An Interpretative Phenomenological Analysis of the Experiences of spouses of people with Young Onset Dementia of Transition from Hospital to a Care Home.

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Francisca Mada

Abstract

Introduction: It is known that people in the United Kingdom with young onset dementia (YOD) go through hospital admissions and are discharged to care homes and that their families support them through these transitions. This thesis explored the lived experiences of the wives and husbands of people with young onset dementia (YOD) of their partners' transition from hospital to a care home.

Methods: The study uses Interpretive Phenomenological Analysis (IPA). A purposive sample of five participants in the United Kingdom, three wives and two husbands of people living with YOD was recruited. Four people with YOD had experienced psychiatric hospital admissions and one had experienced a psychiatric ward in an acute hospital setting. Data were collected using semi-structured in-depth interviews. Participants' experiences were sought and analysed using IPA's layered approach to the data to make sense of the participants' making sense of their world (Smith et al. 2022). Meleis' Transition Framework (MTF) (Meleis et al. 2000) was used to conceptualise the transition on the YOD trajectory.

Results: Transition from a hospital to a care home is a stressful time for families who are being impacted on by YOD and are trying to support the person with YOD as effectively as they can and deal with the difficulties they encounter along the way. The four convergent group experiential themes (GETs) identified are "The burdens of caring", "Dementia grief", "The system itself is not clear" and "The impact of YOD on dependent children". The two divergent PETs are "Do it yourself dementia (DIY dementia" and "Receiving assistance". Participants felt the health and social care system is unclear, does not have awareness or knowledge of YOD and the needs of those affected, processes are complex for families to understand, and focus is solely on the person with YOD. They described wanting professionals to be proactive in providing support and information, talk about YOD and form therapeutic relationships with families and especially consider the young children who might be involved.

Conclusions: The process of transition from a hospital to a care home for people with YOD and their families is complex and multifaceted. The narratives clearly show that both the person with YOD and family's needs cannot be separated. There is need for a knowledgeable and competent health and social care workforce. YOD is a specialist area that needs a workforce that is specialised in that specific area.

Families go through several critical points and need professionals to understand this to be effective in their work. This study emphasises the recognition of young children of those with YOD and the need to provide age-appropriate support which was lacking for the children in this study.

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To my supervisors, Dr Tessa Watts, Dr Jane Harden, and Dr Anna Jones, look what we have produced! You have been my cheerleaders who have shown encouragement along the way even when I was about to throw in the towel. You all went the extra mile and kept me going. It has been an amazing experience working with you all. The support, knowledge, expertise, and guidance throughout the project from you all has been invaluable and you have been a strong part of this thesis.

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Thank You

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Abbreviations

Admiral Nurse (AN)

American Psychiatric Association [APA]

Alzheimer disease (AD)

Amyloid protein precursors (APP)

Behavioural and psychological symptoms of dementia (BPSD)

Behavioural variant frontal temporal dementia (BVFTD)

Bovine spongiform encephalopathy (BSE)

Behaviour variant (bvFTD)

Central nervous system (CNS)

Cerebrospinal fluid (CSF) analyses

Computerised tomography (CT)

Consultant Admiral Nurse (CAN

Chronic traumatic encephalopathy (CTE)

Critical Appraisal Skills Programme (CASP)

Clinical Commissioning Groups (CCGS)

Creutzfeldt-Jakob Disease (CJD)

DAT scan (I-FP-CIT SPECT).

Diagnostic and Statistical Manual for Mental Health Disorders (DSM-5)

Department of Health………… (DOH)

Dementia UK Admiral Nurses (DUK ANs)

Dementia with Lewy bodies (DLB)

Dementia UK (DUK)

Electroencephalography (EEG)

Frontotemporal dementia (FTD)

Fluorodeoxyglucose positron emission tomography (FDG-PET)

General Practitioner (GP)

Group Experiential Themes (GETS

Human immune virus-related neurodegeneration (HIV)

Huntingtin protein (HTT)

Interpretive Phenomenological Analysis (IPA)

Llywodraeth Cymru Welsh Government (LCWG)

Lewy Body Dementia (LBD)

Magnetic resonance imaging (MRI),

Mental Health Act (MHA) 1983

Meleis Transitional Framework (MTF)

National Health Service (NHS)

Non-fluent variant primary progressive aphasia (nfvPPA)

Office of National Statistics 2022) (ONS)

Parkinson’s Disease (PD)

Personal experiential themes (PETs)

People with dementia (PWD)

Polyglutamine (ployQ)

Posterior Cortical Atrophy (PCA)

Positron emission tomography (PET)

Randomised control trials (RCT),

SARS-CoV-2 pandemic (COVID-19)

Single proton emission CT (SPECT)

Semantic variant primary progressive aphasia (svPPA)

School of Healthcare Science Research Ethics Committee (SREC)

Sporadic Creutzfeldt-Jakob disease (sCJD)

Transition framework (TF)

Vascular dementia (VaD)

Young-onset dementia (YOD)

Young Onset Dementia advisers (YODAs)

Prologue

This study is about understanding the experiences of wives and husbands of people with young onset dementia (YOD) regarding their transition from hospital to a care home.

I was born and raised in a small town in Zimbabwe. My interest in dementia did not come naturally to me. I believe this stemmed from the fact that as a baby until about the age of 5 or 6 years old I was looked after by my paternal grandmother in the village while both my parents worked in town. I spent a lot of time with my grandmother, her friends, and older relatives. They had great stories, some had travelled extensively (visiting their children in different towns), running their households, raised families, or they were involved in the war of liberation of the then Rhodesia in one way or another. During my teen years, I visited both my paternal and maternal grandmothers regularly. I saw my grandmothers each change in personalities as they grew older, and their memories became very poor. My maternal grandmother was even sweeter tempered than she used to be, would do a lot of walking around the village, sitting down was a problem for her, and it was the role of the children in the village to ensure they called for adult reinforcement when she was going too far away from home. My paternal grandmother on the other hand, was not easy to live with as she grew older, a few people could get closer. I was a lucky one, I could spend a night in her room when others didn't dare even consider it. Everyone believed it was all because of old age and so these behaviours were accepted. More recently, my mother, Violet Erika died in 2017 following a diagnosis of vascular dementia in 2011, she was 75 years old.

The only profession I understood something about was nursing because my dad's cousin was a nurse. I wanted to be a nurse and so in January 1987 I started General Nurse training. It was on one of the student nurse placements that I stumbled onto a psychiatric ward. The chaos of that shift on that first day made me want to experience more of that department. It was a different way of working from other departments I had been on. As time went on, I realised that talking to patients and listening to them were very important skills when working in this department. I love stories so I found my place and enjoyed my time there. Six and half years later I was a qualified psychiatric nurse.

For eleven years as a general and psychiatric nurse in Zimbabwe, each time the discharge destination from hospital was the person's original home. I never nursed anyone with a diagnosis of dementia in hospital. In Zimbabwe society accepted that memory loss, personality changes and behaviour changes were normal for an older person and the family and society had a responsibility to care for them. This is still a belief in many families today.

A move to the UK and working in both acute hospitals and then psychiatric hospitals exposed me to a different kind of nursing where discharges are concerned. I trialled working on different wards and felt comfortable on the older adult wards and eventually settled on an acute older adult mental health ward for many years. Although this was a mixed diagnosis ward, a large percentage of patients had a diagnosis of dementia.

I noticed that unlike the patients with other conditions, the patients diagnosed with dementia were often not invited to the meetings to discuss their care, they tended to stay long on the ward so staff would get to know them well and most of them would be discharged to care home. At times I understood why the care home was considered the safe place for the older person to move into and at times I thought maybe they would have stayed in their home a bit longer if only there was something we could put in place for them. A lot of the time people with dementia had no choice but to move to a care home.

The situation got very confusing and emotional for me when we admitted a 55-year-old woman onto an older adult ward because she had dementia. On reflection, the patient was close to some of the senior nurses and staff in age, yet she had no capacity to attend to her own personal care. She had a working husband who could not visit often because of his job and a young son.

From then on, we tended to admit more younger people with a dementia diagnosis. It was clear to me from that first patient that even the very experienced members of staff were uncertain how to care for younger people in terms of occupying or engaging them or what form of psychological support to provide the patient and the family.

The topic of discharge destination was usually a difficult one to start where a younger patient was concerned compared to when the discussion was about an older person. I remember that in staff meetings there would be a discussion to try and allocate someone who would start the discussion with the family.

While in the NHS I worked on a research study looking at improving the quality of life of people living with dementia in care homes, and as discharge liaison nurse. In this role I supported discharges for people with dementia from psychiatric wards and community hospitals in the county transitioning to care homes. In these roles, I obtained more evidence that not much is known about the needs of both the person with YOD and family members.

There are times in my work that I have felt that the person living with dementia and their family, or carer, had felt excluded and not given an opportunity to express themselves. For many years, I do not recall discussing family support post discharge from hospital, or referral to any other services, nor do I remember there being any written information about it. As nurses working with families living with young onset dementia, we had to develop our own ways of supporting these families, often without the confidence of knowing that we were being effective.

I am doing this study to understand the experiences of partners of people with YOD in order to better support them.

Chapter 1: Introduction

This thesis examines the experiences of husbands and wives of individuals living with YOD during the transition from hospital to a care home in the UK. It is estimated that there are over 700,000 family carers for people with dementia in the UK (Lewis et al. 2014) and these include carers for people with YOD. Considering that the current numbers of people with dementia and YOD have increased, I imagine that the number of family carers has increased too. These are the people who can answer the question: *What are the experiences of spouses of people with YOD of transitions from hospital to a care home?*

This introductory chapter presents the aetiology and pathophysiology of the most common subtypes of dementia; Alzheimer disease (AD), vascular dementia (VaD), frontotemporal dementia (FTD), Dementia with Lewy bodies (DLB) and some rarer subtypes; Posterior Cortical Atrophy (PCA), chronic traumatic encephalopathy (CTE), Huntington’s disease, Korsakoff and Creutzfeldt Jakob disease (CJD). This is followed by the history and policy context of the management of people with dementia. Lastly, it will address managing transition to the third sector and for-profit care of people with dementia.

1.1. Background

Dementia is a general term, often referred to as an umbrella term, to describe a range of neurodegenerative changes in the brain which cause a progressive decline in cognition and in abilities. The symptoms of dementia vary and as well as cognitive decline, are characterised by problems with thinking sufficient to impede independent activities of daily living (Sachdev et al. 2014; NICE 2018; Nwadiugwu 2020).

Worldwide, it is estimated that there are 50 million people living with dementia, and this number is predicted to increase to 152 million by 2050. The higher numbers are expected to be from low-income and middle-income countries where around two-thirds of people with dementia live (Mukadam et al. 2019; Livingstone et al.2020). Factors such as genetic predisposition, increasing numbers of people in low-income and middle-income countries living to an older age, culture, poverty, poor heart health, caused by potentially modifiable individual risk factors such as high blood pressure, obesity, depression, and diabetes are important obstacles to preventing or slowing dementia (Mukadam et al. 2019; Livingstone et al. 2020).

Latest research shows that there are more than 944,000 people in the UK living with dementia (Luengo-Fernandez and Landeiro (in preparation)). The UK dementia population is expected to rise to 1.6 million by 2040 due to increasing life expectancy and ageing risk factors (Wittenberg 2019). It is estimated that one in eleven people over the age of 65 have dementia in the UK. However, both age-specific and all-cause dementia incidences have been reported to be lower in the UK. This may be due to improved educational, socio-economic, health care, and lifestyle changes (Mukadam et al. 2019; Livingstone et al. 2020).

1.2 Definitions

The terms “young onset dementia”, “younger people with dementia” “young people with dementia”, “early onset dementia” or “dementia of working age” are commonly used to describe dementia in someone under the age of 65 years (Rossor et al. 2010). The age of 65 years has no specific biological significance but is suggestive of a sociological divide in terms of working and retirement age (Rossor et al. 2010; Viera et al. 2013). This study will use the term “young onset dementia” (YOD) so as not to be confused with early stages of dementia which can be used in relation to dementia in any age group. Late-onset dementia refers to dementia in individuals over 65 years of age.

1.3 Young-onset dementia (YOD)

Figures from the recorded dementia dataset indicate that 3.4% of all people with dementia are currently aged under 65 (NHS Digital 2022). There is a consensus from all stakeholders with interest in YOD that this does not give a complete picture of the number of people diagnosed with YOD. The incidence and prevalence of YOD are less well-known than late-onset dementia (Green and Kleissen 2013; Burns et al. 2017; Carter 2022) as statistics on YOD are not routinely published. There is a school of thought that advocates that the measurement of people with YOD should be changed because it is misleading (Burns et al. 2017; Carter 2022) and has substantial implications for service provision. Burns et al. (2017) and Carter (2022) argued that the national Dementia Diagnosis Rate counts those over 65. Clinical Commissioning Groups (CCGS) in England only record the current age, not the age at diagnosis. The current suggested YOD figures in the UK are 44,000 (over 97% of those on the register) and these are figures that are available to CCGs. Some points from Carter's 2022 report that are related to statistical data and are of concern are:

- New figures estimate that 7.5% (33,454) of all those currently alive with dementia were diagnosed under 65.
- 55% of those currently aged between 65 and 69 were diagnosed under the age of 65.
- Of those in this 65-69 age group, 25% have lived with dementia more than five years and 5% more than 12 years.
- Recorded Dementia Diagnosis data (aggregated from all general practices in England) published by NHS Digital in September 2020 reported that there were 441,909 individuals with a formal diagnosis of dementia in England, of which 3.4% (15,172) were people currently aged under 65 years.

However, there is a suggestion that 70,800 of the estimated 944,000 people living with dementia in the UK are diagnosed with YOD where the onset of their symptoms occur under the age of 65 years (Carter et al. 2022). This statistical information is of interest and importance to all stakeholders such as those supporting YOD causes, people with YOD and their families. Burns et al. (2017) and Carter (2022) suggest that the routine availability of data on the prevalence of YOD and the time lived with a diagnosis, would allow local health and social care commissioners to understand better the proper extent of local services. Individuals who receive a diagnosis, whatever their current age, have specific needs related to atypical forms of dementia, as well as the stage of life.

1.3.1 Aetiology of dementia

Dementia is categorised as a neurodegenerative disorder in the Diagnostic and Statistical Manual for Mental Health Disorders (DSM-5) (American Psychiatric Association [APA] 2013), and the Classifications of Mental and Behavioural Disorder guidelines (ICD-11) (Gaebel et al. 2018). Within ICD-11, dementia is recognised as a neurocognitive condition which separates it from other psychiatric conditions. This name change partially reflects the way the condition is currently conceptualised as well as the idea that the word "dementia" is considered derogatory by some. The diagnostic criteria include Alzheimer's disease (AD), vascular dementia (VaD), dementia with Lewy bodies (DLB) and fronto temporal lobe (FTD). The term "neurocognitive" emphasises that the symptoms are a result of a brain disease and disrupted brain function, and these conditions are characterised by cognitive impairment as the most prominent and defining feature of dementia (Rossor et al. 2010; APA 2013). This standard criterion can lead to delays or misdiagnosis in someone with YOD, who might not present with memory problems in the early stages (Rossor et al. 2010; Kuruppu and Matthews 2013). The presentation of YOD in the initial stages can be atypical. Currently, with the exception of individuals with genetic mutations, postmortem examination of brain tissue remains the only definitive means of establishing diagnosis in most cases (Harper et al. 2014). However, biological markers (biomarkers) including computerised tomography (CT), magnetic resonance imaging (MRI), specialised cerebrospinal fluid (CSF) analyses, electroencephalography (EEG) and positron emission tomography (PET) in combination with clinical assessments are particularly important in this age group. These tests have value in improving diagnostic accuracy during life and help to narrow the differential diagnosis (Harper et al. 2014). It is also important because some causes of subtypes of YOD can be altered by treatments, human immune virus-related neurodegeneration (HIV) and vitamin B12 deficiency, for example (Rossor et al. 2010; Kuruppu and Matthews 2013).

Evidence concerning the risk of developing dementia indicates that, apart from age and genetic characteristics, there are potentially modifiable biomedical, behavioural, psychological, and social factors associated with disease risk (Smith et al. 2014; Livingston et al. 2020). These lifestyle risks include socio-economic circumstances, environmental, educational levels, and childhood experiences (Regan 2016; Livingston et al. 2017; Livingston et al. 2020). The potentially reversible causes include inflammatory diseases, infectious diseases such as HIV can be limited and syphilis as well as poisonous/metabolic abnormalities and abnormal pressure hydrocephalus (Kuruppu and Matthews 2013). These represent important and broad differential diagnostic considerations in YOD and can be challenging in distinguishing between neurological and psychiatric manifestations in this age group. It can be complicated further by overlaps caused by shared neuroanatomy and neurochemistry (Kuruppu and Matthews 2013), meaning that symptoms can be mistaken for a psychiatric disorder instead of a neurological disorder hence the need for thorough investigations.

1.3.2 Issues with diagnosis

YOD is a diverse range of cognitive disorders that are poorly understood, as the focus of dementia is based on older populations. Consequently, YOD is more poorly recognised, underdiagnosed, misunderstood, and inadequately treated, with limited services and resources in many countries, including the UK (Rossor et al. 2010; Vieira et al. 2013; Nwadiugwu 2020; Carter 2022). Younger people are also more susceptible to other, more unusual forms of dementia (that is, not Alzheimer's disease which is the most common type) (Vieira et al. 2013).

Missed diagnosis, late/delayed diagnosis, and under-diagnosis have been reported as major concerns for individuals and families of people with YOD (Rossor et al. 2010; The Royal College of Psychiatrists 2018; Rabanal et al. 2018; Kilty et al. 2019; Nwadiugwu 2020; Carter 2022). These anomalies in diagnosis may possibly be attributed to the fact that healthcare clinicians do not always look for the signs of dementia in younger people. This may be influenced by the general perception that dementia is a condition for older people, (Rabanal et al. 2018; Nwadiugwu 2020) and presenting symptoms are complex (Carter 2022). Furthermore, dementia has a long and highly variable dormancy period. Therefore, it may be confused with symptoms from other conditions and may remain undetected for a long period of time (Prince et al. 2016; Nwadiugwu 2020). Many people present late to clinicians with the symptoms (Smith et al. 2017) and consequently have delayed referrals for specialist diagnostic support (Durchame et al 2014; Carter et al. 2017). Draper et al. (2016) showed that the time from symptom onset to first consultation took an average of over two years and the time from first symptoms to an official diagnosis of YOD an average of five years. These time spans can be very difficult and create chaos for a family living with symptoms and without support.

Another factor that causes difficulty in the diagnosis of YOD is often that there are prominent psychiatric manifestations in this age group which is further complicated by the overlaps as a result of the shared neuroanatomy and neurochemistry (Kuruppu and Matthews 2013). This means that signs and symptoms can be mistaken for a psychiatric disorder rather than a neurological disorder.

Unlike later-onset dementia, YOD is reported to be more prevalent in men than women (Regan 2016; Nwadiugwu 2020), with black-African and Caribbean men being more susceptible (Regan 2016; Berwald et al. 2016) than their white counterparts in the UK. Along similar lines, studies examining racial and ethnic disparities in dementia incidence in the United States have consistently reported higher rates of dementia for black adults than for white adults (Mehta 2017). Black and ethnic minority groups are also less likely to receive a diagnosis of dementia (Nwadiugwu 2020). Berwald et al. (2016) found that people from black and ethnic minority populations have been reported to present later for a range of reasons. These include normalisation of memory problems, concerns about stigma, culture, the belief that families rather than services are the appropriate resource, previous negative experiences of health services, concern about the threat of receiving a diagnosis, and, at times, language barriers and lack of knowledge. On the other hand, Vieira et al. (2013) reported that general practitioners (GPs) often lack cultural competency, thus creating further barriers to a timely diagnosis. There is also insufficient awareness that people from different ethnic groups may have different symptoms in the early stages of dementia, and this could also delay diagnosis. In summary, many risk factors cluster around inequalities, which occur particularly in Black, Asian, and minority ethnic groups and in vulnerable populations (Livingston et al. 2020). These need to be attended to sensitively as tackling them will not only be through health promotion but also societal action to improve the circumstances in which people live their lives.

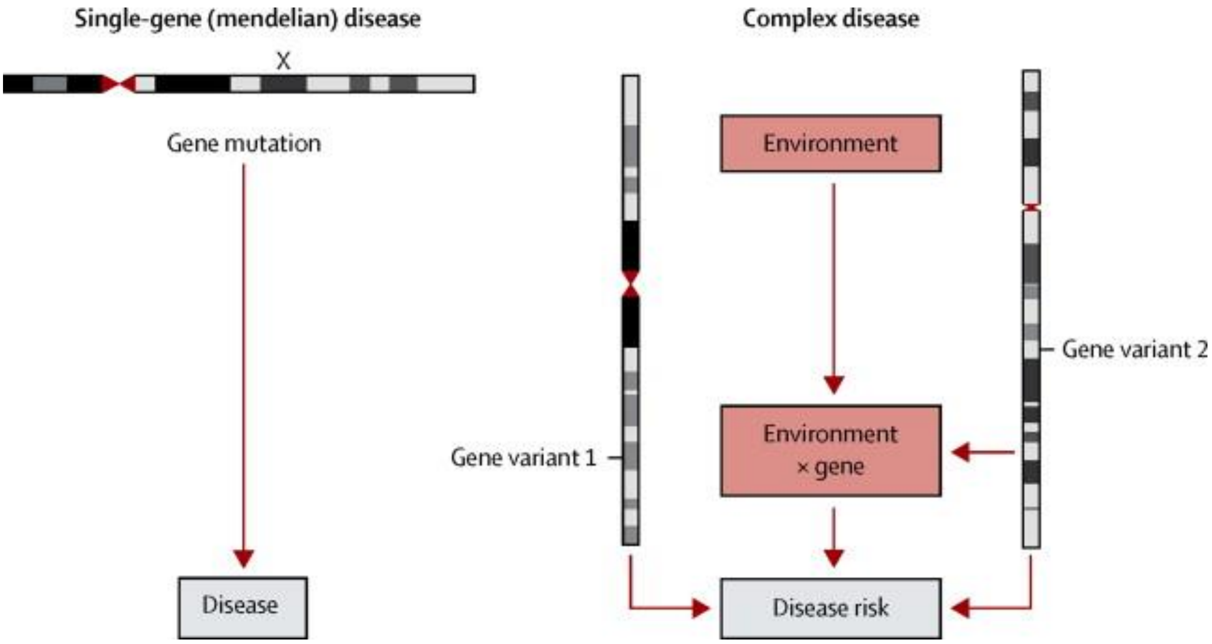
1.3.3 The Role of Genetics in Dementia

Genetics play a key role in the pathogenesis of dementia. Gene mutations are associated with 10% of early onset Alzheimer's dementia in individuals under the age of 65, especially those with a family history of late-onset dementia (Loy et al. 2014; Nicolas et al. 2015). Genetic factors can contribute to familial dementia in two ways: by causing mendelian forms of dementia or as a contributing factor towards genetically complex disease. Other familial forms of dementia include VaD, FTD, DLB, as well as rarer types, such as Huntington's disease and CJD (Kuruppu and Matthew 2013; Kwok et al. 2020).

1.3.3.1 Mendelian diseases and clinical implications

In a mendelian disease or single-gene disease, a mutation in one of the 25 000 genes in the nuclear genome (see figure 1) is necessary and sufficient to cause disease (Loy et al. 2014; Kwok et al. 2020). Many such genes were discovered in family genetic studies called linkage studies (Loy et al. 2014). A linkage study compares the inheritance patterns of genetic location markers and sickness in a family to identify the location of a gene that causes the disease. Individuals carrying pathogenic mutations have a 95%, or greater, lifetime risk of dementia. The precise risk varies based on the family's related age of onset and the gene's penetrance. Penetrance of a gene is defined as the probability that an individual who has inherited a mutation in a disease gene goes on to develop the disease phenotype (Kuruppu and Matthews 2013; Loy et al. 2014; Kwok et al. 2020). Because mendelian forms of dementia are known to be caused by autosomal dominant genes that have a high penetrance rate, family trees for affected families typically show many affected members in successive generations. Therefore, accurate family history is important.

Figure 1: Pathogenesis in mendelian versus complex disease.



Adopted from Loy et al. 2014. Genetics of dementia.

1.3.3.2 Complex diseases and clinical implications

A genetically complex disease (also known as susceptibility genes, polygenic or multifactorial) is caused by genetic and environmental factors, individually and in interaction with each other (Loy et al. 2014; Kwok et al. 2020). Normally these genetic factors are present in the normal population. These genes are associated with increasing a person's risk of developing dementia, but they do not always result in the development of the condition. Dementia develops through the interaction between several different risk factors. Well known examples of complex disease include common diseases that result in poor heart health, such as stroke and diabetes. These diseases are also referred to as lifestyle disease and can therefore be classed as modifiable diseases.

Unlike mendelian diseases, passing the one genetic fault to the offspring is sufficient to cause disease, and parent–child transmission can be seen in the family tree. Complex disease pattern of inheritance is not so clear-cut due to the need for numerous genetic variations and environmental factors. An individual with a genetically complex disease is unlikely to pass on every one of the many genetic variations to their offspring. However, because these genetic variations are common, the offspring might also inherit other risk-conferring genetic variations from the other parent. Consequently, genetically complex diseases can skip a generation, and there can be people affected on both sides of the family. Genetic testing for any individual genetic variation has been shown to have poor predictive power for dementia and is not recommended in clinical practice (Loy et al. 2014).

In summary, obtaining a detailed and accurate family history, to identify families with family histories consistent with mendelian rather than complex inheritance is the first step in considering molecular genetic testing for dementia (Loy et al. 2014). The second step is to obtain an accurate phenotype for the family to inform the choice of genetic test. Genetic testing can then be considered, ideally starting with an affected family member. The presence of pathogenic mutation will confirm the diagnosis at the molecular level and makes testing available for other family members (Loy et al. 2014). These are the families who will benefit most from genetic testing. Genetic testing can be helpful in this context for confirming the diagnosis and evaluating the risk in family members.

1.3.4 Biomarkers in dementia diagnosis

Biomarkers such as brain imaging includes CT, MRI, PET, CSF, and neuropsychological tests are used to diagnose, and predict the progression of mild cognitive impairment to dementia where possible (Eyigoz et al. 2020). The imaging biomarkers can also assist in enabling targeted therapeutic interventions in early diagnosis (Stark 2020). Further specialist imaging can only be considered if it would help to diagnose a dementia subtype and knowing more about the dementia subtype would change management (London Dementia Networks 2018). The specialist imaging includes fluorodeoxyglucose positron emission tomography (FDG-PET), single proton emission CT (SPECT) and I-FP-CIT SPECT (DAT scan). These approaches to imaging have high specificity and sensitivity in distinguishing Parkinsonian syndromes from other neurodegenerative disorders. These investigations are still technically and logistically demanding and require specialist training (Eyzigoz et al. 2020) and are not readily available to everyone. The highly specialised equipment is also located in specific locations and the person with dementia might not tolerate the environment in which the investigation would be carried out resulting in it not getting done. The financial cost of specialist imaging such as PET scans are higher than a CT and MRI scans which are commonly used imaging modalities in the diagnosis of dementia (Harper et al. 2014; Wahlund 2020). CT scans are generally more cost effective and readily available compared to MRI scans. However, MRI is considered superior in terms of sensitivity and specificity for detecting dementia in the early stages. Nevertheless, the choice between a CT and MRI may also depend on other factors such as availability, patient characteristics, and specific clinical circumstances (Harper et al. 2014). Furthermore, the National Institute for health and care excellence (NICE), and other European and US diagnostic guidelines on diagnosis of dementia recommends brain image CT or MRI scans to help rule out other possible causes of cognitive symptoms (Harper et al. 2014). With this knowledge it makes sense that CT scans are more accessible and widely available as well as being the first imaging method used systematically in these contexts (Harper et al. 2014; Wahlund 2020).

Nutritional or nutrient-dependent risk factors are especially important because dietary modifications or use of dietary supplements may lower the risk factor level. One such risk factor is a raised concentration of the biomarker plasma total homocysteine, which reflects the functional status of three B vitamins (folate, and vitamins B12 and B6) (Smith et al. 2018).

1.3.5 Pathophysiology

Alzheimer’s Disease is caused by changes in the brain that includes the build-up of abnormal forms of amyloid and tau proteins which cause plaques and tangles that damages the brain cells (Stark 2020; Wahlund et al. 2017). It typically starts in the entorhinal cortex in the hippocampus. Beta-amyloid (Aβ) protein forms amyloid protein precursors (APP), which originally appear as a monomer, just a single molecule, which then tends to accumulate until it forms an oligomer of many molecules. As it continues to accumulate, it becomes solid and aggregates, forming plaques. Neurofibrillary tangles start to form once amyloid has been present in the brain over a period of time, typically years. Cell death and the onset of AD symptoms are frequently linked by neurofibrillary tangles (Stark 2020). This cell destruction will be more extensive than that seen in normal ageing. Other factors, such as poor health, increased homocysteine levels (plasma total homocysteine (>11 μmol/L), and presence of the APOE e4 allele are also known to increase the risk of AD. However, the presence of beta-amyloid plaques is one of the hallmarks of AD.

There is a genetic role identified for both YOD and late-onset AD (Santos et al. 2017). Three familial autosomal-dominant genes associated with YOD have been discovered. Individuals with Down Syndrome represent the largest group of people with dementia under the age of 50 years (Ballard et al. 2016; Regan 2016). These individuals are born with an extra copy of chromosome 21, which carries a gene that produces a specific protein, amyloid precursor protein (APP). Down syndrome (trisomy 21) is a risk factor for YOD and results in a high occurrence of Alzheimer's pathology in these individuals (Loy et al. 2014; Ballard et al. 2016).

Vascular dementia (VaD) is the second most common form of dementia in young people in the UK. VaD occurs because of cerebral tissue ischemia causing gliosis, reduced blood flow to the brain, and demyelination. Ischemia may occur because of atherosclerosis, thrombosis, or vasculopathy (Kuruppu and Matthews 2013; Uwagbai and Kalish 2022). This is associated with poor heart health diseases such as large vessel stroke and cognitive deficits (Kuruppu and Matthews 2013; Livingston et al. 2020; Kuo et al. 2020). This suggests that the risk of VaD can be reduced or prevented by modifying behaviour and lifestyle. Where the individual has already acquired a vascular factor, emphasis should be on early treatment and good control to reduce severity and any complications that might result (Kuruppu and Matthews 2013).

Mixed dementia, also known as Alzheimer's disease with cardiovascular disease, is a coexistence of both dementias. The brain lesions associated with each pathological process often occur together and when Alzheimer’s and vascular brain lesions interact, they increase the likelihood of clinically significant cognitive decline (Kuruppu and Matthews 2013).

Frontotemporal dementia, sometimes called frontal lobe dementia (FTD) is a rarer form of dementia and a spectrum of clinical syndromes characterized by neuronal degeneration involving the frontal and anterior temporal lobes of the brain (Kuruppu and Matthews 2013; Khan and De Jesus 2023). In patients age ≥ 65, it is the third most common cause of dementia and is the second most common cause of YOD (age <65) and usually involves patients with age ranges from 45 to 65 (Khan and De Jesus 2023). FTD is classified into two distinct clinical types; behaviour variant (bvFTD) and language type. The language type of FTD is further classified into non-fluent variant primary progressive aphasia (nfvPPA), and semantic variant primary progressive aphasia (svPPA) depending on the areas of neuronal loss in frontal and temporal lobes. Diagnosis is based on clinical history, brain imaging and in some cases genetic testing (Kuruppu and Matthews 2013).

FTD is mainly a sporadic disease. The main characteristics are the intracellular deposition of abnormal proteins aggregates in the frontal and temporal lobes resulting in the degeneration of neurons, microvacuoles formation, and astrocytosis. Genetics play a key role and 40% of cases are familial in origin. Among them, 13.4% of cases have an autosomal dominant inheritance (Khan and De Jesus 2023). Mutations in over 20 genes have been identified in the possible development of FTD while head trauma and thyroid disease have been linked with the development of FTD causing an increase in the risk of its development (Khan and De Jesus 2023).

The abnormal tau protein aggregates have been identified as the main culprit in individuals with both sporadic and familial types of FTD and TDP-43 aggregates are predominant in the svPPA. Khan and De Jesus (2023) suggest that genetic counselling, in terms of genetic testing and recommendations, should be provided to individuals with FTD and their families.

As part of laboratory biomarkers, neurofilament light chain can be increasingly seen in blood and CSF of patients with FTD however other biomarkers including MRI, CT scans, EEG have not been found to be helpful in diagnosis but can help rule other conditions out.

Posterior Cortical Atrophy (PCA) is a rare form of dementia which people often develop between the ages of 50 and 65. However, it can also affect older people. PCA is a neurodegenerative syndrome that affects brain regions that process visual and sensory information, such as the occipital and parietal lobes. Individuals often present to optometrists, ophthalmologists and/or neurologists with non-specific visual complaints. Unless clinicians seek the specific symptoms and signs of PCA beyond that of the standard neurological examination, this infrequent disorder is easily missed, delaying its diagnosis and treatment (Beh et al. 2017; Crutch et al. 2017). PCA is primarily caused by brain cell changes, in most cases similar to Alzheimer's disease. However, it presents differently, in early stages, PCA preserves episodic memory, and insight, but eventually leads to cognitive dysfunction.

There is no single diagnostic test for PCA, so a combination of investigations maybe carried out to rule out treatable conditions. Investigations can include specialised visual tests, neuropsychological tests of cognitive skills, and blood tests. Brain scans (MRI/FDG-PET/SPECT) may reveal shrinkage/ hypometabolism/hypoperfusion of the back part of the brain because of brain cell loss. Examination of the fluid circulating around the brain and spinal cord and EEG can also be used.

Chronic traumatic encephalopathy (CTE), sometimes called sport-associated dementia, is associated with a history of traumatic brain injury or repetitive head impact. It contributes to 3-15% of cases of dementia (Livingston 2020). A link between traumatic brain injury in contact sport and neurodegenerative disease was first proposed almost a century ago with descriptions of punch-drunk syndrome among boxers, later called dementia pugilistica (Stewart 2021). In the past 20 years, however, the pathology of CTE has been increasingly recognised. This is partly because of media reports and personal testimonies of high-profile athletes (former and present) in other high-profile sports, including soccer, rugby, and American football, and among others with traumatic brain injury unrelated to sport. Efforts are being made to raise awareness of, and concerns about, the dangers of contact sports. In response to the increased prevalence of the condition, in 2023, Dementia UK (DUK) appointed the first-ever Consultant Admiral Nurse (CAN) for Sport and Dementia. This sees the creation of a specialist dementia service and pathway for sport and dementia for Admiral Nurses service and collaboration with the Professional Footballers’ Association in the UK.

Lewy Bodies (LBs) are insoluble, intraneuronal protein inclusions first characterized over 100 years ago. They have long been considered the pathological hallmarks of Parkinson’s Disease (PD) as well as prominent pathological features of other neurodegenerative diseases of the central nervous system (CNS) (Ahmed et al. 2014; Marotta et al. 2021; Haider et al. 2023). The core pathology of DLBs is the presence of LBs in the brainstem, limbic regions or cortex comprising αlpha-synuclein (a-Syn), a presynaptic protein whose function remains debatable and a primary component that defines LBs (Ahmed et al. 2014; Haider et al. 2023). It is the protein a-Syn which misfolds to produce beta-sheet-rich amyloid fibrils. α-Synuclein protein is found in high levels in CNS neurons and is localised to the pre-synaptic termini where it participates in vesicle maintenance, recycling, and release. The aggregation of α-Synuclein protein causes changes in neurotransmitters dopamine and acetylcholine and so leads to neurocognitive changes (Marotta et al. 2021). Genetic mutations, environmental toxins, and the aging process can lead to misfolding of α-Synuclein and its accumulation in the form of LBs via oxidative stress and mitochondrial dysfunction. Lewy Body Dementia (LBD) is widely thought to be on a continuum with Parkinson’s disease dementia (Kuruppu and Matthews 2013; Ahmed et al. 2014). Like AD, LBD presents with acetylcholine deficiency, but it is more pronounced in LBD. Decreased levels of acetylcholine in temporal and parietal cortex result in visual hallucinations (a prominent feature of LBD), while up-regulation of muscarinic M1 receptors in the temporal lobe results in delusions and dopamine levels also diminish (Haider et al. 2023). A family history of LBD and Parkinson disease increases a patient's risk.

There is no precise test to accurately diagnose LBD. Diagnosis is made with clinical history and examination, and it is suggested that MRI imaging is not as helpful for diagnosis except to rule out other causes (Kuruppu and Matthews 2013). Imaging studies are not helpful because the changes in the brain often mimic those seen in patients with vascular dementia. As a result, a postmortem biopsy or autopsy is the only method to secure a definite diagnosis.

Other, less common types of dementia include Huntington’s disease (HD) a rare, autosomal dominant genetic and trinucleotide repeat disorder that affects men and women equally (Kuruppu and Matthews 2013). HD results from expansion of polymorphic CAG repeats in the exon 1 of huntingtin gene that translates into elongated polyglutamine (PloyQ) tract in huntingtin protein (HTT) (Dabhi et al. 2023). PolyQ expansion alters HTT structure resulting in abnormal protein-protein interactions, aggregation, mitochondrial dysfunction, oxidative and endoplasmic reticulum stress, inflammation and altered gene expression leading to neuronal cell death (Dabhi et al. 2023). The cognitive and behavioural symptoms and signs of Huntington’s disease have been shown to be evident at least 15 years prior to the time at which motor diagnosis is typically given (Paulsen 2011). A genetic test can diagnose this condition.

Korsakoff syndrome, also known as Wernicke-Korsakoff syndrome is a non-progressive type of dementia most commonly associated with chronic alcohol abuse, resulting in brain damage. Wernicke encephalopathy and Korsakoff syndrome are different conditions that often occur together. Both are due to brain damage caused by severe deficiency of thiamine (vitamin B1). Korsakoff psychosis results from permanent damage to areas of the brain involved with memory. It is largely characterized by large-scale amnesia, and in more severe cases also by cognitive and behavioural dysfunction (Nicolaas et al. 2017)

Creutzfeldt-Jakob Disease (CJD), sometimes called prion disease, is caused by abnormal forms of the prion protein, which folds into an abnormal three-dimensional shape. This shape change gradually triggers prion protein in the brain to fold into the same abnormal shape (Sikorska 2012). The normal function of prion protein is not yet known. CJD is a rapidly progressive neurodegenerative disease. There are four types of CJD are known: Sporadic familial or genetic, iatrogenic, and variant. The variant CJD results from the transmission of bovine spongiform encephalopathy (BSE) from cattle to humans. Genetic CJD is caused by diverse mutations in the PRNP gene. Amyloid plaques are encountered in 10-15% of sporadic Creutzfeldt-Jakob disease (sCJD) cases and in variant Creutzfeldt-Jakob (vCJD) the particular type of plaque known as "florid”, or "daisy" plaque exists in 100% of cases (Sikorska 2012). People tend to die young and quickly.

In summary, regardless of the diversity of the clinical features observed, neurodegenerative diseases are characterised by the accumulation of protein and deposition at the molecular level (Desai and Bandopadhyay 2020; Koch et al. 2020). The nature of such intracellular protein aggregates is dependent on the disease type and is specific to the disease type (Desai and Bandopadhyay 2020).

1.4 Historical Context of dementia

I present here the history of dementia from ancient Greece to the rise of genomics, by way of the Renaissance, Industrial Revolution, and the post-war period. Here I will give an overview of history, rather than a definitive account. What became very clear, however, is that the language used to describe dementia at different eras not always been kind and examples will be given at various points.

1.4.1 Ancient Period

Greek philosopher Pythagoras (570-490 BCE) created the concept of senium, or old age. Pythagoras suggested that people over the ages of 63 and 81 years could face the unavoidable loss of higher cognitive functions that came with advanced age (Boller et al. 1998; Fotuhi et al. 2009; Taheri-Targhi 2019). It was accepted as normal that old age was accompanied by the deterioration and degeneration of the human body and deterioration of mental capabilities.

Pythagoras's observations of extreme mental capacity regression in old age must have been commonly observed because legislators in ancient Greece incorporated the lack of lucidity into some laws. One such example is that of Solon (died 560 BCE), a Greek judge who took senile cognitive decline into consideration and amended inheritance laws. Solon's amendment ensured that a will would be valid only if the writer was considered fully competent to make the decisions. At that time incompetence was judged by a lack of pain, violence, drugs, old age, or 'persuasion of a woman' at the time of will writing (Boller et al. 1998; Fotuhi et al. 2009; Taheri-Targhi 2019**).** Interestingly, this seems to have relevance today because of the similarity to the considerations when assessing for capacity according to the guidelines of the Mental Capacity Act 2005. Though the Mental Capacity Act is more detailed, it still has to be ensured the person making the decision is not under duress or the influence of drugs or pain.

Hippocrates (ca.460-377 BCE) in his writings on old age-related mental decline, used the term, "paranoia" which was thought to have an organic aetiology. There is a conflicting idea, that although Hippocrates recognised 'incompetent behaviours' in older people, he did not include it among his mental disorders (Bechtold and Cotman 1998). This may indicate that Hippocrates viewed these behaviours as normal in old age.

Plato (429-347 BCE) and his student Aristotle (384-322 BCE) also believed that mental and cognitive decline were unavoidable consequences of old age. Aristotle was reported to have made comments stating that old people were useless because there was not much left of their capabilities to make judgements, power of reasoning and memory (Bechtold and Cotman 1998). As a result, they were seen as little or no purpose in society or to themselves. The Roman scholar Cicero (106-43 BCE) described senile debility, dotage, and madness and said they were signs of old men who were weak in will. Cicero went on to further suggest that an active mental life could prevent or at least postpone mental failure (Bechtold and Cotman 1998). This is still an activity that is encouraged in our lives today. Galen, a Greek-Roman physician (129-216 CE) referred to dementia, as 'morosis' or mental slowness, and indicated that old age is one of the situations in which it may occur.

1.4.2 Medieval age

During the Medieval age, there were almost no relevant scientific reports on age-related cognitive decline. Neurological disorders and mental illness were not understood within the Church and scriptures were used as the main source in explaining phenomena, including dementia. In the 13th century, philosopher Roger Bacon (1220-1292), repeated the religious dogma that dementia be related with God's punishment for previous sins. During this period, people with dementia were said to be possessed by evil spirits and this led to exorcism or incarceration and even the ritual killing of sufferers.

1.4.3 Early Modern Period: The Renaissance to the Enlightenment

Ideas about the causes of disease and illness did not hugely change in the Renaissance period. People's lives were still dominated by clerics and religious scholars, so they continued to believe that God sent 'sicknesses' as punishment. One of the main features of the Renaissance was a change from respect for tradition to the search for change and new ideas about science which encouraged people to challenge old ideas.

In the 17th Century, autopsy of the human body was allowed. This increased research seeking to understand the underlying physiological changes in the brain that might be the source of mental disorders. Thomas Willis [1621–1675], an expert in anatomy, suggested a precise classification of dementias in 1684 and some of the causes to be congenital factors, age, head injury, including strokes or bruising of the head for example, from accidents, alcohol and drug abuse, other disease, and prolonged epilepsy. The 17th century seems to be the period when the different branches of dementia became better categorised behaviourally and were shaped into more defined and definite concepts. However, terms such as stupidity, idiocy and foolishness were generally used to describe the disease (Bechtold and Cotman 1998).

1.4.4 Late Modern Period: Industrial Revolution to the Second World War

Up until the 19th century, those living with mental illness, including those with senile dementia, were confined into asylums or prisons and conditions were terrible. It was Phillipe Pinel (1745-1826), a French physician and professor of pathology and hygiene, who argued that madness was not a crime or divine punishment but a disease that needed to be treated, thus helping to change attitudes towards the mentally ill and people with dementia (Bechtold and Cotman 2017). Pinel gave the first noted reference to 'demence senile'. Firmed up by Pinel, this shift caused the abandonment of the religious view. Pinel's efforts led to widespread clinical and pathological observations of mental disorders and a realisation that there was need to create systems of classification, redefine old terms and give terms to the newly identified subtypes and categories of mental disorders.

After Pinel, Jean Etienne Dominique Esquirol (1772-1840) correctly articulated the symptoms of dementia according to the new medical definition of the term: a disease including all states of intellectual incapacity for varied reasons.

Esquirol distinguished acute dementia from chronic and senile dementia (Hineman 2017). Between 1814 and 1838, Esquirol grew increasingly aware of the unique nature of senile insanity in comparison to other types of dementia. He did, however, consider dementia to be a ‘constitutional illness of old age’. Another major change in the understanding of dementia followed the embracing of different research methods. One example is Jean-Martin Charcot (1825–1893), who utilised the anatomo-clinical method. Charcot was able to maintain careful documentation of clinical signs with longitudinal observation when the person still lived and also carried out their autopsy examination of the brain and spinal cord at death and the result was clinical-anatomical correlations (Goetz 2009). From the 1860s, efforts began to identify a separate brain pathology for senile dementia in people who had not previously suffered from mental illness. This period saw a shift from viewing dementia as a pathological variant of normal aging to viewing it as a distinct disease.

1.4.5 Contemporary History: Post-War Period to the Human Genome Project

The sexually transmitted infection, syphilis, seems to have appeared around the 15th and 16th centuries in the history of dementia and remained the major cause of ‘insanity’ for many years (Boller and Forbes 1998). In 1857 German psychiatrists identified the condition of ‘general paresis’ which ultimately led to insanity and connected it to contracting syphilis infection years earlier (Ballenger 2017). Also known as neurosyphilis, the condition became commonplace during World War 1. This is most likely due to the lack of an adequate treatment for early syphilis and the use of prostitutes by soldiers while fighting overseas. Ultimately, with the lack of antibiotics they brought the disease home, often infecting their wives. It was estimated that up to 5% of British soldier’s wives became infected causing a public health crisis in the early 1920’s. Neurosyphilis was probably the most common cause of dementia until the mid-twentieth century and many subsequently died. Those who survived, were left with different degrees of mental instability. In more recent years, neurosyphilis has greatly reduced but has been replaced by another sexually transmitted infection, the human immune virus (HIV), as one of the causes of dementia although now very rare, due to advances in medical care.

