from 2 memory clinics Norway	Explorative, descriptive study to gain new knowledge. Follow-up semi-structured interviews	Mainly expressed better well-being then first interview. Main theme of Detachment with aspects of Moving apart; Greater personal distance; Calmer emotional reactions	Follow-up study Appears to show time allows adjustment.	Follow-up participants - some changes in living arrangements Metaphor analysis. Generalisability issues may be transferable. Norway system
Wawrziczny (2016)	Couples' experience with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics	32 (16 couples) France	Semi-structured interviews with IPA applied.	7 main themes being Protective behaviours; Divergence about help; Difficult to implement adaption; Protection to control; Do not recognise each other; 2 Strangers under one roof; There's no couple anymore	Useful findings regarding changes in relationship and time to diagnosis	Article only reports on 2 partners experiences. Themes underdeveloped – missed intimacy/sexuality Researcher skills = data bias
Johannessen et al (2015)	Adult children of parents with young-onset dementia narrate the experiences of their youth through metaphors	14 (18-30) 9 male and 5 female Norway	Qualitative phenomenological hermeneutic approach. Semi-Structured interviews with interview guide	4 core metaphors being My parent is sliding away; Emotional chaos; Becoming a parent to my parent; A battle	Analysed metaphors – unique. three-step metaphor analysis applied. Part of a follow-up study. (Johannessen, 2016)	Interview venues were not consistent. Metaphor analysis. Generalisability issues may not be transferable. Norway system
Roach & Drummond (2014)	'It's nice to have something to do': early-onset dementia and maintaining purposeful activity	20 participants from 9 families Canada	Semi-structured interviews using Framework analysis	4 themes of Diagnosis; Finances; Relationships; Meaningful activity	Sense of citizenship important. Framework analysis.	Non-statutory agencies. Family members females and all YOD male. Mainly spouses

Millenaar et al (2014)	The experiences and needs of children living with a parent with young onset dementia: results from the NeedYD study	14 (15-27) children of YOD parent Netherlands NeedYD Study	Semi-structured interviews Inductive content analysis	3 main themes - impact of dementia on daily life; coping with disease; the need for care and support.	Gender balance in sample Findings	Gender issues in YOD. Siblings may skew. High refusal rate – bias. Life stage differences
Barca et al (2014)	Nobody asked me how I felt: experiences of adult children of persons with young-onset dementia	14 with mean age 23 (12 daughters and 2 sons) Norway	Grounded theory with semi-structured interviews and stepwise analysis. Recruited by health professionals.	2 main themes being experiences in social relationships and experiences/needs related to services	Grounded theory and stepwise method. Children views of YOD parent	Mainly mothers/daughters 4 were adolescents Norway specific. Snapshot
Hutchinson et al (2016)	The emotional well-being of young people having a parent with younger onset dementia	12 young people (8-24) with a parent with YOD Australia	Semi-structured interviews Purposive sample - advertised in organisation. thematic analysis using a framework	Themes identified were Emotional toll of caring; Keeping the family together' Grief & loss; Psychological distress	9 prompted questions Thorough data analysis team and process.	Purposive sampling. Gender bias. Reliability on data recall Life stage differences 8 to 34 years most aged 19-33 at time of study.
Roach et al (2016)	'Nobody would say that it is Alzheimer's or dementia at this age': Family adjustment following a diagnosis of early-onset dementia	20 participants from 9 families Canada	Semi-structured interviews using Framework analysis	4 themes of Diagnosis; Finances; Relationships; Meaningful activity	Framework analysis applied. Follow-up study	Non-statutory agencies. Family members females & YOD male. Mainly spouses. Snapshot on its own.
Roach et al (2014)	'We can't keep going on like this': identifying family storylines in young onset dementia	5 families total 13 participants (32-76) UK study	Longitudinal narrative. Created biographies and analysed ongoing narrative.	Storylines identified Agreeing storyline; Colluding storyline; Conflicting storyline; Fabricating storyline; Protecting storyline	Narrative biographies analysed. Findings focused on family storylines unique	Mainly spouse pairs. Small sample. NHS recruitment Low recruitment rate
Ducharme et al (2013)	The Unique Experience of Spouses in Early-Onset Dementia	12 Spouse carers of YOD recruited sequentially via memory clinics. Canada	Qualitative study informed by principles for phenomenology. Semi-structured interviews.	6 themes of Difficulty managing behavioral/psychological symptoms; long quest for diagnosis; nondisclosure to the res and denial; caregiver role prematurely; difficulty planning for future.	Selection criteria. Data source matched aim.	75% AD diagnosis. Mainly males. Small sample via memory clinics

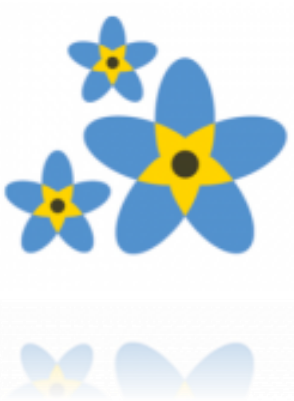
Flynn & Mulcahy (2013)	Early-onset dementia: the impact on family care-givers	7 family carers. Convenience sample recruited by Alzheimer's Society Ireland	Descriptive qualitative. Semi-structured interviews with thematic analysis.	4 themes emerged of Diagnostic problems; impact of caregiving; relationship change; Lack of resources	Inclusion criteria applied. Interview guide for consistency In-depth data collected	Convenience sample and small sample Burden tool restrictive
Nichols et al (2013)	When Dementia is in the House: Needs Assessment Survey for Young Caregivers	14 (11-18 young carers) for 7 families Canada & USA	Semi-structured focus groups via Skype.	7 overlapping themes - Emotional impact of living with parent with FTD; Caregiving; Coping; Symptoms; Diagnosis; Relationships; Support.	Skype enabled participants wide geographical area	Siblings may skew. Self - identified. Ethical issue Focus group leader and her children
Lockeridge & Simpson (2013)	The experience of caring for a partner with young onset dementia: How younger carers cope	6 (49-61) carers with YOD partner UK study	Semi-structured interviews IPA applied	4 themes - This is not happening; let's not have any more of this demeaning treatment; I've had to fight every inch; what will become of me	Gender balance in sample. UK study Semi-structured interview	2 widows at time of study Interview venue varied Snap-shot. Small sample
Roach et al (2011)	'It's easier just to separate them': practice constructions in the mental health care and support of younger people with dementia and their families	5 members of care staff - Purposive sampling UK	semi-structured interviews with staff	3 themes of Maintaining separation; Providing practical help; Acknowledging the family context.	Useful aspect of staff views of YOD families/support approaches	Interviews conduct issues. Small purposive sample Staff not just YOD services
Van Vliet et al (2011)	Caregivers' perspectives on the pre-diagnostic period in early onset dementia: a long and winding road	92 carers from larger study Netherlands NeedYD Study	Selected relevant parts of interview from larger study - secondary data analysis. Comparative analysis and grounded theory	7 themes - Changes in family member; Disrupted family life; Misattribution of symptoms; Denial; Lack of confirmation from social context; Lack of GP responsiveness; Faulty diagnosis.	Part larger ongoing study	Secondary data analysis – relevant data from interviews used. Gaps in records
Bakker et al (2010)	Needs in Early Onset Dementia: A Qualitative Case From the NeedYD Study	Single case study - a carer NeedYD study Netherlands	Single case study - Random selection from larger study. Netherlands and	3 main themes being Making choices in care; Conditions for care use; Involvement in care.	Detailed personal views experience highlighting changes needed to care.	Single case study Person with YOD's view collected via carer

Harris & Keady (2009)	Selfhood in younger onset dementia: Transitions and testimonies	US - 23 people with YOD UK - 15 carers of people with YOD US & UK	Grounded theory with purposive samples from 2 studies – one in UK and one in US	5 themes being Identity as a worker; identity of abandoned individual; sexual identity; family identity; and identity as an individual engaged in living.	Included PwD and focused on the impact of YOD on the person and the carer.	Difference in geographical areas - country and culture

Figure 4 - Summary of Mixed Method Study

Author	Title	Sample	Method	Key Findings	Strengths	Weaknesses
Cations et al (2017)	Why aren't people with young onset dementia and their supporters using formal service? Results from the INSPIRED study	86 PwD (64 interviewed with their caregiver) and 50 (PwD and caregivers) in 7 focus groups INSPIRED study Australia	Cross-sectional study of YOD epidemiology and subset included in 7 focus groups	barriers age, inaccessible, financial constraints. Mismatch of older Vs younger	Inclusion and exclusion criteria applies	Only 10 PwD included in the focus groups Small sample may have been underpowered. Lack of diversity and only 1 PwD living alone.
Svanberg et al (2010)	'Just Helping': Children living with a parent with young onset dementia	12 x aged11-18 years old - 50:50 gender, but from 9 families (3 siblings from 1 and 2 from another)	Grounded theory - in-depth interviews and 3 quantitative measures for triangulation.	4 main areas of: discovering dementia; developing new relationship; learning to live with it; going through it together	mixed methods and Triangulation. Only mixed method found.	Tool not used with children. Mainly males. Small sample quantitative = data weak only supplement qualitative & not representative. Majority of parents with dementia were male.

Appendix 2:
Poster on Research



Let's talk about dementia

Do you or someone in your family have young onset dementia?

Do you want to contribute to services for people under 65 years old with dementia?

We want to understand more about the impact of young onset dementia on families.

Information sessions will be held in local dementia cafes as follows:

Place – date

Place – date

Place – date

If you are interested in finding out more or cannot attend one of the sessions, please contact:

Nicola Armstrong

[redacted]

[redacted]

Appendix 3:

Participant Information Sheet

Participant Information Sheet

Study title

'The impact for the family of young onset dementia'

Invitation and brief summary

You are invited to take part in a research study on the impact of dementia for younger people and their family. Before you decide, it is important that you understand why this research is being done and what it will involve. Please read this information carefully and discuss it with your family to see if it is something that you and your family would like to take part in. If there is anything that is not clear or you want to discuss, please feel free to contact the researcher (contact details are below). Please take your time to decide whether you and your family wish to take part or not. Talk to others about the study if you wish.

What is the purpose of the study?

To understand how young onset dementia (dementia diagnosed before the age of 65) impacts on the family as a whole unit, and to use this understanding to inform and improve services for people with young onset dementia and their families. The research is being undertaken as part of a Professional Doctorate in Nursing at the University of Essex.

Why have I been invited?

This study is looking for families with one member diagnosed with young onset dementia to consider taking part to find what the impact of young onset dementia is on the family as a whole. Family members who are over 18 are invited and all members will need to be able to consent to participate. We are looking for 4 to 6 families to take part including the person with dementia.

In order to participate, you will need to:

- be able to consent to participate.
- be over 18 years of age
- be the person with young onset dementia or an immediate family member

Do I have to take part?

It is up to you and your family to decide if you would like to take part. This information sheet tells you about the study to help you make a decision. If you agree to take part, you will need to read and sign an expression of interest form and a consent form. You are free to withdraw at any time, without giving a reason. This will not affect the care you receive from any services in any way. This study is separate from those services and you can continue to use them whilst taking part in this study.

Why is the study being done?