In the same era, other developments and discoveries were made in relation to dementia. Alois Alzheimer and Otto Binswanger are both reported to have described atherosclerotic brain atrophy in the 1890's. The atheromatous degeneration of blood vessels with accompanying stroke became accepted as an event that would cause senile atrophy and senile dementia (Bechtold and Cotman 1998). This might be the origin of the explanation for vascular dementia. This theory stayed as the prevailing cause of senile dementia till the 1960s.

Kaplan and Henderson (2000) gave an insight into Dr Solomon Carter Fuller's (1872–1953) life and contribution to dementia research. Fuller was a Liberian neurologist, psychiatrist, and pathologist, who worked with Alois Alzheimer and was responsible for publishing the first instance of presenile dementia. Fuller emphasized that amyloid plaques and neurofibrillary tangles may be relevant indicators for the research of AD in addition to arteriosclerosis, which was previously thought to be the origin of the disease. Fuller saw the neuropathology of prolonged alcoholism while working with patients.

Around 1906, histology became more routine, and the use of staining methods led scientists to discovering microscopic plaques and tangles on the brains during autopsies. In 1906 Alzheimer reported on the case of 51-year-old Auguste Deter who had developed progressive dementia that had seemed to be identical to senile dementia (Boller and Forbes 1998; Ballenger 2017). On autopsy, Auguste's brain showed plaques and tangles identical to those Oskar Fischer had observed on the brains of older people. Alzheimer distinguished early onset presenile cases that occur before the age of 65 years, from the more common senile dementia occurring at later ages. Alzheimer further explained that they were not caused by syphilis or vascular changes. This dementia would come to be named Alzheimer's disease in 1910 by Emil Kraepelin.

Fuller delivered a speech on dementia to a large conference attended by leading physicians in 1909. His key work, a two-part analysis of AD, was the first English translation of the first Alzheimer's case and was published in 1912. Many of Fuller's contributions to the scientific literature are said to have been lost for decades, yet his discoveries continue to influence study today. Between 1910 and 1960 researchers concentrated on trying to understand the relevance of plaques and tangles and discussions began on the role of genetics in AD and senile dementia. The pathological processes of deterioration in old age that produced senile dementia were understood to be on the extreme end of “normal”. Dementia occurred at earlier ages, as in the case Alzheimer presented, even though seemingly associated with the same brain pathology and clinical symptoms, seemed to suggest some kind of disease process. It is therefore thought that Kraepelin might not have thought that a condition strongly associated with aging could affect someone earlier in life.

In the UK, during the latter half of the 20th century, British psychiatrists, like other practitioners in varied health care fields, increasingly employed standard tests and numerical rating scales to diagnose illness, differentiate the ‘normal’ from the ‘pathological’ and standardise diagnosis. This helped change attitudes about the causes and prevalence of dementia and helped old age psychiatrists to present arguments for dementia as a disease in its own right. They argued that dementia should be considered a vital component of the recently formed Welfare State, that more reliable modes of diagnosis of the disease were necessary and that needed allocation of resources. The result was that policymakers, funding bodies, patient groups, caregivers and family members struggling to deal with dementia in the context of new expectations for aging, all agreed that research into the causes and prevention of dementia should be prioritised. Dementia thus was recognised as a major public health issue. The use of rating scales is also thought to have helped that old age psychiatrists to assert and consolidate their professional expertise during the late 20th century.

During the 1970s and 1980s, biomedical research raised hopes of the possibility of treating dementia. Both clinical judgement and the use of rating scales were seen as crucial first steps in identifying early cases of dementia and identifying recipients of drug treatments. Both are still used today. Diagnostic strategies continued to improve and expand as was microscopy in the 1960s which enhanced the study of the plaques and tangles of the diseased brain. By the 1970s, AD was known to be the most common form of dementia, and it recognised that cognitive decline caused by Alzheimer’s is different from that caused by normal ageing. Other biomarkers such as CT scans, brain imaging continued to improve and be utilised more widely to make diagnosis of dementia. By the 1990s, genetics and its role in some types of dementia was better understood, risk factors had been identified and stages of dementia had been categorised. As the improvements happen in histology and biochemistry, so are the attitudes of society towards dementia and more advocating for better care.

1.5 Summary

The history of dementia is important in showing us how far we have come and how we got there. It has paved the way for how dementia is viewed today, not only based on science but also within the socio-political context. Ongoing research has some of its basis in the historical events and some facts and discoveries made long ago that continue to change our understanding of dementia. The move towards changing to a ‘neuro-cognitive’ term is also believed to be in the forward-thinking direction. Society is largely much more aware of the risk factors to developing dementia, knowledge of which help prevent or reduce this risk and general cognitive health awareness has increased. It is through the implementation of health policies and strategy documents that healthcare professionals (and the general population) are alert to the multifactorial causes of dementia. Biomedical research is ongoing. However, research has also broadened to highlight the importance of psycho-social interventions: social support and inclusion through the concept of dementia-friendly physical and social environments.

1.6 Policy Context of dementia in the UK.

In the UK, health and social care affairs are decentralised therefore England, Scotland, Wales, and Northern Ireland are responsible for setting their own policies. A key priority in dementia care is the development of interventions and support systems that enable people experiencing dementia to 'live well' (Banerjee, 2010; DoH 2009) as shown in Table 1. Policies were and still are driven by an acknowledgment that in the UK, dementia is a public health priority.

Table 1. Policies in different countries in UK.

Date	**Policy**	**Content**	**Country**
2009	The National Dementia Strategy for England '*Living well with Dementia'*	The strategy aimed at raising public awareness, removing stigma, improving rates of diagnosis as well as, increasing the range of services for people with dementia and their families or carers	England
2012	'Dementia: A National Challenge'	This aimed to deliver major improvements in dementia care and research by 2015	England
2015	The 'Challenge on Dementia' 2020	The challenge is a five-year plan that will focus on boosting research in UK while placing emphasis on risk reduction, health and care, awareness and social action (Powell and Baker 2019).	England
2013 and 2016	*The Making a Difference in Dementia: Nursing Vision and Strategy*, published in March 2013 and 2016	Sets out a vision of how nurses could maximise their unique contribution to high quality, compassionate care and support for people with dementia and their carers/ families (Department of Health 2016).	England
2016	*Joint declaration on post-diagnostic dementia care and support* (Department of Health).	The policy promised post diagnostic support for people living with the effects of dementia and their families and carers	England
2019	Other recent policy developments include '*The NHS Long Term Plan'*, (2019).	This policy commits the NHS to continue improving the care provided to people with dementia and their carers whether they are in hospital or at home.	England
2010	The Scottish Government Dementia Strategy.	This first strategy was published in 2010 and focused on improving the quality of dementia services through more timely diagnosis and on better care and treatment.	Scotland
2013-2016.	The second Scotland's '*National Dementia Strategy*	This strategy was focused on improving post-diagnostic support and strengthening integrated and person-centred support.	Scotland

2017	Scotland's ‘*National Dementia Strategy 2017-2020’* was published in June (Scottish Government 2017).	Within the 2017-2020 strategy, there is a recognition of the importance of taking a person-centred and flexible approach to providing support at all stages of the care journey (Scottish Government 2017). Policies that underpin and reinforce our vision and strategy. • Health and Social Care Delivery Plan. • Integration of Health and Social Care and Primary Care Transformation • National Clinical Strategy • Carers Strategy and Act • Self-Directed Support • Palliative and End of Life Care Strategic Framework • Housing Strategy. *Age, Home and Community: A Strategy For Housing For Scotland's Older People: 2012 - 21* recognises the important role of housing support in enabling people to live safely and independently at home for as long as possible	Scotland
2008	National Dementia Vision for Wales	*The National Dementia Plan for Wales Task and Finish Group* was established by the Welsh Assembly Government in October 2008 to oversee the development of a national dementia plan for Wales.	Wales
2011	The *“National Dementia Vision for Wales – Dementia Supportive Communities”*	Was developed particularly to advocated for people living with dementia to have a voice. It was also that community is consulted and listened to, in discussion and plans around dementia as a way of developing Dementia Supportive Communities (Welsh Assembly Government and Alzheimer’s Society 2011).	Wales
2016-19’	*Together for Mental Health*’	*Together for Mental Health 2016-19’* priority area 10, ‘Wales is a Dementia Friendly Nation Initiative’. ‘*Together for Mental Health*’ is the Welsh Government’s 10-year strategy to improve mental health and well-being of all residents in Wales including those required to support people with severe and enduring mental illnesses (Welsh Government 2016).	Wales
2018	The ‘*Dementia Action Plan for Wales*	The ‘*Dementia Action Plan for Wales 2018-2022’* (Welsh Government 2018) aims to create new ways of caring, training and increasing the number of	Wales

		support workers among other elements. This also replaces the *Together for Mental Health 2016-19’* priority area 10, ‘Wales is a Dementia Friendly Nation Initiative’ (Welsh Government 2016).	
2009,	The ‘*Listening Well project’*	incorporated people living with dementia informing the development of health and social care policy. Listening Well findings are incorporated throughout ‘*Improving Dementia Services in Northern Ireland: A Regional Strategy* ‘(Alzheimer’s Society 2009).	Northern Ireland
2011	A Northern Ireland strategy, ‘*Improving Dementia Services in Northern Ireland’*	set out a holistic model for supporting people with dementia.	Northern Ireland
2017	*Dementia Together NI’*	The Northern Ireland Executive’s Dementia Services Programme, ‘*Dementia Together NI’,* ran for four years from 2013 to 2017 (Powell and Baker 2019).	Northern Ireland

1.6.1 Comments on policies

Despite the decentralised health and social care affairs in England, Scotland, Wales and Northern Ireland, the National Dementia Strategy shares common priorities. These include raising awareness of the disease, combating stigma, identifying support services, quantifying the number of individuals with dementia, assessing, and improving the quality of dementia care, and assessing the availability and access to diagnostic services (Chow et al. 2018; Cahill 2018).

Chow et al. (2018) reviewed and compared 25 of the 29 National Dementia Strategies published globally, including countries from the UK. Of the UK’s four nations, most implementation plans were vague and lacked structure and detailed plans (Chow et al. 2018). This makes it difficult to see how the strategies could be effective as no guidelines are provided. They are also likely to cause confusion, and the lack of appropriate preparation can be a barrier to implementation.

The English Dementia Strategy (Department of Health (DoH) 2009) is reported as being strongly bio-medically driven, while more recent strategies and particularly the Dementia Action Plan for Wales (Llywodraeth Cymru Welsh Government (LCWG) 2018) and updated plans for Scotland, have framed dementia as a public health issue, emphasizing the importance of brain health, risk reduction and primary prevention. This seems more in line with empirical evidence emphasizing the important role cardiovascular risk factors play in increasing risk. Most modifiable preventive measures of dementia depend largely on the individual to act. Clearly, a rights-based approach, with an emphasis on autonomy, self-determination, independence, participation, equity, and choice should be spread to all the countries' new dementia policy plans (Cahill, 2018). The rights-based approach also means that countries must ensure that their policies, legislation, and programmes are planned with the needs of the people, their cultures, and sensitive to the human rights of people with dementia as in that particular country.

The joint declaration on post-diagnostic dementia care and support (DoH 2016) remains unfulfilled in many families living with dementia. For example, families frequently talk about how, following a diagnosis, there is no clear pathway of how they can get further support and no guidance for them on available resources. The inequalities are even more noticeable in people with young onset dementia, where getting a diagnosis can be a challenge and resources available are usually not age appropriate (Rossor et al. 2010; Rabanal et al. 2018).

The '*Challenge on Dementia'* 2020 (DoH 2015) has faced many challenges, especially since the onset of the SARs-Cov2 pandemic in 2020. *The Making a Difference in Dementia: Nursing Vision and Strategy* (DoH 2016) promises that all nurses will be equipped to support people living with dementia and their families. This point is not met yet because not all care home staff are competent in working with people with dementia and this leads to people living with dementia being placed far away from their original homes in some cases.

1.7 Chapter Summary

This chapter has provided on overview of the historical and contemporary context of dementia, discussing the evolution of understanding, knowledge, societal perceptions, and current challenges and advancements in diagnosis and management. The chapter also gives an overview of the policies aimed to ensure improvements in dementia care pre, during and post diagnosis in UK by each of the four nations. Within these policies attempts are made to address YOD as well.

1.8 Thesis overview

Chapter 2 presents the literature review process and findings that gives the justification for carrying out this study. Chapter 3 outlines the study design, methodology and methods, and theoretical framework as well a rationale for their choice. Chapter 4 presents the individual idiographic analyses and cross-case analysis with themes identified for further examination and discussion. Chapter 5 presents a discussion of the group experiential themes, both convergent and divergent themes and findings in relation to literature that is available. Chapter 6 presents my conclusions and recommendations for practice, education, research, and policy are presented.

Chapter 2: Literature Review

2.1 Introduction

This chapter aims to situate the study within the existing knowledge through a narrative synthesis of the literature to gain insight as to what is known on the topic of people living with YOD and their transition to care homes. There are conflicting ideas about when literature reviews should be carried out in IPA methodology. Willig (2008) for example, advises that detailed literature reviews should not be conducted before the analysis is undertaken because the analysed data is expected to inform the literature review. However, following Smith et al. (2022) I conducted a narrative review using a systematic approach before data collection. This was to enable me to get a sense of the broad context about the current landscape regarding the of care of people with YOD and those important to them, as well as insight on the processes involved in IPA.

The review question was: *What do we know about the experiences of people with YOD, and their families, in relation to care and the transition from hospital to care home?*

The specific objective was to better understand the lived experiences of people living with young onset dementia and their families in relation to care and the transition to a care home. The review follows the steps as set out by Aveyard et al. (2016). I chose Aveyard et al.'s (2016) guidance because it was developed specifically for post-graduates in nursing and health care. It provides different approaches to literature reviewing. As a novice researcher this guidance was of value to ensure that I did not miss any important areas in the literature review process.

2.2 Rationale for a narrative review approach.

There are many types of literature reviews including systematic, scoping, or narrative reviews. They each can help to locate research gaps and needs.

However, a systematic and scoping review would need more time to complete the necessary procedures. As a novice researcher, and a part time student with time constraints I opted for a narrative review. Narrative reviews have been criticised for not being systematic nor transparent in their approach to synthesis (Popay et al. 2006). However, narrative synthesis is part of a larger review process that includes a systematic approach to searching for and quality appraising research-based evidence as well as the synthesis of this evidence. A narrative synthesis is also appropriate because the literature included in my review used different research designs (Aveyard et al. 2016) which permits me to include synthesised findings from multiple studies. This allowed for the interpretation and understanding of the data, weaving together different perspectives, and experiences, to create a meaningful narrative synthesis of the data for search findings. Popay et al. (2006) advised that narrative synthesis will help increase the chances of a scientific synthesis because the methodology focuses on analysing and synthesising textual data such as interviews, and written narratives to create a coherent story that represents the findings of the search.

This narrative review is a summary of previously published articles on dementia and YOD, with the introduction of some modifications to enhance structure, rigor, and transparency (Tulandi and Suarthana 2021) such as the use of PRISMA flow chart (Moher et al. 2009)-Figure 2.

2.3 Searching for Literature

From a preliminary scoping exercise on Google, I noted that there was a considerable body of literature pertaining to dementia and transition, which was largely related to older adults (over 65 years). I sought help immediately and started searching for literature with the help of a specialist librarian who, in turn, invited another specialist librarian very early on in this stage. This was because the two of us had not found any papers on people with YOD and admission to a hospital ward. So, we agreed a second opinion would be helpful and may produce a different result. With the support of the two specialist librarians, I conducted a preliminary search to help identify potential keywords for the search strategy. Alongside working with the librarians, I had ongoing discussions with my supervisory team who supported me with advice and perfecting my research question.

2.3.1 Database Searches

The electronic databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), British Nursing Index (BNI), PsycINFO and MEDLINE were systematically searched. The initial step was identifying the important components of the question to consider during the search (Aveyard and Sharp 2017) through highlighting these terms, identifying synonyms and other terms that had the same meaning, as the key concepts. Boolean operators were further combined with identified terms to enhance sensitivity in searches. Key terms were then used in different combinations to filter the results as shown in Appendix 1. Even though no search limitations were applied on dates, study design and geographical area, no literature relating to YOD, hospital admissions and discharge to care homes was identified. Consequently, I widened the focus to dementia in general and all adult age groups. I carried out the initial search in 2019 (as in Appendix 1).

2.3.2 Grey Literature and hand searching.

A search for' grey' or unpublished literature was carried out to find papers that were not from commercial sources. I also engaged with relevant existing networks such as Young Dementia networks and Dementia UK and trawled through them for publications. The Dementia UK website produced the only paper that examined the care of people with dementia on a psychiatric unit (Edmans et al. 2021). Back chaining, hand searching of key journals (for example Journal of Dementia Care) and exploring websites of relevant organisations was done.

2.4 Search Results.

The initial database search produced 727 papers. Additionally, 20 papers were identified through hand searching. After duplicates were removed, 270 papers were retained. Following screening of titles, initially skim reading the articles and abstracts, 69 papers were retained. Further reading of full texts was carried out which led to the retrieval of 26 full texts of potentially useful abstracts. After going through the full texts, the result was that 18 full text articles were eligible for inclusion in the review.

From the beginning of the search all relevant references were imported into EndNote bibliographic software. I set alerts to ensure new potentially new literature relating to dementia, YOD and transition might be identified.

To allow for clear record keeping and demonstrate the study selection process I used the PRISMA flow chart (Moher et al. 2009) below.

2.5 Inclusion and exclusion criteria

The initial plan had been to include papers that reported findings from primary research with a focus on YOD. However, due to the limited number of research studies specifically relating to YOD and transition to hospitals and care homes, some of the chosen articles in this literature review do include studies about dementia in older people. The final 18 articles were selected included are empirical research studies (n=9), and literature reviews (n=9).

2.5. 1. Extracting relevant information

Following the identification of studies to include in the review, data extraction was guided by Popay et al. (2006) and included elaborating on the key components of the review question so as to aid the process of making sure that decisions I made were transparent. For the preliminary synthesis I produced a descriptive paragraph on each included study presenting the significant data that were recorded that relate to the review questions and objectives. I created a data charting summary recorded information related to database(s), title, target population, sample size, research design and method, author(s), publication year, journal or publication title, type of source, type of publication, country of origin, major themes/findings, and recommendations.

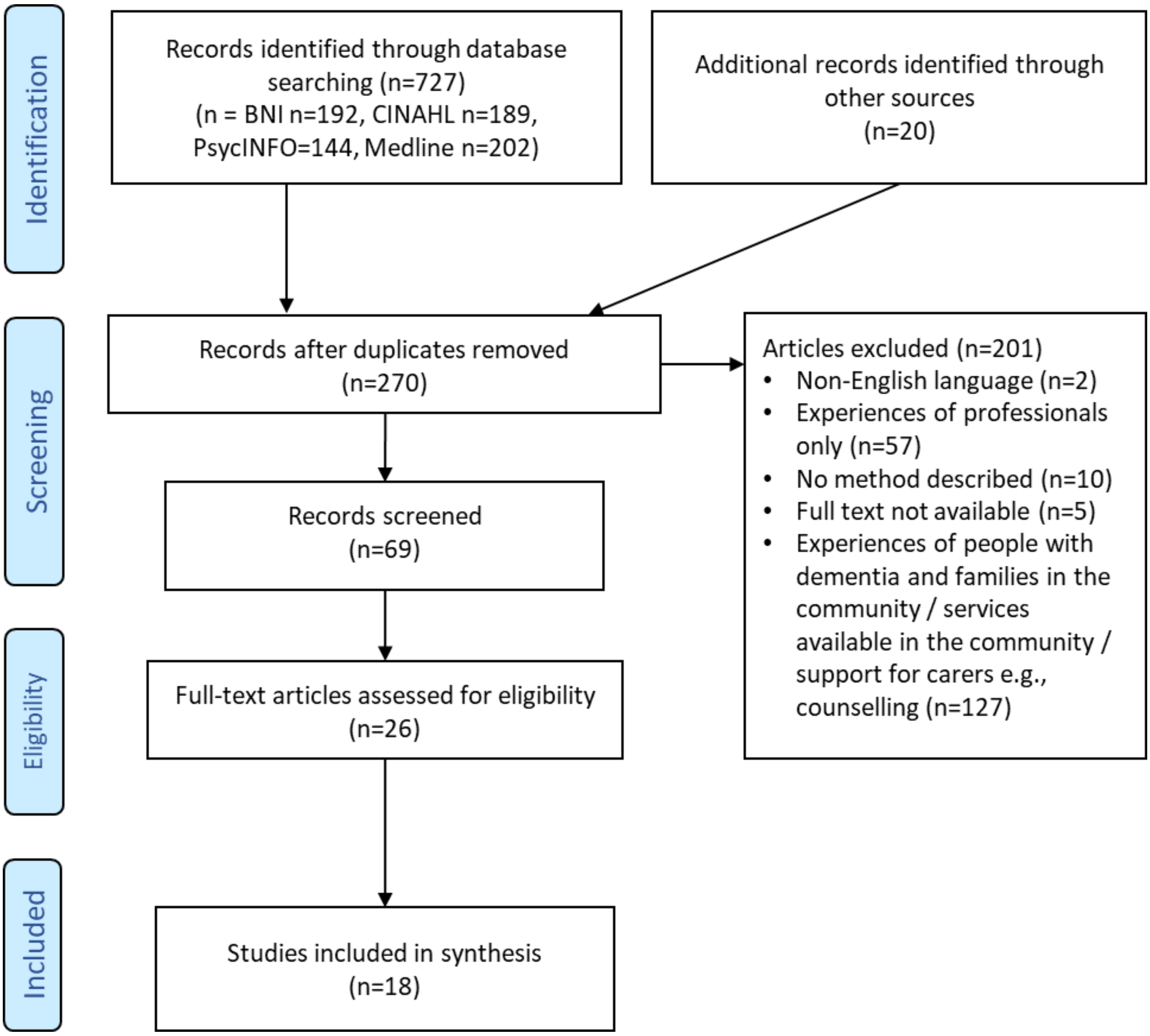
The following step was the development of a preliminary synthesis of findings of the 18 included studies. This included exploring relationships within and between studies to identify patterns across each study results and organise them into groupings and clusters according to the main themes addressing specific areas e.g. those addressing grief were grouped together (Popay et al. 2006) to make the process more manageable. Thematic analysis provided a means of organising and summarising the findings from the diverse research studies included. Primary themes or concepts reported across studies were used to explore similarities and/or differences between different studies.

A summary of reviewed literature is in a synthesis grid attached in Appendix 2. The reviewed literature primarily related to dementia in general and in older people. Literature focusing on YOD was scarce. Generally, literature focused on the care of people with dementia (PWD) and their families in primary and secondary care, through the pre diagnostic, diagnostic and post diagnostic stages. Themes were identified from each of the 18 papers and later grouped according to similarities to lead to the identification of key themes that will be discussed in section 2.8.

2. 6 The search results.

The PRISMA diagram below in Figure 2 shows the process of screening, rejecting, and selecting papers for inclusion in the study. 18 papers were deemed suitable for the study, empirical studies (n=9) and literature reviews (n=9). Six papers used qualitative methodologies (Schur and Whitlatch 2003; Bur et al. 2006; Caron et al. 2006; Bakker et al. 2013; Johannessen et al. 2017; Lamech et al. 2019, and two used mixed methods (Sanders et al. 2008; Chan et al. 2013) with data mainly collected via individual interviews, semi-structured interviews, and focus groups. Bakker et al (2013) and Bur et al. (2006) were longitudinal studies run over two and four years respectively. The included articles spanned a time frame of 19 years (2002–2021). They covered five countries- UK (n=7), USA (n=7), Europe (n=2), Canada (n=1) and India (n=1). All publications were in English. The synthesis grid is in Appendix 2.

Figure 2: PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009).

2.7 Appraising quality

To review the research articles, critical appraisal checklist was carried out using the Critical Appraisal Skills Programme (CASP) (2022). I chose CASP because it offers a range of checklists for a variety of different types of evidence quality so allows for a wider range of papers to be critically evaluated. Accordingly, I used the qualitative research, randomised control trials (RCT), and systematic reviews checklists. CASP has its focus on healthcare which is a main advantage for me a novice researcher. CASP gives guidance to consider three broad questions when appraising a paper; are the results of the study valid? What are the results? Will the results help locally? CASP (2022) checklists were helpful in assessing articles for credibility, reliability, and transferability. The description of the included papers is in a synthesis grid (Appendix 2).

2.8 Narrative synthesis results.

Analysis of the papers identified four key themes:

- factors associated with hospital admissions and care home placements.
- the impact of dementia on the family: transitions and issues,
- issues related to services, and
- models of dementia care.

Each theme has been discussed in detail below.

2.8.1 Factors associated with hospital admissions and care home placement.

Most people with dementia live at home with carers and family. While they may want to live at home, advancing dementia comes with greater needs and increases the likelihood of moving into a care home. However, research has shown that most people hope to avoid this at all costs (Harrison et al. 2017) and having to make that decision is a difficult experience for families (Caron et al. 2006). Caron et al. (2006) used grounded theory to explore the decision-making process with regards to long term placements from the perspective of 14 family carers who moved a relative into placement in the six months prior to the interviews.

Yaffe et al. (2002) found that information about factors that influence care home placement could shape interventions to delay placements and so, could reduce healthcare costs and possibly improve the quality of life of the PWD by maintaining their independence. The study carried out a randomised control trial in a study of a large population of PWD and carers (5788), in eight sites in USA to determine predictors of care placements. Yaffe et al. (2002) identified that both PWD and carer characteristics can interact and mutually reinforce risk factors that lead to a care home placement. Some of these are the old age of the carer and the PWD requiring care for over 90 hours a week and PWD being functionally dependent on the older carer. Factors associated with an increased risk of admission to a hospital and later care home placement are demographic and include carer or family’s relationship to the PWD, employment, financial resources, and age of the family member providing care. In YOD, carers can be older parents or a spouse who is still in employment. Other factors of influence can be whether the family feels that they are providing good care and whether the PWD has a problem with household tasks according to Schur and Whitlatch (2003) who carried out a study called “Caregiver Options Program and Evaluation” (COPE), to establish a program to provide additional service options to the participating caregivers, a two-part study in which 127 family carers took part. The first interview was completed prior to the introduction of the optional caregiver services, and this helped to confirm the financial needs which would have been a barrier to accessing extra support. Following confirmation of the need, carers were given an amount of cash to purchase additional services that would give them respite from caring to explore if this might postpone the decision to place a PWD in care. While the stipends were said to be useful, the result was that some PWD still went into care (Schur and Whitlatch 2003). This study echoes findings from other studies such as Yaffe et al. (2002); Bur et al. (2006); Caron et al. (2006); Harrison et al. (2017) and Lamech et al (2019) that have pointed out that there are several factors related to both the carer and the person with dementia that can lead to institutionalisation. Schur and Whitlatch (2003) showed that there are reasons for care home placements that go beyond financial needs and short-term respite for the carer.

Natalwala et al. (2008) and Harrison et al. (2017) discussed factors influencing a discharge to a care home following acute hospitalisation. This is against the backdrop that in the UK, health and social care policy and guidelines discourage direct discharge from the acute hospital to a long-term care institution such as a care home. Hospital admissions for older people have been associated as contributing to preventable moves into care homes (Harrison et al. 2017). Natalwala et al. (2008) carried out a retrospective study reviewing the notes of patients admitted between 2002-2007. The study explored the main reasons PWD were admitted to hospital and identified that many of the PWD were admitted as emergencies and for conditions such as urinary tract infections or fractured neck of femur rather than dementia itself (Natalwala et al. 2008).

Buhr et al.'s. (2006) survey of 2,200 caregivers identified that factors related to both carers and patients have valid underpinnings, especially for dementia patients. The reasons for placement were mostly carer related which included the need for more skilled care (65%), the caregivers' health (49%), the patients' dementia-related behaviours (46%), and the need for more assistance (23%). Dementia-related behaviours have been termed ‘behaviours that challenge, behavioural and psychological symptoms of dementia (BPSD), behaviours of concern, distressed behaviours. Any of these terms refer to a group of emotions and actions, including wide ranging behaviours such as depression, apathy, aggression, repetitive questioning, psychosis, sleep problems, walking with a purpose (previously wandering), and socially inappropriate behaviours. For the remainder of this article, however, I will use the term BPSD.

Behavioural and psychological symptoms of dementia (BPSD), also termed neuropsychiatric symptoms, were a major reason for care home placement for PWD and specifically among people with YOD (Yaffe et al. 2002; Bur et al. 2006; Caron et al. 2006; Roache et al. 2008; Bakker et al. 2013; Larger and Slinger 2013; Harrison et al. 2017; Johannessen et al. 2017). People with YOD tend to have higher levels of BPSD and there is no single aetiology for it. These symptoms can be frequent and severe leading to hospitalisation and in some cases increases the likelihood of discharge to a care home due to their complexity. In the USA, Bakker et al. (2013) found that the decision to place a relative with YOD in a care home is likely to be complicated by specific issues and problems that the families face as that in most instances, relationships change. The study investigated the time from symptom onset to institutionalisation in people with YOD in comparison to late-onset dementia and to determine which factors predict institutionalisation in the younger people in comparison to older people. This was a longitudinal study of community-dwelling younger and older people with dementia and their caregivers. A total of 226 people with YOD and 102 with late onset dementia and their informal caregivers were recruited through memory clinics and health care facilities. However, in people with YOD, apathy significantly predicted time of institutionalisation. The carer's ability or how they felt they were able to do in providing care for the person with dementia was a significant factor that led to institutionalisation in both people with YOD and people with late onset dementia (Bakker et al. 2013). Carer inability to cope was a high predictor for urgent hospital admissions and consequently institutionalisation resonated with Gaulger et al.'s. (2009) study findings.

Supporting someone with BPSD is a huge contributing factor to carer strain. The strain is often complemented by emotional instability as individuals try to redefine themselves, modify and adapt to new life circumstances (Lamech et al. 2019). Lamech et al. (2019) identified BPSD as a reason for increased carer distress. Lamech et al.'s (2019) study explored experiences of caregivers from two different groups, those from low income and from the high-income group. While they were differences in financial income and what could be afforded both groups reported that managing risks due to BPSD required caregivers being constantly vigilant, which left them anxious and mentally exhausted a lot of the time (Lamech et al. 2019).

2.8.2 Impact of dementia on family; transitions, and issues.

Lamech et al. (2019) carried out a qualitative study in which they held focus groups and interviews with 19 participants in order to explore the needs of family caregivers in Chennai India. The researchers acknowledged that the results from this study might not be transferable to the rest of India because of the uniqueness of the setting in which it was carried out. To start with, this was an urban area where literacy was high, and people were financially stable compared to other parts of the country. Participants’ demographics might influence how they viewed their caring role. Lamech et al. (2019) described the experience of caring in India as unique, and influenced by variables that are distinctive to this sociocultural context such as that support is from the family; older people are somewhat overprotected and are not allowed to function independently by concerned family members. Lamech et al. (2019) identified social challenges, challenges of family carers, emotional strain of caring and needs of family caregivers. As with other papers’ findings, the social and professional lives of carers are impacted by their caring roles, lifestyles are changed owing to prioritising caring responsibilities, which resulted in the restrictions of social interactions, leaving little opportunity for recreation and respite (Yaffe et al. 2002; Shur and Whitlatch 2003; Caron et al. 2006; Sanders et al. 2008; Roache et al. 2008; Larger and Slinger 2013; Gaugler et al. 2009, 2010; Bur et al. 2006; Johannessen et al. 2017; Mayrhofer et al. 2018). Carers in all papers reported a lack of support and sharing of care responsibilities by family members which left them feeling isolated, and often overwhelmed with high levels of emotional strain from caring (Lamech et al. 2019).

Financial constraints were raised in some studies (Schur & Whitlatch 2003; Lamech et al. 2019). Shur and Whitlatch (2003) provided carers with cash to subsidise some of the needs that would give them some respite. Though receiving some financial support did not stop PWD from being placed in care homes, the carers reported that the money had been useful for use around care needs of the PWD (Schur and Whitlatch 2003).

Negative emotions such as losses, helplessness, guilt, anguish, rage, frustration, loneliness, and despair were reported in all papers irrespective of the country the research was conducted in. Carers mentioned feelings of anger, shame, distress, or embarrassment due to the behaviour exhibited by the persons with dementia (Sanders et al. 2008; Gaugler et al. 2009, 2010; Large and Slinger 2013; Lindauer and Harvath 2014; Lamech et al. 2019). Some researchers went deeper in investigating the phenomenon of grief. The high prevalence of grief and its persistence in families prior to the physical death of the PWD and after the PWD dies has been described in research. Sanders et al. (2008), Large and Slinger (2013) and Lindauer and Harvath (2014) in pre-death studies found out that as the families experience the loss of the person they know, they go through intense pre-death grieving that is like post-death bereavement. Sanders et al.'s. (2008) empirical study examined the lived experiences of 44 carers (female spouses and children) with high levels of grief. Twenty-four of the PWD were being cared for at home while 20 were in care homes. The results showed that participants experienced grief and carer burden and stress (Sanders et al. 2008). Grief reactions were reflected in the descriptions of craving for the past, expressed guilt and regrets, while reports of restricted freedom, isolation, coping strategies, and spiritual faith indicated carer burden and stress (Sanders et al. 2008).

Chan et al. (2013) in a retrospective study of 31 papers examined family carers' grief both before and after physical death of PWD. These were studies of carers of PWD who were in dementia households in long term care. Compounded and serial losses that increase in frequency and size as the disease worsened meant that family members endured grief reactions over the course of the lengthy trajectory of the dementia which extended to post physical death (Chan et al. 2013). Transitions and grief created new challenges for carers all the time. Adult children in this study reported that they had conflicting thoughts when it was time to visit their parent with dementia in a care home (Chan et al. 2013).

While Lamech et al. (2019) did not consider care home experiences, they found that the impact dementia had on families was like other countries. Participants in Lamech et al.'s (2019) study found that providing care for the PWD was very stressful.

Other studies discussed carer’s distress after the placement of PWD in a care home. Dementia care giving does not end with care home placement and carer distress is known to continue after the PWD has been placed in a care home or when the PWD is not physically living with them (Gaugler et al. 2009; 2010). Some may experience continued emotional and psychological distress well after the PWD is settled in a care home (Gaugler et al. 2010). Gaugler et al.’s. (2009, 2010) empirical studies examined symptoms of burden and depression in carers at six months and twelve months after the PWD they cared for was in placement. In both studies they found that family carers remained involved in regular visits, still provided different forms of direct care, and the interaction with staff. While some carers reported less burden and depression after care home placement, a larger group of carers continued to experience distress (Gaugler et al. 2009, 2010). Gaulger et al. (2010) suggested that care home admission should be viewed as a key transition faced during dementia as opposed to a clinical endpoint and rightly so.

2.8.3 Issues related to services.

A review conducted by the UK NHS Health Advisory Service in 1997 looked at specialist health care provision for YOD across the UK, and through consultations with health-care service providers, service users and carers, some needs were identified. These needs included earlier diagnosis for YOD, increased support and information provision, early referral to specialists, and access to memory clinics and interdisciplinary teams’ post-diagnosis (Barker et al. 1997). While this is a dated review it does serve as a reminder of the length of time that improving services for YOD has been an issue reported in health and social care for many years as this directly impacts on improving transitions for this population. Since the 1997 review not much has changed with specialist provision still lacking in many areas and young-onset dementia services frequently being integrated into older people's care. People with YOD and their families are at risk of not receiving age-sensitive needs-based care (Roache et al. 2008).

Mayrhofer et al. (2018) in a bid to provide an evidence base of age-appropriate services and to review the perceived effectiveness of current interventions, undertook a systematic review of twenty peer reviewed articles, spanning a time frame of 26 years (1990–2016), covering five countries. Participants were 195 participants (persons diagnosed with YOD [*n* = 94], carers [*n* = 91] and other [*n* = 10]). Included were a range of primary studies relating to interventions for YOD. Results regarding age-appropriate services for those with YOD and their families were mostly fragmented, geographically dispersed, variable, and frequently short-term due to project-based commissioning. Some services were run as pilot studies or demonstration projects. Whilst this is consistent with the experience of living with dementia regardless of age, the experience of living with YOD added extra significance to being able to access community-based services (Mayrhofer et al. 2018). Newly diagnosed individuals and families felt services at the point of diagnosis were useful for the purposes of information, education and if they were able to signpost to critical community-based support such as support concerning employment, legal and financial issues. Mayrhofer et al. (2018) identified that post-diagnostic support services designed specifically for people diagnosed with YOD and their families varied considerably and comprised community services, hospital-based services, and a mix of statutory and non-statutory services in the UK and the National Health Service (NHS) Trusts were also part of this mix. This shows that for many years in UK care homes have been built for older people. More recently homes have been built that are specific for younger people. However, they are sparse in the country and non-existent in most parts of the UK. This concurs with Carter et al.'s (2018) report on the current national and international state of YOD specialist care. Carter et al. (2018) reported that the UK is, in many geographical areas, lacking behind providing specialist YOD care. They compared the situation the Netherlands where there are age-specific units that provide more targeted support to people living with YOD, and so provide more age-appropriate active activities.

In Norway, between 2014 and 2015, Johannessen et al. (2017) conducted qualitative interviews with 16 participants (aged 51–69 years; nine wives, six husbands and one male cohabitant). This study was carried out in Norway

therefore transferability to the UK situation might be an issue. The aim was to examine experiences and needs for assistance in daily life from the perspective of the spouses/ partners of people with young onset frontal temporal lobe dementia. Participants were recruited from seven memory clinics, one municipality dementia team, and a care home designed for persons with YOD. Johannessen et al. (2017) identified themes described as life turning upside down at the late stage of dementia and covered three subthemes: the torment, interference with work and vanishing social relations. Another main theme, needs for assistance through all stages of dementia, was described under three subthemes: relief of the diagnosis, support at home and the path to the care home. This study focused on a subtype of dementia which could be considered a limitation. However, these results can be transferrable to all families of people with YOD and their need for services and support. The transferability is because a common feature is that most brain disorders that cause dementia gradually led to a decline in cognitive and adaptive functioning, resulting in problems with memory, recognition, and reasoning.
Lamech et al. (2019) found out the same point that support for the carer at home is a need. It is important to note that these results might not be transferable to the UK population because of differences in cultures, financial differences, differences in dementia pathways, and possibly living styles.

In the UK, the National Dementia Strategy (Department of Health 2009) identified the importance of ensuring that existing services for dementia services must meet needs of younger people and that inappropriate placement with older more physically frail people should be avoided. Despite such recommendations, this model of best practice is not currently reflected in many services in the UK. Dementia services continue to be predominantly focused on the needs of older people, therefore getting an early and accurate diagnosis and access to age-appropriate assistance remains difficult for younger people in the UK despite their rising visibility (Mayrhofer et al. 2018). YOD is often underdiagnosed, difficult to diagnose and misdiagnosed partly due to the diverse range of types of dementias, where degenerative dementias are less common and secondary dementias more common than in late onset dementia (Mayrhofer et al. 2018).

This has been reported to have adverse physical and psychological consequences in both the person with YOD and their families, especially when institutional support during this process is low or non-existent (Mayrhofer et al. 2018).

2.8.4 Lack of knowledge and information sharing

In India the care is usually provided by families. Even so, participants raised issues about their own lack of their own knowledge, wider society, and healthcare professionals' lack of awareness and skills (Lamech et al. 2019). Health care professionals included doctors, nurses, and nurse assistants and this was identified as a significant issue for the carers. Lamech et al. (2019) suggested a need for trained staff and person-centred care and proposed that appropriate training for health-care professional is top priority on their list of needs. Participants identified that inadequate understanding of dementia, coupled with insensitivity of health care staff were identified as causing unpleasant experiences for families. Perceived and experienced stigma limited disclosing the diagnosis to family and friends with some families even moving homes because of neighbours who lack understanding of dementia behaviours (Lamech et al. 2019).

Issues relating to lacking awareness and knowledge of YOD symptoms, diagnosis and management were raised in studies in different countries including the UK (Bakker et al. 2013; Johannessen et al. 2017; Mayrhofer et al. 2018). A person's lack of awareness can be detrimental to their relationship with family members and can raise carers' burden (Caron et al. 2006). Both the person requiring care and their carer may either over- or underestimate the functional capacities of the person with dementia (Caron et al. 2006). This also applies to professionals who lack awareness and knowledge of dementia can underestimate the challenges a family and PWD faces therefore fail to provide adequate support.

The studies exploring services for YOD identified a need for age-appropriate dementia services (Johannessen et al. 2017; Mayrhofer et al. 2018) and participants in Lamech et al.'s (2019) study identified a need for dementia police such services in India.

2.8.5 Models of dementia care

Dementia has no cure, and some researchers, families and participants have called for alternative treatment options for both PWD and carers. The lack of development of dementia services in India, particularly nonpharmacological interventions has been identified as the reason for the continued use of the medical model of care (Lamech et al. 2019). However, the need for nonpharmacological treatments is not unique to India because studies in other countries have made the same recommendations such as Bakker et al. (2013) in Netherlands, Gaulger et al. (2009, 2010) in the USA. Biopsychosocial models of care have been proposed that attribute neuropsychiatric symptoms to interactions between an individual's biology, prior experiences, and current environment (Gaulger et al. 2009, 2010; Bakker et al. 2013). Gaulger et al. (2010) also suggested more widespread implementation of effective psychosocial interventions to reduce carer burden and depression in view of the transitions experienced by families. Psychosocial interventions can ease the symptoms of burden and depression and increase the likelihood that a care home placement event is not premature, but instead occurs at an appropriate time (Gaulger et al. 2009, 2010; Bakker et al. 2013). Lamech et al. (2019) identified the need for utilising person-centred care in India where care is mainly provided by family, and culturally it is their responsibility to do so. It is important for service providers to have an integrated approach, wherein medico-social interventions that will support families to provide care to PWD are developed.

2.9 Limitations

The limitations of this narrative review are that the papers did not all focus on families of people with YOD. The paucity of research in this area also led to inclusion of people with dementia of all ages, as well as any hospitals and not a specified type of hospitals. The papers were not all empirical research (n=9) empirical, and (n=9) literature reviews of which one paper, Edmans et al. (2021) was approved as a service evaluation. Only one paper, Roache et al. (2008) reported that all the papers were assessed for quality assurance for hence the credibility and dependability is questionable.

The papers are not all from the UK which can lead to issues of generalisability and transferability. The decision to include this breadth was because of the findings between situations. Another limitation is that the age of family carers varied. Some were older, particularly those caring for older partners which brings differences in family structures to people with YOD, who are more likely to have young children in their households. Additionally, spouses may also be in full or part-time employment and therefore present different considerations to older people.

2.10 Chapter Summary

The aim of this narrative review was to synthesise research that investigated the care of people with YOD and other dementias, and their families or those important to them, their experiences of care and transition from hospital to a care home. The paucity of research specifically relating to YOD, and transition meant that literature relating to older people was mostly included this review. Despite these factors the review has identified areas of research needs. Importantly the review identified issues of multiple and complicated transitions that families or people that are important to people with dementia experience while on the dementia journey. These necessitate that professional need to be aware of and be able to support these people effectively.

Eighteen papers spanning over 20 years, were included in this narrative review. The papers discussed experiences of hospital admissions and care homes placements, emotional impact of transition and the types of transition experienced by families of people with dementia and YOD. Generally, themes reported similarities in the way families experience several losses as they live with dementia and particularly the several transitions lead to grief for the PWD and for the carer themselves (Caron et al. 2006; Gaugler et al. 2009; 2010). Families of people with YOD faced services that are fragmented, not uniform in all countries and even areas of the same country lack of age-appropriate services and YOD as an under researched area (Yaffe et al. 2002; Mayrhofer et al. 2008; Johannessen et al. 2017). Both carer and PWD reasons for hospital admission and care home placements were identified (Bur et al. 2006; Sanders et al. 2008; Gaugler et al. 2010; Larger and Slinger 2013; Chan et al. 2013). Families of people with YOD experience caring roles twice as long as people with late onset dementia and neuropsychiatric symptoms are common (Roache et al. 2008; Bakker et al. 2013). YOD presents problems which include life stage issues, diagnostic difficulties, coping with symptoms and relationships changes necessitating a constant assessment of the caring situation. Considering the complexity of needs it follows that their care needs usually have an impact on the entire family unit.

Only one paper, Edmans et al. (2021), reported experiences on admission to a psychiatric hospital and was the only one that reported on the vulnerability of ward staff who cared for these complex patients. Overall, this review helped to identify gaps in research and situate the current study.

Chapter 3: Methodology and Methods.

3.1 Introduction

This study aims to answer the question is *“what are the experiences of spouses of people with YOD of transition from hospital to a care home?”*

This study aimed to obtain rich, detailed insight into the lived experience of wives and husbands of people with YOD. For the purposes of this study wives and husbands will be referred to as family. The study seeks to reveal families’ experiences of transition as they navigate the dementia journey from a hospital to a care home setting and identify factors that impede and facilitate a successful transition. This chapter outlines how my philosophical position that influenced the choice of methodology for this study to answer the research question, together with theoretical frameworks through which I interpret the findings.