Dementia in younger people presents different challenges for the person and their family than for older people with dementia. Younger people with dementia often have responsibilities connected to their age like employment, children living in the family home, and mortgages. Often services do understand the needs of younger people and their family. This is an important area to research to inform services how best to support the specific needs of the younger person with dementia and their family.

Many research studies focus on the individual perspectives, but this research thinks that a diagnosis of young onset dementia impacts on everyone in the family. This study wants to understand the impact for the family as a whole by listening to the views from the family. To do this the research aims to talk to between 4 and 6 families to hear their views and experience of young onset dementia.

What will happen if I take part?

If you and your family agree to take part, you will be asked to read all the information and complete some forms to ensure you understand what you are being asked to do. You will then be interviewed with your family and then interviewed individually. The interviews will ask you to talk about your experience of young onset dementia and what that has meant to the family.

What's involved?

If you and your family are interested in taking part, you will be asked to complete an Expression of Interest Form. This form is very short and tells the researcher that it is ok to contact you. The researcher will then contact you to arrange a family interview at a time and place that suits you and your family. The researcher will ask all family members to read the information leaflet and sign a consent form before the interview. At the start of the interview the researcher will discuss the study and you will be able to ask any questions about the study. The researcher will discuss consent to make sure everyone understands the research and is freely consenting to participating in the study.

The interview will take approximately an hour. The interview can be done in your home at a time convenient to all the family. Arrangements can be made for the interview to be held at an alternative venue if you would prefer. At the start of the interview you will be asked to provide some general information like your age and gender. Then the researcher will facilitate a discussion about your experiences as a family and how dementia for the younger person has impacted on the family. The family interview will be recorded.

The researcher will then interview each family member individually at a time and place that suits you. The individual interview is to focus on the individual views and personal impact of young onset dementia. The individual interview will be recorded. Your name and personal

details will be confidential which means that your details will not be used with any of the information you provide or in any reports.

What are the possible benefits of taking part?

Dementia not only has a profound effect on the person but also on their family. It is important that the family needs as a whole are understood to improve current and future services. This has the potential to improve the current and future services for many people. Some people find sharing their experiences a positive thing to do.

What are the possible disadvantages and risks of taking part?

You may find the time for the interviews causes you additional pressure. Some people find that thinking about the situation can make them feel low in mood or more stressed. If this is the case you are free to stop taking part in the research and it is important you seek support from your GP and local services to decide appropriate treatments that are most suitable for you. It is important that you maintain input from your regular services as this study is not designed to replace any social or health care you already have or may need in the future.

What happens when the research stops?

The study is expected to run for 3 months and when everyone's data have been collected, the results will be analysed. A report will be written which will be submitted to the university and may be published in a scientific journal. The information collected is totally confidential and no-one will be identifiable in any reports.

What if there is a problem?

If you have a concern about any part of the study please contact the researcher who will answer any questions you have. If you remain unhappy and wish to complain formally, you can do this. You can contact the research supervisor Dr Sheila Black by telephone [redacted] or by emailing [redacted]

Further Supporting Information

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time without giving a reason. If you withdraw you can tell us if you want your information to be included or if you would like it to be removed from the study and destroyed.

Will my taking part in this study be kept confidential?

All information collected will be totally confidential and will be kept securely in line with Data Protection principles and compliant with the Data Protection Act (1998). The data will not include your name, just a study number. A separate list will be kept securely with your name, contact details and study number. This is so the researcher can contact you, but as soon as the study is completed your data will be completely anonymised so you cannot be identified. Only the researcher will have access to your data for analysis.

If during the course of the research you share information, which raises concerns about your safety, the safety of others, criminal activity or malpractice of a professional then the researcher will follow NHS procedures. This is because the researcher is bound by a professional code of conduct and has an obligation to prevent harm.

What will happen to the research study results?

Results will be obtained from anonymised data and those results will be presented in reports, which may be shared with the University of Essex and may include publication. No individual participant will be identifiable and it will not be possible to link to any individuals once it has been anonymised.

Who is organising and funding the research?

The lead researcher is Nicola Armstrong, a Nurse Consultant working for [redacted] NHS Trust, who is conducting this research as part of a Doctorate in Nursing as a student at The University of Essex. The sponsor for the research is the University of Essex who is responsible for making sure the study runs in a proper way. There is no funding allocated to this research.

Contact details:

Thank you for reading this information and if you and your family would like to take part in the research please complete the expression of interest form and return to the researcher. If you would like more information before you decide to take part or not, please contact the researcher on the contact details below.

Researcher Name: Nicola Armstrong

Nicola Armstrong, Professional Doctorate Student, School of Health and Human Sciences, University of Essex

Phone: [redacted]

Email: [redacted]

Appendix 4:

Expression of Interest Person with Dementia

Person with Diagnosis of Young Onset Dementia

Expression of Interest Form in participating in 'The impact for the family of young onset dementia'

I hereby express my interest in participating in this research to share my views and experience on the impact of dementia for the younger person and the family.

Each family member will need to complete and expression interest form.

I have been diagnosed with dementia before the age of 65 years old – please circle

Yes No

Contact Details

Name _____

Signature _____

Address _____

_____

_____

Telephone number _____

Mobile Number _____

Email _____

Please return this form to the researcher - contact details below.

Thank you,

Nicola Armstrong, Professional Doctorate Student, School of Health and Human Sciences, University of Essex

Phone: [redacted]

Email: [redacted]

Appendix 5:
Consent Form
Person with Dementia

Person with Dementia

Family Number:

Participant Identification Number:

CONSENT FORM

Title of Project: **'The impact for the family of young onset dementia'**

Name of Researcher: Nicola Armstrong, Professional Doctorate Student, School of Health and Human Sciences, University of Essex

	Please initial box
1. I have been diagnosed with young onset dementia before the age of 65.	
2. I confirm that I have read the information sheet for the above study.	
3. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
5. I understand that information gained during the study may be published, but I will not be identifiable and my personal details will remain confidential.	
6. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.	
7. I understand that data will be stored in a way complying with the provisions of the Data Protection Act	
8. I understand the researcher has a responsibility to act on disclosure of harm to self or others including malpractice or criminal activity.	

9. I understand that the interview to be recorded.	
10. I agree to take part in the above study.	

Name of Participant _____

Date _____ Signature _____

Name of Person taking consent _____

Date _____ Signature _____

Appendix 6:
Support and Advice Leaflet

Further Support and Advice

Your GP and any other services you are currently using can be contacted for support. Here are some additional places where you and your family can access support, information and advice.

Alzheimer's Society provides the National Dementia Helpline on 0300 222 1122. It offers information, support, guidance and signposting to other appropriate organisations.

Website - https://www.alzheimers.org.uk

YoungDementia UK provides information, advice and support for people under 65 diagnosed with dementia, their family and friends.

Website - https://www.youngdementiauk.org

Dementia UK provides mental health nurses who specialise in dementia, called Admiral Nurses. They provide practical and emotional support to families affected by dementia. They can also provide advice on referrals to appropriate services and liaise with other healthcare professionals on your behalf. To find out if Admiral Nurses are available in your area, you can call their helpline – 0800 888 6678

Website - https://www.dementiauk.org

Carers Direct provides a national helpline service for carers, offering confidential

information and advice. This service is part of the NHS and can be contacted

on 0300 1231053. A webchat is available 9am – 6pm Monday to Friday on the website.

Website - http://www.nhs.uk/conditions/social-care-and-support-guide/Pages/what-is-social-care.aspx

The Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. Call 0844 800 4361.

Website - https://www.carers.org

Carers UK provides advice and information to carers. This is available through the

Website, booklets, factsheets and their Advice line 0808 808 7777.

Website - http://www.carersuk.org

The Counselling Directory brings together the information required to help people find a qualified counsellor or psychotherapist in their local area. Please note, the professionals listed on this website will charge for their services. Contact number is 0844 8030 240.

website - http://www.counselling-directory.org.uk

Appendix 7:
Expression of Interest Family Member

Family Member

Expression of Interest Form in participating in ‘The impact for the family of young onset dementia’

I hereby express my interest in participating in this research to share my views and experience on the impact of dementia for the younger person and the family.

Each family member will need to complete and expression interest form.

What is your relationship to the person with young onset dementia - please circle

Partner/Spouse Son Daughter Sibling Other _____

Contact Details

Name _____

Signature _____

Address _____

_____

_____

Telephone number _____

Mobile Number _____

Email _____

Please return this form to the researcher - contact details below.

Thank you,

Nicola Armstrong, Professional Doctorate Student, School of Health and Human Sciences, University of Essex

Phone: [redacted]

Email: [redacted]

Appendix 8:

Consent Form Family Member

Family Member

Family Number:

Participant Identification Number:

CONSENT FORM

Title of Project: **'The impact for the family of young onset dementia'**

Name of Researcher: Nicola Armstrong, Professional Doctorate Student, School of Health and Human Sciences, University of Essex

	Please initial box
1. I am a family member of someone who has been diagnosed with young onset dementia before the age of 65.	
2. I confirm that I have read the information sheet for the above study.	
3. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
5. I understand that information gained during the study may be published, but I will not be identifiable and my personal details will remain confidential.	
6. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.	
7. I understand that data will be stored in a way complying with the provisions of the Data Protection Act	

8. I understand that the researcher has a responsibility to act on disclosure of harm to self or others including malpractice or criminal activity.	
9. I understand that the interview to be recorded.	
10. I agree to take part in the above study.	

Name of Participant _____

Date _____ Signature _____

Name of Person taking consent _____

Date _____ Signature _____

Appendix 9:

Alzheimer's Society Service User Reference Group - Immediate project feedback form

Immediate project feedback form

We would appreciate your feedback on how our group contributions have influenced your project. Your answers will be shared with the group members and form part of our evaluations.

Project title: Young onset dementia and its impact on the family
Please give a brief overview of the mains points you took from your discussions (or from the facilitator's notes) with our group. We discussed the leaflets and forms to see if they easy to understand and clear. I was able to improve the layout of the forms and later some questions. Specific areas: • Expression of Interest form - Make the lines on the more spaced as currently too busy and confusing. • Consent Form - Need to be clear in questions 5 and 6 on the, as question 5 states it will be confidential and then question 6 says it may be published. Agreed it is important to have supporting discussion with people about the study and make sure they can ask questions. • Further Support & Advice sheet – agreed clear. • Poster – agreed clear, but needs the dates and times finalising.
Please tell us how the information we provided is planned on being used and how our discussions may influenced your project? Please give examples if possible: The information you provided will be used to improve the leaflets and forms to make sure they are easy to read and understandable. This will be used in a study involving families where someone has a diagnosis of dementia. It is hoped this study will increase our understanding of young onset dementia to improve services and support available for this group and their families.
Direct message to the group.... Thank-you very much for welcoming me to your group, which I very much enjoyed attending. Your help and advice will help improve the forms and leaflets for people with dementia and their families that take part in the study. Many thanks Nicola Armstrong

Thank you

Appendix 10:
Ethical Approval

University of Essex

27 September 2016

MRS N. ARMSTRONG

[redacted]

Dear Nicola,

Re: Ethical Approval Application (Ref 15051)

Further to your application for ethical approval, please find enclosed a copy of your application which has now been approved by the School Ethics Representative on behalf of the Faculty Ethics Committee.