3.2 My Philosophical Assumptions

Firstly, some insight into how the research came about. As a nurse of over 30 years, I have extensive experience in supporting people with dementia, and their families, in different roles in my career. Sixteen years ago, I made a conscious decision to work in dementia care. I became more engrossed in this specialism, and I am now an Admiral Nurse (a dementia specialist nurse). This route started initially as a nurse in the older adults’ acute mental health wards, and later as a Research Therapist in a dementia study. I worked between a mental health NHS Trust and supporting care homes with implementing and enhancing psychosocial interventions for people with dementia before embarking on a role as dementia and mental health discharge liaison nurse. In this role my work focused on supporting people with dementia moving from hospitals to care homes. By virtue of my areas of work, I have provided care to people with YOD, and their families at different stages from before diagnosis, post diagnosis, in hospital, through to the discharge processes and settling in a care home.

My practice experiences have illuminated the devastation that family members of people with YOD can experience during the transition from a mental health ward to a care home. The realisation that, as professionals, my colleagues and I felt insufficiently equipped to support them effectively led to the question:

What are the experiences of wives and husbands of people with young onset dementia of transition from hospital to a care home?

3.2.1 My Philosophical position

In order to state my philosophical position, I need to first describe the ontological and epistemological elements that shape it. Ontology relates to what we think reality is (Crotty 1998) while epistemology is concerned with what we think we can know about our world or how we make knowledge (Gaudet and Robert 2018). As for my ontological standpoint, I believe that "reality is human experience and human experience is reality" (Levers, 2013 p. 3). In the context of this study, this means that two people transitioning from the same hospital ward to the same care home can present with different experiences depending on a number of factors. I believe the world has several realities some of which I have discovered such as that of care homes, which I came to know through my own transitioning from one country to another. This makes it clear to me that knowledge gained from one study or area cannot be generalised as the only truth because there are multiple realities depending on where one is or who they are, places they have been, periods of time, people around them, and their cultures. The construction of my reality is because of my personal, educational, and professional experiences. It was important for me to talk to spouses of people with YOD because they understand their experiences, they define them and interpret those experiences as they have lived them. I can learn from these experiences from the spouses.

Epistemology is about how I can know reality, the relationship between me as the knower and what they (participants) know, the principles, and the assumptions that guide the process of knowing. As I planned this study it was clear that I had to talk to people that lived the experience because of the belief that there are different ways of thinking and diverse ways of explaining the occurrence and implications of the phenomena existing in the world (Burr 2015). I was aware that constructs are created and sustained by interpersonal relationships, cultural norms, and shared ideas rather than being inherent or universal. Individuals can create meaning when they interact with each other and with the environment they live in, and so meaningful learning occurs when individuals are engaged in social activities such as interaction and collaboration (Amineh and AsI 2015). This belief helped me to better understand how family members of people with YOD construct and provide meaning to different facets of their reality. As a qualitative researcher, I believe that the world is made up of interpretive, active people who create deliberate paths of action to carry out daily tasks. People observe the world around them, interpret or give meaning to it, and then plan their next steps. This is all subjective. As a culture or society, people construct their own versions of reality. Therefore, I had to interact with people directly experiencing transition for me to get the truth of what ‘transition’ means to them.

The inclusion of a portion of my own history in this thesis enables others to identify any potential biases I may have, as well as how my prior knowledge of the topic under investigation may influence the study (Wertz 2011; Etherington 2004). What has surprised other people is that my personal experiences, and history prior to coming to the UK does not include care homes at all. In fact, I come from a culture where many still do not understand the concept of placing a relative in a care home. I have come to gain knowledge on care homes and appreciate their purpose through my interactions with others. However, self-reflection is something I do often in my practice and as a researcher to prevent my own biases and be able to realise when tensions arise. Creswell and Poth (2018) warned that consciously or unconsciously, people always bring certain beliefs and philosophical assumptions to their research. It was important for me to be self-aware of facts that underpinned and shaped the route of my study from formulating the research question, considering how to examine the issue and the research design, the sampling considerations, including methods of data collection and analysis.

3.3 Towards a choice of IPA.

Having adopted a philosophical paradigm that fits me as a researcher that was seeking to understand how spouses of people with YOD make sense of their everyday lives in their natural settings and experiencing transitions I moved on to identify a research methodology that would help answer the question in the best way possible. Silverman (2014) advised that the methods should fit the research question and the choice between research methods should depend upon what the researcher is trying to find out. It was important to identify a methodology that aligned with my ontological and epistemological assumptions and one that would best answer the question without compromising the participants' sense making of their experiences. With these points in mind, qualitative research was favoured and IPA methodology particularly. Punch (1998) stated that in planning research one should consider what exactly they want to find out, the focus of the research, how other researchers had approached the topic and practical considerations and what would work best for me. As a novice researcher I found this guide helpful. From the outset it was important to find studies in my field that used the same strategies for similar topic as mine that I could follow examples of. I spent time reading research reporting on lived experiences and transition. I discovered that there is a rich tradition of using qualitative research in mental health services research (Palinkas 2014) to provide deep descriptions of phenomena, provide in-depth understandings and contextualise phenomena of interest. This research focuses on exploring the personal, lived experiences of the participants and their life worlds. Accordingly, a qualitative methodological approach was considered to best answer the research question. Qualitative research is concerned with lived experience and the individual's realities it asks questions with a focus on seeking 'understanding' of phenomena in context (Silverman 2014). Therefore, it is ideal for establishing and describing the viewpoints of those being studied.

Many studies exploring lived experience in the context of mental health have used IPA as a methodology. Harman and Clare (2009) for example studied illness representations and lived experience in early-stage dementia. Pringle et al. (2011 p.24) advised that:

> IPA is an approach that emphasises the importance of individual accounts so has much in common with nurses' desire to deliver care that is evidence-based, the findings of IPA studies are firmly rooted in the 'evidence 'of the words of participants.

IPA is an experiential qualitative approach to research in psychology which is gaining favour in health and social sciences. An IPA researcher has their focus on three theoretical orientations of phenomenology, hermeneutics, and idiographic analysis of a particular phenomenon apprised by a person who is in a particular context (Smith et al. 2012).

My philosophical foundations agree with the use of IPA methodology. According to Smith et al. (2009) to understand the world in which we live we must understand experience. IPA considers people as "embedded and immersed in a world of objects and relationships, language, culture, projects and concerns" (Smith et al. 2009, p.21). For these reasons related to my ontological and epistemological positions I was drawn towards IPA methodology. IPA researchers are engaged in analysing and interpreting the interpretations and understanding of participant experience (Smith and Osborn, 2009). The researcher must remain cognisant of their own values, beliefs, experiences, and knowledge with particular focus on how this might impact upon the analysis and interpretation. This acceptance of the researcher's part in the sense-making process attracted me to the methodology.

3.3.1 Phenomenology

Phenomenology is an inductive, qualitative research practise adopted in the 20th century philosophical traditions of Edmund Husserl and Martin Heidegger. Husserl claimed that the essence of a phenomenon could be understood through an investigation and description concerning core components of one's experience. Heidegger expanded Husserl's work, moving beyond description and giving focus to interpretation, (Smith et al. 2009; 2022; Reiners 2012). IPA, through its phenomenological commitment, enables every interaction with a participant to be a chance to acquire knowledge and to add depth to my understanding of the participants' reality, in their own terms, their words, rather than through my assumptions or conceived ideas. Phenomenology is about identifying, describing, understanding and, importantly, interpreting the experiences people have in their day-to-day lives (Silverman 2014) and precisely as those people have the experiences and understand them. With this knowledge I used interview questions to ask participants to describe what the experience was like to them. This study asks, “What is the experience like?” as it attempts to unfold meanings as they are lived in the everyday existence of the family members of the people with YOD regarding the transition from hospital to a care home.

3.3.2 Hermeneutics

Hermeneutics based on Heidegger’s phenomenological view of person assumes that based on common background meanings given in our culture, language, knowledge and experiences as a researcher I have a preliminary understanding of the topic being studied (Smith et al. 2022). This means that by virtue of the nursing roles working with people affected by YOD I have some preunderstanding of the phenomenon. Smith et al. (2022) introduced the double hermeneutic which is about the researcher making sense of the participant's sense making. This sits well with my belief because as a researcher I seek to interpret participants’ interpretations. I understand that rules of culture and society are not universal but applicable only in a certain location and time therefore only those affected by YOD, who have been in hospital and transitioned to a care home can give the facts of what is real of the situation. Hermeneutics as an interpretive process is critical in the process of trying to understand a phenomenon as it acknowledges that the researcher has a part to play in the interpretation of data and yet does not simply focus on their own perspective. Hermeneutics uses an interpretive approach to study the participants’ everyday worlds from the perspectives of the people experiencing a particular phenomenon (Dowling 2011). Smith et al. (2021) suggested that researchers must be skilled in delving beneath the surface of accounts. From this perspective, researchers must attempt to make sense of the participant’s understanding. This is known as the double hermeneutic (Smith and Osborn 2007) and encapsulates the duality of researchers as both observer and part of the interpretative process.

IPA recognises the existential as well as personal meaning that participants attach to experiences and as such the role of the researcher is to remain sensitive whilst attempting to make sense of what the experience means to the individual participant (Smith 2011). This is achieved through the idiographic process of analysing the data.

3.3.3 Idiography.

IPA distinguishes itself by its idiographic leanings and strong focus on understanding participants' lived experiences from their perspective, while also acknowledging that this is not ever truly possible as the researcher is also involved in the process of meaning making (Smith 2011).

This study sought to identify the experiences of each participant and examine their narratives about how they react and respond to their situations and shape perceptions of what their experience meant to them as individuals. Using idiography, I examined the details of each individual participant in turn before making any type of claim and to explore every single case before producing any generalised statements.

Idiographic analysis of data is mostly inductive, retrieving the most interesting and most important aspects of the participant’s narrative (Smith et al. 2022). These are experiential statements are further used for interpretating the experiences of each participant and are used to construct Participant Experiential Statements (PETs). All PETs are then compared to each other and compiled into themes of commonalities and of uniqueness too and Group Experiential Themes (GETs). It is here that meanings are developed and shared. A phenomenological inquiry is therefore able to consider not only the individual meanings of a situation but also the intersubjectivity of human experiences, the shared meanings that act as a basis for social interactions (Smith et al. 2009).

IPA acknowledges that the participant is a cognitive, linguistic, affective, and physical being and adopts a sequence of links between people’s talk, their thinking and emotional state. Participants could express their emotions, themselves in whatever way they felt consciously or unconsciously and through IPA all these would be taken to mean something and so the researcher would prompt further to get a meaning from the participant. In the data collection I recorded the words, behaviours, movements, sounds like sighing, exhaling, and pauses in order to explore the meaning. IPA is therefore congruent with the increase in patient centred approach and is in line with increased efforts within the National Health Service to make greater efforts to acknowledge the voices of service users. These study results may contribute to the development of new theories, changes in policies, or changes in responses.

All these qualities of IPA led to the decision that it is an appropriate methodology for this study and IPA gives a voice to the person with the lived experience of the phenomenon and values the researcher's role therefore is best suited to answer the question.

3.4 The Research Design, methods, and procedures

3.4.1 Ethical Considerations and Approvals

Since this research involved people, the protection of participants and their safety was imperative to address initial and ongoing strains between the needs and goals of the research and the rights of participants. This is also in line with my nursing professional code of conduct. I was obliged to be conscious of any potential ethical conflicts that might arise from our contacts, from how I as a researcher gained access to this community group, and from the potential influences I might have on participants. Ethics also includes appropriateness of the research design, the methodological design, the questions posed to participants, the venue where interviews would take place, as well as behaviours in reporting data (Orb et al. 2001).

The study received ethical approval before any contact was made with potential participants. I submitted the initial application for ethical approval in November 2019 and received a favourable ethical opinion in March 2020 from Cardiff University's School of Healthcare Science Research Ethics Committee (SREC) reference: REC708. By this time the SARS-CoV-2 pandemic (COVID-19) pandemic had started, and restrictions were in place. In line with the protocol at the time I contacted 32 care home managers in two counties by email and telephone. Only four responded and none were in a position support recruitment, so I had to revise the whole research strategy, making amendments to the initial protocol, ethics application and all documents required and widen the recruitment area. This is further discussed in the recruitment approach below. Ethical approval for the amendments was granted by Cardiff University's School of Healthcare Sciences Research Ethics Committee in March 2021, and I then proceeded with recruitment (Appendix 3).

3.4.2 Recruitment & Sampling

To establish how best to access, contact and select potential participants, considerable thinking, discussions with colleagues, study supervisors and learning from IPA groups was undertaken. As previously mentioned, initially I sought to recruit potential participants through care homes within the boundaries of my workplace. However, the onset of Covid-19 meant a different strategy was required. I contacted and sought support from gatekeepers at Dementia UK, local dementia organisations, and other organisations supporting people living with YOD. This resulted in a recruitment flyer (Appendix 4) being placed in the Young Dementia Network newsletter in January 2021. This was an appropriate route through which to recruit because the newsletter reaches people with YOD, their families and others interested in YOD. The involvement of the Young Dementia Network in recruitment expanded the study's geographical scope to cover the entire UK and led to recruitment of four potential participants, although one withdrew prior to the interview interviews. Word of mouth also helped with recruitment of two participants for this study.

Recruitment took place between March to June 2021. The target sample was 6-8 people. Six people expressed interest however, one withdrew and so five individuals completed interviews. As is the case with IPA research the sampling for this study is small, purposive, and homogeneous. This is a sample for whom the question was meaningful, a sample that can offer insight into this particular experience, and they represent a particular perspective rather than a population (Smith et al. 2022). Too big a sample can lead to a researcher getting overburdened with data for analysis which can lead to the loss of in-depth analysis and less rigorous results (Smith and Osborn 2007; Smith et al. 2009; 2012). In this study a small sample produced a huge amount of rich data and allowed me to gain a more detailed and nuanced analysis of the lived experience of the participants. This sample size made it easier to afford each participant as much time as they needed because I was not rushing for time.

To ensure the people living the experience were recruited, inclusion and exclusion criteria were formulated (Table 2).

Table 2. Inclusion and Exclusion Criteria

Included	**Excluded**
• Spouses of people with YOD who have been in hospital and discharged to a care home in UK. • People from diverse backgrounds who can participate in an interview in the medium of English. • Eighteen years and older • People who are willing. • People who are able to articulate their experiences. These people do share common characteristics and have lived experiences of the same phenomenon.	• Spouses of people with YOD who have not had the lived experience of hospital admission and discharge to a care home. • People under eighteen years old. • People who are none English speaking. • People who are unsure about participating. • People that cannot articulate their experiences.

Once someone expressed interest in taking part in the study, I made contact with them. I introduced myself and the study and provided them with a copy of the participant information sheet (PIS) (Appendix 5). The introduction and PIS established the context, gave background details and my reasons for interest in the topic. My interest was mainly grounded in my professional observations, yet I understand dementia from my personal life. This part of my life story was useful in establishing my relationships with participants for it showed that I understood dementia and had genuine interest in hearing their stories.

At the initial contact, I made a quick robust check that they met the study criteria. Once inclusion was established, in the interest of autonomy and respect, verbal consent received for further contact. Participants chose the method of interviewing they preferred; either a video call, such as WhatsApp, Teams, Zoom or a telephone call at a date and time of their choice. A copy of the consent form (Appendix 6**)** was posted or emailed to participants, as per individual preference, for them to complete and return to me. I ensured that the signed consent form had been received before each interview took place. Without being asked, some participants emailed and provided me with information about themselves and the person with YOD, for example, if they were in hospital or a care home. One described the difficulties they were facing. This communication meant we had a relationship and something to talk about at start of interviews which eased the interview feeling because we both knew something about the other person. The participants' personal descriptions are given in Chapter 4: Findings.

3.4.3 Data Collection, management, and storage

The way data are collected, the purpose for which data are used, what the data can produce, and their overall orientation depends on the larger context of the strategy of inquiry or methodology employed. In this study, data were collected using in-depth semi-structured interviews. To guide the questioning, I created an interview schedule comprised of semi-structured, open-ended questions. The questions were informed by the reflections I had on what I had observed and had been involved with in practice, discussions with colleagues about what they would want to learn or know from families living with someone with YOD regarding transition. I then compiled a list of what I called the 'high-level' topics I wanted to cover in the interview and listed with the questions I wanted to answer under each topic. Preparing an interview schedule created an opportunity for me to give more thought to what exactly I wanted to know or learn from this study and therefore developed prompts along each area that would help to meet the aims and objectives of the study. The schedule (Appendix 7) included descriptive questions that were used to prompt an extensive account based on the participant's expert knowledge of the topic under investigation. I used the interview schedule to guide the interview as recommended by Smith et al. (2009; 2012) and kept in mind that I needed to obtain statement high-quality data because that leads to high-quality data analysis (Smith et al. 2022). The first interview was in March and the fifth one was in May 2021.

3.4.3.1 The interview

This was the stage I was looking forward to because I enjoy listening to other people telling their stories. In my job, I hear a lot of stories that make me emotional and, at times, cheerful and I always learn more about the person and their lives from them. I was aware and prepared for emotive stories and had a plan for my own debrief. If I felt overwhelmed, I would seek support from my work colleagues because they understood the emotions that some of the stories can bring, and I also had the opportunity of contacting the supervisors when I needed them. As it happened, we increased supervision appointments from the usual four to six weeks to two weekly during this period. In preparation for interviews, I used the same questions to interview some mental health nurses to get feedback on my questioning style and to test the relevance of the questions. I also interviewed my own family and a friend’s family members, all of whom had experienced living with someone living with dementia, because I wanted to ensure that the questions made sense to a lay person: that the language I used was clear. I also received comments on things like my sitting positions, for example I had to move my laptop to a position where the person on the other side could see at least my chest upwards. This also increased my confidence in my interview style.

On the day of interviews, before proceeding with interview questions the purpose of the study was reiterated and consent was checked in case of potentially changing their mind about taking part. Issues of confidentiality and data protection were revisited, and participants were given the opportunity to ask any questions. It was also explained to them that they were still able to withdraw from the study at any point. I anticipated each interview would last for between 60 and 90 minutes. The four interviews carried out on Zoom were audio-video recorded and the phone call was audio recorded. The Zoom interviews all lasted for two hours and the telephone call just over an hour. This is acceptable in IPA as the participant is given the chance to give their narrative until they have exhausted their story. The participants guided the length of time of the interview such as they could take a break if they wanted to. The semi-structured, one-to-one interview was used because they allow for rapport to be developed and give the participants the space to think, speak and have their voice heard (Smith et al. 2012; 2022). They are therefore appropriate for in-depth and personal discussions which allow for rich data to be acquired. The flexibility of this form of interview meant I could ask questions in a different order, questions could be dropped or added, and prompts were employed for follow-up on any interesting points that I might have not thought of in preparation of the study (Seidman 2006). This is a key requirement of qualitative interviewing.

During the first interview, I realised that the participant wanted to tell their story from when they first noticed symptoms and changes in the person with YOD. In the second interview I learned that some participants had more than one experience of hospital admission and more than one care home move and I anticipated that I would have a huge volume of data. At the heart of in-depth interviewing is understanding the lived experiences of other people and the meanings they make of that experience. Hence all participants were given the opportunity to tell their stories from the beginning of noticing untoward symptoms. Another point I realised was that each participant had also prepared a question or two for me. As much as they were giving information, they also wanted to know more about different areas in dementia care or where they could seek support going forwards. All participants were still on the dementia trajectory, just at different stages.

At the end of each interview, participants were thanked, given another opportunity to comment, ask further questions or say anything they might have forgotten to tell me earlier. Following the interviews, a brief email and letter was sent to thank them for their participation.

3.4.4 Data Management and storage

In planning the interviews, I also planned how I would handle the data as part of analysis and data storage post interviews. The participants were aware that they were being videoed and audio recorded. Smith et al. (2012) highlighted the need for a verbatim recording in the form of audio or video media or written format so that the result is what each participant said in their own words. While transcripts were available through Zoom, they required further work to reflect the interview fully and accurately. The Zoom generated transcript was not clear in several areas, I put this down to my accent meaning that when I spoke words were changed or sounded different to that which the technology understood. I amended areas in the transcript that lacked clarity or changed wording early after the interview. Therefore, data were transcribed verbatim. To ensure that individuals could not be directly identified and to ensure that their confidentiality was protected all transcriptions were anonymised. Pseudonyms and numbers functioned as unique identifiers. In accordance with best clinical practise rules, (National Institute of Health Research 2020) I retained the files on a password-protected shared drive site that was only accessible by me, and supervisors. The data will be deleted after five years in accordance with Cardiff University policy.

3.4.5 Data analysis

An idiographic approach to data analysis was used as per guidance and structure offered by Smith et al. (2009; 2012; 2022). Smith et al. (2022) recently revised the terminology in IPA analysis as follows: emergent themes are now called experiential statements, whilst personal experiential themes (PETs) refer to the collection of related experiential statements. Group experiential themes (GETs) refer to the similarities and differences across the PETs. I chose to adopt the new terminology. In part this was because the IPA support groups to which I belong used the new terminology. I also thought I should familiarise myself with the terminology rather than play catch up later.

Smith et al. (2009) provided guidelines for data analysis (Figure 3). As a novice researcher I found guidelines helpful and adopted them as I sought to enhance, ensure, and sustain high quality of data analysis (Smith et al. 2022).

Figure 3: The analytic steps of IPA analysis.

Step 1	Close and detailed line by line reading of the transcript (data) to obtain a holistic viewpoint. This is on individual participant level until familiar with the data.
Step 2	Exploratory noting. Examines semantic content and language use while noting anything interesting on the transcript.
Step 3	Constructing experiential statements. Themes are refined, condensed, and examined for connections between them. This is subsequently across multiple cases.
Step 4	Searching for connections across experiential statements. A narrative account of the interplay between the interpretative activity of the researcher and the participants ‘account of their experiences in their own words is produced.
Step 5	Naming the personal experiential themes (PETs) and consolidating and organising them in a table.
Step 6	Continuing the individual analysis of other cases.
Step 7	Working with personal experiential themes to develop group experiential themes across cases (GETs).

Idiographic analysis enabled me to understand how families made sense of the situations they faced. Any day allocated for an interview/s was not allocated for anything else and that meant I was off duty from my usual work. Following an interview, I took a break of about an hour then went back to watching and listening to the Zoom recording. This was important to make sure I could hear the voices properly to understand both myself and the participant to observe any silences, mannerisms, facial cues, and anything else that had happened during that interview and so would be incorporated in the transcript. I then read the

Zoom written transcript as I listened to the recording again. While reading the transcript, I also noted on the left or right-hand margins what I considered interesting or significant about what the participant had said, and I also highlighted in different colored pencils/ markers (Appendix 8). Any information that could make it easy to identify the participant was removed.

The process of reading and re-reading was done several times until I was confident, I understood what information the participant intended to pass to me. As English is not my first language, I also had to use Google search, ask others and my supervisors for meanings of some of the phrases or metaphors that participants used to ensure that I tell their story as closely aligned as possible to how they wanted to be understood.

Once I was familiar with the story, I moved on to identifying experiential statements that I used in the constructing Personal Experiential Statements (PETs) for each participant which saw the reduction of the data from the larger transcript to summarizing this into smaller notes that still meant the same as the transcript and captured the key points from the interview. The PETs reflect both the participant's thoughts and words as well as the researcher's interpretation (Smith et al. 2022). Therefore, the story is still the same and they reflect my understanding of the story.

The next step was to search for connections across PETs which involved consolidating some PETs that seemed to have a similar meaning and discarding some that did not seem important for this part. At this point I had each participant's PETs on an A4 paper joined in the middle to make it larger, clearer to see and then pinned together all these papers (PETs from the five participants) on the wall to make it easier to go through each of them. I used color coding with a different highlighter pen for similar PETs on each sheet (Appendix 9). The results from each stage of this process were shared, discussed, and agreed with the research supervisors for guidance, to allow triangulation of the data and to ensure the fit of PETs and GETs (Appendix 10 & 11) was an accurate representation of the data. These are presented in Chapter 4.

As a novice researcher a challenge for me was that of maintaining rigour. I was conscious that I could potentially present with biases because I share the experience of study participants in that dementia impacted on my life too, and that I am moving from the position of an outsider to the position of an insider over the course of the study (Berger 2015). Reflexivity was very important throughout the process. Smith et al. (2022) described reflexivity as a technique for investigating the connection between one's own experiences and expectations and the process of learning about the research participants' experiences. Self-awareness was very important for me especially at points when participant asked questions that maybe in normal discussions I would have answered differently. For example, by giving justifications for why a professional might have reacted the way they did in certain situations. I reminded myself that this was what the participant understood and so should be that way.

3.5 Chapter Summary

This chapter informs the reader of the decisions undertaken in preparation for the study’s execution using an interpretative phenomenological analysis approach. the procedures as they that took place. IPA study is a study with a dynamic process with the active role of the researcher who influences the extent to which they get access to the participant’s experience and how through interpretative activity, they make sense of the subject’s personal world.

Chapter four presents the findings from the interviews with the five participants.

Chapter 4: Findings

4.1 Idiographic Data Analysis

In this chapter, I present the idiographic analyses of each individual participant's interview. Each analysis is introduced by a short biographical history of the participant's life story as it is important in relation to the person with YOD. Each participant's experiential statements are presented, followed by a description of their PETs using their own words.

The following part gives the findings beginning with Table 3 showing the participants' demographic data.

Table 3. Participants demographic data.

Participant	Participant Age	Person with YOD	Approximate Age of symptoms onset	Age at diagnosis	Age at interview	Type of dementia
Alana/wife	61	Mike	53	57	64	Alzheimer's disease and vascular dementia
Ellen/wife	54	Amir	51	56	60	Fronto temporal lobe
Mary/wife	59	Tim	+/-54	+/-57	+/- 63	Behavioural variant frontal temporal lobe
Maxwell/husband	60	Gillian	54	57	59	Alzheimer's Disease
Thomas/husband	63	Susan	51	55	58	Alzheimer's Disease

Alana, Ellen, Mary, and Maxwell had experienced admissions under the Mental Health Act (MHA) (1983). The MHA (1983) is the main legislation that covers the assessment, treatment, and rights of people with a mental health disorder, including YOD. The MHA gives guidance with respect to the reception, care and treatment of mentally disordered patients, the management of their property and other related matters and is applicable in England, Wales, Scotland, and Northern Ireland.

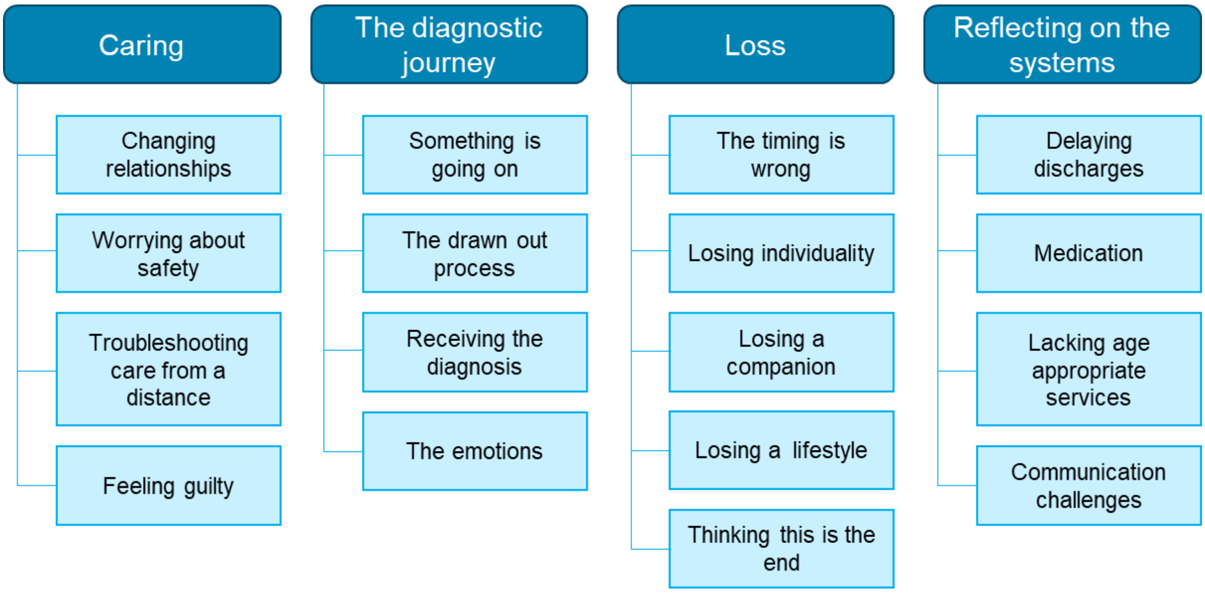
4.2 Alana’s descriptive summary

Alana was a 61-year-old retired nurse married to Mike for 43 years. They had no children. Mike was 64 years old and living with Alzheimer’s disease and vascular dementia. The changes in behaviours started when he was 53 years old, when they were both still working. Mike was admitted to a psychiatric hospital in 2019 because of his severe needs related to behavioural and psychological symptoms of dementia. He was discharged to a care home where he had been for a year at time of the interview.

During the interview Alana appeared calm, was quietly spoken and smiled a lot. She used the word ‘*little*’ thirty-eight times during the interview. At times she used ‘*little and simple’* together. She used the word in phrases such as “*just little things”*, “*a little bit”* and “*just simple little things*” when describing situations, changes in Mike’s capabilities, behaviours, events, and her own feelings. Some of the “*little things*” actually led to major life changes, such as moving house, further loss of capabilities culminating in hospital admission and eventually to a care home discharge.

Alana’s interview was my first, and I was anxious before meeting her. However, it was relaxed, she was easy to talk to and very generous with her answers. Initially scheduled for ninety minutes, the interview lasted two hours. Figure 4 presents the PETs and Experiential Statements identified from Alana’s interview.

Figure 4: Alana’s PETs and Experiential Statements.



4.2.1 Alana’s descriptive experiences and personal experiential themes.

4.2.1.1 Caring

Caring was described by Alana in relation to the “*changing relationships*”,” worrying *about safety”,* “*caring care from a distance”,* and ‘*feelings of guilt*’.

Despite looking calm, as soon as I asked the first question: ‘Do you consider yourself a carer?’ Alana seemed a little thrown, was visibly emotional, and was quiet while looking down, then answered, *“I did do because…I…, I…, this is the start of it now…*”. She tailed off and then repeated my question to herself. Then she apologised and seemed to have collected herself.

Alana described how their relationship, as a couple had changed. Alana was increasingly taking on more responsibilities in the home and of their lives in general. She said:

> “*Mike used to love the driving so much that we'd share the driving en route to wherever we went but… so you know it was just, it was obviously muddling his mind, then you know and the times that I was driving I couldn't rely on him to navigate. So, I was then beginning to look at different holidays. To make life easier for me you know that we used to go self-catering for instance, and you know the self-catering if you've got a cottage you have to tidy up. So, it*

> *was just change all the time".*

Friendships and social gatherings had to be planned carefully:

> *"it was troubleshooting. Mike found noise … he would find noise was the worst, overwhelming, people laughing, and Mike would mimic… which was embarrassing*".

In the end they stopped meeting friends to avoid noise and not upset him.

In the early stages Alana had worries primarily for Mike's safety. However, over time and as Mike's dementia progressed Alana's safety concerns for Mike extended to others. Alana described incidents in the early stages of his illness:

> *"… we both had an eye test, one after the other, and say 'we'll meet you back at the car' … Mike couldn't find the car or wouldn't find his way to the car even, you know, so that was difficult".*

She also described incidents at later stages of Mike's illness:

> *"One day he pushed my father. He had a tussle with my sister who came over. So, he had a tussle in the corridor. Well, he grabbed my dad's sleeve and wouldn't let go, sort of saying and maybe be frightening my father".*

Other people who were helping them at home were worried about their own safety:

> "*We had somebody come into the house to sit with Mike so that I could go and do something. Mike was having a tussle with them, Mike thought they were stealing the coffee and the tea, so he was a bit paranoid too you know, and when I came back it was okay. It's just they were quite worried, and the thing is, ..., but then, then as time went on, he got worse, you know, so those things had a bearing on it, too, so that service had to stop".*

It was mainly these behaviours that led to the hospital admission as Alana was feeling more and more unsafe at home. Alana still worries about Mike's and other's safety in the care home.

Describing how she "*troubleshoots from a distance"* Alana explained that she asks questions about Mike's wellbeing, and if anything is said that she finds concerning then she prompts the staff on what actions could be helpful. She continued:

> "…*Even more so now, because you can't visit,* [due to Covid] *certainly inside anyway…, I ring up twice a day normally and I'm, if I hear he had the slightest change in his condition for instance he is not moving, then why…I feel that I'm sort of removed from it, but still sort of overseeing it and in a distant way…".*

Alana expressed feeling guilty for having moved to a bungalow. The move was prompted by Mike's needs, and he lived there for a short time:

> "*I think I knew that I just couldn't cope here you know, and I suppose the other thing was that we've got the home, I got the home here for a change…You feel guilt, because I sold up where we were..., and you know, you feel guilty, you know. Should I have moved? But when I reflect, I think, well, yes, that was part of the journey really".*

4.2.2 The diagnostic journey

This journey involved Alana identifying that "*something is going on*"," *the drawn-out process of seeking for a diagnosis*", *receiving the diagnosis*, and "*the emotions"* that she experienced such as shock, disbelief, and denial.

The more Alana was convinced that "*something is going on"*, she said:

> *"I was like spying on him in a way, I was trying to sort of get evidence in a way to try and prove my point that there was something going on, that I couldn't put my finger on…"*.

There came a time when she realised that Mike had no insight into these changes. Use of the term "*spying*" implied that she closely, even covertly, observed him in order to obtain evidence for her suspicions.

Alana described the protracted route to Mike's diagnosis and said: "*that was a drawn-out process too, so you know".* Alana described several trips to the GP who initially conducted a memory assessment. However, as Mike scored well, he did not meet the threshold for further referral. Alana stated: "*at that point I don't believe that the doctor pursued it*". She described trips to accident and emergency department, and the stroke clinic before a referral was made to the memory clinic.

Despite her own suspicions, receiving the diagnosis was not easy for Alana. Alana was puzzled because Mike's ageing parents were not living with dementia:

> *" He was sort of lost…I just felt...it was some…daunting it was,* [quiet]*…an eye opener really…I think I knew it was dementia, there was nobody in the family with dementia that I could recall,...on either side, you know so, obviously, but …and his parents were still okay at that time you know?, and they were in the 70s, at that point. So, yes, a shock* [nods], *I suppose shock, but then I'm sort of thinking ahead as to what it could be, and you know? bit numb I suppose really yeah".*

The comparison with Mike's parents who were in their 70s resonates with the general belief that dementia is for older people and that it is more easily accepted in older people.

4.2.3 The loss

The loss refers to all the things that Alana and Mike missed and changed because of YOD. This is explained with the following experiential statements: '*the timing is wrong'*, '*losing individuality'*, '*losing companionship and his presence at home'*, '*losing a lifestyle'*, and *"thinking this is the end".*

'The timing is wrong' relates to the fact that they were both still working and planning for their retirement. As Alana reflected on their situation, she verbalised that if Mike had been over 65 years old, she would have felt differently:

> *"I suppose so because you just think with old age, these things happen don't you and it's not highlighted a lot about young onset…I do feel that it'd be easier to adjust if somebody was older but the younger, because effects, their work and their life more and, obviously, you know it's their job of course, yeah? and affected interest in driving, of course, too, so you know, somebody older, perhaps you do to sort of come to terms with that a bit easier".*

When asked if she had told friends and family immediately after receiving the diagnosis Alana said:

> "Ye*s, I did, and they would always give you examples, I remember, of what, you know, of their experience of somebody in a similar predicament. But often it was older people".*

It seems wrong timing was made worse because of the shock for others and the general lack of awareness of dementia as a condition that affects younger people.

Alana alluded to her losing individuality and independence from the early stages of YOD. One example is an incident when they went to the pharmacy together. Mike sat in the car as he would do while she ran errands. However, on this day Mike disappeared. The police had to be involved and found Mike. Alana explained:

> *“I can't do that again I can't leave him in the car anymore and so that was another thing you know … but I had to be ever closer to him. I just got to gradually think more and more things I couldn't leave him alone”.*

As the dementia progressed, she felt she could not be apart from Mike because he could not keep himself safe and those around him did not feel safe either.

Several lifestyle changes occurred because of Mike’s YOD. These included loss of friendships, discontinuation of the hobbies they enjoyed doing together, as a couple, and with friends, for example, driving abroad, meeting up with their social groups for meals and recreation. Alana articulated the extent to which she missed Mike’s active involvement in activities in her daily life: *“yes practically I miss him so much…”.* In a way, it appears Alana is experiencing pre-death grief:

> *“It's like the grieving process, isn't it? when somebody goes into a care home. I lost him really; he didn’t come back to me…”.*

Alana was preparing for the end of Mike’s life and expressed her wishes:

> *“When it happens … he's … and he's been end-stage dementia for some time, … I want to be there when he… when that change occurs*…”.

Although Alana was clear that Mike was approaching the end of his life, the ultimate loss, it seemed she could not mention the words death or dying. She instead used the words “*the end, palliative, or the change*”.

4.2.4 Reflecting on the system.

Alana discussed the health and social care system in relation to ‘*delaying discharge’*, “*medicating him*”, ‘*lacking age-appropriate services’* and ‘*communication challenges*.

When asked to think of the whole care process, Alana replied:

> “*The journey, it's a little..., it was a long journey both physically and mentally. The time it took that he was fit for discharge and then he couldn't go anywhere…*”.

Here Alana was referring to the delay in discharges. Mike had been in hospital for nine months. For four of those months, he was ready for discharge. However, he had to wait for what she called “*logistics”.* These logistics included funding applications, successive denials and appeals and later the availability of a bed in an appropriate home.

Alana felt uncomfortable with medication use*:*

> *"… there were lots of side effects to the drugs… it took a while to establish what drug, if any, was effective and whether you know, you just got back to square one really. What happened over that time he was tried, I say tried…, they…, it was…, I suppose an experiment in the way I found. I agreed to it, but they tried four different antipsychotics".*

Alana was informed about the difficulties in managing Mike's BPSD including that antipsychotic and anxiolytic medications could be used though they would not treat dementia. She gave her consent for these to be trialled with the hope that Mike would be more amenable to care, and he would go back home. However, she learnt during that time that there was no specific drug that would produce a required effect immediately. Instead, several medications were tried, and discontinued, or more added in until a more desired effect was reached-it seemed like she was not expecting this as it had not been explained. The side effects of these medications frightened her. Alana explained that at one time Mike was too drowsy, he was falling over while walking and from his bed so had to be nursed on a mattress on the floor.

The lack of age-appropriate services was obvious throughout the journey from primary care, hospital and to care homes. This was compounded by the fact that Mike's behaviours needed specialist care. Alana visited four care homes, one of which was a long distance away from their home. Although care homes were registered as being dementia specialist, what surprised her was that some would not accommodate his specific YOD related needs.

> *"What I felt was … that some …a couple of the homes said that they could cope with Mike, and I don't actually think they could have done because of the way they were talking. One home actually, … one manager … she said look, we wouldn't be able to cope with Mike and she said because of this and this, we wouldn't want to take him here…".*

Regarding communication with professionals Alana said: "*Several shocks along the way". She* gave examples and explained that the communication was not helpful and that made her feel inadequately supported:

> *"A lot of things not clearly explained from the beginning…Clear explanations would have helped... Initially that I sort of verbally took down the list of names*

> *of the care homes, when I could have been given a list that they knew was affordable"*.

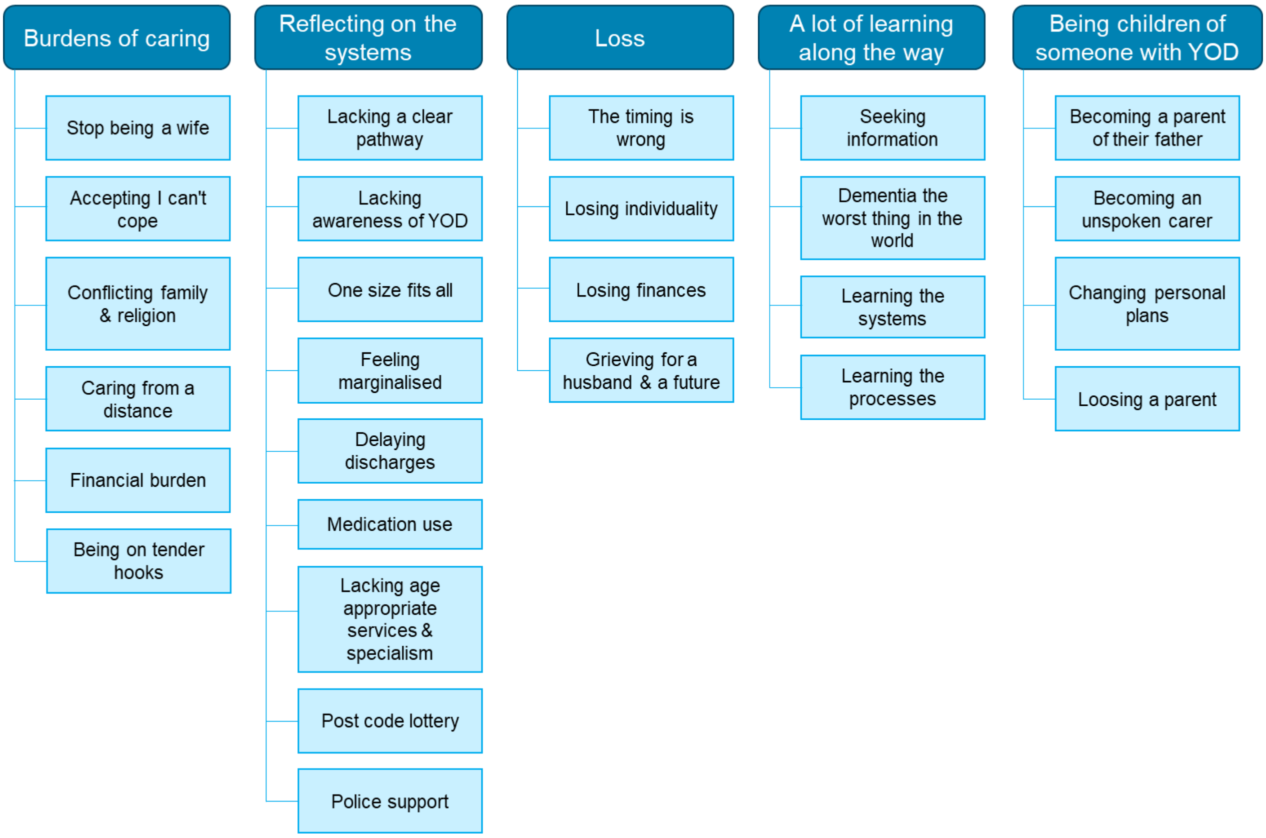
When Mike was ready for discharge from hospital Alana was given names of care homes to consider. However, when she expressed her interest in one home that she felt would meet Mike's unique needs, she was told it was too expensive for the authorities to pay. Consequently, Alana appealed for the home to be approved.

Alana's transcript contained an in-depth and at times emotional, reflection on the past or good times and thoughtful consideration of the present.

4.3 Ellen descriptive summary

Ellen was a 54-year-old woman who was still in employment. Amir, her husband of 35 years was 60 years old and living with dementia. They had experienced a care home placement breakdown, a hospital readmission, and Amir was now in a second care home. When Amir started showing changes in ways he performed tasks in work and at home, then went suddenly deaf in 2010, their three children were teenagers: one at university, another just starting university and the youngest doing 'A' levels. Amir was diagnosed with received a diagnosis of FTD in 2015. Ellen, a non-Muslim, had converted to Islam. Figure 5 presents the PETs and Experiential Statements from Ellen's interview.

Figure 5: Ellen’s PETs and Experiential Statements.



Ellen’s descriptive experiences and personal experiential themes.

From the initial email and phone contacts I had with Ellen she explained:

> “*We are in a mixed marriage. We are practising Muslims. I am English, I was Catholic and converted to Muslim when I got together with Amir when I was 18 years old*”.

This brief introduction, in a way, prepared me for possibilities of a theme/s around religion and culture.

4.3.1 The burdens

The ‘burdens’ encapsulates the experiential statements: “*stop being a wife”,* “*accepting I can’t cope*”, “*conflicts with family and religion”,* “*caring from a distance”*, “*the financial burden*”, and “*being on tenterhooks*”. Ellen shared some of her feelings with me.

Ellen explained that from the point of diagnosis "*there was a point of time to stop being the wife really and become a different person".* It appears this was to enable Ellen to prepare herself emotionally for what lay ahead: *"you've got to battle for him, you've got to maintain the case, their case…".* The word *battle* being used as a metaphor to indicate the magnitude of what she was having to do.

Ellen described "*caring from a distance*"*.* Her narrative seemed to indicate that she had no choice but to take it upon herself to coordinate her husband's care:

> *"I spoke to the consultant of the community mental health team in the end and started to get involved with them… I said, give me the contact numbers of these people, because it is becoming so frustrating".*

It seemed as if no one in the system was advocating for Ellen or Amir. Ellen contacted relevant teams or team members, prompted care home managers to arrange staff training about how to manage the needs of someone with YOD, managing distress reactions / BPSDs. Because "*He* [Amir] *was so awkward to be with him, he only responded to a few people",* Ellen initiated discussions about staffing in the care home and proactively provided instructions to staff of what would work when caring for Amir. Of Amir's discharge from the second hospital to the care home, Ellen said:

> "*The sad thing is none of that stuff came over. It never went with him, and I sent the care home the words because I knew they did not have them"*.