Yours sincerely,

Lisa McKee
Ethics Administrator
School of Health and Human Sciences

cc. Research Governance and Planning Manager, REO
Supervisor

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

School of Health and Human Sciences
T 01206 872854
F 01206 873765
E hhs@essex.ac.uk

www.essex.ac.uk
@Uni_of_Essex /uniofessex /uniofessex

University of Essex

Application for Ethical Approval of Research Involving Human Participants

This application form must be completed for any research involving human participants conducted in or by the University. 'Human participants' are defined as including living human beings, human beings who have recently died (cadavers, human remains and body parts), embryos and foetuses, human tissue and bodily fluids, and human data and records (such as, but not restricted to medical, genetic, financial, personnel, criminal or administrative records and test results including scholastic achievements). Research must not commence until written approval has been received (from departmental Director of Research/Ethics Officer, Faculty Ethics Sub-Committee (ESC) or the University's Ethics Committee). This should be borne in mind when setting a start date for the project. Ethical approval cannot be granted retrospectively and failure to obtain ethical approval prior to data collection will mean that these data cannot be used.

Applications must be made on this form, and submitted electronically, to your departmental Director of Research/Ethics Officer. A signed copy of the form should also be submitted. Applications will be assessed by the Director of Research/Ethics Officer in the first instance, and may then passed to the ESC, and then to the University's Ethics Committee. A copy of your research proposal and any necessary supporting documentation (e.g. consent form, recruiting materials, etc) should also be attached to this form.

A full copy of the signed application will be retained by the department/school for 6 years following completion of the project. The signed application form cover sheet (two pages) will be sent to the Research Governance and Planning Manager in the REO as Secretary of the University's Ethics Committee.

1. Title of project: The impact for the family of young onset dementia

2. The title of your project will be published in the minutes of the University Ethics Committee. If you object, then a reference number will be used in place of the title.
   Do you object to the title of your project being published? Yes ☐ / No ☒

3. This Project is: ☐ Staff Research Project ☒ Student Project

4. Principal Investigator(s) (students should also include the name of their supervisor):

Name:	Department:
Nicola Armstrong	HHS, Student, Principle Investigator
Dr Sheila Black	HHS, Lecturer
Dr Mary Kennedy	HHS, Lecturer

5. **Proposed start date**: October 2016

6. **Probable duration**: 24 months

7. Will this project be externally funded? Yes ☐ / No ☒
   If Yes,

8. What is the source of the funding?

9. If external approval for this research has been given, then only this cover sheet needs to be submitted

External ethics approval obtained (attach evidence of approval) Yes ☐/ No ☒

Declaration of Principal Investigator:

The information contained in this application, including any accompanying information, is, to the best of my knowledge, complete and correct. I/we have read the University's *Guidelines for Ethical Approval of Research Involving Human Participants* and accept responsibility for the conduct of the procedures set out in this application in accordance with the guidelines, the University's *Statement on Safeguarding Good Scientific Practice* and any other conditions laid down by the University's Ethics Committee. I/we have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge my/our obligations and the rights of the participants.

Signature(s): N Armstrong

Name(s) in block capitals: Nicola Armstrong

Date: 12/09/2016

Supervisor's recommendation (Student Projects only):

I have read and approved the quality of both the research proposal and this application.

Supervisor's signature:

Outcome:

The departmental Director of Research (DoR) / Ethics Officer (EO) has reviewed this project and considers the methodological/technical aspects of the proposal to be appropriate to the tasks proposed. The DoR / EO considers that the investigator(s) has/have the necessary qualifications, experience and facilities to conduct the research set out in this application, and to deal with any emergencies and contingencies that may arise.

This application falls under Annex B and is approved on behalf of the ESC ☐

This application is referred to the ESC because it does not fall under Annex B ☐

This application is referred to the ESC because it requires independent scrutiny ☐

Signature(s):

Name(s) in block capitals: W A-/H/C Wilson

Department: S H H S

Date: 26/9/16

The application has been approved by the ESC ☐

The application has not been approved by the ESC ☐

The application is referred to the University Ethics Committee ☐

Signature(s):

Name(s) in block capitals:

Faculty:

Date:

Appendix 11:
Alzheimer's Society Approval to Recruitment

From: ResearchPartnerships [redacted]
Sent: 21 August 2017 16:54
To: [redacted]
Cc: Armstrong, Nicola J [redacted]
Subject: RE: Partnership Application Form - Research

Hi [redacted],

Just to confirm, Nicola's project has been through all the appropriate research partnership approvals, if you have capacity to share information regarding the project or allow a time for Nicola to present the opportunity at your services, it would be greatly appreciated.

Please don't hesitate to get in touch if you have any queries or require any further information.

Best wishes,

[redacted]
Research Assistant
Alzheimer's Society
Office phone [redacted]
Alzheimer's Society, 43-44 Crutched Friars, LONDON, EC3N 2AE

[alzheimers.org.uk]alzheimers.org.uk
[facebook.com/alzheimerssocietyuk]facebook.com/alzheimerssocietyuk
[twitter.com/alzheimerssoc]twitter.com/alzheimerssoc

From: Armstrong, Nicola J [redacted]
Sent: 21 August 2017 12:46
To: [redacted] Anita
Cc: ResearchPartnerships
Subject: Fw: Partnership Application Form - Research

Dear [redacted]

Please see correspondence below regarding the research I am doing. I am focusing on Young Onset Dementia and have been talking to people at dementia cafes in Essex to see if they would be interested in participating. I have completed most of the interviews but need 1 or 2 more families to be able to complete my data, so would like to ask if I can attend the dementia cafes in Brentwood, Billericay, Hornchurch and North Romford.

In the other cafes I have either talked to people at the cafe on tables or done a talk to the group about my project (a very short talk), followed by questions and discussion to see if anyone is interested in me contacting them to participate. I do not interview there, just provide information to then follow up if people want to.

My contact details are below, and I would very much appreciate being able to attend the cafes in your area during September if possible.

Many thanks
Nicola Armstrong
Professional Doctorate Student - University of Essex
[redacted]

From: ResearchPartnerships <[redacted]
Sent: 07 August 2017 12:10
To: Armstrong, Nicola J
Subject: RE: Partnership Application Form - Research

Dear Nicola,

Thank you for getting in touch, that is no problem at all, I will send an email reminder out today. Please let me know again if you haven't heard anything in the next week or so.

Best wishes,

[redacted]

[redacted]
Research Assistant
Alzheimer's Society
Office phone [redacted]
Alzheimer's Society, 43-44 Crutched Friars, LONDON, EC3N 2AE

[alzheimers.org.uk]alzheimers.org.uk
facebook.com/alzheimerssocietyuk
twitter.com/alzheimerssoc

From: Armstrong, Nicola J [redacted]
Sent: 06 August 2017 16:18
To: ResearchPartnerships
Subject: Re: Partnership Application Form - Research

Dear [redacted]

I hope this finds you well.

I have been able to attend some cafes in the area and have completed nearly all the interviews subsequently, however I am struggling a little with the last 1 or if I can 2.

Therefore would it be possible for you to email the Dementia Cafe leaders in Essex again which I hope will open the door again to attend some I haven't attended. The ones I have been to have been really supportive, but as it was March/April time that the original email went out, I think a fresh email would help before I contact again. I hope that makes sense, but please let me know if you need anything else.

Many thanks
Nicola Armstrong
[redacted]

Appendix 12:

Topic Guide Family Group Interview

Family Group Interview

Topic Guide: 'The impact for the family of young onset dementia'

Introduction

Establish rapport by greeting and introduce self.

Background

Provide background to the research study and aims.

Explain process

Explain what will happen.

I am here to hear about your views and experience about the diagnosis of young onset dementia and if it has had an impact on the family. I will record the interview and may make some notes.

I will guide and prompt on some set topics, and it is important to recognise I am a researcher with an enquiring role, so I cannot provide advice or guidance. I will signpost to other professionals if necessary.

I will ask you for some basic information when I start the interview like your age and relationship to each other. This will help me know who is speaking when I listen back to the recordings. I will also check with you that you all understand the study and are freely consenting to participate. I will check that you understand you can stop the interview at any time and withdraw without having to give reasons. I may stop the interview if I think anyone is becoming distressed.

I will explain confidentiality and data storage. I will ask if there are any questions or queries and then check you are all happy to start the interview.

Exploratory Interview - Start Recording

Introduction

Thank for meeting with me and the opportunity this has given me to interview them as the expert so I can learn about the impact of young onset dementia on the family as a whole unit. There are no right or wrong answers and I am not here to make a judgement, just to find out about your experiences and views.

Recording, Data and Confidentiality

I will be recording the interview and making some notes. All data will be kept securely and separately from your contact details. Your contact details will be destroyed on completion of the study and the data will be completely anonymised so you cannot be identified. The only occasion I will break confidentiality is if you disclosed harm to self, other or malpractice as I have an obligation to prevent harm and bound by a code of conduct.

Withdraw or Stop

You have the right to withdraw at any time without giving a reason. You can stop the interview at any time. If I think it becomes too distressing for any member of the family I will stop the interview.

Do you have any questions before we start?

Queries or concerns before the interview starts

Consent

Have all family members have read the information leaflet?

Have all family members completed a Consent form?

Are all family members are happy to continue?

Are you happy to start now?

Questions

Ask for each person to say their first name, age and relationship to the person with dementia.

Tell me what led to seek out a diagnosis?

Ask to expand on any areas to explore further - use informants own language to phrase questions.

Tell me about your experience of diagnosis…..

Ask to expand on any areas to explore further - use informants own language to phrase questions.

Has anything changed in the family since diagnosis?

Ask to expand on any areas to explore further - use informants own language to phrase questions.

Where or who have you received support from?

Ask to expand on any areas to explore further - use informants own language to phrase questions.

What was happening at the time?

If it dries up….

Tell me about that…..

You said that ……. and I am really interested in that……

De-brief/Closing discussion

Is there anything else you would like to add?

Do you have any comments before we finish?

Ask everyone is ok and how they found the interview. Check for signs of distress or upset. If distressed offer support, address anything that arises and if necessary signpost to appropriate services.

Thank you for your time today and the opportunity to hear you views. Sharing your thoughts sometimes stirs your emotions and feelings, so keep eye on this. If you find you feel distressed and need some support please use your GP or the other services you are in contact with. Provide the Further Information Support Leaflet.

Inform about next steps for individual interviews and arrange agreeable to time for individual interview.

Appendix 13:
Topic Guide Individual Interview

Individual Interview

Topic Guide: 'The impact for the family of young onset dementia'

Introduction

Re-establish rapport by greeting participant.

Background

Provide a recap of the background.

Explain process

Explain what will happen.

I am here to hear about your views and experience about the diagnosis of young onset dementia and if it has had an impact on the family. I will record the interview and may make some notes.

I will guide and prompt on some set topics, and it is important to recognise I am a researcher with an enquiring role, so I cannot provide advice or guidance. I will signpost to other professionals if necessary.

I will ask you for some basic information when I start the interview like your age and relationship to each other. This will help me know who is speaking when I listen back to the recordings. I will also check with you that you all understand the study and are freely consenting to participate. I will check that you understand you can stop the interview at any time and withdraw without having to give reasons. I may stop the interview if I think anyone is becoming distressed.

I will explain confidentiality and data storage. I will ask if there are any questions or queries and then check you are all happy to start the interview.