Ellen and the hospital occupational therapist had put together translated words from Amir's original language to English to help staff to communicate with him. Ellen explained:

> *"As you can imagine, this battle is just continuous. I haven't … haven't known anything like this in my life. It gives you no break and you know, no sleep you know? even though he wasn't at home. You still don't sleep because all you're doing is worrying about him and his care and how he's being cared for you know?"*

Again, Ellen used the word *'battle'* to articulate that she found this hard yet still made a determined effort to achieve something positive in a difficult situation. Ellen appeared very worried about care breakdown: "*I am on tenterhooks all the* *time thinking it is going to fail at some point".* Ellen described the loss of his income as another worrisome burden which generated difficulties in daily lives:

> *"Obviously, you've got the financial burden, because you know, he used to earn £45,000 he went to nothing and we still have a mortgage, we have children in university, you know, there is no support for that, he's not on a pension, you know?"*

Ellen explained:

> *"Amir had been working a computer job and he couldn't do anything, then he had a caring job. It was about the sequencing of things, sequencing of tasks that he couldn't do and the understanding of the meaning of words…He wanted to carry on working, of course…There was nobody that would actually take him on".*

Another burden related to conflicts with Amir's family and religion because they did not believe a younger person could be diagnosed with dementia. Ellen seemed upset as she recounted the relationships, and pointed out that they were losing time because dementia was progressing. Ellen said:

> *"His brothers really didn't take a look. They just did not understand at all. His brothers, who basically, didn't see him for two years".*

Ellen had been persisted in trying to let Amir's brothers know more about the condition and Amir's progress through a WhatsApp group she had created. Her persistence seemed to indicate that the relationships were good before the YOD onset. Ellen said:

> *"From a Muslim Community perspective, they see dementia in older people. They've never ever seen it in young people, he's actually first and they don't understand it. They think it's like bipolar and we have this thing, was it, have you heard of things like a spirit taking over him, wasn't it. It was the evil spirit, all the cultural side of things…".*

The relationships difficulties could be related to their culture or religious beliefs in relation to awareness of dementia and particularly YOD.

4.3.2 Reflecting on the systems.

Ellen reflected on the systems several times, stating that it was: "*lacking clear pathways*" and "*lacking awareness of YOD*". Other phrases included a "*One size fits all approach*", *"feeling marginalised"*, "*delaying discharges" and "medication use"*. Ellen described an *"over complicated",* system which "*lacks age-appropriate services and specialism*", "*post code lottery"*, and referred to the need for "*police support*" which she said was traumatic for both her and Amir.

Ellen described what she labelled: "*one size fit all"* systems. Amir was different in that he was South Asian, a Muslim, in a mixed marriage and young. Amir had beliefs, traditions and routines that were different from the rest of the patients or residents that the professionals were used to providing care for. He therefore had specific needs. Ellen said, "*He just didn't fit in and was not accepted*". Her words provided insight into the difficulties families and professionals face when caring for this population and finding younger people's BPSDs complex.

Regarding conflicts between religion, culture and care institutions, Ellen questioned the meaning of person-centred care. She commented:

> "*…it is a massive issue…How are you treating them as an individual, if you are not actually looking at their individual needs, and then the system is pretty poor".*

About '*being different'* Ellen said:

> *"The only thing is, because we're in a mixed marriage and I went to the GP, first question I got asked is am I his carer… not am I his wife, it's, 'am I his carer' or who are you, you know…, so, I've had that all the way through this entire process, because we are different,* with *diverse cultures…"*

While Ellen called herself a carer, her statement, "*Everyone we met the first time assumed I am his carer and not his wife"* might suggest that she would have wanted the professionals to recognise her as a wife first then carer. Ellen seems to feel that she has lost part of her identity. Ellen also explained: "*we were a bit different from other families".* In this instance different was conceptualised in relation to Amir being a person under 65-year-old on the caseloads of the team that had older adult clients.

Ellen expressed that she had felt marginalised on several occasions while on the journey. She spoke of there being, "…*a lot of arrogance in the medical professionals"* which she repeats *"…arrogance side of things, and it is like we are the experts*". Ellen explained how arrogance was evident in professionals use of medical terminology during discussions with her as well as other families, and not being listened to by staff both in hospitals and in care homes:

> "…*and they* [professionals] *were not listening to what we'd actually told them about him, they did not know him, they didn't understand him. I don't think they quite realize that there is this younger element and then".*

Ellen used, "*they"* when describing areas that she was not happy with such as the police, "*they decided that they were going to search pockets*..." and the hospital:

> "*It turned out they* [ward team] *decided he was ready for discharge; this was in December and over Christmas his behaviour deteriorated massively..*." and "*they* [ward team] *decided on the Tuesday and within a day he was moved*".

Ellen made it clear that she had no input in this decision-making.

Ellen described the use of antipsychotics and anxiolytics both in hospital and in the care home. She felt that some staff used these more than others. Ellen seemed to suggest that different staff members could use other non-pharmaceutical interventions when supporting Amir.

Ellen described finding a suitable care facility in the system as the "*post code lottery*", "*the lack of support and diversity*", and that professionals were not proactively offering support. Speaking of her search for the first care home Ellen explained:

> *" When we started looking, aaaah* [giggles] *this is the other part of the wrestle. When we started looking for, so they decided EMI nursing as a care home. Though to try and find an EMI nursing home, it's quite difficult and we looked at the ones in our area and we're not impressed We contacted like the CQC. We had gone on the care homes dot website [waves her hand as if dismissing it], in the end we visited over 50 of them. we looked further afield, …we looked all around different areas…"*

4.3.3 The losses

This PET encompassed the statements "*the timing is wrong", "losing individuality", "he is losing his capabilities", "grieving for a husband and a future*, which were identified from the numerous occasions where Ellen described her future:

> *"You're dealing with the notion that you're dealing with a future you don't want now you've got a different future from what you expected,* and *this is your future, missing your husband"*.

Ellen expressed that while she wanted Amir to be home, she understood that this might never happen. She mourned for Amir's progressive loss of capabilities and that he no longer recognised her or the children:

> "*I am losing my husband… you know and you're going through the grief process…"*

The use of the word '*grief'* suggests anguish. Ellen knew that Amir's disease was progressing, and she seemed to be experiencing anticipatory grief for the loss of a husband and a future. Ellen explained:

> "*a lot* (of conflicts*) ...with our religion people do not understand it at all and so, even if you explain, it is quite hard to get across to them how important it is"*.

She believed that Amir had forgotten his prayers because "*he has been in an environment where they do not understand the importance of it* (religion)".

Although Ellen had given staff Amir's two iPads with his prayers recorded and uploaded, ready for him to use, each time she asked for them, the iPads were neither charged nor in Amir's possession.

4.3.4 A lot of learning along the way

This relates to the "*seeking for information", "researching online" and "learning about dementia itself", "anything that could be helpful",* "*learning the systems*" and "*learning the processes"*, at each stage of the trajectory. Ellen acknowledged that they lacked knowledge about dementia, YOD and the health and social care systems as a family:

> “*we didn't know what to do, we had not really been involved with any of these people, you know, not knowing anybody in the system, not knowing anything about the system”.*

Ellen also said she had not known anyone living with dementia. All these facts prompted her to do a lot of research into dementia.

4.3.5 Impact of YOD on children.

This PET came about when Ellen recounted receiving the diagnosis and their children having to change their personal plans and roles. She explained that they were: “*becoming the parent to their father”,* and “*becoming carers*” and that *“The children who worked in London and then they moved back, the boys”.*

The children became even more present in their father’s care supporting him with activities of daily living. There was role reversal in their relationships: *“decisions are made with all of us together*, *the children and myself*”. The children became more involved in the decision making regarding their father’s care and welfare and Ellen reflected that the children were missing out on what they should be benefiting from their dad:

> *“Your children, that's the point, the children need that dad more, you know? they need that guidance more and you know?... because they're growing as well isn’t it? that’s becoming adults, but obviously they are then becoming the parent to their father, which is not really the way it should be is it?”*

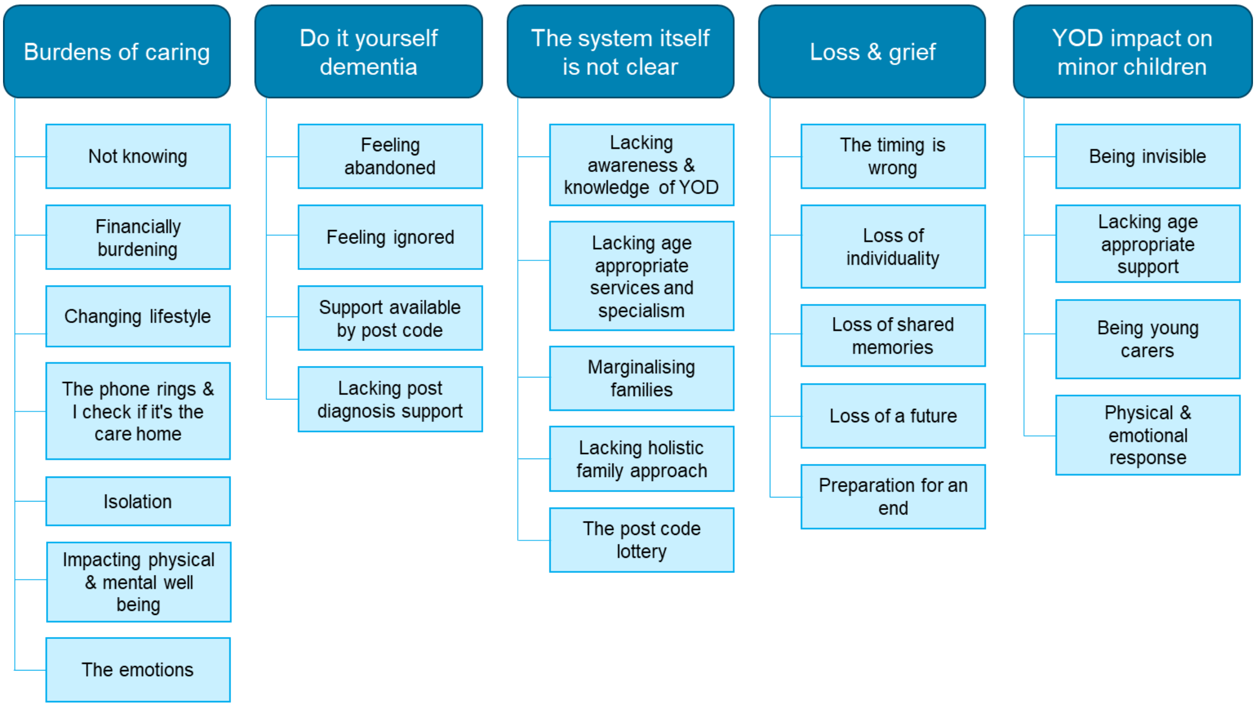
At this point Ellen smiled. However, this was not a happy smile. She became quiet and seemed to be in a lot of emotional pain. We were silent for a few minutes as she recomposed herself.

This interview revealed a wife and a carer who desperately wanted a better quality of life for her husband and knew that the only way this could happen was for all those involved in his care to know him as an individual with unique needs.

4.4. Mary’s descriptive summary

Mary was fifty-nine years old and had been married to Tim for 35 years. They had three sons and Mary had worked up until she had her first child. When she decided, she would like to return to work, fifteen years later, Tim was showing behavioural and cognitive changes. Tim had received a diagnosis of behavioural variant frontal temporal dementia (BVFTD) a year previously and concealed it from his wife and family. Mary only learnt of Tim’s diagnosis following a visit to the GP for things that were “*wrong at home*” but mainly related to Tim’s behaviours. At that time the children were about 15, 14 and 12 years old. Figure 6 presents the PETs and experiential statements identified from Mary’s interview.

Figure 6: Mary’s PETs and Experiential Statements.



Mary’s descriptive experience and personal experiential themes.

Mary was a very confident, assertive, and articulate woman. For the first fifteen minutes of the interview, Mary would answer a question or give a narrative and then stop and look at me as if she expected me to make a comment. However, as the interview progressed, several times she asked, “*You see what I mean?”* at the end of a statement*.* This behaviour and preface I came to associate with seeking validation and that I agreed with her examples from her narrative are that the family "*never believed he* [Tim] *had dementia"* and to social workers visiting:

> *"I say look, if you don't believe me, my sons are happy to talk to you".* Mary stated, "*I've lost quite a lot of friends because they really almost didn't believe what I was saying".*

When getting an effective response from the on-call psychiatrist Mary explained:

> *"for the first time ever… somebody had believed, somebody has …, you will never understand".*

Mary sought to make sure that I followed the conversation, understood the meaning of what she was saying and that I provide affirmation to that.

4.4.1 The burdens of caring

The **'***burdens of caring*' PET encompasses the "*not knowing*", "*the phone rings and I check if it's the care home", "the financial burden"*, "the *changes in lifestyle",* "*impacting physical & mental wellbeing", "isolation" and "the emotions"*.

Mary reflected on her role:

> *"I definitely cared for him all these years…I worry everyday about how he is, is he breaking or hitting someone, am I going to get a phone call, you see what I mean? The phone rings and I check if it's the care home. Yeah, its continuous you see, don't you think so? I am at home and thinking all the time. I think its caring, yeah..."*

Mary believed that accessing support, providing support and caring for Tim was more difficult because he did not accept that he had dementia:

> *" …denial, oooh… the whole way through which didn't help, certainly didn't help me in dealing with him, because every time I tried to get help, he wouldn't let them in the door, or he'd be very aggressive towards them because he didn't want to deal with people. So, that was hard sort of thing…".*

In her narrative Mary mentioned not knowing of the of YOD diagnosis for a year after Tim received it and seeking knowledge in this regard:

> *"Basically, my husband knew about a year before me, but he hid it, hid everything and because of this confidentiality with doctors, no doctor was going to tell me. So, he chose to hide it…it was by a process of me thinking something's not right here and I went to my doctors and said I think I've got a*

> *problem at home and like explained various things that have been going on with speech and behaviour…"*

Mary wished she had known sooner. While she was aware of patient confidentiality, with regard to a dementia diagnosis, she said:

> "*From my experience I think when somebody is given a diagnosis on their own, one to one with dementia I think…certainly their married partners should be told that sort of thing because it has a massive impact on them…".*

Mary was clearly annoyed by this lack of information from Tim and the healthcare professionals because it impacted greatly on her and the children.

4.4.2 Wellbeing

'Wellbeing' is of particular significance in Mary's narrative as she articulated the physical and emotional impact of living with dementia on her family:

> *"I've become diabetic with all the stress, we've all just caved under, all the stress and we were all fit and healthy before all this started…it's weird to describe to people. We thought, with him no longer in the house the stress levels would go, and we'd be able to bounce back but it's not been like that at all…it's almost like post traumatic sort of stress on…, and we've all been so tired and it's never going to be the same family again ever. The pain and stress lives with us".*

Mary revealed that her youngest son has self-harmed and attempted suicide several times. She conceded that:

> *"he's never going to be right mentally now; he's never going to be like ok mentally now. He's got big issues, he wouldn't be alive today, but for me…it is battling, battling each day*…."

Clearly, Mary and her sons were struggling with health and wellbeing which is likely to have been compounded by Tim's illness.

4.4.3 "Do it yourself dementia (DIY dementia)"

In her frustration Mary discussed their post diagnosis experiences which featured a series of unexpected, and seemingly random incidences and negative responses from professionals as a 'DIY dementia". This was found to be a particularly rich statement, or 'gem' (Smith 2011) that informed the overall interpretation of the post diagnostic experience. Mary explained:

> *"… and that was in July 2015, and we sat there to December 2015 with no contact with anybody no follow up nothing and literally we were just crying on the sofa thinking you know, we have just been left and you…, again…*".

The use of 'again' seem to illustrate that this was not the first time the family had felt this way.

Mary claimed that:

> *"It was DIY dementia. We were making decisions on the spot for ourselves, dealing with it. Trying to deal with it the best we can because you weren't going to do anything for us, you weren't going to change, and you weren't going to help us".*

Mary felt that there was divide between herself, and the children, and the professionals. In her narrative she would often refer to 'them' or 'you' and 'us'. Mary explained that the family felt invisible or non-existent to the professionals who seemed focused only on supporting Tim:

> *"we'd had so many incidences that we'd reported and had no concrete help, we were always made to feel the villain. It was Tim's right, Tim this, Tim that, we just thought, what, we would deal with this ourselves and our saying in our family was we called it 'DIY dementia', do it yourself so, we've got used to dealing with all these things which any other family if they'd have had one of them would have been in complete meltdown, so you can imagine the psychological impact on my sons over the years, all these things that they've dealt with".*

As she said this, Mary was looking straight at me, and I thought she was observing my facial expressions and how I would react to what she was saying. All the time I reminded myself to remain as neutral as I could, remembering that she had mentioned about not being believed and being judged several times in her narrative.

Mary seems to suggest that her experiences with professionals also contributed to *DIY dementia*:

> *"…because it was happening to you couldn't phone every week, every day just you…just it just wasn't possible that's why, in the end we just took it on ourselves to do and because, then you go for all these; oh well it's this is that not and nothing changed ever. So, you think there's no point we're just wasting our time nobody's listening".*

It seemed as though Mary was reflecting on the frequency of incidents and justifying that there was no other way because there was no help. At the same time, she was ensuring I understood much she had gone through. This term "*DIY* *dementia"* is both powerful and poignant in that Mary is appearing to convey a diminishing confidence in the system that is supposed to be making life easier for them. DIY dementia will be discussed further in the discussion chapter.

4.4.4 System itself is not clear.

The **"***system itself is not clear"* refers to Mary's reflection on the journey through the systems as being a system that "*lacks awareness and knowledge of YOD*", "*does not understand YOD*", "*does not want to talk about dementia", "marginalises families", "lacks family approach", and "lacks age-appropriate facilities and specialism*", operates on "*the post code lottery* "and *"professionals' lacking knowledge of YOD".*

Mary seemed to say that the system marginalised families, did not involve them, nor give them choices, and treated them as if they were invisible, not recognising their needs and importance:

> *"Not all healthcare professionals know that and…if not for the carer you know 80 or 90% of people with dementia would not be in their own homes, without the other people living in that house looking after them. They try to deal with the dementia patient in isolation, instead of looking at…you can't disconnect the family from that if you're living under one roof"*.

Mary emphasised that professionals need to recognise the importance of relationships and family-centred care considering the impact YOD can have on the family and not only the person with the diagnosis. At times family situations such as that families need to work can lead to person with YOD admission to care home.

Mary described a period of six months after being informed of the diagnosis when the family received no support:

> *"We sat there with no contact with anybody, no follow up, nothing and literally we were just crying on the sofa thinking you know, we have just been left…and in the end, I started googling I thought there's got to be some help out there, there's got to be some help".*

In her narrative, she made a comparison of dementia and cancer pathways and tried to make sense of how the two work:

> *“it's so much more formal ... regimented, yet this you're forever trawling [the internet] and looking for little groups here and that. When you're diagnosed with cancer, there is a follow up plan, where you see a consultant, you're told where you're at, what the treatment is, what the timeline is and that doesn't happen with dementia…”*

Mary touched on funding:

> “*The fact that there is a lot of talk about who pays and what ..., is wrong for the family and that certainly is discrimination against the dementia people… that's not a conversation with a cancer patient about money”.*

Mary compared with other conditions and even COVID-19 and still felt that there were anomalies in dementia care:

> *“...one biggest killer in the UK is dementia, so back up there above heart disease and that and yet it's still ignored, to some extent, for some reason, all the time. No one wants to talk about it, all the professionals I have met anyway. It’s quite sad really because it is here in young people, yeah, yeah or maybe they don’t know what to talk about…you think the GPs would have specific clinics in their GP like they do for diabetes and other areas you know. It just needs a lot more… bit more coordinating in that between you know”.*

Mary explained her frustrations with the lack of support for the younger families and also the available support:

> *“one of the biggest things I found is…, I was always trying to be slotted into the box of the 85-year-old couples with dementia and it's nothing like an 85-year-old couple with dementia, that the young ones get...there’s been much more than just about memory, I suppose, really not just memory, you know, not all the other bits that we've had with the behaviour”*.

As a mother, Mary found the available support lacking:

> *“All the services tend to be geared towards the over 65 and that's what I was battling with all the time. They were trying to fit me in, that all the forms, everything you fill in are heading that way that you're over 65 and one of my biggest challenges was because I had the three boys at home and so, dealing with the dementia with them living, you know 12,14, doing GCSE and trying to have friends around which when you're at 85 your children are not still at home, you haven't got all that to deal with”.*

Mary seemed to suggest that she could not get appropriate peer support as the wife of someone with YOD. Summarising her experiences Mary said, “*It was like a catalogue of disasters or something…, it was*”.

4.4.5 Loss

‘Loss’ as a PET includes her own feelings as she experienced her husband losing his abilities, “*not knowing her anymore*” and all the “*lost shared memories*”, *“loss of a future and preparing for end of life*”. She summed this up by saying, “*it's awful to watch how, it robs you of everything you can do”.*

Mary revealed the devastation she felt:

> “*He doesn't know who we are, but the others seem to know who their visitors are. I know people at 85 say ‘hello’ to their daughter, or whatever. He's not got a clue... I can be in the room, and he walked straight past the room. He didn’t know; if I call him, he walked straight past me”*.

The comparison to people at 85 years old suggests that dementia at an earlier age is unexpected, the timing is not right and maybe, if Tim had been older, she (and other people) would have understood.

Mary further reflected*:*

> *“…40 years of memory just gone…you're just left with a physical being and nothing in the head…I couldn’t believe it…I really, really, I really thought, even if he didn't particularly recognise me, he’d recognise my voice, my tone sort of thing, but there was nothing, it was almost like I wasn't even talking”*.

As she said this, Mary looked sad and spoke quietly. She shook her head and went quiet for a few seconds, while looking down. I could sense how hard that had been for her to understand and accept.

Mary exposed the tensions and vulnerabilities she had felt amongst her friends, the isolation and losses appear to increase and be more heightened in these words:

> *“It does alienate you; I mean I’ve found on a number of occasions I’ve been out and then all of a sudden, you go into this goldfish bowl because they're all talking like everything's gone to plan…I’m sat there thinking I can't listen to this anymore because I can't compete on this level now, I’m not doing any of this I just want my kids alive and safe. It’s like I don’t have a husband anymore”.*

Mary seemed to mourn the loss of a future that was full of good plans. She said “*I don’t have a husband anymore”* metaphorically as she knew he was still alive and his whereabouts, but she didn’t have a husband both in physical and emotional sense. Unlike her friends she could no longer go on holidays with or retire with her husband anymore and she was now prepared for his end of life.

4.4.6 Impact on dependent children of someone with YOD

Mary talked about the children’s relationship with Tim as YOD progressed. I asked if the children had seen Tim after he had left the family home for hospital and was permanently staying a care home. Mary said:

> *“They don’t want to see him. The boys have got mixed feelings about him because they feel, …they feel he’s ruined their lives; it's ruined…, the dementia has ruined their lives, plus trying to disassociate him from the behaviours that he was showing towards them is hard to do”.*

‘*Impact on dependent children of someone with YOD’* became a PET from observations that whenever Mary talked about her children, I could see her fighting her emotions. She talked about the children jointly as “*my sons, my boys*” and rarely mentioned their names. Mary recounted events and how she had been protective of the children both emotionally and physically.

Mary explained how dementia impacted on the children’s lives:

> *“He couldn't cope with the youngsters coming in at midnight if they've been out with friends…we’d scaled back our life so much, we never had anybody come into the house because …,even if he knew…he didn't recognize them, who they were and it created agitation in him having strangers to him in the house, if my boys had something different on schedule, you always think if he was going to attack the other people,…It just wasn't worth the risk of everything. So, our life is very low key, it was…, just us in”.*

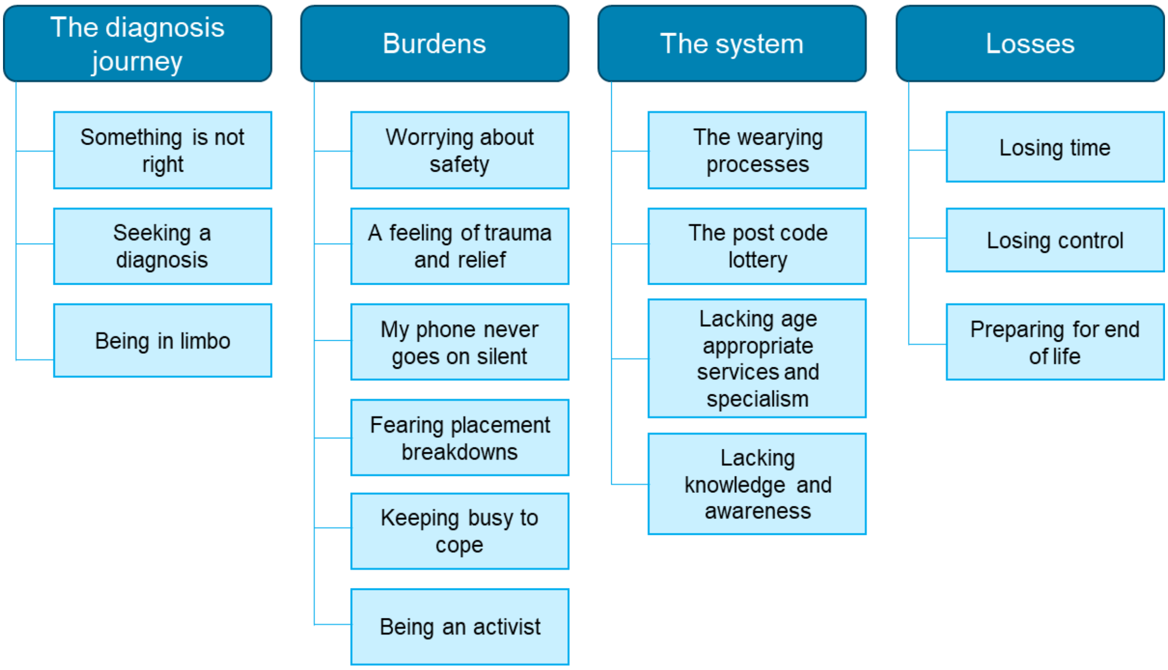
By virtue of being in the family home, the children became carers. Considering the risks they faced, Mary questioned the meaning of safeguarding minors. She felt that her children were not safeguarded and that several professionals “*turned a blind eye to it”.* She felt that the children, especially the youngest were let down by the systems. Mary discussed the lack of support for children of people with YOD. Mary felt her children had been invisible to the many professionals that they encountered.

4.5 Maxwell’s descriptive summary

Maxwell was 60 years old and still working. His wife, Gillian was 59 years old. They had a 23-year-old daughter who would have been 19 or 20 when Gillian started showing symptoms of YOD. When Gillian was diagnosed at 57 years old with Alzheimer's Disease, she was being treated for what was thought to be depression. Gillian was discharged from a psychiatric hospital to a specialist dementia care home for people under 65 years old. The care broke down after two months because she was agitated, physically and verbally aggressive and destroyed property a few times. One day these behaviours escalated, and the care home was not a safe place for her and others around her. She was moved urgently to another specialist dementia care home. Within a week she was readmitted into hospital because the care home staff could not meet her needs. Gillian had been in a psychiatric hospital for 10 months at time of interview and the search for a third home had begun.

Maxwell was well read and had undertaken considerable research into dementia, YOD, what works and what does not. He had thought about what a specialist dementia home should look like. During the interview Maxwell chose to focus on the system, not on himself, his feelings, or his wife nor their daughter, whom he just mentioned in passing. Questions like: How did you feel? were answered with a scenario or an example of what happened or did not happen. The one way I could tell that he was showing emotion was the repeated, and at times, long sighs. He would look outside the window while talking and rarely looked at me directly. Figure 7 presents the PETs and experiential statements identified from Maxwell's interview.

Figure 7: Maxwell ’s PETs and Experiential Statements.



Maxwell's descriptive experience and identified themes.

4.5.1 The diagnosis journey

This PET covers the changes which started with Gillian's disinterest in things and activities she previously enjoyed while acquiring interests. These changes led to Maxwell thinking *"something is not right"*. He explained:

> "*The first thing that changed, she rather suddenly decided to retire from work.…this was so much of a surprise. But I suppose and you know, I didn't really know what to make of it, but to be honest with you…".* This led to "*seeking a diagnosis*", and "*being in limbo".*

Maxwell gave a narrative of the long time it took to receive a diagnosis, the several visits to the GP and hospital. Maxwell described the difficulties he had faced in trying to get Gillian to the doctors for assessments. On one visit they managed to get to Accident and Emergency which he seems to feel that professionals had delayed attending to them until Gillian became distressed. He said:

> *"… they shuffled us around for about four hours. Then eventually actually, … and by then Gillian just wanted to go home, wouldn't engage. I think the hospital was quite pleased... They had no apparent, they were not geared up to Gillian's condition so they're quite happy to have us walking".*

Maxwell seemed to suggest that professionals were not keen to attend to Gillian because they lacked confidence in supporting someone with YOD.

4.5.2 Burdens

'Burdens' summarises the "*worrying about safety*", "*a feeling of trauma and relief*", "*my phone never goes on silent*", "*fearing placement breakdowns",* and "*keeping busy as a way of coping*".

Maxwell explained that he watched Gillian's behaviours deteriorating. She had altercations with family members, and people using the road close to their house, and he had to intervene before these situations deteriorated. All that had made him worry and said:

> *"It was very clear to me that she was getting worse, more and more confused...it was obvious to the GP and me that Gillian at this point was in a crisis. Gillian is a risk to herself and potentially others".*

Gillian had also gone missing, and he worried about her safety:

> *"In this instance I had to call the police, because I couldn't find her, and I was genuinely concerned…"*

"*A feeling of trauma and relief*" is how Maxwell explained the mixed emotions he felt when his wife was admitted to a psychiatric hospital. On one hand Maxwell knew that his wife needed the admission. At the same time, he felt discomfort that this happened. Maxwell said:

> *"I think we had this Friday in limbo and then on the Saturday the AMHP came around, surprise, okay?* [A big sigh, quiet and looks down]".

A meeting had taken place a few days earlier and the decision had been reached that a hospital admission was needed. However, nothing happened for another few days. Maxwell described this state as being *"in limbo"* to emphasise the difficulties he faced and the unclear situation he was in.

Explaining **"***my phone never goes on silent"* Maxwell explained:

> *"You constantly worry about what's next,* [quiet] *yeah that, that, that…that's never going to go away, I suppose as you said when you care you worry. I worry all the time; she is away, and I still worry…* [goes quiet]. *My phone never goes on silent. I have to hear it and act accordingly…".*

Maxwell described the times he was asked to assist with de-escalation, either by going into the home or using the telephone when Gillian was in distress. However, COVID-19 restrictions had precluded him going into the care home in some instances:

> *"They were somewhat limited by the ability to call me and calm her down because of COVID restrictions and it would have happened more often if it hadn't been COVID. I'd have to accept that, I think we're just going to have to accept that you know, I don't think…, I don't think there's any silver bullet for that one that's going to be there. That one's not going to go away but… specialist homes…* As he tailed off…, [he sighed and went quiet]".

Fearing care breakdown is something Maxwell spoke about at length. This was probably because Gillian had already had two failed care home placements and now, they were searching for a third home. He seemed despondent because the only care home that had been identified, did not seem known to anyone in the team that who suggested it. He asked me if I had heard of this home, and I had not heard of this specific one, but I knew of the types of home he had described, and they are considered highly specialised. Regarding the proposed home Maxwell said:

> *"…not a lot of information online so, yeah, very hard to…. Yeah, the comments from the nurse practitioner, and the ward is that they are confident that they could discharge Gillian to that hospital* [home] *today and that Gillian… that hospital* [home] *has the resources necessary to look after her".*

As he said this, he shook his head from side to side,

> *"I haven't been able to get any feel for what's offered in their environment you know, how does it feel, like a prison, does it feel like a hospital, does it feel like residential home what it feels like? I don't know. No one seems to know".*

Maxwell did not seem worried about the distance of this care home away from their home. However, he was concerned about the professionals' lack of knowledge of the place they were proposing. In fact, he said:

> *"I'm in a position where if somebody said there's a fantastic care home in County 1, or even County 2 or in County 3 and it's just the right place for Gillian, I'd say fine let's go"* [chuckles].

Maxwell explained that he would move to any county were Gillian would find care that met her needs. He was flexible because he was self-employed and worked from home. Therefore, he could choose the jobs he wanted to do and when. This decision seemed to illustrate his desperation to find a home with staff that would be competent enough to meet Gillian's needs.

Keeping busy as a way of coping was revealed as we talked. Maxwell referred to his notes on occasions, and he offered asked to share a medication list with me that he had kept over the years. When I mentioned that he seemed to keep detailed records, Maxwell commented that his extended family had also noticed the same:

> *"Yes, I do and sometimes I put it on this spreadsheet and sometimes I don't. I talked to my family about this you know, my sister's comments were me keeping a list like this has been a bit OCD and it's not really helping anything".*

He seemed to be thinking and rationalising why he does that and said:

> *Probably… I guess you kind of do things… well I'm finding I kind of do things to be doing something as the thing. I suppose, would you call this displacement activity… (He covered his face with his hand and goes quiet for a minute or so) but at least you feel at least…, it gives me some feeling that I am in touch with Gillian's hmmm medication levels. He went quiet still covering his face)".*

Maxwell seemed to be using this as a coping strategy and a way to feel that he knew what was going on so to not completely lose control on the situation.

Maxwell also kept himself busy as an activist, raising awareness of YOD and especially the challenges families faced with the processes, from seeking a diagnosis, to the specialist homes that had no real skills to meet the needs of people with YOD and their families. Maxwell forwarded to me several email correspondences between him and politicians in the local area as well as the local authority.

Maxwell reflected that he was at an age that he could retire:

> *“I’ve turned 60, I potentially could stop working, can potentially stop doing what I’m doing and... I mean, I guess or less…, a job that's less mentally challenging but actually, …I find that helpful. So, I don’t think it would to be good for me to retire tomorrow though sometimes I feel like it [smiles].*

It could be that Maxwell liked work because it also kept him busy and was something that he understood well, he could control and helped his brain to keep active.

Though Maxwell explained that the financial situation was not impacted on by Gillian’s condition because she had retired. He however said, “*The first thing that changed, she rather suddenly decided to retire from work”.* This was a job she enjoyed and risen in professional ranks in. He reflected that the sudden change of jobs was probably because she was struggling to cope with it as it involved managing people.

4.5.3 The system

On the system Maxwell detailed what he termed wearying processes and said:

> *“It is wearying and ...now in truth…, in truth I could opt out of it because I don't have lasting power of attorney so ownership of Gillian's care is currently with Dr K. Ultimately, any decision he makes, if I wanted to really challenge it, it would be a matter for the courts, the courts protection, yes and I’d have to bring a lot of my own consultants and let's not think for a second that's gonna happen. It wouldn't… it wouldn't be in my nature to step back and say okay you guys look after Gillian you know what you're doing”.*

Maxwell seemed to be thinking deeply about what could happen and where he stood in the eyes of the law. He looked out through the window, went quiet, sighed again, then spoke slowly:

> *"I think the process is hard work, if you want to stay involved and, of course in the end, there's no good outcome. You know you're not going to…Well, I've never yet come away from any engagement feeling, well that's good I've achieved something I feel better now. So, I think wearying is the term, a good way of describing the process".*

Maxwell talked about the lack of age-appropriate services and specialist care:

> *"It's a lot of gaps you know. Where do we go, she is young ok, older people's memory clinic, older people's ward, and worse, older people's care home. I am not saying it's all bad but where is young people's service. I spent a lot of time on the Internet, looking for something that jumped out as...things I look for, if one was somewhere that seem to have a specialist focus on young dementia sufferers".*

On the post code lottery Maxwell talked about the lack of specialist care homes in many counties. Commenting on receiving support Maxwell commented on his experience with volunteer organisations which he said:

> *"There seems to be a desperate, desperate, desperate group of volunteer agencies like young dementia, like Alzheimer's UK, like, …. hmmm Mind that you're told are available to support you and if you do engage with them, you get something back on…, on a piece-by-piece basis there's no strategy, there's no structure, there's no...it lacks coherence. Any support, you have to go find it yourself, and I think you have to work hard to maintain …".*

Even support from voluntary organisations was on post code too, especially for people with YOD and their families. Through internet-based research Maxwell had found out about and spoken to a Young Dementia Adviser in another county far away, yet there were none in his local area. He had also made contact with an Admiral Nurse in a care home his wife had moved to. Yet Admiral Nurses were not readily available to every family living with dementia in that area.

Lacking knowledge and awareness of YOD is an area that Maxwell seemed to feel very strongly about. He felt that many difficulties people with YOD and families continued to face were as a result of professionals lacking awareness and knowledge of YOD. Maxwell commented:

> "*…you could ask adult services to have somebody within their team with an understanding of the clinical needs because I don't…, I never came across anybody in adult services who came across as understanding of the clinical*

> *needs of young person with dementia. That might be unfair, but I just haven't you know*".

Maxwell discussed the researching, learning from other people's experiences and missing forthright information along the journey. Maxwell said he had learnt about dementia through his own initiative by:

> *"Online research primarily. Also email conversations with my GP who is no specialist in dementia, but he gave me a lot of support by email and then, principally online research, you talk to other people that sort of thing...".*

He showed me some books he had read and explained that the book written by Wendy Mitchell, who lives with YOD, had been the most insightful and helpful. Maxwell gave an example of what he meant when he said he was not provided with information:

> *"They* [health care professionals] *weren't in any way proactive in offering me any support or put me in touch with support groups or anything like that. I don't… in fact… I sat on the… I was sitting on the… in the psychiatrist's office…I saw the psychiatrist… I was sitting in her office. I am sitting in her office and there was a cardboard box on the floor with this* [shows me a book and I read out aloud] *Alzheimer's society book, young onset dementia: Understanding your diagnosis. Have you seen this book? There was a bunch of them in the box on the floor, so I said Oh, can I have one of those and she said yeah help yourself, which I did, well I did. Well, thinking back on that, yeah surely to God she could have said I've got this book, you might find it helpful. Don't you think so too?".*

4.5.4. Loss

The PET of loss came about as Maxwell talked about his current situation and his understandings of dementia. Maxwell spoke about the end of life and said when he explained this to their daughter:

> "*She understood that this was a one-way condition...Gillian's condition is not going to improve though the situation may improve if Gillian moves into maybe in a better place"*.

His words seemed to reflect that he felt time was running out:

> *"I would like to see Gillian for the rest of our days in a place somewhere, and it is a calm environment"*.

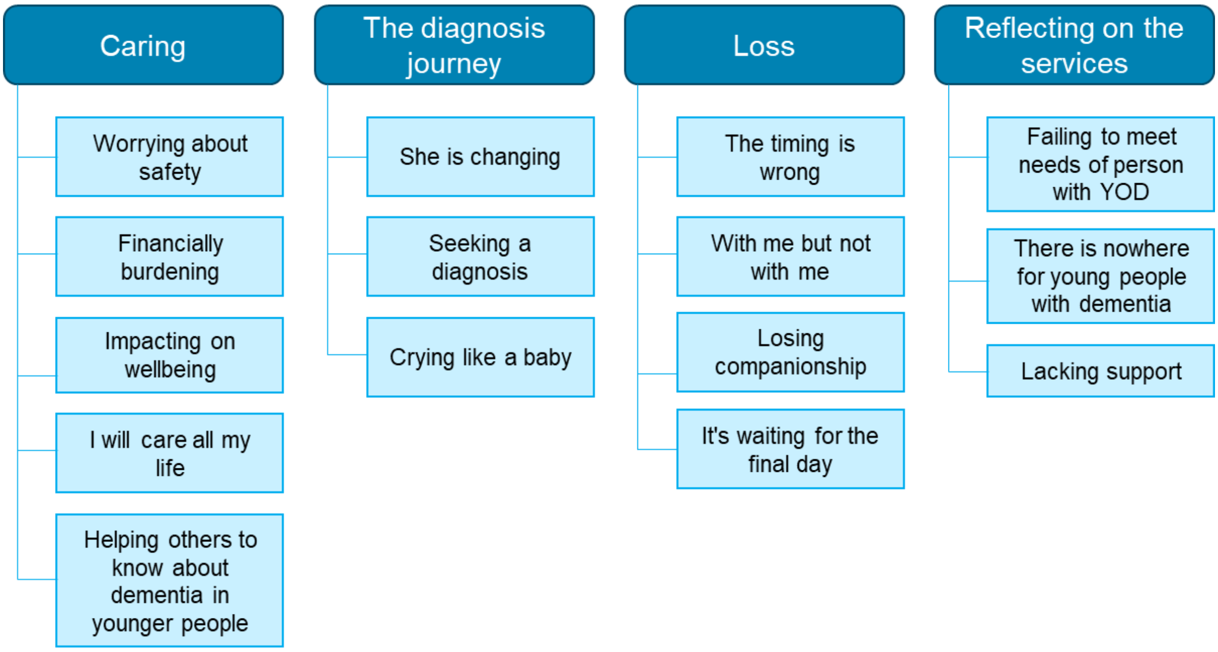
Maxwell's frustrations rested on the fact that Gillian was often admitted to an acute psychiatric ward where incidents of distress happened occasionally. Maxwell said that he would be involved, and he was clear that "*of course in the* *end, there's no good outcome".* He acknowledged that she would die with this disease.

4.6. Thomas's descriptive summary

My last interview was with Thomas, a 63-year-old man who had retired a month before his interview. His wife of 39 years, Susan was the person living with dementia, a diagnosis they received when she was 55 years old. Susan was 59 years old at the time of Thomas' interview. She had been in the current care home for three years. This was the second as the first care home placement broke down leading to a hospital readmission resulting in a move to the current care home.

Thomas was the only participant who had a telephone interview as he did not have access to video calls. He also told me he 'wasn't educated' and wondered if that might impact on the study negatively. I reassured him that his experiences were important, and he was not being judged or 'marked'. I was apprehensive before this interview because I was conscious the interview touched on sensitive issues that might bring memories of sadness and unhappiness. A telephone interview might mean I could miss the non-verbal indicators of distress. This aspect was in the ethics section considering doing no harm and the plan was to signpost anyone whom I would consider to be in distress as a result of the research. Figure 8 presents the PETs and experiential statements identified from Thomas's interview.

Figure 8: Thomas 's PETs and Experiential Statements.



Thomas's descriptive experience and identified themes.

4.6.1 Caring

'Caring' covers *"worrying about safety"*. This developed from the narrative from when Susan was still at home and had continued while in the care homes too. Thomas worried about safety for Susan, himself, and others. Thomas referred to the time that Susan was at home, and he was the sole carer. He said:

> *"I couldn't cope…she could hurt me. I couldn't sleep because she didn't sleep you see, and I was frightened she would hurt herself…She was very difficult you know. At times I could give her a shower but most days I couldn't, she would refuse and get angry."*

He spoke about his assessment of his capabilities as a carer and said:

> *"I can't control her anyway. She is aggressive and gets nasty."*

Reflecting on the challenges the care home faced as they cared for Susan he said:

> *"With COVID now you can't see your wife and you are afraid all the time and not sleep, maybe the phone will ring, she may die. They phone when she falls, when she hits other people, or such things you see and it's not good".*

Regarding ‘*financially burdening’* Thomas explained that he had to work, and partly fund the care home fees saying:

> *They told me to pay £200 for her toiletries when she first went in. So, I have done that, and I don’t mind. But now they have said she has deteriorated, and they have filled in forms so that all her care can be paid for I don’t know if they will want me to continue with the top up. If they say so, that’s ok my wife is using our money and that’s ok. The money will get finished then I don’t know what will happen then, you see*” [he went quiet].

Thomas had paid the top up care home fees for three years and while he was happy to pay for his wife, he was now starting to think about the future when their money runs out.

Thomas was very open about how living with a wife with YOD, even though it was three years since she been physically in their home, was ‘impacting on his wellbeing:

> *“I was stressed, at work my mind was at home. I couldn’t eat, I couldn’t be bothered, I lost weight, I found it hard to get out of bed. We were both crying at times and many times”.*

Thomas expressed his wish which he was aware would not be fulfilled:

> *I want her back home, but I know I can't cope, and I am stressed. I have been off sick from work with stress…*

He explained the impact YOD had on his psychological wellbeing:

> *“In the end, before Christmas last year, I thought I better retire and create some time without too much pressure for myself, I am getting more and more stressed with this all the time. I have talked to the GP before, and they said I need to rest more. Now I have retired I will rest more. Its trauma for me isn’t it, we didn’t expect dementia”.*

“*I will care all my life*” relates to Thomas explaining that he was always ready and involved in caring for his wife, even though she was not physically with him:

> *“They call me all the time especially when she is bad, she has done this and that, my phone is always on at night as well, oh, we need new clothes and that, can you talk to her, can you come in. Yeah, she is bad I go in if they ask and yeah…I will care all my life now”.*

Thomas shared his feelings and explained his involvement in her care, using *“we”* to emphasise he was part of the care home team at the same time expressed his own feelings of helplessness:

> *"Yeah, yeah, we don't know what to do. Why can't I do something for her that is helpful. It's blaming myself, you see, when they call me like that. Heart breaking, heart breaking. If I could stop the bad parts I would, heart breaking, honestly".*

"*Helping others to know more about dementia in younger people*" is a theme which had seen Thomas work with different agencies to support YOD causes. Thomas said:

> *"I have done fundraising events for a few years now, Alzheimer's society and others. I fundraised for the ward Susan was admitted and I do for the care home she is in. I just want other people to know about this horrible disease and what it does, I can say I want to help others. I didn't get help, people must get help, so I fundraise. We also made a video for valentine. You can see that as well and share with others. I just want to help others know. It's all about dementia and you can share it I don't mind. Give as many people as you can if you think they can learn something".*

Thomas wished this work, the YouTube clips he shared with me could make others impacted on by YOD feel better in their journeys in future.

4.6.2 The diagnosis journey

Thomas described 'the diagnosis journey' using statements like, "*she is changing",* "*seeking a diagnosis*", "*crying like a baby*" and "*the timing is wrong".*" *She is changing"* relates to the changes that Thomas witnessed and led him to start the process of seeking a diagnosis*:*

> *"I saw Susan change. Susan's personality changed. There was a nastiness about her that frightened me. If we got into an argument, she would become very nasty, storm out of the house and go missing. This happened more often now too you see what I mean. …she didn't sleep you see…She wasn't that sort of person you know before this, she wasn't a fighting person, she changed like, she is not Susan".*

The changes continued as dementia progressed and that was hard for Thomas:

> *"Now she is bad again, she is deteriorating, they say it is now rapid Alzheimer's. They have told me that, yeah, she is bad again. She doesn't know me… She is painful to look at now, I cry a lot".*

"*Crying like a baby*" was Thomas' description of the devastation he felt when learning of the dementia diagnosis and he still "*cries like a baby*". Thomas said:

> *"I don't know what shocked me most, hearing dementia, my wife has dementia or the first time she was nasty. I guess I was shocked by both, yeah, yeah. I cried like a baby; they couldn't console me. I felt like something hot and heavy had*

> *been suddenly thrown on me and I couldn't move myself. They took me to a side room and that you know, just crying like a baby. They didn't warn me, they threw this on me. I thought of the children. How they would feel with a mum with dementia. I felt sick immediately. What would happen to Susan? I didn't know. I was frightened, I have never been this frightened even now I am frightened by it all…I was just devastated…".*

It seemed that at diagnosis his shock of the diagnosis was not acknowledged by the healthcare team, leaving him and devastated and frightened for Susan, himself and their family.

4.6.3 Loss

The PET of 'loss' encapsulates everything Thomas was trying to cope with as an individual without his wife**.** "*The timing is not right"* arises from the unexpected diagnosis of dementia a condition he had associated with older people since his own mother had it:

> *"They sprung it on me, I said what? I didn't expect dementia. We didn't know what to do except cry together… I said I can't cope. I thought mental illness and she will be treated and come home because people come home with mental illness. I was shocked really, my old mother, then my young wife, how does that make sense. Anyway, I got to carry on, don't I".*

Thomas described the "loss of c*ompanionship",* and being unable to do ordinary daily life activities together:

> *"Oh, I miss her so much you know; she can't speak now. Last year I missed Christmas so much. The other years, I go into the home and have the Christmas dinner with Susan then go to the children later. Well, I feel sad, but it is what it is. I am just on my own now. You just make the best of what you can".*

Thomas explained his devastation related to Susan being unable to recognise him saying "*That's how I lost her; I couldn't cope".*

"*With me but not with me*" explains the fact that Susan was alive, but no longer had capacity to sustain relationships, which she would have otherwise cherished:

> *"The grandchildren… she doesn't know me anyway she wouldn't know she is a granny, would she? You feel very sad and alone. People talk about their wife, and you have nothing to talk about because she is in care and you can't do anything with her except walk and hold her hand, she doesn't know you anyway. We live separately, we are not divorced, are we? All the questions, why? why?".*

Speaking of his understanding of the progression of dementia he explained it as *“It’s waiting for the final day”.* He added that:

> *“She does not speak now, and she is not going to recover. We will not have a good life again will we. The doctor said about resuscitation, and we thought no. She is suffering enough. I will be heartbroken that day, but she will never leave my heart. Its waiting for the final day isn’t it, so I go in and hold her hand and do nice things for her. Maybe she doesn’t know it, you see.”*

Despite the sadness Thomas explained his way of showing affection to Susan:

> *“So, I go in and say let's walk about, and we hold hands, well you can't kiss or cuddle, you see. I miss her very much; she is my wife, you see, but she is now dead in a way. I cry and am bereaved, do you understand?”.*

“*Dead in a way”* is a phrase that Thomas used to describe their lost relationship. Thomas was conscious that Susan was heading toward the end of her life, and he was experiencing anticipatory grief.

4.6.4 Reflecting on the services.

Reflecting on the services Thomas discussed a system that is “*failing to meet needs”,* “*there is nowhere for younger people with dementia*”, and “*lacking support*”.

While on this journey Thomas said:

> *“I also came to know that there is nowhere for younger people with dementia to go to. There are nice homes, but they are for old people. The nice care home Susan went into first, couldn’t cope with her because it was for old people, and she was young. She was too much for them you see”.*

“Failing to meet needs “describes the challenges care home staff faced that were age related:

> *“In the care homes you just see old people with dementia as well, you see. I don’t know if they know their husband or wife, they are not aggressive when I see them. She is young and she gives them more problems than the old ones. The staff in care homes are not used to coping with young people with dementia.”*

About “*lacking support*”, Thomas said he did not receive support specific to YOD, neither had he been signposted to such support. He said, *“I found a group that was for people affected by mental illness that someone told me about*”. This experience led him to think of ways of helping others similarly affected to know more about YOD.

This interview highlighted the emotional struggles he experienced on a daily basis as he tried to lead a life with a wife who did not live in the same house anymore and that there was nothing, he could do to change that. He was powerless.

4.7 Group Level Analysis

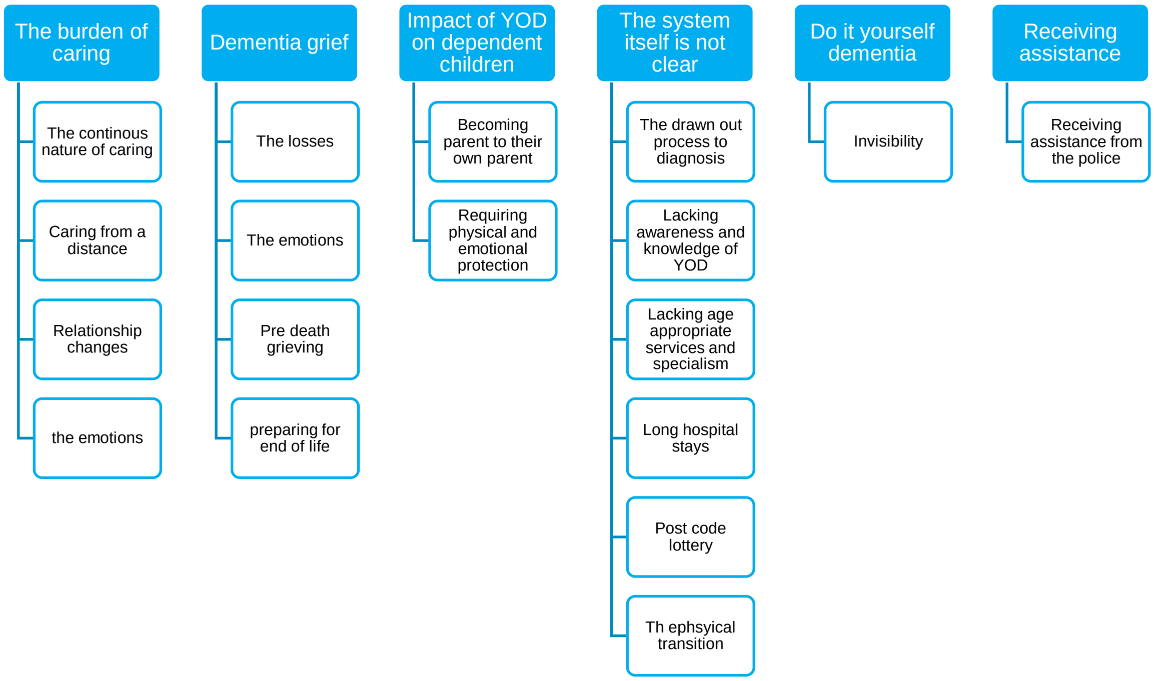
After conducting an in-depth idiographic analysis and identifying personal experiential themes (PETs) for each participant, the next step was to look for patterns/ themes across all five cases to develop group experiential themes (GETs). To create a set of GETs, I worked with the collection of PETs across the cases. I highlighted the common and distinctive aspects of the experience among the participants and searched for patterns of similarity and difference across the PETs, across cases (Smith et al. 2022)-see Table 4.

Table 4: Summary of frequency of PETs across the group.

Superordinate Themes	**Alana**	**Ellen**	**Mary**	**Maxwell**	**Thomas**
The burden of caring	YES	YES	YES	YES	YES
Dementia grief	YES	YES	YES	YES	YES
Impact on dependent children of someone with YOD		YES	YES	YES	YES
The system itself is not clear	YES	YES	YES	YES	YES
Receiving assistance		YES			
Do it yourself dementia			YES		

The shared and unique features of the experiences across the contributing participants became GETs, as shown in Figure 9**.**

Figure 9: Summary of the Group experiential Themes.



4.7.1 The burden of caring

All participants deemed that caring came with unavoidable burdens. The PETs '*the continuous nature of caring*, '*caring from a distance*, '*the changing relationships', 'worrying about safety', 'fearing placement breakdowns*, and *'the emotions'* together summarised 'the burden of caring'.

All participants discussed how caring started before the diagnosis and continued when the person living with dementia was either in hospital or in a care home. Describing how they continued '*caring from a distance'* and *'it doesn't give you rest',* Alana described what she called "*troubleshooting from a distance".* Ellen explained that she made scheduled phone calls to the care home as a way of keep up to date with what was going on with her husband's wellbeing.

Each participant described how caring meant that they were always worrying about the safety of the person with YOD, and of others. Ellen said:

> *"A bit worrying really* [physically aggressive behaviour], *you know…, so a lot of the staff were kind of realising that he could be quite volatile if you do stay in the way. They were quite nervous of him because, of course, he will be throwing chairs about and I think cabled, you know those kinds of things that behaviours that have been there, you know".*

Sadly, this concern for Ellen became even more shocking when a safeguarding incident happened:

> *"He* [Amir] *was constantly in people's rooms, and he wouldn't move, so one of the new carers and he punched him* [Amir]*…Amir wasn't meant to be lashing out with him* [carer] *and he* [carer] *punched Amir in the face".*

Mary explained:

> *"I worry everyday about how he is, is he breaking or hitting someone, am I going to get a phone call, you see what I mean".*

The participants also described how they were always ready and prepared to be called into the home to help with practical care when staff failed to effectively support the person with YOD. Maxwell said:

> "*They were* [care home staff] *somewhat limited by the ability to call me and calm her down because …it would have happened more often if it hadn't been COVID* [sighs, quiet]. *I'd have to accept that; I think we're just going to have to accept that you know".* Thomas said that he had been called in to the care home to calm his wife down *"she is bad I go in if they ask and yeah…".*

A fear of placement breakdown is something all participants had in common. Alana and Mary had not experienced failed placements, yet they talked about what they had heard from others and expressed their fears. Ellen, Maxwell, and Thomas had been through the experience and expressed their fear of a further placement failure. Ellen described her situation on this matter: "*I am on tenterhooks all the time thinking it is going to fail at some point...*".

The changes and interpersonal invisibility were marked in the form of relationships with the person living with YOD for all participants as they transitioned from a partner to a carer. For Ellen and Mary, the relationships with the cared for person's family members changed, leading to communication breakdown and misunderstandings. Ellen also faced conflicts with religion, while Alana and Mary's relationships with friends were impacted as a result of YOD. All these situations resulted in isolation for the participants and their nuclear families. The changes included financial depletion for some, and changes in lifestyles.

Mary and her family changed their lifestyle, moved to a smaller house and she said:

> *"I couldn't financially afford it with him not working or maintain the big house, we were in, so we moved. We had to downsize by about four fifths to a much smaller house, which has been very difficult for us. And so, we moved to the new house and obviously for him, that was big trauma, a whole new surrounding and everything. I've lost quite a lot of friends… It does alienate you…".*

Ellen, Mary, and Thomas discussed the burden of finance though this affected them in different ways. On financial issues Ellen stated, *"…obviously you've got the financial burden".* Ellen said Amir had been in paid work which he had to leave because of YOD and at that time they had financial commitments such as a mortgage, credit cards to pay for, and children in university who were dependent on them for financial support. Mary described how support services such as day hospitals required payments and that affected the financial situation.

Table 5: Quotes expounding the identified GET of the burdens of caring.

	The burdens of caring
Alana	*I feel I'm still troubleshooting from a distance if that makes sense. It's like you can't switch off.*
Ellen	*It gives you no break and you know, no sleep you know, even though he wasn't at home* *You still don't sleep because all you're doing is worrying about him and his care and how he's being cared you know.*
Mary	*I definitely cared for him all these years, I worry everyday about how he is, is he breaking or hitting someone, am I going to get a phone call, you see what I mean. The phone rings and I check if it's the care home. Yeah, its continuous you see, don't you think so, I am at home and thinking all the time. I think its caring, yeah.*
Maxwell	*I worry all the time; she is away, and I still worry. My phone never goes on silent. I have to hear it and act accordingly…* *I worry all the time; she is away, and I still worry* (goes quiet*). My phone never goes on silent. I have to hear it and act accordingly…*
Thomas	*They call me all the time especially when she is bad, she has done this and that, my phone is always on at night as well, oh, we need new clothes and that, can you talk to her can you come in. Yeah, she is bad I go in if they ask and yeah…I will care all my life now.*

4.7.2 Dementia Grief

All participants shared elements of grief and all the losses they experienced as a result of YOD. The commonly shared elements were *losing individuality, losing a companion, losing lifestyle, grieving for the lost capabilities, grieving for the future* and they all described *being prepared for end of life*. With the symptoms of YOD and its progression, their present lives changed, as did their futures. Ellen spoke of "*facing an unwanted future".* All participants expressed that living with someone with a YOD diagnosis meant the whole family lived with YOD. This meant that in whatever they did the person with the YOD diagnosis had to be considered first. Four participants openly described and showed the negative emotions experienced. The participants also talked about the person living with YOD as being," *with me yet not with me"* when describing how the person with YOD could not recognise family or spouse and so not showing the normal interactions as they used to do. This resulted in the identification of this GET.

Table 6: Quotes expounding the GET of the dementia grief.

	Dementia Grief
Alana	*...we lived in a village, it was seven miles out of the town… and we had an upstairs so going upstairs, we lived on the main road as well, so all these things had a bearing on Mike, so I felt it was necessary that we needed to move. So, I put the house on the market….* *…very strange but yes practically, I miss him so much, and I feel this setup here in the bungalow would be so good for him, but I know that it's just not possible, I realised that yeah.* *It's like the grieving process isn't it when somebody goes into a care home. I lost him really; he didn't come back to me.* *…to think, well this is the end here, you know because I know that's what will happen.*
Ellen	*…yes, and the thing is I'm losing my husband, I've been with him for those 36 years, you know and you're going through the grief process yourself, you know. Now you've got a different future from what you expected isn't it, because we all think that we've got this, this plan we can, this can happen isn't it, you know.*

	...you're dealing with the notion that you're dealing with a future you don't want, one is dealing with guilt, because this is something that's happened to submit to something he does not want either...
Mary	*He didn't recognize me, first time he's not recognized me or any photographs that I took of the boys and all he does all day now is march.* *I couldn't believe it* [Looks sad and quieter] *because I really, really, I really thought, even if he didn't particularly recognise me, he'd recognise my voice, my tone sort of thing, but there was nothing, it was almost like I wasn't even talking.* *I think what hit me when I left there was, I got back to the car and I just sort of thought, all those memories just gone, 40 years of memory just gone. It's almost like you're just left with a physical being and nothing in the head,* *There's probably 4 or 5% of Tim left there now, the rest is like a completely different person.* *The dementia it prepares you, it prepares you that there's going to be an end. You obviously don't know when there's going to end and then you soon, not initially I don't think but certainly once you get to a certain stage you realize this is…this is not good, it is only getting…because you see such a big deterioration sort of thing.*
Maxwell	*By the time I told her, she understood that this was a one-way condition…you know Gillian's situation is not… that Gillian's the condition is not going to improve though situation may improve if Gillian moves into may be in a better place…*
Thomas	*We live separate, we are not divorced are we.* *She doesn't know me, but they say in the home she knows you. I am sad she doesn't know me, it's painful you know after 39years.* *I go in and say let's walk about, and we hold hands, well you can't kiss or cuddle you see. I miss her very much; she is my wife you see but she is now dead in a way. I cry and bereave, do you understand? She is with me but not with me you know what I mean…* *Oh, I miss her so much you know; she can't speak now. Last year I missed Christmas so much. The other years, I go into the home and have the Christmas dinner with Susan then go to the children later…*

4.7.3 Impact of YOD on dependent children

Ellen, Mary, Maxwell, and Thomas talked about their children and how YOD impacted on their children's lives. The PETs of becoming a carer, becoming a parent to your own parent, and requiring protection are summarised under this GET. The children here are of different age groups with Mary's children all minors below the ages of 15 years when the YOD symptoms began. The common features were that all children were involved in caring for their parent with YOD, they supported the parent who became the main carer, their own lives and personal plans changed. An example is that Ellen's children had to move back home from the towns they had moved to in order to support both their parents.

Table 7: Quotes expounding the GET of Impact of YOD on dependent children.

	YOD impact on dependent children
Ellen	*The children need that dad more, you know, they need that guidance more and you know, because they're growing as well isn't it, that's becoming adults, but obviously they are then becoming the parent to their father, which is not really the way it should be is it.* *The decisions are made with all of us together.* *The children and myself.* *The children who worked in* [redacted] *and then they moved back, the boys. We've got three children and they would take him to the mosque and doing his prayers with him, you know. Taking him to play football and cricket, you know those kinds of things that he loved to do.*
Mary	*my biggest challenges was because I had the three boys at home and so, dealing with the dementia with them living, you know 12,14, doing GCSE and trying to have friends around* *we've got used to dealing with all these things which any other family if they'd have had one of them would have been in complete meltdown, so you can imagine the psychological impact on my sons over the years, all these things that they've dealt with.* *if my boys had something different on schedule, you always think if he was going to attack the other people, do you know what I mean. It just wasn't worth the risk of everything. So, our life is very low key, it was very…, just us in*

	that the boys have got mixed feelings about him because they feel, it's awful (touches her mouth*) to say, they feel he's ruined their lives, it's ruined… the dementia has ruined their lives, plus trying to disassociate him from the behaviours that he was showing towards them is hard to do, do you see what I mean? So, to me…*
Maxwell	*She's the one who's more likely to remind me that the situation is… you know Gillian's situation is not… that Gillian's the condition is not going to improve.* *She's been a great support to me, actually, I think I would find it much more difficult; I didn't have her to clean up after you know.*
Thomas	*I thought of the children. How they would feel with a mum with dementia.* *They stopped crying quickly and asked what we need to do. We didn't know what to do except cry together. I said I can't cope. The children said we will help you do whatever you think is necessary.* *The grandchildren… she doesn't know me anyway she wouldn't know she is a granny, would she?*

4.7.4. *"The system itself is not clear".*

Participants described their encounters with the health and social care professionals which they simply called 'the system'. From the participants' narratives of issues, they faced as they navigated the YOD trajectory, PETs were identified pre and post diagnosis as *the diagnosis journey, lacking age-appropriate services and specialism, the post code lottery, delaying discharges, the support, medicating people living with dementia, and lacking holistic care.* There were similar issues on the diagnosis journey in which the confirmation came later than families expected. Delays in diagnosis were partly because symptoms were mistaken for other conditions. Mike, Amir, Gillian, and Susan were all diagnosed with depression when they first approached their GPs. The delays were also marked with several visits and referrals to see different professionals. The referral times meant the person living with YOD was deteriorating, the family had no guidance or support on how best to care for the person which increased the risk to safety. Post diagnosis challenges included insufficient age-appropriate services including memory clinics, support groups, hospital wards and most importantly finding the care homes which would be most suited to their needs moving forwards. Specialism in YOD is reported to be lacking and an example is that of Amir whose family were expected to provide hands on care on a daily basis both in hospital and then in the care homes too. Ellen said:

> "*These are specialists* [care homes], *so surely, they should know all these things* [referring to terms appropriate to use when supporting someone with dementia and working with behaviours such as aggression] *So, they kept saying oh yeah, we're doing more training with ourselves, we are doing this and that…*".

Ellen also spoke about trying to identify suitable homes on CQC and Care Homes websites:

> "*Even CQC website …if they have specialist in the name and what you need is specialists that can deal with challenging and complex issues, and so there needs to be another category within there that you can actually find these homes and get them, you know, the names of them and because I wouldn't say that the care home he was in the first time, is a complex needs actually specialist care home".*

Maxwell shared his experience:

> *"She* [Maxwell's daughter] *will not entertain anywhere without having referred to a CQC websites. The challenge is ..., every care home has put their information on the database driven by their marketing department, and they said, you know …, we're specialists in everything. So, it's very difficult… I spent a lot of time on the Internet, looking for something that jumped out as…...things I look for, one was somewhere that seem to have a specialist focus on young dementia sufferers".*

Maxwell further asked:*" If you said this specialist care home, okay, maybe it's just me but I… What does it need?"* [sighed, went quiet].

All participants spoke of how they felt they were not listened to, or not involved adequately in the care of their loved ones even in some of the decision making both in hospital and care homes.

Table 8: Quotes expounding the identified GET of "The system itself is not clear".

	"The system itself is not clear".
Alana	*…but what happened over that time he was tried* [medication], *I say tried, they, it was I suppose an experiment in the way I found. I agreed to it, but they tried four different antipsychotics, and, in the*

	end, I said no more because, as time went on, and he had the responses to those undesired antipsychotics were bad at one point… *…to get to that point, whereby the one drug that was suitable for him, you know it was like 4 months later, I suppose,* *and I said, you know I think we need to stop here.* *…it was a long journey both physically and mentally and they were very…, there were lots of side effects to the drugs…* Delaying discharge: *...but I suppose the time it took that he was fit for discharge and then he couldn't go anywhere* *…8 months so that was mmm April, May, June.9 months, 9 months, but he was fit for discharge earlier than that. Hmm in July. Probably five months in but we had to wait for funding and all the logistics of it all, you know, bed availability, that bed availability and availability.* About communication: *Several shocks along the way. A lot of things not clearly explained from the beginning you know.*
Ellen	*This whole system is quite a shock to get your head around and the diagnosis and the way the health service works.* *I think, I think there's a lot of arrogance in the medical professionals. I think they've lip service to, about listening to relatives and don't feel. I think they go in thinking really, well you don't understand the system. Actually, you have to be quite articulate in putting across your points and you've got to be less emotional …so you've got to step back as an individual and be okay what, what and what do I need to say here, what are your words. I need to get through to you about what you need to do about his care, how you need his path to look you know and then yes, they do listen.* *I'm so frustrated with the entire system you know. So, actually for it to be working is quite a surprise but I am on tenterhooks all the time thinking it is going to fail at some point, and if it fails and they're telling me is going to another home or too far away, that will be the time I'll make decisions, we can come back home.* *…and they've rewritten his care plan and have not shared a copy of that at all with me and I only found out that…quite a few months later* *…they were not listening to what we'd actually told them about him and that's what I mean about arrogance side of things, you know. It's like we are the experts*

Mary	*…a lot of issues in the way the health system works and its complicated and not clear. More issues, yeah but we want something now. Yeah, I know there's no medication, yes, but what bothers me what's with the system is not clear you know, it's not you know. Someone up there seem to believe that everybody with dementia and the family should fit in with everybody else with dementia you see what I mean.* *my sons are happy to talk to you, and in the early days they used to go to social services meetings and talk and in the end, they said we're not going mum, it's a waste of our time because none of them are listening to what we're saying, none of them* *then you go for all these oh well it's this is that not and nothing changed ever so you think there's no point we're just wasting our time nobody's listening*
Maxwell	*It is wearying and …now in truth…in truth I could opt out of it because I don't have lasting power of attorney…* *I think the process is hard work, if you want to stay involved...* *It wouldn't… it wouldn't be in my nature to step back and say okay you guys look after Gillian; you know what you're doing.* *if Gillian was to transfer to a sort of home she would, her care would be under the ownership of a community mental health team and …they are resource limited and while they might want to be able to do better, there's no guarantee they would be able to do better* *…my feeling is that adult services have let Gillian down.* *…yeah, and they can stay very long. Actually, you know, Gillian has been in hospital for 10 months now, in a ward, that's expensive. Is it expensive, yes, do a cost benefit analysis of that you know, if you say, well, if she was in an appropriate care home, she wouldn't spend the last 5 months in hospital.*
Thomas	*Very upsetting* [moves from hospital to a care home and then hospital and another care home], *but…. what…... you have to do what's right for your wife.* *The staff in care homes are not used to coping with young people with dementia.*

4.7.5 Receiving assistance

All the participants described experiences of receiving support from the police and the person with dementia requiring assistance with activities of daily living such as personal care or shower, pad changes, support with food and fluid intake.

However, interaction with the police at their home was traumatic and different from other participants and professionals both in hospital and care homes failed to meet basic needs of daily living and seemed to accept that as a normal for him. This was very different from what she had expected.

4.7.5.1 Receiving police assistance

The intervention was aimed to provide support when Amir needed to return to hospital following the breakdown of a trial at home. Ellen stated that Amir was: *“a very sick patient, he's not a criminal, he is a patient”.* Ellen explained that:

> *“Six police officers came in. He was on the bed screaming and I’ve never heard screaming like it honestly, he was hysterical, they put handcuffs on him, and they restrained him, it was just hideous, seriously hideous to watch and to hear you know because he was so distressed… All six of them dragged him in that police van”*.

This experience was difficult for Ellen to share. She was visibly emotional, looked angry and shook her head as she continued to talk and express: “*That isn't right at all is it you know. It's appalling”.*

4.7.5.2 Receiving assistance with fundamental activities of daily living.

The complexity in Ellen’s experience rested in the fact that in hospital and the care home there was a constant failure to meet Amir’s fundamental care needs such as supporting him with food and fluid intake, toilet use and personal care to the extent that Ellen was expected to provide hands on care on a daily basis:

> “*I had to come out of work early to make sure I can fit the hospital to feed him lunch, get him washed and changed...”*

This practice continued in the care home. Ellen pointed out that:

> “*If they have specialist in the name* [institutions] *and then what you need is specialists that can deal with challenging and complex issues”.*

Despite Amir being in a specialist dementia care home, Ellen seemed to feel that she had to meet his fundamental needs in the absence of the care home doing that, or indeed meeting his specialist needs either.

Amir’s situation became even more complicated with COVID 19 restrictions which saw care homes closed to any visitors. Ellen believed that the care in the home broke down because staff could not give him the assistance her required.

4.8 Summary.

The findings reported in this chapter highlighted the various struggles the participants and families were going through daily. For all participants it appeared that burdens of caring had started from the time the participants saw changes in the person with YOD and continued even though the person with YOD was no longer in the same house.

Participants explained having a range of emotions mostly negative and these are similar to those felt when one is grieving. It would seem that all participants experienced pre-death grief. Earlier in the literature review pre-death grief in dementia care was acknowledged to be real and more complicated than in other chronic conditions. The grief was termed dementia grief.

Impact of YOD on children was experienced in some similar ways however, for Mary this seemed to be more severe issue because of the children being minors and that Tim presented with behaviours that could cause harm to others and themselves. It seemed that all the children cared for the parent with YOD and became a support for the parent without YOD.

Reflecting on the system, the participants seemed to feel that support was provided in response to events or incidences and not offered proactively. All participants expressed how they believed they would have benefited from being allocated a named professional who would be their first contact when they needed any support.

It would seem like participants had to each identify ways of coping with their situation. All participants verbalised the need to raise awareness of YOD, the difficulties in caring, and the support needed when one has YOD. Ellen, Mary, and Maxwell had written to senior people in health, social care and politicians in their local areas such as councillors and members of parliament, with Mary going further to contacting the then Prime minister and Minister of Health.

Despite that the spouse with YOD were no longer living with them in their homes, YOD still had a major impact on how the participants lived their lives.

Some unexpected or divergent themes were identified too from Mary and Ellen's narratives. Mary brought about the idea of Do it yourself (DIY) dementia and Ellen described what she called harrowing experiences while receiving support from the police.

The findings will be discussed in more detail using a theoretical framework in Chapter 5. The Meleis et al. (2000) is the framework of choice, and this is explained below.

4.9 Theoretical Framework

In the very early stages of the ethics application, I attended a session on philosophical underpinnings facilitated by the Doctoral Academy. The explanation of what 'philosophical underpinning' was, and how it would be useful, were vague and confusing to me. This is most likely because I was unable to relate to the examples provided in the context of my own research. At a progress meeting I presented the question of what theoretical frameworks are to my supervisors and in brief, they explained theoretical frameworks and confirmed that I was expected to utilise one.

Early in the thesis journey, I therefore was aware that I would need to employ a transition framework (TF) for this study. The specific TF selected, Meleis et al. (2000), was the outcome of reading and discussion with my supervisory team. It was confirmed after the data analysis. Grant and Osanloo (2016) suggested that in qualitative studies the theoretical framework frequently materialises during data analysis. Qualitative studies may start with a formal, or possibly less structured, theoretical framework and this can help in preventing the researcher from applying assumptions to the data (Grant and Osanloo 2016). By integrating

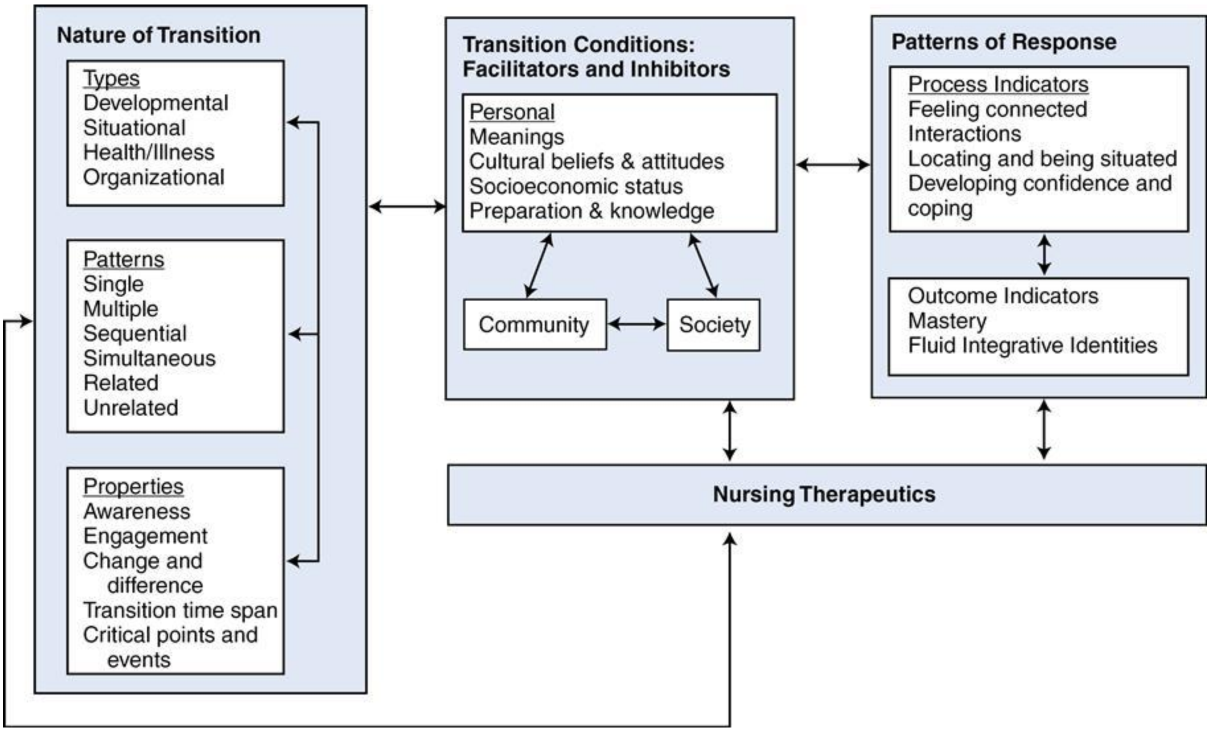
Meleis Transitional framework helped to gain deeper understanding of how transitions are experienced and interpreted with social and cultural contexts, and this understanding can inform more effective support strategies.

4.9.1 Meleis’ Transition theory

For this study I searched for a theoretical framework (TF) which originates in nursing, that can be applied to mental health care, and more specifically, for people with long-term illnesses such as YOD. Additionally, the TF had to relate to families undergoing transition in various ways. This led me to the Theory of Transitions by Meleis et al. (2000). Meleis et al. (2000) recognises that people can go through several life and illness transitions that result in distinctive patterns of responses. These are categorised as developmental, organisational, situational, and health-illness transitions (Meleis 2000). These patterns might occur concurrently, sequentially, singly, in multiples, or they can be connected or unrelated. Transitions can occur at any time in life and can affect our environments, relationships, and our health.

The MTF summarises the types, patterns, and characteristics of a transition, in addition to defining the circumstances and nursing interventions that can help or hinder the process of obtaining healthy transitions. The major claim of transitions theory is that people are more susceptible to health risks during transitions and nursing interventions can help with ensuring a positive transition. The Meleis Transitional Framework (MTF) is often illustrated in diagram form and there are various adaptations of this available, including the one shown below in Figure 10.

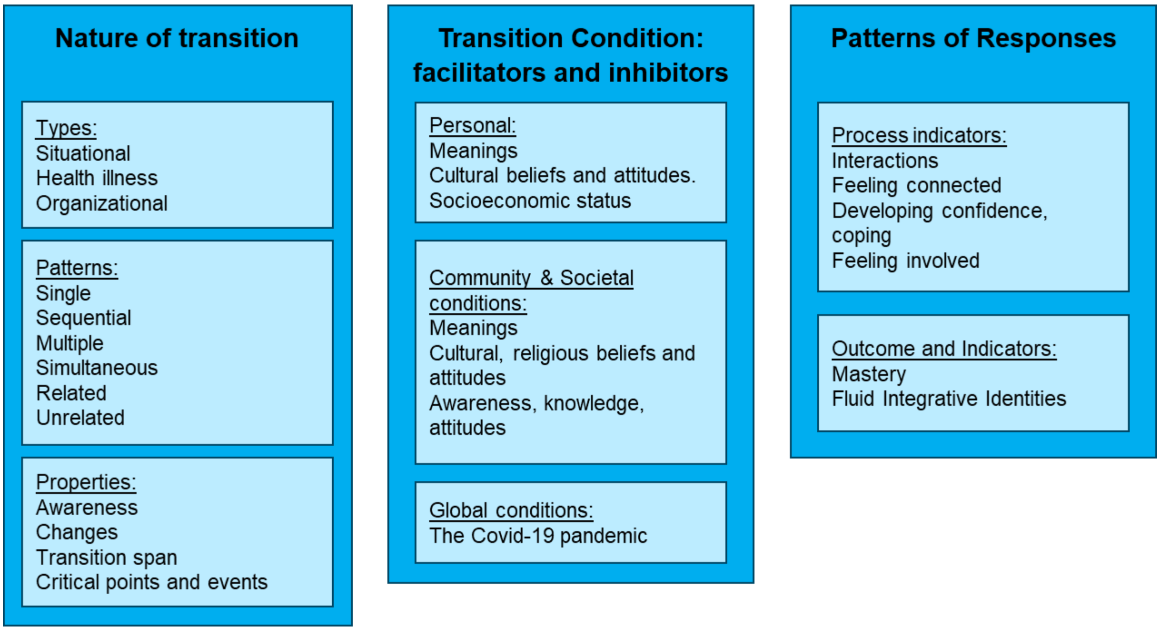
Figure 10: Transitions Framework



From Meleis et al. 2000.

This study uses an adapted version of Meleis et al.’s (2002) transitions framework, as shown in Figure 11**.**

Figure 11: An adaptation of Meleis' Framework for this study.



Transitions in health and sickness include the diagnosis, healing process, leaving hospital, (Meleis and Frankenstein 1994). The focus of health-disease transitions such as YOD is on how people and families deal with various illness contexts as well as changes in care levels as an illness progresses. Organisational transitions are described as shifting external circumstances that have an impact on both service users and employees' lives (Schumacher and Meleis 1994). It is especially important to plan for and anticipate what will happen during a transition in order to develop management strategies (Meleis et al. 2000). Lack of resources or assistance can hinder healthy transitions and lengthen the time needed for role adjustment. Nursing professionals need to have a full awareness of the transition process in order to implement therapeutic interventions "aimed at promoting healthy responses to transition" (Meleis et al. 2000 p. 27).

According to Meleis (2011), analysis of a theory's structural and functional elements is necessary before utilising it. The theory's presumptions, concepts, and assertions make up its structural elements. Focus, client, nursing, health, nurse-client interactions, environmental, nursing challenges, and interventions are just a few examples of functional components which make MTF a fit for this study. These participants had no warning and were caught unprepared for the eventuality of YOD. MTF is appropriate for this study because the framework concentrates on information seeking and is particularly useful as a framework for information giving. The MTF's comprehensive nature has stimulated a sizable body of research on the nature and features of transitions, and the theory has been strengthened with formal information behaviour principles (Willson 2019). This framework has consideration for the individual and the way in which, change and transition affects them. Meleis et al. (2000)'s MTF offers ways to reduce anxiety, and the effects triggered by change and transition on the individual thus it provides a humanistic component, which sits well within the principles of this study. The notion of transition in YOD care is complex and multidimensional with important aspects such as awareness, engagement, change and difference, time span, critical points, and events (Meleis et al. 2000). Support and care are needed throughout the transition process and not only at the onset or at any specific time.

Meleis' theory is adaptable and flexible. It offered a lens through which to view the challenging meanings that existed in the patterns that appeared from data analysis as well as to understand the psychological and social transitions. The development of the transition theory came from clinical practice, and it is supported by research data. It offers a framework for use in practice, research, and theory development. MTF will be used to explain and contextualise the findings within the wider research community in Chapter 5.

Chapter 5: Discussion

5.1 Introduction

In this chapter, I aim to present and discuss the main findings from this investigation and review these in relation to existing literature. I adopted an IPA methodology to understand the meanings individuals attached to their experiences. The findings for each of the personal experiences, statements, claims, concerns, and understandings of each participant, presented as PETs, were identified. These were further examined for similarities to identify GETs, and differences were acknowledged as required by IPA (Smith et al. 2022). The overarching PETs and GETs are summarised in Figure 9.

An adapted version of Meleis et al.'s (2000) Transition Framework (MTF) is used as a lens to make sense of the participants' experiences and findings presented in Chapter 4.

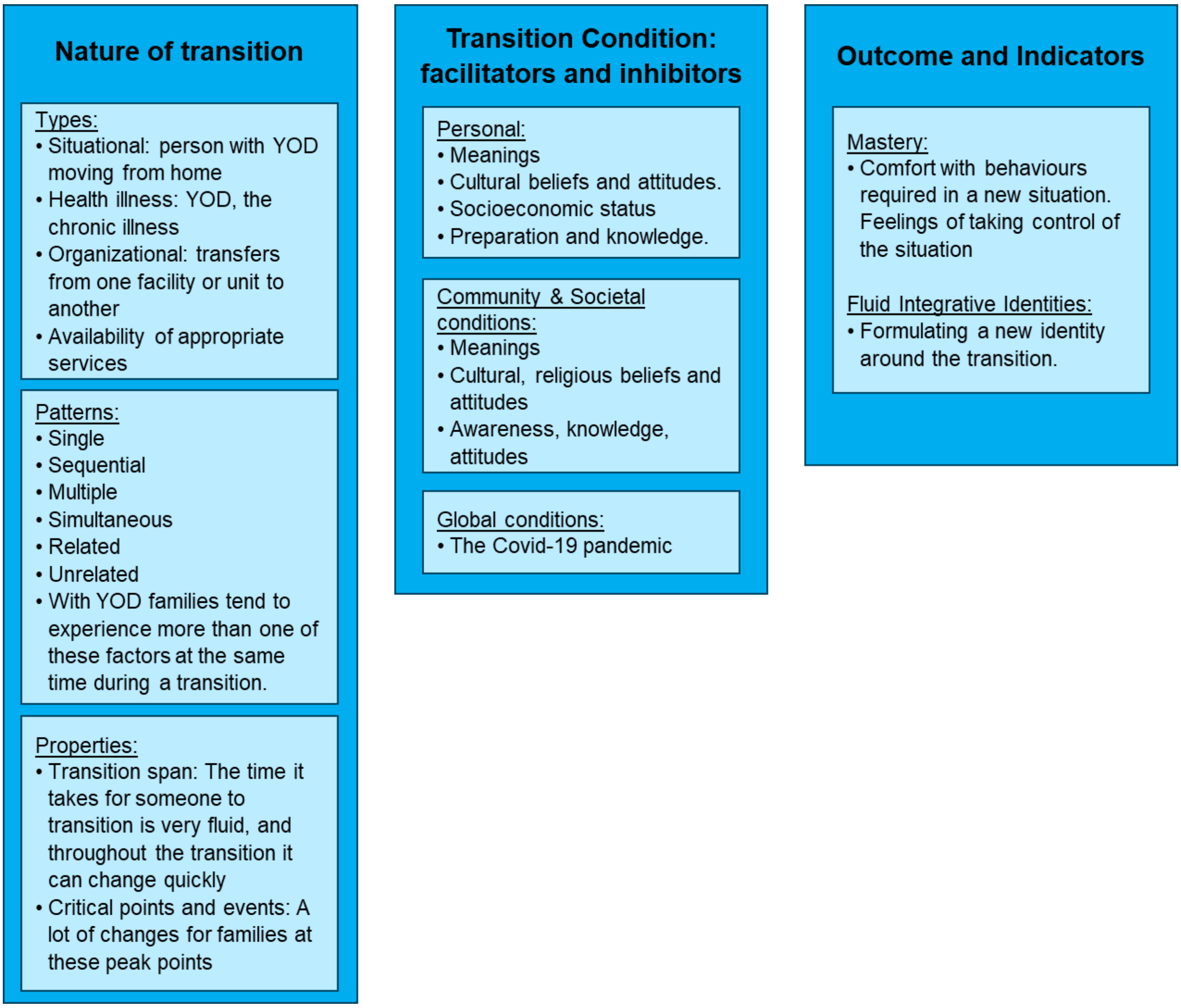
This study sought to better understand the *experiences of wives and husbands of the person with YOD of the transition from a hospital to a care home.*

All participants experienced burdens of caring in different ways at every stage on the trajectory which resulted in various emotions that were mainly negative feelings. A lot of the emotions were related to grief in response to the several losses encountered. These were said to have been made worse by the fact that the health, social care systems and third-party sectors are not clear to follow and makes support which is scarce even more inaccessible. YOD was reported to have had an impact on dependent children and children adopted caring roles irrespective of age. Two participants, Mary and Ellen reported experiences that were very different from the rest. These will be discussed as divergent themes.

5.2 Meleis' framework and transition from hospital to a care home.

All participants described the transitions that they were experiencing in the context of their spouses' YOD. The MTF and the methodological 'match' with IPA has already been identified. MTF was designed to better understand transitions in diverse situations, in health and illnesses, in healthcare settings and other organisations (Meleis et al. 2000). The key concepts of the MTF of value to my study are the nature of transition; transition conditions: facilitators and barriers and outcomes and indicators. These are presented in the adapted version of the MTF in Figure 12.

Figure 12. Adapted version of MTF applied to PETs and GETs.



Nature of transition

Types:
- Situational: person with YOD moving from home
- Health illness: YOD, the chronic illness
- Organizational: transfers from one facility or unit to another
- Availability of appropriate services

Patterns:
- Single
- Sequential
- Multiple
- Simultaneous
- Related
- Unrelated
- With YOD families tend to experience more than one of these factors at the same time during a transition.

Properties:
- Transition span: The time it takes for someone to transition is very fluid, and throughout the transition it can change quickly
- Critical points and events: A lot of changes for families at these peak points

Transition Condition: facilitators and inhibitors

Personal:
- Meanings
- Cultural beliefs and attitudes.
- Socioeconomic status
- Preparation and knowledge.

Community & Societal conditions:
- Meanings
- Cultural, religious beliefs and attitudes
- Awareness, knowledge, attitudes

Global conditions:
- The Covid-19 pandemic

Outcome and Indicators

Mastery:
- Comfort with behaviours required in a new situation. Feelings of taking control of the situation

Fluid Integrative Identities:
- Formulating a new identity around the transition.

Chick and Meleis (1986) and Meleis et al. (2000) described transition as the passage from one life phase, condition, or status to another. Meleis’ theory of transitions proposed that assisting people to manage life transitions is a key function of professionals (Meleis et al. 2000). MTF proposes that change is a trigger for transitions.

In this research, it is possible that in the first instance, YOD is the independent variable and the transition, the dependent variable. This means transition refers to both the process and the outcome of complex person-environment interactions. The GETs I will take forward for further discussion of findings are the burdens of caring; dementia grief; YOD impact on dependent children; and the system itself is not clear. The GETs will be discussed in relation to the content of the MTF and vice versa. However, this does not necessarily mean the MTF will be presented in the same order (Nature of transition, Transition Condition: facilitators and inhibitors, Patterns of Responses and Outcome and Indicators) within the GETs. This is because, in keeping with a non-linear approach to transitions in YOD, some PETs have the potential to sit within more than one section of the MTF. This signifies and communicates the labour related to the data analysis as well as and to understanding the psycho-social transitions.

Transitions are consistently related to change and development (Meleis et al. 2000). For this study, change and development were important. Participants experienced multiple changes and developed in different ways in response to these changes. For example, all participants developed new skills as they tried to manage their spouses' distress, behavioural and psychological symptoms of dementia (BPSDs). The people with YOD and their families had to accommodate changing care needs along the disease trajectory (Bakker et al. 2013). The nature of transitions in YOD, and the BPSDs, led to moves into institutional care. Often this was via hospital admissions and subsequent moves to a care home. In Chapter 4, families' changing life plans and the participants' narratives around their changing life plans, indicated that transitions involved the person with YOD and all those around them.

The patterns of transition experienced by participants in my study are non-linear. Therefore, multiple types of support for the families are required. The people with YOD and their families all experienced various changes and losses throughout the dementia trajectory. Each participant described, in detail, the impact that living with a person living with YOD, a chronic health illness had on them and their families which is similar to what was stated by Meleis et al. (2000). The impact was in various ways and at different stages on the YOD trajectory.