Exploratory Interview - Start Recording

Introduction

Thank for meeting with me and the opportunity this has given me to interview them as the expert so I can learn about the impact of young onset dementia on the family as a whole unit. There are no right or wrong answers and I am not here to make a judgement, just to find out about your experiences and views.

Recording, Data and Confidentiality

I will be recording the interview and making some notes. All data will be kept securely and separately from your contact details. Your contact details will be destroyed on completion of the study and the data will be completely anonymised so you cannot be identified. The only occasion I will break confidentiality is if you disclosed harm to self, other or malpractice as I have an obligation to prevent harm and bound by a code of conduct.

Withdraw or Stop

You have the right to withdraw at any time without giving a reason. You can stop the interview at any time. If I think it becomes too distressing for you I will stop the interview.

Do you have any questions before we start?

Queries or concerns before the interview starts

Consent

Reconfirm read and remember the content of the information leaflet?

Reconfirm that the participant has completed a Consent form? (Check they are still consenting)

Are you happy to continue?

Are you happy to start now?

Questions

Ask them to say their first name, age and relationship to the person with dementia.

Tell me about how the diagnosis came about?

Ask to expand on any areas to explore further - use informants own language to phrase questions.

What was happening at the time?

What did you experience when you told about the diagnosis?

Ask to expand on any areas to explore further - use informants own language to phrase questions.

Do you think the diagnosis has an impact on the family?

Ask to expand on any areas to explore further - use informants own language to phrase questions.

If it dries up….

Tell me about that…..

You said that ……. and I am really interested in that……

De-brief/Closing discussion

Is there anything else you would like to add?

Do you have any comments before we finish?

Ask if they are ok and if how they found the interview. Check for signs of distress or upset. If distressed offer support, address anything that arises and if necessary signpost to appropriate services.

Thank you for your time today and the opportunity to hear you views. Sharing you thoughts sometimes stirs your emotions and feelings, so keep eye on this. If you find you feel distressed and need some support please use your GP or the other services you are in contact with. There are some additional support services on this leaflet. Provide the Further Information Support Leaflet.

Appendix 14:
Excel Theme Chart Example on Changes

Excel Theme Chart Example on Changes

Family/ Person	1.1 Relationships	1.2 Social	1.3 Independence	1.4 Self/Person	1.5 Activities	1.6 Future Plans	1.7 Memory	1.8 Coping	SUMMARY
F1	Blames husband as he needs to make decisions for her Ref 1 Doesn't want him to make decisions but needs him to - frustration Ref 2 Carer recognised the mistakes made - not making a 'song & dance' Ref 6 Weekends mostly supervising Ref 19 Needs him as carer can't cope without him - "selfish" Ref 25 Told me off so	Loss of friends and social activities Ref 2 Used to go out more Ref 18 Friends don't invite anymore Ref 20 Carer taking out as friends wouldn't give care needed. Ref 21	Loss of abilities and having to depend on partner and carers Ref 1 Cannot understand value of money or accounts Ref 3 wouldn't trust myself to travel alone Ref 3 Loss of independence Ref 4 Afraid of going on own - loss of confidence Ref 8 Need help to keep independence and abilities Ref 13 When cooking	Not the person I use to be and loss of confidence Ref 5 In own world Ref 8 Change in mood / reaction to things - confrontational Ref 23 Forget words - doesn't notice Ref 26	Sleep issues - loss of day/night routine Ref 7 Ref 8 Ref 29 Hobbies Ref 16 Loss of ability to do stamp collecting / cross stitch Ref 17	not knowing and not able be plan - not knowing how dementia will be Ref 9 When cooking skills lost then "I'm a goner" Ref 15	Remembers negatives not positive from early life Ref 12 Forgets how to do things - open car door, work the dish washer Ref 26 Loss of time - need reminding Ref 28 Won't make tea - until I forget about it again Ref 29	Not the worst thing in life. Frustration Ref 1 Keeping mind busy - iPad Ref 16 Don't even try as I know I can't Ref 26 Writing down instructions Ref 27	Changes in the abilities and need for carer to help impacts on relationships - blaming carer and the carer adjusting and not drawing attention the PwD mistakes. Carer supervising and PwD dependent. Feeling of cannot cope without him, but loss of control/independence. Describe losing friends and social activities. PwD not who she used to be, loss of time awareness and losing skills. carer describes not being able to plan for the future

	many times Ref 29 Understanding from the family of carers role Ref 10 Don't share with family - stigma not understanding Ref 11 Daughter will laugh but son will won't Ref 24		skills lost then "I'm a goner" Ref 15 Weekends mostly supervising Ref 19 fear of getting lost Ref 21						
F2	On-call 24 hours a day - responsible for the PwD Ref 2 Loss of shared activities Ref 3 Worries about PwD safety Ref 4 Loss of shared routine Ref 6		Loss of abilities - reading Ref 7		Loss of abilities to do activities within the home Loss of shared activities Ref 3			Leaves instructions Ref 4 Ref 5	Carer responsible 24 hours and worry about PwD safety. The impact includes loss of shared activities, household activities although tries by leaving instructions.

F3	Loss of ability to provide childcare for grandchildren Ref 1		Transport/driving Ref 2						Impact of dementia meant loss of driving and ability to provide childcare for her grandchildren.
F4	Doesn't recognise them Ref 1								Does not recognise family members
F5	Loss of shared interaction Ref 2 Misunderstanding frustrating Ref 2 Children not realising how bad PwD is Ref 5	Carers social restricted as PwD needs support Ref 4	Mobility car Ref 3 Carer sorts all mail, bills etc. Ref 6	PwD used to use the phone and pay the bills Ref 7		Not knowing how it's going to be in 5 years Ref 1	Anxiety experienced as thinks lost dog Ref 4		Describes loss of shared interaction and the frustration of misunderstanding that happens. Social impact and loss of independence. Worry about the future
F6	Forgets wife and won't accept help Ref 3 Family help as forgets wife Ref 3 Couldn't do it on own and moved closer to family Ref 6	Stopped working Ref 1		PwD loss of work role Ref 2 Doesn't realise but sleeps in day Ref 5	Sleep issues Ref 5	Home adaptations for future deterioration Ref 7			PwD forgets his wife is his wife. Carer values the support from her family. Impact of dementia meant both PwD and carer lost work role. PwD loss of time awareness - night/day.