Primarily, behaviour change in those with YOD prompted the search for an explanation. Ultimately, this led to a diagnosis of YOD. The transitional span was described as protracted by all participants. This lengthy journey to diagnosis in itself caused various issues. These finding echoes Bakker et al. (2013)'s findings. The time from the onset of symptoms to care home placement was identified as being twice as long as compared with people who have to late onset dementia. This equates to approximately nine years for YOD compared to four years for late onset dementia (Bakker et al. 2013). This finding highlights that people with YOD, and their families need continuous professional support, not just at particular times during the trajectory. Support should be offered to all those who are impacted by YOD, for as Mary articulated, *“when a person receives a YOD diagnosis, the whole family lives with YOD”*. Support is required during several critical points across the YOD trajectory including periods of anticipation of events, for example, waiting for a diagnosis; waiting for a hospital admission; hospital discharge; waiting for a care home placement and as people approach the very end of their lives as well as post death (Meleis et al. 2000).

Simultaneously, critical points in terms of changes in the person with YOD’s capabilities further complicates transition. Meleis et al. (2000) recognised the need for professionals to facilitate transition because often they are the primary carers of patients and their families who are undergoing transitions. The diversity of critical points and events encountered throughout the YOD trajectory calls for professionals from different backgrounds supporting these families to understand multiple types of transitions that YOD brings to person and their wider families.

Meleis et al. (2002) described transitions in health conditions as being comprised of facilitators and inhibitors. Personal, community and societal conditions, as well as global conditions, can have an impact on how individuals' experience transitions, be it negative or positive. The interviews were carried out in the global COVID-19 pandemic which will be discussed in section 5.3. COVID-19 impacted on the global, community, individual, and societal conditions which were not favourable for those with YOD and their families. The narratives in this study rich insight into the participants’ feelings and several emotions they talked about in a period complicated by COVID-19 experiences.

5.3 The global SARS-CoV-2 pandemic (COVID-19) and institutional care in UK.

Meleis et al. (2000) considered that global situations can have an impact on individual or groups of people. Thus, the global conditions when I conducted my study (Melies et al. 2000) at the time of the interviews were unfavourable and threatening to society, particularly for people residing in care homes, in hospitals, and in other institutions. Mortality rates in UK care homes also increased during the pandemic.

In UK the waves of the COVID-19 pandemic have been defined as:

- first wave: 14 March to 11 September 2020,
- second wave: 12 September 2020 to 11 June 2021 and
- third wave: 12 June 2021 to 21 January 2022 (Office of National Statistics 2022).

Prior to the pandemic, people aged 65 years or older living in care homes in England had approximately ten times higher mortality compared to those living in private homes. However, in the first wave of the pandemic this difference increased substantially, peaking at an 18-fold difference (Schultze et al. 2022).

Total deaths of care home residents in England and Wales increased by 16.5% between the first and second waves of the pandemic (85,305 and 99,380 deaths respectively) and decreased by 23.9% between the second and third waves (75,664 deaths). In the first wave of the pandemic alone there were more deaths of care home residents compared with the five-year average (26,035 and 1,046 excess deaths for England and Wales respectively). Dementia and Alzheimer’s disease were the leading causes of death across all pandemic waves in both England and Wales. By the end of the first wave in England and Wales, it has been estimated that almost a third of all deaths occurring among care home residents in the pandemic had been due to COVID-19. These COVID-19 deaths of care home residents accounted for approximately 40% of all COVID-19 deaths in England and Wales (Hodgson 2021; ONS 2022). All participants in this study had their spouses in institutions, four in care homes and one in hospital at the time these statistics critical time. During that time the media openly broadcasted these happenings too. The facts about COVID-19 and the impact this had on care homes could have had an impact on the feelings the participants went through during that period.

5.4 The Burdens of caring

Meleis et al. (2000) proposed that transition may involve more than one person and is embedded in context. This is echoed in research that has shown that the person with YOD and the family carer's variables can have an impact on the other person, and either one's unmet needs can lead to person with YOD's being moved to an institution (Yaffe et al. 2002; Schur & Whitlatch 2003; Caron et al. 2006; Larger and Slinger 2013). It is therefore vital that professionals recognise that it is important to recognise and assess how YOD impacts the family as a whole, and not just the person who has the diagnosis.

One question asked the participants at the interview was: *Do you consider yourself a carer*? In asking this question my aim was to have an idea of what participants thought of their role and identity during the YOD trajectory till the stage they were at. While all participants confirmed that they were aware that they were now carers, for Alana the question seemed to confirm that she was now a carer. Alana did not give a straight answer immediately. Instead, her response was to become quiet, think and then explain. Again, she went silent, looked down, apologised, and continued to say "*yes*" and give her reasons for her response.

Ellen acknowledged that she was a carer. However, she also conveyed that she would prefer to be called Amir's wife. Ellen talked about the many times she was asked if she was Amir's carer and not who she was to him, nor if she was Amir's wife. Ellen said this irritated her because professionals assumed based on Amir and her differences in ethnicity and looks. This led to discussion about the burdens of caring. Family members in this study, irrespective of age, had acquired new roles, become carers of and advocates for the person with YOD, and in the process had acquired new knowledge and skills. They had altered their own behaviours, and therefore changed the definition of self in the new social context (Meleis et al. 2000). The participants and families were finding new identities e.g. from wife to a carer as stated by Ellen and Mary, and for the children Ellen said, from being children to being parents of their parent with YOD and the families continued to try and live a 'normal' life.

In this study the hospital admissions and the decision to continue caring at home or in a care home was influenced by many factors related to both the person with YOD, the participants or family. These findings resonated with Yaffe et al. (2002); Bur et al. (2006), and Caron et al. (2006). In Thomas's case, he was in work. He said of receiving the diagnosis and making the decision that placement was the best option that he was not expecting a diagnosis of YOD. Thomas had thought all along that Susan had a mental illness that would be treated, and he gave the impression that he would have considered a discharge come back home if that had been the diagnosis. Thomas said he was frightened that Susan could hurt him or herself because of the BPSDs and used the term," vile" to describe the behaviours. Thomas perceived his own ability to and competence in provide care for Susan as inadequate, as was identified by Caron et al. (2006) and Bakker et al. (2013)'s studies. He made the decision based on the evaluation of the experiences he had of caring before the diagnosis.

Ellen explained that she was desperate to leave her job and be with Amir at home. However, on top of the BPSDs she also explained the financial dilemma, she had to work. She now had the financial obligation she and Amir had initiated together such as the mortgage, and their three children were still dependents. Ellen discussed that Amir had left work without a pension because of YOD. This finding echoes Bakker et al.'s (2023) who found that YOD caregivers are usually faced with the double burden of providing care while performing other roles, such as parenting, and working.

Alana on the other hand had retired from work so believed she could live with Mike at home with support from paid carers. She had been persuaded by professionals and family to realise the complexity of the needs and support required for home care. Though Alana understood that Mike's care needs were very high to be effectively supported at home and accepted that a care home would provide the needed care the thought that Mike would never come back home was devastating for her.

The decisions for placement for Ellen, Alana, and Thomas echo Bur et al.'s (2006) findings that caregivers' reasons have valid underpinnings for institutionalisation of someone with dementia. It is important for health and social care professionals to understand these experiences and plan appropriate support for families. To be able to address the issue of caregiving strain and to gain a deeper understanding of the specific needs and challenges the families face.

5.4.1 The continuous nature of caring

The findings revealed that YOD onset was subtle, incomprehensible, not easy to understand, they were unclear and were not immediately obvious. Carter et al. (2022) reported symptoms of YOD as complex because of unusual presentations. In this regard Alana summarised by saying she 'could not put her finger on what was wrong' though she could tell something was not right. On a similar context participant in Johannessen et al. (2017) 's study described what they called 'sneaking signs' when explaining the vagueness of the early symptoms. In all cases, the person with YOD lacked insight. As such participants had assumed the role of caring before they quite realised that they were doing it. Participants in this study did not always consider themselves as carers. Yet at the same time caring had gone on for many years and participants explained the caring continuum as stretching from caring about the person to caring for the person. Bakker et al. (2013) identified that families of people with YOD had longer periods of caring as compared with late onset dementia.

These long periods of caring meant participants in this study witnessed the person with YOD deteriorating cognitively and they dealt with BPSDs. For Alana, Ellen, Mary, and Maxwell this started while the person with YOD was still in paid employment. Mike's work involved maintenance of medical equipment in a hospital. Alana became concerned and fearful about Mike's work because an error on his part could have fatal consequences. She took it upon herself to try to alert his teammates and workplace that Mike might need support. Eventually Mike left the job on medical grounds.

Tim chose not to disclose his diagnosis to Mary, or family and the GP would not reveal this to her either. This situation shows that the process of disclosing a diagnosis of YOD is complex and brings about ethical dilemmas concerned with autonomy for the person with YOD who in this case is Tim. In contrast to Mary's case, Merl et al. (2022) found that most clinicians disclosed the diagnosis of dementia to the carer or family member, and not the person with dementia. This study discussed contemporary approaches to balancing truth with the provision of hope during the disclosure of a dementia diagnosis. The ethical significance of these practices was discussed as they relate to the person, the carer and the clinician at the point of diagnosis and beyond. Other studies that had people with dementia and carers as participants reported that both participant groups agreed that they all preferred to be told of a dementia diagnosis rather than have it withheld (Pinner and Bouman 2003; Mastwyk et al. 2016). Though Mary understood the importance of patient confidentiality in ‘normal everyday life’, she also looked disgruntled [rubbing her face, looking angry] and thought that someone close to the person with a diagnosis should be told *“…because it has a massive impact on them, and it can delay any treatment.”* Non-disclosure of the diagnosis removed the opportunity for Mary and the family to adjust to the diagnosis and be involved in Tim’s care, and treatment decisions until later. This family had a very complicated relationship with Tim and partly as a result of not knowing his diagnosis they had no support for over a year. That same reason might also have been part of the reason for Mary’s negative experiences and relationships with professionals.

Mary revealed her frustrations with the way professionals had attended to the family. Mary used the metaphor, “*we were screaming for help*” referring to living with Tim’s behaviours, and professionals did not help. As she explained this Mary sighed and closed her eyes, she looked sad. She recounted times that Tim would not let professionals into the house, he got distressed and at times professionals had said Tim had capacity to make the decisions to see them or not. The metaphor ‘screaming for help’ is meant to empathise the desperation Mary and the children felt each time this happened. These incidents happened after the diagnosis had been disclosed to Mary by the GP in Tim’s presence. It is not clear if Tim gave the consent for disclosure. However, his presence might be an indication to that effect. I want to think that healthcare professionals have an obligation to try and facilitate a discussion with the person with YOD and families at diagnosis or as early as possible post receiving diagnosis. This way professionals could provide support to reduce distress and anxiety for families. In

Mary's case it might be that if the family had known about the diagnosis and received support earlier, they might have taken on caring with some knowledge of YOD progression. Also, their relationship with Tim, the extended family, and perhaps professionals might have been different, even though they faced the same difficulties. Caring was in some instances associated with interpersonal and contextual invisibilities by participants and this will be discussed further.

5.4.2 Caring from a distance*.*

Participants described being worried about their spouse's care and safety, and the safety of others in the hospital or care home. They were always on standby, ready to attend the physical environment when needed to help, or to inform staff of any changes in their spouse be it physical health, emotional or behaviourally. Their phones were never turned off and always within reach. Even though her husband was now physically away from her, Ellen said, *"I feel I'm still troubleshooting from a distance if that makes sense".*

Thomas and Maxwell had each been called to help care for their wives when they were distressed in the care homes. They shared the sentiment that COVID-19 restrictions had limited the number of times the homes asked each of them for the physical presence to support. They were accepting that the homes or hospitals will call on this form of support, there was no avoiding it and they could not see this stopping anytime even in dementia specialist care homes. In Maxwell's case at times, he was asked to talk to Gillian on the phone to deescalate when she was in distress.

Mary described her anxieties, whenever her phone rang. Mary said the first thing that came to her mind was that it could be the home calling, and she always thought about what the call might be about next time. Those thoughts were continuous.

Ellen explained that even though Amir was not in their home YOD did not give her a break, she still could not sleep because she worried about him, his care and how he was being cared for. Ellen explained that sometimes she made three phone calls per day to the care home to check up on what was going on. She would enquire e.g. if he was walking about as his normal, had he opened his bowels and eating habits. If anything was reported to her to be not have gone as was expected, Ellen would prompt the staff to involve other professionals such as the physiotherapist.

The sudden rise in deaths of people in UK care homes during the COVID-19 pandemic and imposed care home visiting restrictions would increase fear and other negative feelings for families and people with dementia, including those with YOD as found in this study.

5.4.3 Relationships changes

Much of research related to people with YOD highlights family dysfunction, social isolation, unmet support, and service needs for the whole family (Larger and Slinger 2013; Roach et al. 2014; Johannessen et al. 2017; Stamou et al. 2021). Other studies Caddell and Clare (2011); Johannessen et al. (2015); Hutchinson et al. (2016) found that negative social stereotypes and challenges brought about by YOD can impact on identity, social relationships, and family dynamics. Findings from this current study are no exception. The participants' narratives point to invisibilities, both interpersonally and contextually. Interpersonal invisibility provides insights into how individual, attitudinal, and behavioural barriers impacted interactions and relationships between them and the person with YOD, family members, friends, and significant others. Contextual invisibility describes the way in which specific policies, practices and attitudes adopted by the very organisations and service providers they sought support from, added to whole family's experiences of isolation, discrimination and marginalisation when living with YOD. Roach et al. (2008) identified that stigma often accompanies a diagnosis of YOD, resulting in those close to the person at times disengaging and withdrawing from future social contact or interaction, which negatively impact on the affected family. The participants in this study spoke of situations that depicted stigma and invisibilities because of YOD diagnosis which created anxieties.

The changes YOD causes in intimate and family relationships, and Millenaar et al. (2014) added that this included the children who may not yet be independent. The rearrangement YOD causes in family roles, increases the potential for conflicts and misunderstandings. In my study some participants highlighted the many ways in which they experienced prejudice from their own families, friends, religious groups and the communities: people that they had expected to support them.

Ellen took all steps she could to educate the family about YOD and for two years there was no contact. Mary and her children do not speak to her husband's extended family as a result of misunderstandings around YOD. About friendships Mary said that YOD had "*alienated*" her. She described that she lost friendships because when she met friends, she felt out of place. Mary explained that she could not listen to her friends talking like "*everything has gone to plan*" while for her all she wanted was her "*kids to be alive and safe*". Mary further explained that the children could not have friends at home because Tim did not like noise and young people. Tim would get physically aggressive towards them. The children tended to stay hidden in their rooms to avoid being in his way whenever possible.

Alana and Mike's friends for example appeared unable to accommodate them. An alternative reading could be that they just did not know how to respond to their good friends or their families and so avoided them. This study reiterates that interpersonal relationships are significant to enhancing the well-being of persons with YOD and the family (Ericsson et al. 2013) and their quality of life.

A recent UK-wide survey conducted between August 2017 and September 2018 exploring positive experiences of post-diagnostic services for people with YOD gives insights on the nature of post-diagnostic support services that were perceived positively by people with YOD and carers (Stamou et al. 2021). Stamou et al.'s (2021) study showed that the experiences that were valued and rated as positive by the participants, (people with YOD and carers) either had the participation of all stakeholders, communicating well or as a result of good interactions.

In my study participants reported negative experiences and described professionals as lacking awareness of families' needs, under-identifying families, and failing to give families a mode for affirming patient values or provide them a buffer against the burdens they were experiencing. Participants felt that their quest to be involved in their spouse's care was perceived by some professionals as problematic at times. This was indicated in the way they judged themselves for example Alana said, *"I must be like a sort of… not difficult relative but sort of an inquisitive one…".* Mary said she was seen as "*demanding*" because of the several attempts to get help from professionals and the several questions she asked in order to understand what was happening.

Participants explained that they felt ignored and their wishes were not considered. Ellen said that jargon used in meetings meant that she did not understand information and felt looked down upon in several encounters with professionals. Mary stated that the lack of her involvement was evident during Tim's discharge planning from hospital to care home. She was not involved in the choice of the care home nor the physical transition itself, despite her wish to do so. Mary had childcare commitments on the nominated day for Tim's move to the care home. The hospital would not delay the move by a day. She missed being part of this critical point (Meleis et al. 2000) and major event for her family thus highlighting contextual invisibility of Tim's and family needs.

As a result of the negative experiences from the first hospital admission Ellen was more prepared when a second hospital admission came about. She appointed a solicitor who liaised with the ward team on her and Amir's behalf with engaging through the process which needed understanding of the Mental Health Act (MHA) (1983) and any others that would be appropriate. She said, *"I was so fed up with the process. It's a very complicated system. It's over complicated for my perspective".* It was unfortunate that she had to resort to paying a solicitor while money was already an issue for her and the family.

Ellen described her experience of ward meetings and what she called *"arrogance in the medical professionals".* Ellen talked about professionals using medical jargon in discussions with her, the *"lip service about listening to relatives".* Ellen said this was made worse because she did not understand the system. The “*arrogance*” was also experienced in the care homes*.* Ellen said professionals would not listen to families because they [professionals] felt they were the *“experts”.*

Ellen suggested that professionals lacked understanding of the ‘personal’ dimension of the concept and ‘transition conditions’ such as social, religious, and cultural factors which affect families and their unique perspectives (Meleis et al. 2000). She also suggested professionals were focussed on a narrow medical approach rather than a holistic view that is encouraged with a person-centred care approach. As a practising Muslim family, she found professionals would not support Amir with activities of his faith while in institutions and even meal choices were limited. This finding supports those reported by Lamech et al. (2019) who conducted a study in India. Lamech et al. (2019) found that they still had to consider the different cultural beliefs, language, and religion of the participants as these factors influenced how caring was viewed. Lamech et al. (2019) found that caregiving was more readily viewed as duty towards a loved one, unlike individualistic, western care models that encourage professional services like care homes. This made me think that Ellen and her family might have found institutions difficult to accept and especially that Amir’s beliefs and faith did not seem to have been supported and thus bringing to light contextual invisibility and a lack of PCC approach.

5.5 Dementia Grief

A diagnosis of YOD came unexpectedly and prematurely for all participants and their families. Participants described a range of negative emotions including fear, numbness, anxiety, shock, guilt, denial, anger, stress, depression regret. The feelings of loss and grief expressed by all participants and family members were not unusual, there was congruency with existing literature (see, for example, Roach et al. 2008; Gaugler et al. 2009; 2010; Larger and Slinger 2013; Lindauer and Harvath 2014; Kilty et al. 2019). At times emotions were mixed such as with relief and trauma which was expressed by Maxwell when he talked about when his wife was admitted to hospital. These emotions have been associated with grief (Kilty et al. 2019). Kilty et al. (2019) reported similar findings in their study and said the findings also reflected elements of ambiguous loss and anticipatory grief because of the many changes they were going through. The participants experienced sudden changes to relationships and family structure, along with the anticipation of a changed future (Larger et al. 2013; Lindauer and Harvath 2014; Kilty et al. 2019).

It has been proposed that from the point when a diagnosis of dementia is made and as they continue across the illness trajectory, families move through a recognised grieving process for the loss of a loved one who is still alive (Sanders et al. 2008; Chan et al. 2013; Large & Slinger 2013). Pre-death grieving for the living has been researched in relation to chronic conditions such as cancer (Sanders et al. 2008). Participants in this study openly shared that they realised they were grieving. I believe that it is good for people to realise their grief, acknowledge it, and the symptoms because that might help them take required self-care. In the same regard, Meleis et al. (2000) proposed that personal and environmental ‘transition conditions’ influence the pattern of response for families as they live with an illness and go through multiple critical points. This is relatable to participants in my study who went through changes in personal lives which provoked different emotions. Some emotions were in response to the environments, the services provided by the system, and society which the participants had not been expecting.

Meleis et el. (2000) further allude to that awareness and knowledge of one’s own grief symptoms was important as they can identify their own coping mechanisms. The participants in my study talked about their own coping mechanisms. Finding something to do and keeping busy was one thing they all had in common. Four participants had become activists, working to raise awareness of YOD and the challenges the condition brings to families. For the four participants with children, they found the children providing support resulted in participants finding ways of coping. Alana had recently found religion and found that very helpful. It seemed that the church helped Alana because they talked to the people in the congregation at the time and acknowledge people that were not present because of illnesses so they prayed for them (those not present) as well. Knowledge of own grief symptoms was significantly related to their readiness to coping with living with YOD (Meleis et al. 2000).

As a professional with rational inclinations, understanding families' grief really helps me to make sense of what they are going through for me to shape my support in an effective way. Therefore, to try and understand how grief was for the participants I utilised Meleis et al. (2000). The MTF provides real sense of the emotional impact of change.

The range of emotions experienced from the very beginning and especially at the time of diagnosis, continued as dementia progressed. Therefore, the grief had not resolved despite the length of time since diagnosis and that the person with YOD was now in a care home. Research has shown that grieving for someone with dementia starts before the person dies and extends to after the death of the person (Sanders et al. 2008; Gaugler et al. 2009, 2010; Chan et al. 2013; Larger and Slinger 2013; Lindauer and Harvath 2014). While most chronic illnesses might provoke the same symptoms of pre-death grief, literature has gone further to distinguish the grief caused by these conditions. Dementia grief is heightened by the serial losses of varying magnitude. These include losses of communication and insight that occur even early on in the disease (Chan et al. 2013; Lindauer and Harvath 2014), deteriorate with disease progression, and can go on for many years. Because of the language deficits and a lack of insight on the part of the person with YOD resulting from disruptions in reasoning that manifests in dementia, the opportunities for conflict resolution and sharing feelings between the person with YOD and their family members are limited (Lindauer & Harvath 2014). This was evident in Mary's case when she also referred to the grief in and for her children because of the disease.

In keeping with the literature on dementia grief, participants in this research discussed grieving for a future the person with YOD would no longer have such as retirement and having grandchildren. They also referred to the grief and distress of not being recognised by the person with YOD often speaking of them as if they no longer lived. Examples are offered in Thomas, Ellen, and Mary's narratives. Thomas expressed that he felt very sad and alone especially when he was around people that talked about their wives. Ellen said *"I've been with him for those 36 years… and you're going through the grief process yourself, ... Now you've got a different future from what you expected."* Mary expressed the realisation that Tim did not recognise her: *"I think what hit me when I left there was…I just sort of thought, all those memories just gone, 40 years of memory just gone".* Participants found this part very hard that the person with YOD for example in Mary's case could not recognise even her voice. Not recognising her voice gave a final indication to Mary that everything they had done together was "wiped out" of Tim's brain by YOD.

Participants used statements such as grieving for an uncertain and unwanted future without their spouse. In a way YOD, the grieving, and preparing for end of life were closely related and seemed a highly prioritised need as YOD progressed.

Participants in this research also grieved for the lives they had. Each participant narrated the good lives they had. Alana talked at the length about the group of friends they travelled Europe with. Thomas yearned for the days he used to take his wife to the local pub, and while she loved dancing, she could no longer dance. Mary talked about the cruise holidays they used to take pre YOD and it was on one of these cruises that an incident happened, and she became convinced something was wrong with Tim. It became the last cruise, if not their final holiday together. Sanders et al. (2008) and Lindauer and Harvath (2014) reported that families experience a strong sense of yearning for the past. This is relatable to participants in my study who each yearned for aspects of their relationship and life with the person with YOD that had now been lost. The participants in this study yearned for normalcy in their lives. They expressed sorrow about how their lives had changed and the lack of control that they had in returning their life to how it was pre YOD and the uncertainty of the future they faced. Each one told me that life would never be the same for them. The yearning of the participants was also related to the past dreams that were shared with the person with YOD. All participants told me of stories that they would wish their spouse with YOD would remember and especially that they wished their spouse would recognise them (participant) or at least something about them till the end.

5.5.1 Losses discussed.

Losses described included that of individuality, companionship, lifestyle, and finances. The participants' narratives of loss echoed results from Roach et al.'s (2008) study in which participants experienced the loss of the person with YOD, and the several changes happened in their lives. They also described experiencing loss of control as the person with YOD experienced losing their independence as their symptoms progressed (Chan et al. 2013; Lindauer and Harvath 2014). Maxwell described what seemed to be loss of control; as he struggled with professionals taking the lead in decision making for the care for his wife, a role that he had always taken. Alana explained: *"I lost him really, he didn't come back to me",* a statement echoed by all participants. This finding was congruent to a study by Kilty et al. (2019) that referred to losing a partner as losing a valued source of support at a time when an individual is experiencing unplanned disruptions to family life. This was said to be among the most difficult problems related to providing dementia care to a spouse. Control was also lost as they did not know what to do and felt helpless as they were witnessing continued loss of capabilities in the spouse with YOD**.**

Loss of individuality and autonomy were described as lost by participants. This was related to being with the spouse with YOD all the time for safety reasons usually, and also because the person with YOD would get distressed if left alone for the shortest period. Alana said that she realised she could not leave Mike alone anymore when he went missing on a trip to the pharmacy. Mike went missing after Alana had left him alone in the car. That incident made her realise she or someone had to be with him all the time. Ellen had an even more intense situation that she had to be within his eyesight for Amir to remain settled. She explained, *"… he would follow me around, so I can put it as shadowing and so he would follow me everywhere, if I went to the toilet and shut the door".* Ellen said Amir would get physically aggressive and destroy property if she "*disappeared*" in this way. This paused own difficulties because Ellen was still in work, needed to leave the house and for Alana that meant a reduction in activities out of the house.

While individuality was an issue, participants also described loss of companionship. Participants expressed how the physical absence of the person with YOD made them feel lonely. Larger and Slinger (2013) found that carers needed to adapt to the physical separation from the person with dementia as this was another factor that increases grief in dementia care. Thomas reflected on losing a companion related to the loss Susan’s capabilities and her love of parties, music, and dance, he had bought her a karaoke machine pre YOD and the visits to the pub now this was no more.

Loss of finance was discussed in terms of leading to changes in lifestyles as a consequence of loss of income due to the inability to continue working. Hidden costs were also discussed. Participants pointed out that they had to pay for most community support, for example day centres. All participants explained losing their lifestyles, and they would never be able to get that back to how it was before YOD. Mary was forced to downsize to a smaller house because Tim was the breadwinner and now unable to provide. He lost his job and she never found out why. However, she suspected he underperformed as she reflected on the simple tasks he couldn’t perform at home. The financial impact of having YOD is significant (Kilty et al. 2019) and needs to be fully understood for policy makers to make arrangements that are unique to this age group who in this study still had responsibilities such as mortgage loans and children in school.

Chan et al. (2013) reported that grief in dementia carers, which may be normal or complicated, is a complex reaction to losses occurring before and after death. Meleis et al. (2000) advises that each change can be a critical point or event and they are life changing. A lot changed for the families at the peak points that needs acknowledgement.

YOD meant that families grappled with feelings of infinite losses, as they had lost the ‘normal future’, the hopes and dreams which encompass the normal development of the person without disabilities brought by YOD. The infinite loss, though was, constantly shifting and resulting in further insecurities in the participants and families, as they were unsure of the appropriate response to the various landmarks of their experience.

5.5.2 Preparing for end of life.

The move of the spouse with YOD to a care home seemed to equate to imminent death. Participants talked of the "*last peaceful place for the time that they had left" and* making decisions about resuscitation status in case of a cardiac arrest for their spouse. Four participants had already agreed and signed the do not resuscitate status in case of a cardiac arrest (DNACPR) for the spouse which made the participant mentally prepared for the person with YOD's death. This seems to be confirmed by the fact that in practical terms most people with dementia who transition into care homes will never come back to live in their own home, however long they live. According to Official Statistics (ONS 2020) people dying with dementia are most likely to die in a care home in England, accounting for 58.1% of all deaths in 2018. This is compared to 10.4% dying at home in 2018 and 29.8% dying in hospital (ONS 2020). Not only had YOD come at a time and age that it was not expected and untimely but the knowledge of the past and current death rates of people with dementia in care homes, would greatly influence how participants viewed the situation and got themselves prepared for end of life (Meleis et al. 2020).

5.6 Impact of YOD on dependent children.

5.6.1Becoming a parent to their own parent.

Ellen, Mary, Maxwell, and Thomas discussed the impact YOD had on their children. The ideal is comprised of loving parents who care for and are available to their children and always have their children's best interests in mind. However, participants revealed that their children's future plans had been shaped by their other parents' illness. Empirical research involving young people aged between 11-18 years (Svanberg et al. 2010) and 15-27 years (Millenaar et al. 2014) all children of people with YOD has identified that most did not describe themselves as and even disagreed with being called a 'young carer'. This is even though they agreed that they undertook 'significant, substantial or regular care' of their parent and described periods of time when they had sole responsibility for looking after their parent (Svanberg et al. 2010). The young people talked about 'just helping' their parents (Svanberg et al. 2010). Supporting Millenaar et al.'s (2014) findings, in my study all children mentioned were experiencing a loss of care from their parents due to YOD. All children, including Mary's minor children took on the role of caring and experienced role reversal with the parent with YOD. This was said to be heart breaking for participants. The fact that the younger children did not have the awareness that they were carers in Svanberg et al.'s (2010) study would mean that they would not seek support for themselves for any form of difficulties they could face that could be related to the caring role and the impact of living with someone with YOD (Meleis et al. 2000). This might be because these children were still too young to recognise the enormity of their situation. Unlike these very young people, the 15–27 year-olds in Millenaar et al.'s (2014) study were aware of the need to get support and the impact YOD had on their lives. It is the role of professionals to educate and inform families living with YOD of this specific piece of information that could help the very young people to proactively seek support or for some get offered support while going through these transitions.

5.6.2 Requiring physical and emotional support

Mary revealed that the stress at home meant the children struggled emotionally, and physically to cope, and had expressed this in their behaviours such as substance abuse, self-harm and for one, attempting to end their own life. Mary could not get support for the children even though she approached and informed several professionals. In the practice area, it is a fact that support for children, especially the very young, when a parent has dementia is very limited and this valuable support is non-existent in most areas of the country. The lack of support was also reported in reference to the experiences of children in Kilty et al.'s (2019) study which investigated the experiences and needs of children living with a parent with YOD.

Ellen's children who were now young adults adapted their plans and moved back home. All children irrespective of age became the support for the parent without YOD. All the participants' children in the current study were having to form new relationships and accept the loss of the parent they knew before (Meleis et al.

2000; Svanberg et al. 2010; Millenaar et al. 2014). For Mary's children however, they were at a stage that they blamed Tim's dementia on destroying their own lives so did not want to see him.

5.7 'The system itself is not clear'.

Although the research question asked about the experiences from hospital to a care home, the first participant, Alana made it clear that she wanted to tell her story from the events that led to the diagnosis. Every participant thus did the same. This was also consistent with literature that sought to obtain experiences of receiving the diagnosis of Alzheimer's disease (Czekanski 2017) and is accepted in IPA research as the participant can tell their story as long as it is relevant to the current topic. I also realised that I could follow the story and make sense of it when it was recounted from the beginning, pre diagnosis through to hospital admissions and discharge to a care home. I reflected after the first interview that we had avoided asking a lot of questions at different points of the interview if the participant had not started from when they first realised something was wrong. The chronological order of events helped me to understand how things happened earlier on had impacted on the later stages of their caring role.

Johannessen et al. (2017 p 779) described symptoms in of YOD as "sneaking signs at the early stage of dementia". This is congruent with the experiences of participants in this study. For all participants small incidents pre diagnosis had begun to increase in number, suggesting that something other than the odd error of judgement justified the erratic behaviour or poor judgement that was witnessed. They described events that did not initially cause alarm, but that taken together over time began to cause anxiety. These events included inability to complete routine tasks, reduced concentration during activities, and changes in personality.

Alana said, *"I knew there was something going on, that I couldn't put my finger on"*. Ellen thought there was: *"something completely wrong with him*" following him purchasing the wrong things from their usual shopping routines or purchasing items that were not on their shopping list or that they had never purchased as a family. Thomas saw "*short temperedness. Susan's personality changed. There was a nastiness about her that frightened me.*" Maxwell's wife suddenly changed jobs and then: "*she rather suddenly decided to retire from work". He* also realised she was losing interest in things she loved doing and acquiring new activities specifically watching TV, which was new to the family. Mary described how soon after her husband lost his job and stayed more at home *"then it was by a process of me thinking something's not right here…various things that have been going on with speech and behaviour."* These things happened more and more which prompted them to seek answers from healthcare professionals and for some researching online. Participants reflected on these incomprehensible early signs of YOD describing those symptoms as those first seemingly strange reactions or simply, "something was not right". These were ordinarily interpreted as variations of the person's normal personality (Roache et al. 2008; Johannessen et al. 2017)

Participants' reflections highlighted that systems that should have supported them were unclear, difficult to navigate, disjointed, and unprepared for families with YOD. They also all felt that they were receiving a "*one size fits all"* approach with individual age-related needs not considered. The invisibility they felt, the lack of consistency and continuity of care experienced for example when transitioning from hospitals to a care home and, within same and different Trusts were described. In some instances, participants took on the complete role of coordinating the person with YOD's care, for example, by managing and organising care, ensuring relevant information and documents were in place and moved to the care home with the person with YOD. This was to try to ensure continuity of care was maintained and to avoid or reduce the negative impact of transition on the person with YOD's quality of life. The participants became the go-between for professional groups, for example, the GPs or social services or mental health teams or and hospitals. This was both time consuming and stressful for the participants and at times overly complicated. Ellen expressed this about hospitals, care homes *"…basically it's been stressful and tiring, it's been frustrating, for you fear because you don't know what's going on and everything."* All five participants had this experience of coordinating care at some point on the trajectory.

It was also found that the transition between hospitals and care homes disjointed and fragmented, with little recognition of the family's needs or wishes during the process. This was eloquently described by Mary when she referred it to 'DIY Dementia'.

This disregard of family's values contrasts with Meleis et al. (2000). Meleis et al. informs professionals that providing holistic care during transition will help families to address their own feelings, to understand and justify for themselves why and how the transition is happening. In that way they remain connected in the process and locate ways that can help them even if it is requesting for support from others. Participants explained that the challenges they faced because of YOD were made worse by the fact that the health and social care system was not clear, without a clear dementia pathway to follow or refer to. For some of the participants such as Ellen this was their first time being involved with the system ever and this was frightening on its own.

5.7.1 The drawn-out process to diagnosis

In most cases, a diagnosis of YOD is considered devastating (Roache et al. 2008; Johannesen et al. 2017; Kilty et al. 2019). However, Roach et al. (2008) and Johannessen et al. (2017) identified that receiving a diagnosis early can have positive outcomes. Johannessen et al. (2017) described participants who felt at 'relief of the diagnosis' . Receiving a diagnosis in some instances was welcomed as it opened the gates to services, support and tailored services, support at home and the path to the care home. Early diagnosis allowed families to plan and anticipate what will happen to them in the future and so they felt empowered to make these decisions. They could now explain what was wrong, whilst concurrently lowering expectations about their level of cognitive functioning (Roache et al. 2008).

In this study although the families noticed symptoms early, the diagnosis was made at later stages of YOD. Consequently, the person with YOD had little time to maintain their independence post diagnosis. Describing transitioning from primary care to secondary care, the memory or stroke clinic, and specialist teams, for example psychology, Alana's phrase, "*a drawn-out process"* summed up for all five participants' frustrations. Participants expressed how they felt ignored and that their concerns were not taken seriously, especially in the earlier stages when professionals could not see the changes themselves. Each participant described several trips to their GP and emergency departments and, in Alana's case, the length of time to access the psychologist for the psychometric tests that would show that her husband had more difficulties than even she had realised. Mary described trips to another town to obtain a specialist opinion and diagnosis. Maxwell received Gillian's YOD diagnosis while in hospital following a crisis with behaviours expressed at home. Both the early symptoms and the long processes were experienced with a general sense of ambiguity, anxiety, confusion, fear among other negative feelings.

YOD numbers are rising however, YOD still has a low prevalence in the population and differences in the aetiology and symptoms from late onset dementia, which is widely known. YOD is chronic, involves multisystemic dysfunction, has no treatment and requires complex care. As it is uncommon, YOD is often underdiagnosed, difficult to diagnose and misdiagnosed (Mayrhofer et al. 2018; Kilty 2019). This has been reported to have adverse physical and psychological consequences in both the person with YOD and their families, especially when institutional support during this process is low (Mayrhofer et al. 2018). Before a YOD diagnosis was confirmed, all of the people with YOD had received other diagnoses. One was work related stress (Mary), depression (Alana, Thomas, Maxwell & Ellen), at times termed a "*melt down*" (Maxwell) and on top of the depression the two women were also diagnosed with menopause symptoms or "*women's troubles"*. The long waiting times for appointments for the various investigations and later their results increased this anxiety. For example, Alana said*," My mind was racing away, I suppose I'm thinking what it could be. Then I'm sort of thinking ahead as to what it could be what's going to happen and, what is this, you know because they didn't give a diagnosis, at that point".* The families did not know what they were dealing with, or how to deal with what was going on though some, Alana, Ellen, Mary and Maxwell had their own suspicions that this could be YOD and Thomas suspected a mental illness which he did not specify. All participants in this study experienced delayed diagnosis which frustrated them.

I think that the poor experiences to get a diagnosis, early on the YOD trajectory impacted on the participants' experiences as they progressed from hospital to care homes. The first impressions of seeking support from professionals seems to have continued the whole journey e.g. the feeling of not being believed or being listened to. There is need for professionals to form relationships with families and ensure continuity in healthcare professionals and instil trust to ask questions (Meleis et al. 2008).

5.7.2 Lacking age-appropriateness and specialism.

" *There just was not the facilities for a young person. Everything is geared, especially in our area, around or on the older people*", Ellen's words said in frustration. This is on the backdrop that the National Dementia Strategy (DoH, 2009) acknowledged the importance of ensuring that people with YOD must access services are age appropriate, that meet needs of younger people and that inappropriate placement with older more physically frail people should be avoided. A national survey in UK, Rodda and Carter (2016) reported that only 11% of respondents could identify access to local age-appropriate respite care and only 14% could identify access to local age-appropriate long-term care. These low numbers accessing age-appropriate care home placements are of concern for stakeholders who have interest in YOD.

Each participant discussed at length how all services for dementia were, in most cases set up for older people, a result that was also identified in some of the more recent studies, Rodda and Carter (2016); Carter et al. (2018); Kilty et al. (2019). More recently care homes have been built that are specific for people with YOD. However, like other YOD specific services they are geographically dispersed, variable and non-existent in most counties of the UK. In practice the result is that people with YOD transition to a care home for older, frail people or move to a care home that is far away from their original home. Over the years studies have highlighted the same gaps in the care of YOD (Roach et al. 2008; Mayrhofer et al. 2018) and state that such situations directly impact on transitions for this population. More recently Carter et al. (2018), Kilty et al. (2019) identified that receiving a timely and accurate diagnosis and gaining access to age-appropriate support for people with YOD and their families remains a challenge both in the UK and internationally. Ellen in particular recounted the difficulties she faced in the community while trying to ensure Amir was involved in meaningful activities. Amir was turned away or not accepted by some of the services, due to age related criteria, they did not accept people under 65 years, and from others because of the YOD diagnosis. Ellen was frustrated and saddened because*, "he did not fit"* in any groups in the area because of his age and that people did not understand YOD. This study provides evidence that not much has changed with specialist care provision still lacking in many areas and YOD services are still frequently being integrated into older people's care. These services include specialist services such as the memory clinics, hospital wards, and care homes. People with YOD and their families are still not receiving age-sensitive needs-based care in most areas around the country.

Participants described searching for appropriate care homes moving long distances away from home, for some two hours' drive from the person close to home. Ellen and her family visited 50 care homes many of those being dementia specialist care homes. Because of Amir's complex needs, only three said they would meet his needs, and some were far from home.

The transition from home care to institutional care is a significant event in the experience of families (Gaugler et al. 2009; 2010). It is a critical point for the person with YOD and their families (Meleis et al. 2000). The lack of specialised care both in hospitals and care homes was of concern for participants. The lack of institutions, specialist hospitals / beds and care homes closer to the person with YOD's own home increased anxieties and distress for participants and also resulted in time and financial losses.

The participants understood that dementia has no cure or medication. However, they voiced concerns about the use of medication, especially in hospitals, as a way of managing BPSDs. Of particular concern was the prescription of antipsychotics, anxiolytics, and some antidepressants to reduce behaviour symptoms. Despite being a nurse, Alana did not expect this. The side effects Mike experienced resulted in her asking the team to stop further medication trials. Alana said, "*it took a while to establish what drug, if any, was effective and whether you know, you just got back to square one really".* All this time Alana observed Mike experiencing severe side effects such as increased falls risk and drowsiness. Ellen explained, *"I contacted the doctor, his consultant, and just said what's going on?... if you're having to have that many medications on a daily basis you know, it's ridiculous and I said, … what are you doing?"*

Banerjee (2009) examined the use of antipsychotic medication for people with dementia in the NHS in England and recommended a reduction in the use of these medications. Banerjee said that there was overuse of antipsychotic medications and yet they could produce severe adverse effects. These same concerns and facts that psychotropic drugs are often ineffective are also identified in studies carried out by Gaugler et al. (2010) and Lamech et al. (2019). NICE (2018) guidelines state that non-pharmacological guidelines should be the first-line treatments in the management of BPSD. The skilful use and delivery of non-pharmacological alternatives to drugs is required because psychotropic medications are associated with major side-effects such as the link to an increased risk of vascular incidents and deaths. Specific multicomponent interventions decrease neuropsychiatric symptoms in people with dementia and are the treatments of choice. My experience of working in a psychiatric hospital gives me the knowledge that admissions occur when meeting care needs of the person with YOD has been impossible elsewhere. It might therefore be anticipated that prescribing rates may be even higher in hospitals. However, it is also possible that skilled nursing staff, good staffing ratios and appropriate environments decrease the use of medication (Edmund et al. 2021). It is the later that the participants expected in institutions that were labelled specialists.

Participants described how they had to seek out professionals when they needed them and did not always get the attention immediately and this was usually at crisis moments. Some said they were rarely sought out by the named person unless at stipulated points e.g., to discuss discharge to a home, a change in situation in the home. Participants were more concerned about events especially from the time of receiving the diagnosis onwards, was described as being left to deal with it. While other participants did not use the same term "*DIY dementia*" they expressed their situations through phrases such as *"we were abandoned, left again, ignored, left alone, left in limbo",* phrases used to describe how they felt. The nature of post-diagnostic support as experienced by people with YOD was explored by Stamou et al. (2021). Participants in that study reported that working collaboratively with a named professional who coordinated care was rated as having resulted in positive experiences for people with YOD and their families.

Despite the differences in cultures, health, and social care structures (with India reported to have none on dementia care), and financial positions, findings from this study connect with those reported by Lamech et al. (2019) who found that families needed sensitive, and skilled health workers, information on dementia and advanced care needs and cost-effective services. This is relatable to the participants in the current study where in general health and social care systems are well developed. Post diagnosis Ellen, Mary, Maxwell, and Thomas found themselves with no proactive follow-ups from either primary or secondary care, an experience which extended for some post discharge from hospital to the care home. Alana had a named person allocated immediately. Mary's family was allocated a named person after several crises, and she believed that the last straw was the youngest son self-harming, attempting to take his own life on a few occasions, almost succeeding with one. These experiences left all families having to deal with the impact of YOD alone, especially those related to safety, and their emotions. Professionals were described as disengaging and families had to seek out professionals when they needed support. The participants felt that professionals were unaware of the needs of the person with YOD and so tended to avoid the topic. Mary said," *I think they were certainly in the hospital…, none of the staff want to really talk about the dementia they're just doing the nursing bits of the thing".*

In some instances, allocated / named professionals were also described as not being available. When available, they presented as lacking knowledge, understanding and confidence in YOD, being reluctant and avoiding talking about YOD. Maxwell summed up his experience of services, that he was yet to meet someone in adult mental health services that come across as "*understanding of the clinical needs of young person with dementia".* This sentiment was shared by all participants.

Sanders et al. (2008) examined the notion of grief in people caring for people with dementia and found out that these carers with high levels of grief encountered many obstacles when interacting with the social service and health care delivery systems.

These experiences are noteworthy because they occurred when the person with YOD and their families were most vulnerable, both physically and mentally. It is imperative for professionals take these transitional experiences into account and ensure they go as smoothly as possible (Meleis et al. 2000) for families to reach a point they can cope with the situations that keep changing.

5.7.3 Post code lottery

Post code lottery was defined by participants as the lack of integrated partnerships and collaboration by professionals and organisations to provide effective support to families. The organisations included the NHS Trusts and a range of agencies offering various practical dementia support, such as social and financial advice. However, support was said to be disjointed chaotic and confusing. These echoes finding reported by Mayrhofer et al. (2018) and Kilty et al. (2019) who identified that post-diagnostic support services designed specifically for people diagnosed with YOD and their families was disjointed and varied considerably in the UK. These services are comprised community and hospital-based services. A mix of statutory and non-statutory services in the UK and the National Health Service (NHS) Trusts were also part of this mix. Every participant discussed their experiences with non-statutory, third-sector agencies such as the Alzheimer's Society, Dementia UK Admiral Nurses, Young Onset Dementia Advisers (YODAs) and other support groups. The participants all had experiences of receiving support from different agencies. A shared experience was that there were no formal referrals or information about the agencies by professionals in primary or secondary care. After they had ‘found’ a person from an agency, all participants described how they had to seek the person out themselves when they needed support. These experiences were said to be isolating for families and these organisations did not always make transitions as smooth as possible for them.

In response to my question, *did you get referred or be told of support groups that could be in your local area or nationally*? Ellen said, she had not been referred or signposted anywhere. Instead, her daughter “*found*” a book in the GP surgery one day. This happened to have information about dementia support services in the area. Thomas explained that he *“found”* a group that was for people affected by mental illness that someone told him. Mary had had support from the Alzheimer’s society in another county. However, when she moved to another county there was none. Six months after moving she was contacted by an Admiral Nurse who happened to be a YOD specialist. Maxwell said he contacted a lot of online research because he had not been offered support proactively. Maxwell eventually met an Admiral Nurse in one of the care homes his wife moved into along the trajectory. Maxwell and Mary talked about maintaining relationships with professionals from the non-statutory third sector agencies. Maxwell said it was a hard process if one wanted to stay involved, there was no strategy nor structure, lacked coherence and families had to work hard to maintain relationships.

These responses reveal that there is need for all organisations, individuals, paid for or unpaid to work in collaboration, in integrated partnerships and create a climate that is accessible, engaging and allows for continuity of care from the beginning to the end of the dementia journey. They also suggest a need for policy improvements from the first point of seeking for a diagnosis, post diagnosis care that is set up to provide early support intervention for families that are going through several complex transitions due to YOD.

Apart from the variations in availability and accessibility of services other points brought up were that the information provided in writing was not relevant nor was it applicable to YOD care.

It can be argued that these families seek support from professionals who do not understand the impact of YOD, and the nature of transitions involved. Professionals did not seem to realise the importance of their roles in aiding the families in finding ways to cope with the constraints on transitions (Meleis et al. 2000). The families were ‘lost’ in the system. I am inclined to think that maybe because they were younger, they were expected to exercise their own agency as compared to those with late onset dementia and their families as advocates.

5.7.4 Lacking awareness and Knowledge of YOD

Literature shows that sufficient professional knowledge is of critical value in providing high quality YOD care because the people affected have unique needs and experiences, requiring care and support that is timely, appropriate, and accessible (Burh et al. 2006; Harrison et al 2017; Lamech et al. 2019; Kilty et al. 2019). Because of the time in life that YOD affects families, the impact is felt for many years when the person is still alive and post death. Broad professional knowledge is required related to YOD identification, diagnosis, treatment, and ongoing care. Participants in this study raised issues that arose because of what was, in their experiences, lack of knowledge and awareness of YOD.

Concerns were described in terms of insufficient appropriately educated professionals which resulted in the lack of awareness of symptoms that did not present with memory loss. Ellen, Thomas, and Maxwell questioned how and why the dementia pathway does recognise the specific needs of those with YOD. Maxwell asked, “*What does a dementia specialist care home look like and where are specialist YOD professionals?”* It could be argued that YOD is a specialism within a specialism that requires attention and further exploration from wider health and social care service development and research communities. The need for this has to recognise the possibility of such a diagnosis given its protracted route to diagnosis which often starts with presentation in primary care as described by participants in this study. Such negative understanding shown by healthcare providers was experienced in hospitals and care homes. Participants pointed out that they also struggled because professionals did not stay in post or allocated to the family sufficiently long enough to get to know them and the person with YOD which brought complexities of its own. Mary said that her family had been involved with *social services, we've been under social services for 6 years.* She strongly believed that social services did not have a file on the incidences with her husband. In frustration Mary said, *"you're talking to a completely new person every time, they didn't have the history of the cases".*

Ellen explained the trauma of having new professionals on a case, *" you need somebody that knows your story and your history because you are then still battling a system of people that don't actually understand, they don't know you at all and don't know him and you're having to constantly repeat and repeat* [sigh] *and it's quite traumatic, it's your life, you know. To medical professionals he is just another patient isn't it but to me he's my entire life"* [Looks at me quietly].

Participants shared their experiences using statements that showed frustrations at having had several professionals come and go without necessarily understanding Gillian and his needs or implementing effective strategies to maintain Gillian in one home. Maxwell's wife was discharged to a care home that was supposedly specialist for YOD. However, the home failed to meet her needs leading to a hospital readmission.

All participants reported what seemed to be lack of being engaged and interacting with professionals enough to gain trust, that confidence to go through a transition positively and develop ways to cope and solve problems during the process (Meleis et al. 2000). While insufficient resources, including professionals to give information, was an issue, in other cases those professionals present lacked awareness of YOD, had no confidence in caring for the person with YOD nor did they have the knowledge needed for to provide the specialist role. Mary said her experiences were that no one wanted to talk about YOD, all the professionals she had met and that mad her quite sad. Mary said the sadness was because this was like saying YOD does not exist. For these participants the evidence of these issues was through the numbers of hospital readmissions and care homes moves as a result of failed placements that they experienced or got to know about.

Insufficient knowledge and awareness were also discussed in relation to participants themselves and those around them. Participants talked about the need to know. Mary explained: *“We want to know more of the disease, what’s going on. Nobody prepares you for what's ahead sort of thing and it's progressive…”.*

This sentiment about the need to know what to expect as dementia progresses was articulated by participants in Lamech et al.’s (2019) study. The knowledge is useful in this instance as participants would be able to identify and accept when the person with YOD is no longer able to carry out a task they used. These were critical points as they usually meant an increase in the person with YOD’s needs and more dependability on the family (Meleis et al. 2000). The same sentiments were expressed as helping to create positive experiences in Kilty et al.’s (2019) study. In that study knowledge was reported to have been gained from several sources including professionals, and informal meetings for families affected by YOD. In the centre, however, was that a coordinator was available to signpost to relevant areas.

In a study that examined the subjective feelings of people with YOD and their families, Roache et al. (2008) identified an important piece of information. In their study one younger spouse-carer who received considerable information and support from a community psychiatric nurse admitted that this contact played a major role in her ability to cope with her husband’s dementia. The fact that this clinical support continued after her husband’s eventual death meant a great deal and she was grateful for the continued service (Roache et al. 2008 p 68). This is also in line with Meleis et al.’s (2000) suggestion and recommendation for supporting families at all stages of transition.

My study, however revealed that generally, information on YOD was not proactively shared, there was an obvious lack of knowledge of local care homes, and which would be appropriate for the person with YOD. Inadequate knowledge on how to respond to behaviours presented by the person with YOD and what to expect as dementia advanced caused stress, anxieties, fear, and guilt. The knowledge gaps meant that people with YOD and their families were improvising and utilising idiosyncratic sources of meaning, to make sense of their new situation, affecting family members' mental health, employment, financial stability, and social isolation. There is need for professionals to consider Roache et al. (2008)'s findings.

5.7.5 Physical Transition

In relation to the actual process of physically moving along the services, all participants discussed both when and how they transitioned. Four participants experienced admission and moves from psychiatric hospital wards to care homes while one experienced an admission and discharge from a psychiatric ward in an acute care hospital to a care home.

The participants described their experiences through semi structured interviews between March and May 2021. Within this study the impact of transition on all participants was the same with so many changes in their lives and the person with YOD. While it had seemed as though Alana had been the exception, as she had rapid and better support provided, with a care coordinator allocated soon after diagnosis, she also faced difficulties as she progressed on the journey, for example in the care home. All participants experienced the move to long-term care and some more than once as a result of care breaking down. This is shown in table 9**.**

Table 9: The number of hospital admissions and care home moves per person with YOD.

	Hospital admission 1	**Care home 1**	**Hospital readmission**	**Care home 2**	**Hospital readmission**
Alana	X	X			
Ellen	X	X	X	X	
Mary	X	X			
Maxwell	X	X		X	X
Thomas	X	X	X	X	

As shown in table 9 transitions dictated the physical move (Meleis et al. 2000) to a different hospital or a care home which might be further away from home. Ellen, and Thomas went through this experience twice, that is, hospital admissions discharged to a care home and hospital readmission only to be discharged to a different home. In addition, while on the second hospital admission Ellen's husband was moved to another hospital for COVID-19 related reasons not directly related to YOD. At the time of the interview, plans were for Thomas' wife to move to another household in the same care home because her needs had increased and could not be met where she was. Maxwell's wife moved from a hospital to a care home and when care broke down, she was urgently moved to another care home where she stayed for only a week before they confirmed that her needs were too complex, and she was readmitted to hospital. At the time of the interview, Maxwell's wife was still on a psychiatric ward, and they were looking for an alternative care home, which would be a third. Maxwell's wife was the only person who had been in a specialist dementia care home for younger people. Caron et al. (2006) and Meleis et al. (2000) advised that perceived consequences of a placement are important to consider during transition in order to avoid a burdensome transition. For this study physical transitions were challenging as they meant change in the management and development of new relationships for the person with YOD and their family. This was evidenced in the care of Ellen's husband who found it difficult to form relationships with professionals both in hospitals and care homes. Ellen believed that staff turnovers and COVID-19 restrictions compounded this challenge because *“he was with people he didn’t know and they did not know him",* and the result was a hospital readmission.

Common denominators in these participants’ hospital admissions were the extended length of stays and delayed discharges. Edmund et al. (2021) found that long term admissions for people with dementia made using the MHA (1983) are not unusual in UK psychiatric hospitals. In reality, on a ward, the complexity and intensity of a patient’s needs are likely to be reflected in the extended length of stay, with patients staying for months, and at times a year or more. However, in this study long hospital stays and delayed discharges were directly linked to discussions about who and how the care home fees would be funded, bed availability and the care home intended for the discharge. This was considered burdensome by participants*.* Ellen and Alana were surprised that their spouses stayed in hospital for months after it had been agreed that they were ready for discharge. They could not go out because funding discussions had to be finalised.

Alana commented about the funding process: *“that was stressful, felt like fighting for the right to be in a safe place.”* Alana was given a list of homes to consider. However, when she identified one that she considered suitable for Mike, she was told this home was too expensive therefore would not be funded. She went through the appeals procedure which meant a longer hospital stay. That the funding process in England could prevent the person with YOD from moving to an appropriate place of care was considered discriminatory, particularly when compared to other chronic conditions such as cancer.

Changes in health and illness of individuals with YOD created a process that led to physical transitions (Meleis et al. 2000). Physical transition meant that the participants needed to make practical adjustments, for example because their own current home was no longer suitable, they sold and moved homes. The spouse with YOD moved to hospital or a care home so they researched for travel arrangements and routes which could present additional problems related to time and cost. For Ellen, this presented significant issues and meant that her husband struggled to have his basic needs met in the care home, which was an hour away from his family who were still working. Ellen explained how she had tried to encourage the home to get more involved in his basic care. She had no success, and this impacted on her emotionally. Ellen met with the home manager several times, to encourage home staff to get to know Amir better and form relationships with him but this did not happen.

Some participants continued to provide support and hands on care in hospital and again in the care home. For Ellen and her family this was more necessary than others because although Amir settled in hospital, he would not accept any care from the staff. Ellen and family went in every day, to help with feeding, provide him with occupation and activities such as and support him wash / shower, take him to the toilet, so all those things they did. This continued when he moved and even after six months in the home because professionals could not effectively and safely support Amir. For Ellen, these questions deepened when an incident that required safeguarding happened in the care home that saw Amir physically attacked by a carer who was supposed to keep him safe. Ellen had found the incident really difficult and there was a safeguarding report and she learnt that the carer punched Amir in the face. Ellen said the family were quite shocked to hear that because they had not expected that carers in a dementia specialist home would react this way in response to a person with dementia.

5.8 ‘Do it yourself dementia (DIY dementia)’

The search terms that came from the research questions served as the foundation for the first literature review for this study. During data collection and analysis an unanticipated theme was identified. This theme was the idea of *“Do it yourself dementia (DIY dementia)”***.** Therefore, in keeping with IPA methodology I returned to the literature to undertake a second focussed review (Smith et al. 2009). There was no literature that directly related to ‘DIY dementia. This term was used by Mary and her sons to describe or label the way they dealt with Tim’s behaviours which threatened them as well as him physically and mentally.

Like all other participants Mary described that she and her family experienced both interpersonally and contextually. In Mary's case contextual invisibility resulted in Mary making the decision not to seek out professionals even when she thought they should be involved. Failure to provide necessary formal and informal support has been attributed to a range of detrimental effects on immediate and extended family members (Sanders et al. 2008; Roach et al. 2014; Lamech et al. 2019) across a range of ages and developmental life stages. This resonates with descriptions of loneliness and isolation that Mary described. Mary indicated that hers and sons' needs were not understood and were unrecognised within the whole context of living with YOD, including by their own close and extended families

"*DIY dementia"* was a term that was linked to the systems of care. The lack of proactive allocation of a named person, lack of continuity of care by services, lack of proactive information provision and professional follow up throughout the trajectory was highlighted. Mary's explanation,

> *"It was DIY dementia, we were making decisions on the spot for ourselves, dealing with it. Trying to deal with it the best we can".*

"*DIY dementia"* in some ways seemed to explain the desperation, how Mary and her sons struggled to live with YOD in their daily lives and how they dealt with everyday issues in any way they thought would be helpful. Mary told me that her explanation of *DIY dementia* often made professionals in different services uncomfortable, and some had said so.

DIY dementia happened despite that the NICE Guidelines [NG97] (2018) recommended that services should ensure that families receive support from receiving the diagnosis. The guidance is that a single named health or social care professional who is responsible for coordinating their care is allocated. The named professional acts as the family's first contact who provides information about available services and signposts to these and advises on how to access them, involves family members decision-making, and also transferring information between services and care settings (NICE 2018). Despite these recommendations, participants gave many examples related to being invisible in which participants felt excluded or unfairly treated which created perceived inequality of services, care, and support.

On another note, Mary recounted that she and the family had several contacts with health and social care professionals particularly nurses, medical doctors, and the police. All these professionals have duty of care which is a legal and professional obligation to safeguard those they support or those who seek support from them. The obligation is covered in the health and social care codes of conduct for adult social workers and healthcare workers.

An example is that the Nursing and Midwifery Council code of conduct (NMC) (2018), emphasises the professional side of nursing and supports this perception through their code of conduct, which outlines the standards and values expected of practicing nurses. One of the Code's main principles is that nurses must prioritise people, making their care and safety the main concern, ensuring their needs are recognised, assessed and responded to (NMC, 2018). Nurses must ensure that the response to needs or any treatment, assistance or care for which they are responsible is delivered without undue delay (NMC 2018).

Mary had wanted positive experiences of services that addressed relational issues between Tim and their family (Stamou et al. 2021) and she did not get that. Mary expressed that in her experience professionals and service providers had tunnel vision, focusing on the person with YOD and disregarded the people caring for the person with YOD. A holistic approach was described as caring for the whole family. Statements such as "*they decided, they did, they …"* were used by participants describing parts of the decisions about the person with YOD that they felt left out of by professionals**.** Mary gives an indication that she did not feel connected with professionals probably because there was no continuity in allocation of healthcare professionals, and so could not trust them enough to feel effectively supported by them (Meleis et al. 2000).

The narratives of invisibilities offer insight into factors that influenced the participant's interactions and relationships with organisations and service providers from whom they sought support. The lack of family consideration runs counter research findings such as Schur & Whitlatch (2003) who found that avoiding care home placement can depend on the carers' self-judgement of whether they are providing the best possible care or not for the person with YOD. While the person with YOD can present with risks there may be interaction between the person with YOD and carer risk factors in which they are mutually reinforced. It is important that professionals are aware of these issues and work at avoiding them using person centredness, relationship and family centred approaches to influence families to have positive experiences.

In my role as a dementia specialist nurse, I realise the importance of and encourage the idea of triad relationships in which the person with YOD, and the family are involved in their care as much as is possible because both PWD and carer characteristics can influence time to institutionalisation so both come as a unit (Yaffe et al. 2002). The 'them' and 'us' terms used by participant, could have been reduced or eliminated if both parties (professionals and participants) had taken time to contribute to creating relationships. The professionals could have controlled the process because they are bound by policies and other guidance in practice, but the participant would have been permitted to feel as part of the caring team, and opened up, thus making the relationships possible (Ericsson et al. 2013). Good relationships with professionals were critical for the participants' identities and feelings of personhood.

For Mary and her family, the lack of cohesion had a major impact on their lives. Mary's case was unique to the other four in that the children, minors (12,14 & 15 years old), experienced living with a father who presented with unpredictable behaviours and could be physically aggressive towards them. After several attempts to get continued help from professionals from different areas without success Mary stopped contacting professionals. She and the children felt that they had not being believed and felt they had been completely left out during assessments carried out with Tim, including some of the neurological assessments were completed in the family home. While Tim had been in a care home and the children were adults (20,22 &23) at the time of interview, the children were still disputed on how to react, and did not want to see him. Mary said they were "*struggling with trying to disassociate Tim from the behaviours"* that he had exhibited towards them". In Mary's case professionals' actions created more anguish and grief because of the adverse impact that it did or could have on the families which was also identified by (Sanders et al. 2008).

Invisibility by professionals and the system seemed to infuriate Mary as she compared the availability of resources, support organised, available, and easily accessible for other long-term conditions such as cancer and diabetes around the country but no clear support was available for those affected by dementia in general, let alone those affected by YOD.

5.9 Receiving police assistance

Ellen described receiving assistance from the police for as a traumatic experience for Amir and herself. The police were meant to be supporting with providing transport and safety for Amir back to hospital after a failed trial at home. Amir was very distressed and therefore very vulnerable too. Despite the distress, Ellen described that he was treated like a criminal and not a patient because of the force used that included restraining him in handcuffs.

This way of supporting a family, and a ‘patient’ who is already in distress raises questions about the way people with dementia are handled by the police. “*All 6 of them dragged him in that police van”*. This action by the police raises questions about how much knowledge the police have around dementia, communication and de-escalating the distressed patient and whether they understood that they were not only responding to a situation, but also providing care for the family and the person with dementia.

Goel (2022) raised the same questions in America when an elderly woman with dementia was arrested for shoplifting by the police. Despite that she was confused and not giving appropriate answers to questions, excessive force was believed to have been used resulting in injuries to the vulnerable woman (Goel 2022).

Another question that came to mind was should the police have gone out with medical personnel or someone from the ward particularly that Amir was on leave from the ward. This was a medical assistance call and not a criminal one. One study by Sun et al. (2019) was carried through focus groups with police officers. This study showed that knowledge of dementia was related to higher capacities of recognising behavioural symptoms of someone with dementia however the knowledge of did not entail confidence of appropriately reacting to people with the disease. It implies that understanding the facts of dementia does not necessarily transfer to communication skills needed to interact with someone with dementia (Sun et al. 2019). With this fact in mind, I would say that there is need to assess the training packages promoting interactions with or exposures to people with dementia that may be needed to make police officers capable of approaching, engaging, and helping people with dementia effectively.

In the UK collaborating of professionals, police, mental health or social care services is encouraged which would reduce incidences like Ellen experienced. Developments have happened between 2022-2024 with introduction of The Right Care, Right Person approach by the government (Gov.UK 2024). The Right Care, Right Person approach provides a framework for assisting police with decision-making about when they should be involved in responding to reported incidents involving people with mental health needs. In short it is designed to ensure that people of all ages, who have health and/or social care needs, are responded to by the right person, with the right skills, training, and experience to best meet their needs. Though the police will continue to be involved, they should only be involved for as long as is necessary, and in conjunction with health and/or social care services.

5.10 Chapter Summary

The struggle for meaningful lives during transition related to the multiple, multifaceted, nonlinear, and complex difficulties and losses brought by YOD have been discussed. Grief was experienced for long periods by the participants in this study. The fact that professionals in different institutions failed to address fundamental care needs of the persons with YOD makes Ellen and Maxwell’s questions very relevant. Ellen and Maxwell questioned what it means for a home to be called a dementia specialist care home and more so what a dementia specialist home for younger people should be able to provide, what it would look like, staff training needs that would make them competent to meet some of these needs and understand young onset dementia. These questions asked by participants call for further research in the area of YOD.

On the other hand, the participants were left to coordinate their own spouse’s care. This question could be asked in another research.

Chapter 6: Recommendations and Conclusion.

6.1 Introduction

This chapter summarises the research and outlines the contribution it makes to existing knowledge, the strengths and limitations of the study, and concludes by outlining recommendations for practice, education, and further research.

The research question was stimulated by real-life observations, experiences, and events in the health and social care settings that I had worked in my nursing career over the years. The research question was ‘*what are the experiences of spouses of people with young onset dementia of transition from hospital to a care home?’*

The study aimed to explore the experiences of wives and husbands of people with YOD who had made the transition from a hospital to a care home. To fulfil this aim, a qualitative research study was undertaken using the IPA methodology. The sampling and recruitment was purposive in UK. Four spouses with YOD had been admitted on a psychiatric hospital ward and one had been on a psychiatric ward on an acute hospital, and all had been experienced a discharge to a care home.

Although the original intention was only to understand the experiences from post diagnosis stages, hospital to a care home, the first interview with Alana guided me towards including the experiences from pre-diagnosis, when they started to see small changes in the spouse with YOD. I believe this offered a clearer understanding of their experiences through the YOD trajectory, and added depth to the findings, and subsequent discussion. IPA participants should be able to discuss what is important to them so that was in line with the methodology.

Data analysis and interpretation revealed that these spouses had experienced several changes in their lives from pre-diagnosis. These findings give insight into the issues that needs to be addressed in the care of people with YOD and their families taking into consideration the uniqueness of the needs they present with.

Participants used words and phrases / statements such as ‘fighting for safety’, ‘wrestle the system’, ‘the struggle’ ‘left again’, ‘left in limbo’, ‘not listened to’, ‘ignored’, ‘professionals are hard work’, ‘professionals are arrogant’, ‘DIY dementia’ at different points in the narratives. These words, statements and phrases are of concern and were expressed to emphasise participants’ dissatisfaction and seriousness of the negative feelings they had felt about the systems that should be supporting them.

Receiving the diagnosis had not been easy process. The participants felt that their initial attempts at seeking a diagnosis were not taken seriously. All participants went through several departments before eventually being referred to the memory clinic where for Alana, Ellen, Mary, and Thomas, would receive the diagnosis. Participants revealed delayed diagnosis, misdiagnosis and after receiving the diagnosis, except for Alana, participants did not receive any follow ups for at least two months. Four participants had no named person allocated immediately and when eventually allocated, the participants felt they had to seek the person out whenever they (participant and family) were in crisis.

General lack of information that is YOD specific, professionals’ lack awareness and knowledge of YOD both in health and social care systems was an issue raised by all participants. The same points were said to have impacted upon the participants’ experiences of providing patient care for the spouse with YOD. Issues were discussed of the lack of age-appropriate institutions such as designated hospital wards and care homes. However, participants were more concerned about the lack of specialism for the age group and participants said this needed to be investigated. This was reiterated on by Ellen, Thomas and Maxwell who had spouses that had more than one hospital admission each and transitioned from one care home to another because of complex needs that staff in dementia specialist care homes had failed to meet.

Four participants had children who were adults at time of interview. However, Mary’s children were minors at time of receiving Tim’s diagnosis and Ellen’s children were dependent on the parents when Amir’s diagnosis was received. The impact that YOD had on the children was discussed by four participants. Though the ages were different, all children took on roles as carers, changed their lifestyles, supported the parent without YOD and they experienced emotional strain throughout the YOD trajectory. Of concern was the complete lack of professional support for these children. This points to the unintended consequence that the using PCC when supporting people with YOD is problematic as it has the potential to focus on the person with the diagnosis and foster an ineffective transitional strategy that could have lasting consequences for the whole family. Professionals should be aware of the unique needs the population can present with and formulate age-appropriate person centred, relationship and family centred support and resources or materials for information written or online.

6.2 Original Contribution to Literature

To the best of my knowledge, this study is the first to investigate and report on the spouses' experiences of transition of people with YOD from a hospital which happened to be a psychiatric ward in the UK and discharged to a care home.

The contribution of this study to the subject of spouses of people with young onset dementia 's experience of transition between hospital and care homes in UK is significant. It gives a clear indication that transition is not easy, emotionally as well as the physical transition itself. Areas that are flawed are highlighted including that professionals are not equipped to support people with YOD and their families. The spouses took on the coordinating role in most instances to try and avoid errors in care provision for their spouse with YOD because professionals were not available to do so. For all participants there was no guidance either written or given by professionals they encountered on what to look for in a care home for someone young with a dementia.

The study highlights the experience of stress and anxiety amongst spouses and families of people with YOD related to if professionals could meet the person with YOD's needs, and failures of care placements. There may be a commonality of experience across larger populations of families transitioning from hospital to care homes in UK and so a better understanding of the factors that influence care home placement failures may assist all stakeholders including health and social care organisations to mitigate against these issues.

Secondly, this study illuminates the concept of ‘DIY dementia’ during transition which is a critical point where professional support is of vital importance.

The idea that all participants felt routinely marginalised gives rise to the need for further investigation to determine if this is a wider issue or simply a local one.

Even though all participants are from one country, YOD is a worldwide concern. As such the challenges experienced by participants in this study may well be familiar to families elsewhere. The participants’ narratives produced powerful data that helps to describe patterns of practice and areas that needs to develop as well as that need further research.

A major concern is that families experience grief for long periods, and it is known that the grief in dementia and specifically YOD is very unique. However, there is no guidance on how to support these families.

6.3 Commitment to quality and rigour

The notion of rigour, quality and best practices are critical in qualitative research. I used Yardley’s framework to ensure quality as was recommended by Smith (2011). Since Smith’s appraisal, Yardley has continued to improve on the framework, and I will use Yardley (2017). My philosophical position, constructivism stance, claims that all knowledge—both outside world and of ourselves—is inherently filtered and limited by our own goals, language, culture, and perspective (Yardley 2017). Yardley grouped procedures for enhancing and demonstrating the quality of qualitative research into sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. I implemented several procedures to enhance ensure each stage of the study maintained high quality standards. I will explain this below using Yardley’s framework.

6.3.1 Sensitivity to context

Yardley (2017) alludes to that a good qualitative study demonstrate sensitivity to context by showing awareness of the participants' perspectives. The early decision to opt for IPA methodology shows an early appreciation of the need to remain sensitive to context. This was brought by a realisation that this study had to focus on the particular and idiography was a key factor considered on my decision making. Sensitivity was maintained at all stages from planning and designing, conducting, and reporting of study findings by being conscious not to impose pre-conceived categories on the data. I carefully considered the meanings generated by the participants and reflected on carrying out this research, at all times,

I remained fully aware of my role as a researcher and careful to avoid bringing my opinions into discussions. In those early stages I agreed with doctoral supervisors that we would use unified terminology to govern the use of different concepts; and adopted a clear stance on the use of the term 'young onset 'and 'not early onset' as advised by (Johnson et al. 2020). By this we avoided confusion as terms can have different meanings to different people.

At analysis phase reading and reading of transcripts, listening to audio clips several times, ensured that I fully understood the meaning of the words used. This is described in Chapter 3.4.5 and in addition I remained true to participants' words and not mine. I also asked my peer students and nurse colleagues to listen as I told the participant's stories and to read the written work for 'peer debriefing', as a strategy to enhance the credibility and trustworthiness of the research. This was the process through to the discussion chapter.

6.3.2 Commitment and rigour

Yardley (2017) asserts that commitment and rigour can be determined by in-depth engagement with the topic. Knowledge of the topic and IPA methodology were crucial factors for me as a researcher which enabled rigour to be enhanced. The sampling was purposive to ensure that participants were people with the lived experience of the phenomenon of study. Interviews were not timed, and participants were allowed to talk with minimal guidance from the semi structured questions on the interview schedule. To gain in-depth and rich data I collected participants' personal accounts, asked the appropriate questions and prompts to gather accurate reflections of their narratives, without biasing the data with personal subjectivity.

Despite Smith et al. (2022) stating that there is no right or wrong way to undertake IPA I worked very hard to try and achieve the best I could. I joined two IPA groups and attended several IPA discussion sessions, read IPA methodology papers, attended doctoral sessions and lectures in order to gain more knowledge on the methodology. I had the guidance from the doctoral supervisers throughout the process so that processes were followed inorder to produce this rich data. As a novice researcher the above factors were very supportive and important for the study to be of high quality.

Study rigour and quality was enhanced by using a conceptual framework that is well-developed, actively utilising rigorous peer review, and applying researcher reflexivity throughout the study's implementation (Johnson et al. 2020). The use of MTF defined and justified the research question, the methodology selected to answer that question, and the perspectives from which interpretation of results and conclusions were made. I ensured to control biases as explained in Chapter 3.4.5. and by using participants' words in reporting the findings and in the discussion. This ensured that my interpretations truly reflected participants' accounts through my reflection on their thoughts, actions, assumptions, and expectations. I shared the work I planned to complete, and the completed work with the supervisors which helped me to keep focused on the research and maintain openness and transparency.

6.3.3. Transparency

Transparency means that the reader should be able to see clearly how the interpretation was derived from the data (Smith et al, 2011; Yardley 2017).

I believe that this study has been logically presented and the reader can follow each step and processes implemented easily. An example is that the steps taken for idiographic analysis from the initial reading of transcript, identifying of PETs for each participant till identification of GETs are written. Pictures are also presented in appendices for the reader to have a clear picture of the process followed from PETs to GETs. Furthermore, (Johnson et al. 2020) claims that employing philosophical or epistemological stance and framework, the rationale for the methodological stance, means of data analysis and interpretations increases transparency.

6.3.4 Importance

Yardley (2017) explains that importance refers to the requirement for all research to generate knowledge that is useful in whatever way possible. I believe that this study has achieved importance because it was carried out on a phenomenon that is of interest in the world at this point and time.

6.4 Strengths and Limitations

The topic of YOD is a sensitive one and I anticipated that interviews would trigger reflecting on participants' negative emotions. Though a novice researcher, I have a vast experience and expertise as a mental health nurse specialising in the field of dementia. I drew upon the expertise when collecting data and managing the interview process e.g. about following up a line of questioning.

Within IPA participants should be able to discuss what is important to them, my experience allowed the participant to do this, and the result was rich data shared with me from pre-diagnosis stage. A key strength is that I had 'pre-understandings' and knowledge of the present situation, regarding YOD, and institutional (care homes and psychiatric wards) care. This helped me to develop research questions based on rich understandings of the issues needing investigation, providing information about what these institutions are like. These insights may not be as easy to uncover by an 'outsider' or someone without knowledge of psychiatric wards, care homes or YOD (Smyth & Holian, 2008).

However, my professional experience brought about the challenges of the 'insider' researcher in relation to rigour and potential for researcher bias. I had awareness of the potential conflicts of being an academic and researcher within the same context.

My researcher inexperience had impact on the amount of time I took to understand the IPA methodology, the processes and the interpretation of the complex data which was presented to me.

This study was carried out during the COVID-19 pandemic in 2021 which affected recruitment, sample numbers and led to delays. However, IPA accepts the use of small samples. I am aware that COVID-19 might have had an influence on the participants' experiences. Due to doctoral study timelines, I did not have an option to avoid the study occurring during the pandemic.
A strength was that as a result of the pandemic, I had the opportunity to recruit from around UK which makes transferability in UK settings possible.

6.5 Recommendations for practice

The findings of this study have identified important implications for practice and service provision. Furthermore, the findings have highlighted the importance of changing the mindset of professionals from focusing attention only on the person with YOD to thinking about the family therefore family centred care would be proposed.

Early introduction of named persons as recommended by NICE (2018) to coordinate care will help with example, case management within the context of a multidisciplinary team. This will improve transitions in care and enhance the families' quality of life. A named professional can lead in the proactive provision of information about YOD, possible difficulties and signposting to support services in third sector and support in responding to neuropsychiatric symptoms, thus may increase families 'competence and help to reduce or delay hospital admissions and care home placement.

Of importance is the need for collaborative working by all stakeholders interested in supporting people with YOD throughout the trajectory in order to allow for continuity of care and more effective outcomes.

6.6 Recommendations for education

The findings from this study strengthen the need for better education in the area of YOD across health and social care. In UK The Dementia Training Standards Framework is in existence which is commissioned by Health education England. The Framework is a resource which details the essential skills and knowledge necessary across the health and social care spectrum. Recommendations are that health and social care providers and third sector that support people with YOD, and families ensure all staff working with people with dementia have the core skills and knowledge of YOD as advised by the Prime minister’s challenge. Education should focus on awareness of the unique symptoms the person with YOD might present with, the knowledge of YOD, and the practical skills to support the person with YOD and family. People with YOD and their families, are also experts through experience so should work in partnership with professionals in the designing of education materials as well as delivering education sessions as much as possible.

6.7 Recommendations for research

I provide a study of five families of people with YOD, admitted to psychiatric dementia inpatient beds and discharge to care homes in UK. An unexpected finding is the concept of ‘*DIY dementia’*. The idea that a participant stopped reaching out to professionals for help when safety was compromised gives rise to the need for further investigation to determine if this is a wider issue or simply a local one.

This study has shed some insights into the far-reaching consequences of parental YOD for children as described by their other parent. Research studies exploring the experiences of children of people with YOD of different age groups in the moment and later in life as adults are recommended.

Having considered how Mary, her children and Tim were exposed to harm due to YOD symptoms I believe that patient confidentiality in YOD is an area that needs to be researched to understand what best practice would look like.

A psychiatric hospital / ward is a specialist area that provides specialist care provided by specialist trained professionals. I recommend research that focuses on experience of people with YOD and their families on these specialist areas which might guide in the discussions regarding specialist care homes. Research focusing on identifying what would constitute a specialised dementia care institution with focus on YOD is recommended as this question that each participant asked me directly.

6.8 Recommendations for policy makers.

Policies give some guidance on YOD care e.g. in forms of staff patient/ resident ratios to maintain safety. Policy makers to ensure that there is a clear pathway for people with YOD and their families. This pathway has to offer support specifically for young children / minors. There is need to involve people with YOD and families in compiling policies and gain the expertise from those with the lived experience of the condition.

Guidelines for funding for care in this age group needs to be reviewed taking into considerations that this age group has several other responsibilities that others have to take over such as maintaining mortgages, dependant children and at times caring for their own elderly parents.

6.9 Dissemination of findings

The plan is to reach as many people as possible in order to raise awareness on YOD, the issues identified in this study and stimulate discussions on the topic. To that effect I have the shown in table 10 below.

Table 10: Dissemination plan

Event / Audience	Date	Product	Status

1. Dementia UK Summer School.	2023	Transitions in Care presentation	Completed.
2. Health & Social care professionals	2024	Transitions in care presentation.	Completed.
3. Social media	2024	A blog on social media with support from Dementia UK	Plans in progress
4. Dementia UK Summer school.	2024	Impact of Young onset dementia on dependent children	Plans in progress

6.10 Summary

"If not for the carers, 80 or 90% of people with dementia would not be in their own homes, without the other people living in that house looking after them because there's not many who can stay at home or just have somebody popping in to keep an eye."

Mary's summary is a reminder of why this research is very important. It explains the need for understanding that the person with YOD and their families cannot be supported without considering the needs and presentation of the other.

This study shows that people living with YOD, and families tend to have complex needs, requiring support that crosses organisational and professional boundaries, impacting across all areas of social and family structures, wider communities and health and care systems.

In this research the participants had no warning so did not have contingency plans in place, in fact they were unprepared for the eventuality of YOD. They described an understanding of this however, said they would have valued to be supported by professionals in an empathetic way throughout the trajectory. They felt like they were going between coordinating the person with YOD's care while trying to live their own lives.

Though statistically the numbers of people diagnosed with YOD is increasing the lack of specialist care they require is highlighted by the fact that hospital re-admissions for unmet care needs are imminent.

I describe lengthy periods of trying to get a diagnosis, the lack of age-appropriate services for the whole family, long lengths of hospital stays, frequent moves from placements in institutional care on discharge, and some differences of service provision around the country.

The systems are such that various professional groups from different organisations support families attending to the changes and demands that transitions bring into the daily lives of their families. All these professionals should be in a position to prepare families for future transitions and facilitate the process of learning new skills related to YOD experiences.

Epilogue

I have been a 'serial student' according to a friend of mine after acquiring a BSc and an MSc. On completion I thought now, 'no more, I am done studying, it's too taxing'. A few months later I started working at a Clinical Research Facility and met someone who was just like me. She was studying for a Professional Doctorate at Cardiff University. It was hard, but she loved it. I was hooked. However, I did not have a firmed-up question at that time.

My initial idea, before COVID-19 was to explore the experiences of families of the transition from a psychiatric hospital to a care home. With COVID-19 everything changed. Recruitment through care home managers was impossible as they were inaccessible. The question was amended and so the research strategies to allow for wider geographical recruitment area as well as the recruitment procedure which meant I could now approach Young Dementia Networks. Although this meant waiting for ethical approvals, it was beneficial, as it gave me the opportunity to recruit from around UK.

On reflection the whole process from beginning to this stage I can confidentially say that I have learnt a lot about myself. The process has not been all straightforward. For different reasons I had a time or times when I just stopped and thought this is it. I have had many great times that motivated me to carry on especially from the family and supervising team. Some of the reflective notes I wrote in my diary give an idea of the ups and downs I have had through this journey.

Notes from my journal: 23/04/2023 My first 9months review preparation. *This is a daunting task! I have no clue what to expect. I hope they are nice people…well that's why I am doing it. I am learning so I will see. I am sure they will help me understand what I am doing. TW & JH would have said if everything was rubbish anyway.*

05/06/202: *I surprised me. I said things they agreed with and explained my topic no problem there. The advice from the review was helpful.*

•*Always have viva in head. I really want to do this.*

•*Justify IPA use in depth language. Differentiate IPA and phenomenology, language, idiographic approach and what is unique about IPA. Obviously not I didn't understand the methodology. I must go back to reading.*

•*I was asked questions about how I will get rich data. Happily, gave examples of how I would prompt for further information.*

Overall, I am happy with the review process. Reviewers were helpful in making me see areas I need to work harder on and I need to know more about IPA methodology.

However, my mindset changed from the time I contacted the first potential participant the way they welcomed the topic made me realise I should probably carry on. The first interview confirmed to me that I had to get to share the results as widely as possible. When I informed the participant about the use of pseudonyms in the research I was surprised by her response. The majority said they were happy for me to use their real names. One participant sent me a video of himself and his wife who is the person with the diagnosis and gave consent for me to share as widely as possible. Hearing this made me think I had to do this right and share these stories as widely because all participants said this was the reason for taking part. I promised the participants that I would do my best to raise awareness of YOD and their needs using their stories.

It felt like I suddenly joined a campaign, and I couldn't stop now. I was lucky to be the one to be told the stories because I was undertaking research and that the findings of that research would be shared with the wider health and social care community with the aim of improving the transition experience for families with YOD in future. It would be disrespectful and unethical of me to gather this data and then not done as they wished. I couldn't stop-full stop.

Personally, I experienced a range of emotions and thoughts when I undertook the interviews and listened to the audio recordings, which working in the field for many years, I expected however this was too much. This happened with every interview that was completed. For example, I felt sad for Alana that she was now living alone, not travelling as she used to, and also felt pleased that she had found herself a church. Perhaps my experience of being a Christian or belonging to a church gives someone friends, and people that are good at listening. The support I receive from my church is invaluable whenever I have a problem and so I thought she would find that too.

I was angry and disappointed that the ward staff appeared to have failed Ellen and her family when they did not organise for the safe return of Amir to the ward following failed trial at home. I found myself questioning, why they didn't do that because he was still their patient. The police incident made me very cross. I thought about the media coverages of young men of ethnic minority origins being abused by the police, the stories I hear very often as a mother to a black boy. I wondered if race had something to do with the attitudes of the police had played a part. Then again, I thought about the training the police receive. Would that training give them confidence and competence to support someone as distressed as Amir.

Mary’s interview made me very upset probably because as a mother listening to a sad story being told by another mother. After the interview I sat listening to the recording several times and wondered how these children will turn out to be in their middle and older ages. Their childhood was too sad that I don’t think even the friends they meet in universities will believe them. I kept thinking that I will not be one of those nurses / professionals who fail to raise alarm when there is need.

Maxwell’s interview was somewhat difficult to understand. On supervision post this interview one of the supervisors commented on the transcript and said, “He spoke like he was concerned about rescuing the system”. Maxwell seemed like he was not overly concerned about his feelings, emotions and wanted to find solutions the health and social care system to be made perfect. I went back to the transcript and recording, the emails he had forwarded to me several times to get “the emotional and human being”. I also thought maybe this is because he is a man. People say men need to be strong and not show emotions lest they are labelled weak. My conclusion was that I had to dig deeper and listen to the ‘deep’ voice, observe actions, and then I saw the agony. This was a man looking for a third care home in the space of less than two years. He wished for a safe place for his wife.

Contrary to Maxwell, Thomas was open with his emotions. This was the only phone call interview. In my notes I wrote ‘devastated man, hurt, couldn’t cope from before the diagnosis-should be painful’. I had a picture of him and his wife in my head because he had sent me a video of them supporting a hospital ward or care home raising awareness of YOD. They both looked young in that video clip.

Thank God, I had considerable experience working with families living with dementia and YOD in the acute inpatients, psychiatric wards, community, care homes, and voluntary sectors, as well as that I had a strong supportive supervising team. I found the interviews disappointing as a professional listening to what was supposedly behaviours of my fellow professionals. With every interview brought up points that bothered me and I needed to keep reminding myself that I was a researcher and not a nurse, mother, or wife during the interviews.

Here is a summary of reflective piece that I wrote after all the interviews, ‘Strong characters all participants e.g. they end, “I have said everything, if I think of anything, I will email you”. Another said, “That is all I can think of now. I have your phone number; I can phone you right?”. “I can’t think of anything now. Obvious I will remember as soon as we end the call”.

On reflection I look at these statements that didn’t mean much at the time, then I consider the amount of time each interview took (scheduled 90minutes each ended up being 2hours or more on Zoom and over and hour on the phone) and I think they just wanted someone to listen. They found someone very interested to listen so they could tell it all with no judgment and minimal interactions. I never gave the impression that I needed to stop or leave or even needed a break. They led the conversation and asked for breaks when they needed that. Afterall, IPA gives a voice to the person living the experience and they can talk about their situation as much as they want as long as it is related to the topic.

I also wrote, ‘participants came with questions, challenging and personal e.g. asking me, “have you read such and such books?”. Books on YOD, just as well I know something about Wendy Mitchell. I know something they know, maybe that showed my interest in the topic?

My third was very emotive to me as a parent hearing how another parent took what should have been very difficult decisions to protect the children, she loved so much from a man she also loved so much-really tough to imagine-no imagining though, this happened.

Even when they (participants) couldn’t remember the dates, they remembered every detail about how they were handled, how they felt at the time. Even Tim for whom it had been a few years since hospital admissions, he recounts every detail.

This was on the 17 March 2021.

I am a researcher with a biography, who speaks form a particular class, gendered, racial, cultural perspective, an immigrant. I approach the world with a set of ideas. As a researcher I hold to the belief that the individuals living in the world of being a family are able to report their experiences and with this I can blend my own observations with the self-reports provided by participants through interviews (Denzel and Lincoln 2015 p12). Final: This does not make me an expect if I forget these families. I guess what I meant to tell myself was that the participants were the experts in their own lives.

Fast forward, supervision meeting 11/12/2023.

Supervising team very encouraging. The comments on the data are fantastic! I did a good job. Discussions were very good. Seemed a century ago when first 9month reviewers advised me to always think viva in my head. Anna said this is the hardest part now, no time to waste.

Plan agreed today:

- Final draft to supervising team by 30th January 2024. Final submission before March 2024.
- Mock viva end of April or start of May.
- Examiners search in progress.
- To confirm if viva face to face.

I am excited and anxious at the same time.

References:

Ahmed, R.M., Paterson, R.W., Warren, J.D, et al. 2014. Biomarkers in dementia: clinical utility and new directions. J *Neurol Neurosurg Psychiatry*. **85** pp 1426–1434.

American Psychiatric Association. 2013. *Diagnostic and statistical manual of mental disorders.* 5th edition. Washington, DC: Author

Aveyard, H. & Sharp, P. 2017. *A beginner's guide to evidence-based practice in health and social care*, London, McGraw-Hill Education (UK).

Ballard, C., Mobley, W., Prof John Hardy, J. et al. 2016. Dementia in Down's syndrome*. The Lancet Neurology.* **15** (6) pp 622-636 DOI: https://doi.org/10.1016/S1474-4422(16)00063-6

Barnes, D.E. and Yaffe, K. 2011. The projected effect of risk factor reduction on Alzheimer's disease prevalence. *The Lancet Neurology* **10** (9) pp 819-828.https://doi.org/10.1016/S1474-4422(11)70072-2.

Ballenger, J.F.2017.Framing Confusion: Dementia, Society, and History. HISTORY OF MEDICINE.*AMA Journal of Ethics.***19**, (7) pp 713-719

Bechtold, N.C. and Cotman, C.W.1998. Evolution in the Conceptualization of Dementia and Alzheimer's Disease: Greco-Roman Period to the 1960s. Neurobiology of Aging. **19**, (3) Pp 173-189. https://doi.org/10.1016/S0197-4580(98)00052-9 .

Beh, S.C., Muthusamy, B., Calabresi, P, et al. 2015. Hiding in plain sight: a closer look at posterior cortical atrophy. *Practical Neurology* **15**:5-13.

Bakker,C., de Vugt, M.E., van Vliet, D., Frans R.J. et al. 2013. Predictors of the Time to Institutionalization in Young- Versus Late-Onset Dementia: Results from the Needs in Young Onset Dementia (NeedYD) Study. Journal of the American Medical Directors Association. 14, 4, P248-253, https://doi.org/10.1016/j.jamda.2012.09.011

Berger, R. 2015. Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research,* **15**(2), 219–234.

Bogousslavsky J, Boller F, Iwata M .2019. A History of Neuropsychology. Front Neurol *Neurosci. Basel, Karger.***44,** pp118–126 (DOI:10.1159/000494959).doi: 10.1159/000494959

Boller F, Forbes MM. 1998.History of dementia and dementia in history: an overview. *J Neurol Sci.***158**(2):125-33. doi: 10.1016/s0022-510x (98)00128-2. PMID: 9702682.

British Association for Sexual Health and HIV.2017. Available at: https://www.bashh.org/news/blogging-4-bashh/sexual-health-what-happened-100-years-ago-was-remarkable/ [accessed 18/01/2021].

Buhr, G.T., Kuchibhatla, M. and Clipp, E.C. 2006. Caregivers' Reasons for Nursing Home Placement: Clues for Improving Discussions with Families Prior to the Transition. *The Gerontologist,* **46**; 1, 1 pp52-61 https://doi.org/10.1093/geront/46.1.52 [accessed 08/05/2022].

Burns, A. and Robert, P. 2017.The National Dementia Strategy in England. *BMJ* 338: b931.