									Changes to the home to support PwD
PWD1	Feeling like he's taken over Ref 1 Closer through it Ref 1 Being controlled Ref 2 Needs husband to fulfil grandparent role babysit Ref 2		Needs husband to control - pull in the reigns Ref 2	The dementia - frustration changing temper. Ref 2					PwD feeling taken over and being controlled. Husband helps fulfil desire to be a grandparent and keep PwD within boundaries but also frustrating.
PWD2							Memory is the worst problems Ref 1		memory problems the worst
PWD3									
PWD4							Doesn’t remember the carers coming Ref 1		Cannot remember when carers come
PWD5	Needs wife to manage Ref 1 Ref 2								relies on wife
PWD6									

F1 Partner	daughter understands, but the others don't - stigma Ref 3		needs help but she doesn't want to ask Ref 1			Knowing it's going to get worse Ref 1 Hoping it stays the same until retirement Ref 2			Some family members do not understand dementia, but daughter. PwD does not like asking for help and worry about future/hoping she will not deteriorate before he retires.
F2 Partner	Loss of balance 'good days, bad days' but we get along Ref 1 Responsible for PwD Ref 1 Loss of present so support PwD with repetitive questions Ref 3								Impact on balance so there are up and down days. Carer feels responsible for the PwD and repetitive where PwD has lost awareness of present.
F3 Husband	Loss of someone to talk to Ref 2 Frustrating - doesn't share things as she	Holidays with friends getting difficult - unable to hold conversation	Got slower Ref 1 Loss of independence and increase of dependence Ref 3	Progressively worse reducing conversation Ref 2 Forgets she can't just get	language and understanding deteriorated o cannot explains	Not what expected for retirement Ref 4			Impact means carer feels loss of partner-someone to talk to/friend. Unable to share things and PwD doesn't understand

	doesn't understand - Jackal & Hide Ref 3	s and needs friends to be understanding Ref 3		on with it Ref 3	things Ref 4				and this affects holidays with friends as unable to converse. Independence decrease and dependency of carer increase. Not as planned for their retirement.
F4 Son							Forgets I'm at work and gets frightened Ref 1		PwD gets frightened when he forgets carer is a work.
F4 Daughter in law				They still want her to be mum Ref 1				Need support with ways of coping and supporting Ref 1	Family want her to be mum as she was. They need support and coping mechanisms.
F5 Wife	Loss of shared activity - walking together Ref 2 Like having a child Ref 3		Difficult to leave PwD on own as gets confused Ref 1 Shuffles and can't walk far Ref 2			Its going to get bigger and worse Ref 4			Loss of shared activities and trust Carer feels PwD is like having a child and cannot leave him on his own. The diagnosis belongs to both of them.

	The diagnosis is both of ours Ref 4 Loss of trust to do things Ref 4		Leaves fridge, doors open and cooker on Ref 4						Acknowledged the future is going to get worse.
Carer6									
F2 Mother	Changes family interests and activities Ref 1 Ref 2	Changes in friends. Friends supporting Ref 3 Change in social skills Ref 3		Loss of interest, changed preferences Ref 1					Impact on family activities and friends due to change in social and interest in things.
F2 Father									

SUMMARY	1.1 The impact changed the relationship and the PwD now relies on and needs the carer - this causes frustration. 'Like having a child'. There's a loss of shared routine, activities and conversation due to changes in memory, interest and abilities. Relationships with the wider family affected - PwD not recognising them, them not understanding the dementia and the role and relationship as grandparent interrupted.	1.2 Lost some friends and social activities as don't get invited anymore. Goes out with carer as friends wouldn't provide the carer needed. There is a change in social skills which affect social e.g. Going on holiday with friends in hard due to the change in ability to converse. Carers experience reduced social activities as they need to	1.3 Loss of skills impact on PwD confidence in that PwD feels unsafe to go out or travel alone. Unable to drive or read now carer has to sort mail, bills etc. Oxymoron - Depends on carer to keep independence and skills. Safety – PwD feels unsafe to go out alone and carer worries about the PwD safety when left home alone.	1.4 Loss of person once was and awareness – 'in own world'. Sleeps in the day and a loss of interest. Reacts differently to things, changed preferences and change in moods. Doesn't do the things they used to do and reducing ability to converse.	1.5 Dementia impacted on activities through loss of ability to do them, but also night and day routine and sleep issues. Unable to do household activities and a loss of shared activities. The loss of language and understanding impacts as PwD cannot explain or understand things.	1.6 The dementia has impacted on ability to plan for the future as do not know how the dementia will be. Knowing it's going to get worse not knowing how long they have. Adaptations made to the home for future needs. Hoping the PwD doesn't deteriorate before carer can retire but not what	1.7 One PwD remembered the negatives from past not the positives. Forgets how to do things – work the dish washer or open the car door. Doesn't make tea anymore. Forgets carers at work and cannot remember carers coming in. Worries about things as forgotten they aren't there	1.8 Coping with the dementia – the PwD tries to keep busy and doesn't even try things anymore to avoid frustration. Writes instructions down. Need support with coping with it.	

		care for PwD and also had to stop work.				expected for retirement.	anymore - old dogs.		