Cahill, S.2018. WHO's Global Action Plan on the Public Health Response to Dementia (2017-2025): Some Challenges and Opportunities. Journal: *Ageing and Mental Health*

Caron, C., Ducharme, F., & Griffith, J. (2006). Deciding on Institutionalization for a Relative with Dementia: The Most Difficult Decision for Caregivers. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement,* **25**(2), 193-205. doi:10.1353/cja.2006.0033

Carter, J.E., Oyebode, J.R. & Koopmans,R.T.C.M. 2018. Young-onset dementia and the need for specialist care: a national and international perspective. *Aging & Mental Health.* **22**:4, 468-473, DOI: 10.1080/13607863.2016.1257563

Chan, D., Livingston, G., Jones, L., et.al. 2013.Grief reactions in dementia carers: A systematic review. *International Journal of Geriatric Psychiatry*. **28**:1–17. doi: 10.1002/gps.3795.

Critical Appraisal Skills Programme (2022). CASP. [online] Available at: https://casp-uk.net/casp-tools-checklists/ [Accessed 01/09/2023]

Creswell, J.W. and Poth, C.N. 2018.*Qualitative Inquiry and Research Design Choosing among Five Approaches*. 4th Edition. SAGE Publications, Inc., Thousand Oaks.

Crotty, M. 1998. *The foundations of social research: Meaning and perspective in the research process*. London: Harvester.

Crutch, S.J., Schott, J.M., Rabinovici, G.D., et al. 2017. Consensus classification of posterior cortical atrophy. *Alzheimer's & Dementia*, **13**: 870-884. https://doi.org/10.1016/j.jalz.2017.01.014

Dabhi,R., Mehta,R., Paneri, j. et al. 2023.Determination of neuroprotective effects of medium chain fatty acids and their derivatives on mutant huntingtin aggregates, oxidative stress and ATP levels in HD150Q cell line model of Huntington's disease. *Indian Journal of Biochemistry & Biophysics.* **60,** pp. 741-749 DOI: 10.56042/ijbb.v60i9.4047

Desai, P. and Bandopadhyay, R. 2020. Pathophysiological implications of RNP granules in frontotemporal dementia and ALS. *Neurochem Int* 140.doi: 10.1016/j.neuint.2020.104819.

De Brún, C., & Pearce-Smith, N. 2013. *EBMT-EBM Toolkit Ser.: Searching Skills Toolkit: Finding the Evidence* (2). Somerset, GB: John Wiley & Sons, Incorporated.

Dowling, M.2011.Hermeneutics: an exploration. *Nurse Researcher;* **11** (4) pp 30–41

Department of Health. 2001.*National Service Framework for Older People*. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAnd Guidance/DH_4003066. [accessed 18/06/2022]

Department of Health. 2009. *Living well with dementia - a National Dementia Strategy*. Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123475.pdf. [18/06/2022].

Department of Health .2009. *Living well with dementia: A National Dementia Strategy Annex 1, World Class Commissioning Guidance for Dementia.* Online: Available at http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/National

DementiaStrategy/DH_083358. Google Scholar[Accessed 18/11/2020]

Department of Health.2015. *Challenge on dementia 2020*. Online: Available at: https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020 [accessed 23/11/2020].

Ericsson, I., Kjellström, S., Hellström, I. 2013. Creating relationships with persons with moderate to severe dementia. *Dementia* (London). **12**(1):63-79. doi: 10.1177/1471301211418161. Epub 2011 Oct 9. PMID: 24336663; PMCID: PMC4268479.

Eyigoz,E., Mathur,s., Santamaria,M. 2020 Linguistic markers predict onset of Alzheimer's disease, E*ClinicalMedicin*e https://doi.org/10.1016/j.eclinm.2020.100583E

Gaebel, W., Jessen. F., Kanba. S. et al. 2018. Neurocognitive disorders in ICD-11: the debate and its outcome. *World Psychiatry*. **17**(2) pp 229-230. doi:10.1002/wps.20534

Edmans, B.G., Wolverson, E., Dunning, R. (2022), Inpatient psychiatric care for patients with dementia at four sites in the United Kingdom. *Int J Geriatr Psychiatry,* **37**: https://doi.org/10.1002/gps.5658

Gaugler, J.E., Duval, S., Anderson, K.A.2007.predicting nursing home admission in U.S.: a meta-analysis. BMC *Geriatrics* .**7**,13. Doi:10.1186/1471-2318-7-13

Gaugler, J.E., Mittelman, M.S., Hepburn, K.,et al. 2009. Predictors of change in caregiver burden and depressive symptoms following nursing home admission. *Psychol Aging.* **24**(2):385-96. doi: 10.1037/a0016052. PMID: 19485656; PMCID: PMC2699253

Gaugler, J. E., Mittelman, M. S., Hepburn, K., & Newcomer, R. 2010. Clinically significant changes in burden and depression among dementia caregivers following nursing home admission*. BioMed Central Medicine*, **8**(1), 85.

Gaudet, S. & Robert, D. 2018. *A Journey Through Qualitative Research From Design to Reporting*. SAGE Publications Ltd: Canada

Gov.uk. 2024. *National Partnership Agreement: Right Care, Right Person (RCRP).* Available at: https://www.gov.uk/government/publications/national-partnership-agreement-right-care-right-person/national-partnership-agreement-right-care-right-person-rcrp [accessed 15/07/2024].

Goel, R .2022. "Grandma got arrested: Police, excessive force, and people with dementia." *U. Rich. L. Rev*. 57: 335.

Sun, F., Gao, X., Brown, H., et al. 2019. Police officer competence in handling Alzheimer's cases: The roles of AD knowledge, beliefs, and exposure. *Dementia.* 18(2):674-684. doi:10.1177/1471301216688605

Greenhalgh, T., Thorne, S., Malterud, K. 2018.Time to challenge the spurious hierarchy of systematic over narrative reviews? *Eur J Clin Invest*. **48**:e12931. https://doi.org/10.1111/eci.12931

Haider, A., Spurling, B.C., Sánchez-Manso, J.C. 2023. *Lewy Body Dementia.* In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2023 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK482441/

Hao, Z., Ruggiano. N. 2020. Family-centeredness in dementia care: what is the evidence? *Soc Work Health Care.* **59**(1):1-19. doi:0.1080/00981389.2019.1690089.

Harrison, J., MacArthur, J., Garrido, A.G., Logan, G. et al. 2017. New institutionalisation following acute hospital admission: a retrospective cohort study. *Age and Ageing;* **46**: 2 pp 238-244.

Harper, L., Barkhof, F., Scheltens, P. et al. 2014. An algorithmic approach to structural imaging in dementia. *Journal of Neurology, Neurosurgery & Psychiatry* 85:692-698.

Harman, G., and Clare, L. 2009. Illness Representations and Lived Experience in Early-Stage Dementia. *Qualitative Health Research*. **16**(4):484-502. doi:10.1177/1049732306286851

Huneman, P. 2017. From a religious view of madness to religious mania: the Encyclopédie, Pinel, Esquirol. *History of Psychiatry.***28**(2):147-165. doi:10.1177/0957154X17690301

Hodgson. H., Grimm. F., Vestesson. E., et al. 2021. *Adult social care and COVID-19: Assessing the impact on social care users and staff in England so far* | *The Health Foundation* [online]. Available at: https://doi.org/10.37829/HF-2020-Q16 [Accessed 10/12/2023].

Johannessen, A., Helvik, A-S., Engedal, K., Thorsen, K. 2017. Experiences and needs of spouses of persons with young-onset frontotemporal lobe dementia during the progression of the disease. https://doi.org/10.1111/scs.12397

Johnson, J.L., Adkins, D., Chauvin, S. 2020. A Review of the Quality Indicators of Rigor in Qualitative Research. *Am J Pharm Educ.* **84**(1):7120. doi: 10.5688/ajpe7120. PMID: 32292186; PMCID: PMC7055404.

Kaplan, M., and Henderson. 2000. Solomon Carter Fuller, M.D. (1872-1953): American Pioneer in Alzheimer’s disease Research. Journal Of History of Neurosciences. **9** (3) pp 250- 261.

Kilty,C., Boland, P., Goodwin, J et al. 2019. Caring for People With Young Onset Dementia: An Interpretative Phenomenological Analysis of Family Caregivers'

Experiences. *Journal of Psychosocial Nursing and Mental Health Services,* ***57***(11):37–44. https://doi.org/10.3928/02793695-20190821-02

Khan, I., De Jesus, O. 2023. *Frontotemporal Lobe Dementia*. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2023 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK559286/

Koch, T. and Iliffe, S.2011. *Implementing the National Dementia Strategy in England: Evaluating innovative practices using a case study methodology*. Online: available at: https://doi.org/10.1177/1471301211417169 [accessed 20/11/2020]

Kwok., Loy.C.T., Stone.C.D. et al. 2020.The complex relationship between genotype, pathology and phenotype in familial dementia. Neurobiology of Disease. 145. https://doi.org/10.1016/j.nbd.2020.105082

Koch, M., DeKosky, S.T., Goodman. M., et al.2020. Association of Apolipoprotein E in Lipoprotein Subspecies with Risk of Dementia. *Neurology* **3**(7). doi:10.1001/jamanetworkopen.2020.9250

Kuruppu D.K. and Matthews B, R. 2013.Young Onset Dementia. *Semin Neurology.* **33** (4) pp 365-385 doi:10.1055/s-0033-1359320.

Lamech N, Raghuraman S, Vaitheswaran S, Rangaswamy T. 2019. The support needs of family caregivers of persons with dementia in India: Implications for health services. Dementia. **18**(6):2230-2243. doi:10.1177/1471301217744613

Large, S., Slinger, R. 2013.Grief in caregivers of persons with Alzheimer's disease and related dementia: A qualitative synthesis. *Dementia.* **0**(0):1–20. doi: 10.1177/1471301213494511. [PubMed] [CrossRef] [Google Scholar]

LCWG, Llywodraeth Cymru Welsh Government .2018. Dementia Action Plan for Wales, 2018-2022

Lindauer, A., Harvath, T.A. 2014.Pre-death grief in the context of dementia caregiving: a concept analysis. *Journal of Advanced Nursing.* 1–12. doi: 10.1111/jan.12411. [PubMed] [CrossRef] [Google Scholar]

Livingston, G., Sommerlad, A., Orgeta, V. et al. 2017.Dementia prevention, intervention, and care. *Lancet.* **390** pp 2673-2734.

Livingston, G., Huntley, J., Andrew Sommerlad, A. et al. 2020. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*. **396** pp 413-46

Levers, M.J. D. 2013. Philosophical Paradigms, Grounded Theory, and Perspectives on Emergence. SAGE Open, **3**(4). https://doi.org/10.1177/2158244013517243

London Dementia Clinical Network (2018) London Memory Service Clinical Audit http://www.londonscn.nhs.uk/wp-content/uploads/2017/03/dem-audit-150317.pdf [accessed [16/07/2023]

Luengo-Fernandez, R. & Landeiro, F. (in preparation). The Economic Burden of Dementia in the UK. Available online at: https://www.alzheimersresearchuk.org/wp-content/uploads/2023/07/Economic-Value-of-Dementia-Research-July-2023.pdf. [Accessed 10 July 2023.

Marotta, N.P., Ara, J., Uemura, N. *et al.* 2021.Alpha-synuclein from patient Lewy bodies exhibits distinct pathological activity that can be propagated in vitro. *acta neuropathol commun* **9**, 188 https://doi.org/10.1186/s40478-021-01288-2

Mehta, K.M., Yeo, G.. W. 2017. Systematic review of dementia prevalence and incidence in United States race/ethnic populations. *Alzheimers Dement.* **13**(1):72-83. doi: 10.1016/j.jalz.2016.06.2360

Mayrhofer, A., Mathie, E., McKeown,J. et al. 2018. Age-appropriate services for people diagnosed with young onset dementia (YOD): a systematic review, *Aging & Mental Health,* **22**:8, 933-941, DOI:10.1080/13607863.2017.1334038

Marte et al. 2019. ‘The Prevalence and Subtypes of Young Onset Dementia in Central Norway: A Population-Based Study’. **1**.479 – 487.

Mastwyk, M., Dow, B., Ellis, K. A., Ames, D. 2016. Why attend a memory clinic? What do patients and their families want and/or expect? *Australasian Journal on Ageing,* **35**(3), 220–224. https://doi.org/10.1111/ajag.12257

Merl, H., Doherty, V. K, Salmon, K. 2022. Truth, hope and the disclosure of a dementia diagnosis: A scoping review of the ethical considerations from the perspective of the person, carer and clinician. *Dementia*. **21**(3):1050-1068. doi:10.1177/14713012211067882

Millenaar, JK., van Vliet, D., Bakker, C et al. 2014. The experiences and needs of children living with a parent with young onset dementia: results from the NeedYD study. *International Psychogeriatrics*. **26**(12):2001-2010. doi:10.1017/S1041610213001890

Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G. 2009.The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* **6**(7): e1000097. doi:10.1371/journal. pmed1000097

Meleis, A.I. & Trangenstein, P.A. 1994. Facilitating transitions: redefinitions of the nursing mission. *Nursing Outlook* **42**(6), 255– 259.

Meleis, A. I. et al. 2000. Experiencing transitions: An emerging middle-range theory. Advances in Nursing Science, **23**(1), 12–28. https://doi.org/10.1097/00012272-200009000-00006

Merl, H., Doherty, V. K., Alty, J., Salmon, K. 2022. Truth, hope and the disclosure of a dementia diagnosis: A scoping review of the ethical considerations from the perspective of the person, carer and clinician. *Dementia.* **21**(3):1050-1068. doi:10.1177/14713012211067882

Natalwala, A., Potluri, R., Uppal, H., et al. 2008. Reasons for hospital admissions in dementia patients in Birmingham, UK, during 2002-2007. *Dement Geriatr Cogn Disord*. **26**(6):499-505. doi: 10.1159/000171044.

NICE. (2018); [NG97] *Dementia: assessment, management and support for people living with dementia and their carer*. Available from: www.nice.org.uk/guidance/ng97. [Accessed 22, November 2022]. [PubMed] [Ref list]

National Health Services. 2017. *Implementation guide and resource pack for dementia care*. pp5–9.

National Collaborating Centre for Mental Health.2018. *The Dementia Care Pathway. Full implementation guidance*. London: National Collaborating Centre for Mental Health.

National Health Services England. 2019. The NHS Long Term Plan. Online: Available at: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf [accessed 20/11/2020].

Nicolaas. J.M.A., Walvoort, S.J., and Kessels.R.P.C .2017. Korsakoff's syndrome: a critical review. *Neuropsychiatric Dis Traet*. **13** pp 2875-2890. Doi:10.2147/NDT.S130078.

Nicolas, G., Wallon, D., Charbonnier, C. et al. 2016.Screening of dementia genes by whole-exome sequencing in early-onset Alzheimer disease: input and lessons. *Eur J Hum Genet* **24** pp 710–716. https://doi.org/10.1038/ejhg.2015.173

Nursing and Midwifery Council (2018). The Code. Available online at: www.nmc.org.uk/code.[accessed 15/07/2024].

Office for National Statistics. 2020. *Deaths involving COVID-19 in the care sector, England and Wales* - [online]. Available at : https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/deathsoccurringupto12june2020 andregisteredupto20june2020provisional [Accessed 10/12/2023]

Osanloo, A, and Grant, C. 2016. "Understanding, Selecting, and Integrating a Theoretical Framework in Dissertation Research: Creating the Blueprint for Your 'House.'" *Administrative Issues Journal: Connecting Education, Practice, and Research* **4** (2).

Palinkas, L.A. 2014. Qualitative and Mixed Methods in Mental Health Services and Implementation Research, *Journal of Clinical Child & Adolescent Psychology,* **43**:6, 851-861, DOI: 10.1080/15374416.2014.910791

Paulsen, J.S. 2011. Cognitive Impairment in Huntington Disease: Diagnosis and Treatment. *Curr Neurol Neurosci Rep.* **11**(5) pp 474–483. doi: 10.1007/s11910-011-0215-x

Pinner, G., Bouman, W. P. 2003. Attitudes of patients with mild dementia and their carers towards disclosure of the diagnosis. *International Psychogeriatrics/IPA*, **15**(3), 279–288. https://doi.org/10.1017/S1041610203009530

Powell and Baker. 2019. *Dementia: policy, services and statistics.* Online: Available at: https://commonslibrary.parliament.uk/research-briefings/sn07007/ [accessed 19/11/2020].

Popay,J., Roberts,H., Sowden,A., et al. 2006. *Guidance on the Conduct of Narrative Synthesis in Systematic Reviews.* A Product from the ESRC Methods Programme. Swindon. ESRC.

Punch, K.F.1998. *Introduction to Social Research: Quantitative and Qualitative Approaches*. Sage, London.

Prince, M. J., Comas-Herrera, A,. Knapp, M, et al. 2016. *World Alzheimer Report 2016 - Improving healthcare for people living with dementia: Coverage, quality and costs now and in the future.* Alzheimer’s Disease International.

Pringle, J., Drummond.J, McLafferty.E, and Hendry.C.2011.Interpretative Phenomenological Analysis: A Discussion and Critique. *Nurse Res,* **18** (3) pp 20-4 PMID: 21560922 DOI: 10.7748/nr2011.04.18.3.20.c8459

Reinners, G.M. 2012. Understanding the Differences between Husserl’s (Descriptive) and Heidegger’s (Interpretive) Phenomenological Research.

Rabanal, L.I., Chatwin, J., Walker, A, et al. 2018. Understanding the needs and experiences of people with young onset dementia: a qualitative study. *BMJ Open*. doi:10.1136/ bmjopen-2017-021166

Regan, M. 2016. *The interface between dementia and mental health: an evidence review*. London: Mental Health Foundation.

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

Roache, P. and Keady, J. 2008. Young People with Dementia: Time for Fair Play. Comment Piece. *British Journal of Nursing,* **17**, 690. http://dx.doi.org/10.12968/bjon.2008.17.11.29604

Sanders, S., Ott, C.H., Kelber, S.T., Noonan, P. 2008.The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies*. **32**:495–523. doi: 10.1080/07481180802138845.

Santos, C.Y., Snyder, P.J., Wu,W-C. et al 2017. Pathophysiologic relationship between Alzheimer's disease, cerebrovascular disease, and cardiovascular risk: A review and synthesis. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*. **7** pp 69-87. https://doi.org/10.1016/j.dadm.2017.01.005

Sikorska, B., Knight, R., Ironside, J.W.,et al. 2012. Creutzfeldt-Jakob Disease. In: Ahmad, S.I. (eds) neurodegenerative diseases. *Advances in Experimental Medicine and Biology,* vol 724. https://doi.org/10.1007/978-1-4614-0653-2_6

Schur. D., and Whitlatch. C. J.2003. Circumstances leading to placement: a difficult caregiving decision. *Journal: Lippincott's Case Management* **8**(5), pp. 187-197

Seidman, I. 2006. *Interviewing as qualitative research: a guide for researchers in education and the social sciences*. United Kingdom: Teachers College Press.

Schumacher, K. L., Meleis, A. F.1994. Transitions: A central concept in nursing. *Journal of Nursing Scholarship,* **26**(2), 119–127. https://doi.org/10.1111/j.1547-5069.1994.tb00929.x

Silverman, D. 2014. *Interpreting Qualitative Data. Methods for Analysing Talk, Text, and Interaction*. London: SAGE Publications.

Smith, J.A (2011) Evaluating the contribution of Interpretative Phenomenological Analysis. *Health Psychology Review*. Vol. 5, no. 1, pp. 9-27.

Smith, J.A and Osborn, M. (2003) Interpretative Phenomenological Analysis. In Smith, J.A (ed) Qualitative Psychology: A Practical guide to research methods. London, Sage.

Smith, J. A., and Osborn, M. 2007. *Interpretative phenomenological analysis.* In J.A. Smith. (2nd Ed), Qualitative Psychology. London: Sage.

Smith, J. A.2009. *Interpretative phenomenological analysis: theory, method, and research.* Los Angeles: SAGE.

Smith, J.A., Flower, P., and Larkin, M .2009. *Interpretative phenomenological analysis: theory, method, and research*. Sage Publishing, USA.

Smith, J.A., Flower P, Larkin M .2012. *Interpretative phenomenological analysis: theory, method and research.* Sage Publishing, USA.

Smith, J.A., Flowers, P. & Larkin, M. 2022. *Interpretative Phenomenological Analysis: Theory, Method, and Research* (2nd ed.). London, England: Sage.

Smyth, A., & Holian, R. 2008. *Credibility issues in research from within organisations.* In P. Sikes & A. Potts (Eds.), Researching education from the inside. Investigations from within (pp. 33–47). New York, NY: Routledge

Stark, M. R. 2020. *Cognitive impairment and conversion to dementia in Parkinson's disease: an imaging study of amyloid PET and diffusion MRI* (Thesis, Doctor of Philosophy). University of Otago. Retrieved from http://hdl.handle.net/10523/10460

Stamou, V., La Fontaine, J., O'Malley, M., et al. 2021. The nature of positive post diagnostic support as experienced by people with young onset dementia, *Aging & Mental Health*, **25**:6, 1125-1133, DOI: 10.1080/13607863.2020.1727854

Stewart W. 2021. Sport associated dementia BMJ 2021; 372: n168 *doi:10.1136/bmj.n168*

Scottish Government. 2017.*National dementia strategy: 2017-2020*.Online: https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/pages/5/ [Accessed 20/11/2020]

Stuckey, J.C and Gwyther, L.P. .2003. Dementia, religion, and spirituality **2**(3) 291-297

Stuckey, J.C. (2001). Blessed assurance: the role of religion and spirituality in Alzheimer's disease caregiving and other significant life events. *Journal of Aging Studies,***15,** 69–84.

Sullivan, P. 2012. *Qualitative data analysis using a dialogical approach*. London: Sage.

Swan J. 2012.From pottery to plays: arts activities in the home. *Nursing & Residential Care*. **14** (4), 195–198.

Svanberg,E. ,Stott,J., Spector, A. 2010. 'Just Helping': Children living with a parent with young onset dementia, Aging & Mental Health, 14:6, 740-751, DOI: 10.1080/13607861003713174

Taheri-Targhi ,S, Gjedde A, Araj-Khodaei M, et al. 2019. Avicenna (980-1037 CE) and his Early Description and Classification of Dementia. *J Alzheimers Dis*.**71**(4):1093-1098. doi: 10.3233/JAD-190345. PMID: 31524162.

Uwagbai, O., Kalish, V.B. 2022. Vascular Dementia. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Available from: https://www.ncbi.nlm.nih.gov/books/NBK430817/

Vieira, RT., Caixeta, L., Machado, S, et al. 2013. Epidemiology of early-onset dementia: a review of the literature. *Clin Pract Epidemiol Ment Health*. **14**; (9), 88-95. doi: 10.2174/1745017901309010088. PMID: 23878613; PMCID: PMC3715758.

Wahlund, L-O., Westman, E., van Westen, D. et al. 2017. Imaging biomarkers of dementia: recommended visual rating scales with teaching cases. From the Imaging Cognitive Impairment Network (ICINET) *Insights Imaging*. **8**(1) pp 79–90. doi: 10.1007/s13244-016-0521-6

Welsh Government.2016. *Together for Mental Health Delivery Plan:2016-19*.

Online: Available at: https://gov.wales/sites/default/files/consultations/2018-01/160118documenten.pdf [accessed 22/11/2020].

Welsh Government. 2018. *New Plan to transform dementia care in Wales.* Online: Available at: https://gov.wales/new-plan-transform-dementia-care-wales-0 [accessed 23/11/2020].

Willson, R. 2019. Transitions theory and liminality in information behaviour research: Applying new theories to examine the transition to early career academic. *Journal of Documentation*, **75**(4), 838– 856.

Willig, C. 2008. Introducing Qualitative Research in Psychology. 2nd ed. Open University. Maidenhead. https://resv.hums.ac.ir/uploads/introducing_qualitative_research.pdf

Yaffe, K., Fox, P, Newcomer, R., et al.2002. Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA* **24**;287(16):2090-7. doi: 10.1001/jama.287.16.2090. PMID: 11966383.

Yardley, L. 2017. Demonstrating the validity of qualitative research, *The Journal of Positive Psychology,* **12**:3, 295-296, DOI: 10.1080/17439760.2016.1262624

Wertz, F.J., 2011. *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry*. Guilford Press.

Appendices:

Appendix 1: Search strategy.

B. Search History on PsycINFO and CINAHL

	Source	**criteria**	**Results**
1	PsycINFO	(("early onset" OR "young onset") ADJ3 (dementia? OR alzheimer*)).ti,ab	1050
2	PsycINFO	exp DEMENTIA/	72744
3	PsycINFO	("early onset" OR "young onset").ti,ab	8514
4	PsycINFO	(2 AND 3)	1473
5	PsycINFO	"PRESENILE DEMENTIA"/	281
6	PsycINFO	(1 OR 4 OR 5)	1846
7	PsycINFO	(impact? OR experienc* OR family* OR families OR effect? OR perception? OR relationship? OR spous* OR caregiver? OR attitud*).ti,ab	2551026
8	PsycINFO	(6 AND 7)	903
9	PsycINFO	("nursing home" OR "care home" OR residential OR institution*).ti,ab	129965
10	PsycINFO	"RESIDENTIAL CARE INSTITUTIONS"/ OR "NURSING HOMES"/ OR "GROUP HOMES"/	20528
11	PsycINFO	(9 OR 10)	135277
12	PsycINFO	(6 AND 7 AND 11)	27
13	CINAHL	(("early onset" OR "young onset") ADJ3 (dementia? OR alzheimer*)).ti,ab	565
14	CINAHL	exp DEMENTIA/	62357
15	CINAHL	("early onset" OR "young onset").ti,ab	7368
16	CINAHL	(14 AND 15)	623
17	CINAHL	"DEMENTIA, PRESENILE"/	70
18	CINAHL	(13 OR 16 OR 17)	785
19	CINAHL	(impact? OR experienc* OR family* OR families OR effect? OR perception? OR relationship? OR spous* OR caregiver? OR attitud*).ti,ab	1468276
20	CINAHL	(18 AND 19)	364
21	CINAHL	("nursing home" OR "care home" OR residential OR institution*).ti,ab	107081
22	CINAHL	"RESIDENTIAL FACILITIES"/ OR "NURSING HOMES"/ OR "RESIDENTIAL CARE"/	29518
23	CINAHL	(21 OR 22)	123858
24	CINAHL	(18 AND 19 AND 23)	26

Appendix 2: Synthesis grid

	Author, Year of Publication Country, Aim of study, Source of data,	**Sampling**	**Design & Methods**	**Findings**	**Critical comments**
1	Mayrhofer et al. 2018 UK Aims: Explored Age-appropriate services for people diagnosed with YOD. To understand the range of post-diagnostic service needs and service provision and the service users' perceived effectiveness of services, Source*: Aging & Mental Health,*	Review of 20 papers.	systematic review guided by service users. Group discussions with patient and public involvement (PPI) representatives (people with YOD and their carers) held and led to question.	Findings identified;1. Fragmented services, geographically dispersed, variable, and often short-term due to project-based commissioning or as pilot studies or demonstration projects. 2. Newly diagnosed individuals perceived services at the point of diagnosis as useful if they were informative, educational, and able to signpost to community-based support. 3.Approaches to involving individuals living with YOD and their carers in the design of age-appropriate services underexplored.4. Barriers to accessing services were identified.	A strength is that the review question was directed by service users and families, as well as PPI group. Appraisal of used papers.
2	Bur et al. 2006 USA Aims were to identify reasons for institutionalisation as stated by carers of patients with dementia. Examine the relationship between carers' reasons for institutionalisation and indicators of carer	A sample of 2,200 informal carers of elderly veterans with dementia. 580 placed people they cared for in care during over the 3 years of	A 4-year National Longitudinal Study. Initial surveys in 1998, and follow-ups were sent in 1999, 2000, and 2001.	Findings were grouped as carer reasons for placement and predictors of the placement. The most common reasons were 1. needed more advanced or skilled care (n=373 (65%), 2. Carer's health (n=278 (49%), 3.PWD's	Specific group of PWD-veterans. Self-reported data can be biased. There is no way of knowing if intended person completed the questionnaire.

	and patient physical and emotional functioning measured in the year before placement; and (c) to use these indicators to compare carers who placed PWD into care and those carers who did. not. *Source: The Gerontological Society of America*	observation, and 573 reported. their reason(s) for seeking permanent care home placement. 572 were included in this study.		behaviours became too difficult to handle (n=261(46%).4. it was the best thing for placement (n=212 (37%) and 5. carer needed more assistance from others and could not get it (n=133 (23%).	
3	Gaugler et al. 2009 U.S.A Aimed to generate pooled empirical associations for sociodemographic, functional, cognitive, service use, and informal support indicators that predict nursing home admission among older adults in the U.S.A. *Source: Psychol Aging.*	A total of 5,831 persons enrolled in MADDE at baseline. Over 40% (43.9%) of care PWD were permanently admitted to a nursing home at some time during the demonstration. 1,610 dementia carers reported information on burden or depressive symptoms up to 6 months post-placement and 1,116 carers with burden or depressive symptoms data up to 12 months post-placement.	Meta-analysis. Data used was obtained as part of a large multi-regional sample of PWD the Medicare Alzheimer's Disease Demonstration Evaluation (MADDE which was conducted in eight communities between 1989 and 1994.	The results found that carer burden and depressive symptoms still present but decreased significantly in the 6-month post-placement panel. Burden also decreased significantly up to 12 months following nursing home placement. When compared to longitudinal analyses of at-home carers in MADDE.	Part of a bigger study. Methodology explained.

4	Gaugler et al. 2010. USA. A follow-on study from Gaugler et al. 2009. Objectives were to determine whether clinically significant changes in symptoms of burden and depression occur among carers within 12 months of care home admission of the PWD and to identify key predictors of clinically persistent burden and depression in the first year after institutionalization. *Source: BMC Medicine*	A total of 5,831 persons enrolled in MADDE at baseline. Over 40% (43.9%) PWD were permanently admitted to a care home during the study. 1,610 dementia carers reported information on burden or depressive symptoms up to 6 months post-placement and 1,116 carers with burden or depressive symptoms data up to 12-month post-placement.	Secondary longitudinal analysis of dementia carers was recruited from eight catchment areas in the United States with 6- and 12-month post-placement follow-up data. Baseline interview was in-person and biannual follow-up interviews were conducted via telephone over a three-year period.	1.Symptoms of burden and depression reduced among carers post placement compared to preplacement. 2.Wives of PWD were likely to continue experiencing higher levels of burden and depression. 3. Combined and individualised psychosocial interventions and working with families.	Part of a bigger study. Methods discussed.
5	Larger and Slinger 2013 UK The main aim was to provide a detailed and contextualised account of carer grief when caring for someone with AD or related dementia. *Source: Dementia*	11 articles. Care receivers had a diagnosis of Alzheimer's disease or related dementia, carers were informal carers, and the study focused on carer grief.	A qualitative synthesis of articles.	The analysis revealed six themes: 1, challenges of caring, relationship changes, 2, the role of dementia in grief, striving, wider support and relief following caring. 3.Challenges faced including physical health changes and freedom restrictions. Difficulty managing these challenges often provoked negative emotions and feelings such as	Peer reviewed papers used. Transparency, integrity of results and transferability discussed.

				guilt. 4, The changes in personality and 5, losses characteristic of dementia, meant the carer remained in a state of grieving without the closure of death and 6, the opportunity to adapt to a physical separation from the PWD.	
6	Bakker et al. 2013. Netherlands. Aims were to investigate the time from symptom onset to care home placement for persons with YOD and compared to late-onset dementia (LOD), and to determine which factors influenced care home placement in persons with YOD compared with LOD. *Source: JAMDA*	Patients were referred from university medical. centres (n ¼ 56), regional hospitals (n ¼ 10), or regional community mental health services (n ¼ 20), (n ¼ 14) were recruited through YOD-specialized day care facilities (n ¼ 115).	Longitudinal study over 2-year follow-ups. Part of the Needs in Young Onset Dementia NeedYD) study. Baseline data from 215 patient carer dyads were used.	1, Time from symptom onset to institutionalization was more than twice as long for YOD patients (9 years) compared with LOD patients (4 years). YOD, the caregiving trajectory is significantly extended compared with LOD. 2, Neuropsychiatric symptoms are common in YOD, and carers are exposed to neuropsychiatric symptoms for a long period. 3, In the YOD group, advanced dementia emerged as a predictor for care home placement.	Enough detail of methodology and methods used results.
7	Caron et al. 2006 Canada. The aim of this study was to explore the decision-making process with regards to care home placement, from the perspective of family carers.	Fourteen people who moved a relative to long-term care in the preceding 6 months were interviewed.	The qualitative research approach, grounded theory method. Data collection in narrative form, in-depth interviews were conducted.	Findings showed interaction of carers' (other obligations, emotions, attitude toward seeking help, meaning of caregiving role, health), and PWD factors (level of autonomy, capacity to make decisions, manifestation of the	Recruitment was from two university geriatric hospitals in town urban centres could raise issues of generalisability and transferability.

	Source: Canadian Journal on Aging			disease), included (a) contextual factors related to the care situation, (b) the decision-making process, and (c) the decision itself. Another factor was related to how carer viewed interactions with others including family dynamics, professionals. These factors interact and influence how carers perceive their ability to provide care to the PWD	
8	Yaffe et al. 2002. USA Aim was to develop and validate a prognostic model to determine the comprehensive predictors of placement among an ethnically diverse population of patients with dementia. *Source: JAMA*	Data from 5788 community-living persons with advanced dementia and their carers in a study run at 8 sites in the United States. They were interviewed and observed for 36-month/ (3years).	Retrospective data analysis and follow up interviews.	They found that, (a) both PWD and carer characteristics are influencing time to nursing home placement (PWD and the carer come as a unit). (b)There may be interaction between the PWD and carer risk factors in which they are mutually reinforced. (c)Carer risks identified could lead to PWD admission to care home included old age, being married, caring for at least 90 hours a week, and (d) PWD being functionally dependent.	Large number of participants were Caucasian with low numbers of black & Hispanic ethnicity despite the rationale for research in this state was diversity. RCT no mention of blinded or not blinded.
9	Natalwala et al. 2008. Birmingham UK Aim was to explore the main reasons PWD were admitted to a multi-ethnic general hospital in Birmingham during 2002-2007.	PWD n- 505 diagnosed with Alzheimer's disease (AD), n- 283 with vascular dementia (VD) and	A retrospective study analysed data of all patients over 70 years of age admitted during 2002–2007.	They found that; a) many PWD were emergency admissions and b) for many dementia itself was not reason of admission. c) many were admitted due to	Study was in single hospital. Not just PWD on inclusion.

	Dement Geriatr Cogn Disord	n-1,773 classified as unspecified dementia (UnD).	The anonymised data were analysed for type of admission and primary diagnosis on admission.	other diseases such as UTI, infections that were not detected early.	
10	Lindauer, A., Harvath 2014 USA The aim of this study was to understand the concept of pre-death grief in the everyday context of dementia caring. *Source: Journal of Advanced Nursing.*	49 papers (2000–2013) that addressed pre-death grief in dementia family carers were used for the principle-based analysis. For the analysis of conceptual meaning, two examples from popular media were used.	A review of literature.	The literature indicated that important properties of pre-death grief are: (a) asynchronous loss; (b) an ambiguous disease trajectory. (c) impaired communication; and (d) emotional variation. The decline of the PWD may not necessarily correlate with the rate or extent of decline in an individual and can be seen as physical death.	Rigour was discussed-two researchers assessed papers for quality. Limitations were discussed.
11	Johannessen et al. 2017. Norway The aim was to examine the experiences and needs for assistance in daily life of spouses of persons with young onset frontal temporal lobe dementia during the progression of dementia. *Source: Scandinavian Journal of Caring Sci;*	16 informants (aged 51–69 years; nine wives, six husbands and one male cohabitant).	Qualitative interviews were conducted in 2014 and 2015.	Three main themes were identified, a) sneaking signs at the early stage of dementia with subthemes of incomprehensible early signs and lack of self-insight, b) life turning upside down at the late stage of dementia and subthemes: the torment, interference with work and vanishing social relations, c) needs for assistance through all stages of dementia. This was associated with relief of the diagnosis, lack of support	Detailed methods and results given. Issues of transferability to UK.

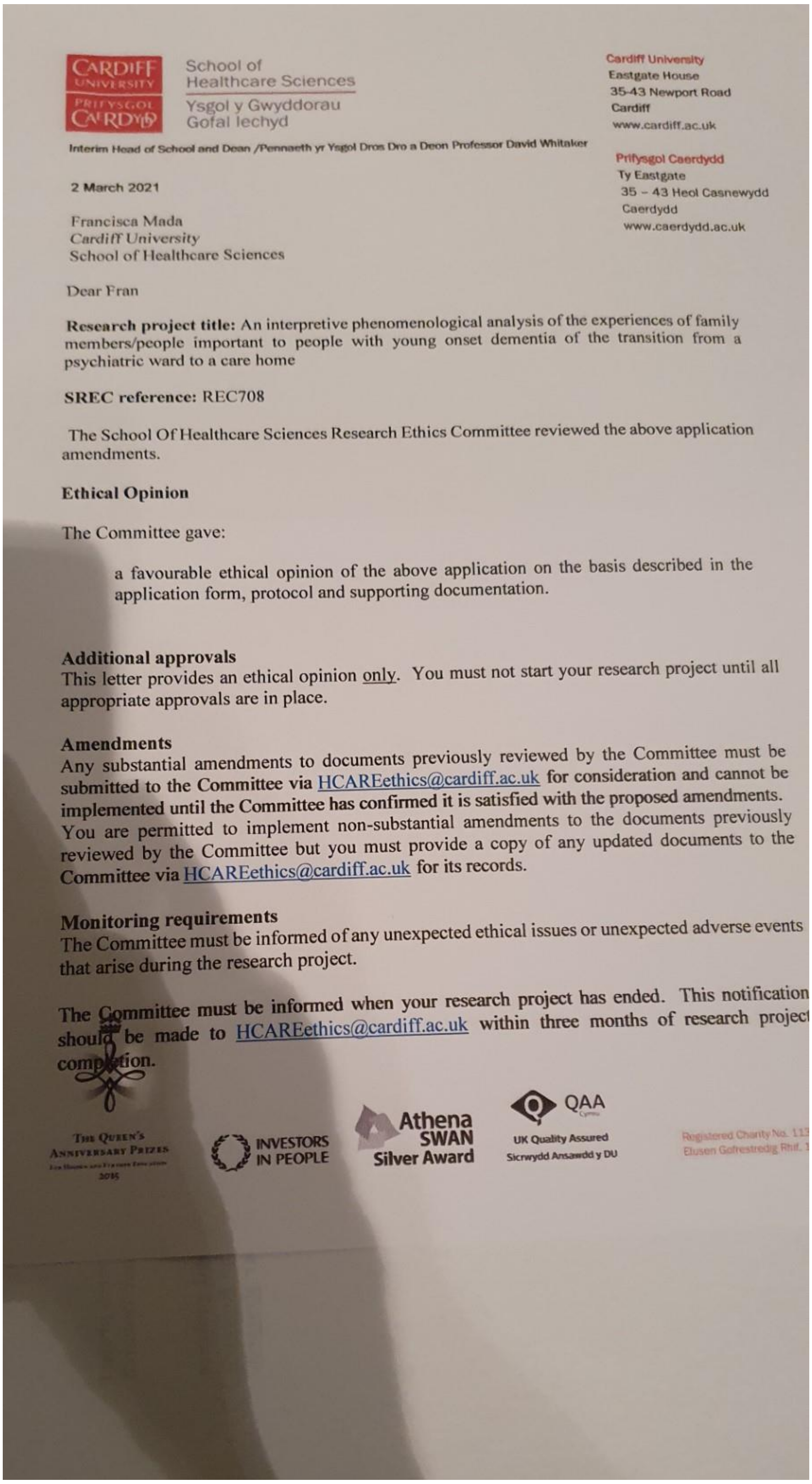
				at home and contributed to the nursing home placement.	
12	Harrison et al. 2017 Scotland, UK The aim was to explore the patient characteristics, assessment processes and reasons involved in discharge to a care home following an acute hospital admission to a single large Scottish university hospital between November 2013 and February 2015. *Source: Age and Ageing*	100 individuals admitted to the acute hospital from home and discharged to a care home.	A retrospective cohort study. Data was obtained from ward-based notes.	The findings were that; a) hospital stays were long (range 14–231) days b) transfers between settings were common, c) Family request, dementia, mobility, falls risk and d) behavioural concerns were the commonest reasons for the decision to admit to a care home.	Carried out single hospital, one researcher extracted data from 100 set of notes, and it is teaching hospital. Results could be biased and issues of dependability and transferability.
13	Roache et al. 2008 UK The aim of this review is to identify and synthesize literature on the experience of people with YOD, their families, and carers, and to highlight gaps in the evidence base. *Source: Reviews in Clinical Gerontology*	27 papers were reviewed. six related to people with YOD and their carers and 21 related to people with YOD in person centred context.	Data from studies included (up to September 2008) were narratively synthesized.	Three over-arching categories and seven mains themes were identified as a) 'Recognizing', which encompassed the following themes: (i) diagnosis and (ii) information provision, b) 'Relating', included: (iii) impact on family and (iv) feelings and c) 'Restructuring', included the themes: (v) relationships and role change; (vi) strategy and coping; and (vii) moving on and adjustment. The themes described both their experience of the processes in involved in the dementia trajectory and the	No quality assurance for all papers.

				challenges they faced along the way.	
14	Chan et al. 2013. UK The aim was to examine family carers' grief before and after the death of the person with dementia for whom they care.	31 total studies: 17 quantitative, 11 qualitative and three mixed methods; 20 anticipatory grief and 11 post-death grief.	Systematic review.	Papers with research of people in long-term dementia units found that; a) grief persisted and created new challenges; adult children carers faced ambivalence around visiting. b) Grief reactions can be described as reactions to serial losses occurring before and persisting when the PWD dies. c) Carers experience grief as multiple losses for themselves (companionship, personal freedom, and control) and the PWD.	Detailed report of findings from both set of studies.
15	Lamech et al. 2019 India This study aims to explore the needs and challenges of family carers in Chennai, India. *Source: dementia*	A total of 19 participants took part in the study	Empirical. A qualitative approach of two focus group discussions and in-depth interviews were conducted using a topic guide.	Results are divided into themes: a) carer and needs. These tackled challenges that included the carer's low knowledge and understanding of dementia, a lack of support and sharing of care responsibilities by family members, the emotional strain of caring, managing challenging behaviour. b) Needs of family carers included a need for appropriately trained staff and utilisation of person-centred	Differences in culture & religions to UK might make transferability difficult.

				care, need for dementia specific health care facilities.	
16	Schur & Whitlatch 2003 USA The study was designed to provide carers with stipends ($1200) to purchase new or additional services so that carers could have some respite from their caring duties and thereby postpone any decision to place their elderly relative in care. *Source: Lippincott's Case Management*	127 primary carers recruited from the existing clients of the social services sector (n= 58) and from Alzheimer Association (n = 69).	Empirical study. Telephone interviews with the carers were conducted, one prior to the introduction of the optional carer services then when additional services had been set up, follow-up interviews were conducted at 3 months and at 6 months.	The findings of the initial data revealed that prior to the offering of respite services three indicators predicted nursing home placement: 1. whether the carers felt they were good carers or they are providing the best possible care for their relative, 2.whether the PWD had a problem doing household tasks, and 3. whether the PWD had disturbed nights and woke up other family members during the night by the PWD. However, the second part of the study still found out that even those who did not disturb others were still placed in care homes. This indicated that sleep alone is not a full predictor for placement.	Cash as could be incentive for taking part and incite biased reports as participants might think they will get more money if they provide certain answers.
17	Sanders et al. 2008 USA The aim of the study was to examine the lived experiences of carers with high levels of grief. *Source: Death Studies*	44carers (spouses and adult children) of people with Alzheimer's disease and related dementias (ADRD) who scored high on	Empirical. Used mixed methods: For quantitative data all participants completed a set of questionnaires and participated in an	The qualitative data identified themes related to: a) yearning for the past, regret and guilt which reflect grief reactions, b) Isolation, restricted freedom, life stressors, and c) systemic issues possessed elements of	All female participants. Maybe results would be different for men.

		Carer Grief Inventory. The people with ADRD (n = 24) were cared for at home, 45% (n = 20) lived in a long-term care facility.	interview for qualitative part of the study.	both grief and caregiver burden and stress, d) Coping strategies included spiritual faith, social supports, and pets. Quantitative analysis confirmed that these themes are unique to individuals with high levels of grief compared with those with moderate/low levels of grief, except for the coping strategies of social support and spiritual faith.	
18	Edmans et al. 2021 UK This study was approved as a service evaluation. *Int J Geriatr Psychiatry*	Nearly 500 admissions to psychiatric dementia inpatient beds at four sites in UK	A multi-centre retrospective service evaluation, using routinely collected data from four diverse sites in the United Kingdom. Data was from 2018 and 2019.	Results revealed; a) route of admissions which could be through the acute hospital, b) long lengths of stay, c) frequent placement in care homes on discharge and d) some died, high rates of falls and assaults and some heterogeneity of service provision, e) the vulnerability and complexity of these patients as well as high rates of assaults on staff which was higher than the prisoner on prison officer rate.	All sites from one country in UK. Enough detail provided. Only study that reported on staff vulnerability.

Appendix 3: Ethics Letter



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Cardiff University
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35-43 Newport Road
Cardiff
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Interim Head of School and Dean /Pennaeth yr Ysgol Dros Dro a Deon Professor David Whitaker

2 March 2021

Francisca Mada
Cardiff University
School of Healthcare Sciences

Dear Fran

Research project title: An interpretive phenomenological analysis of the experiences of family members/people important to people with young onset dementia of the transition from a psychiatric ward to a care home

SREC reference: REC708

The School Of Healthcare Sciences Research Ethics Committee reviewed the above application amendments.

Ethical Opinion

The Committee gave:

> a favourable ethical opinion of the above application on the basis described in the application form, protocol and supporting documentation.

Additional approvals
This letter provides an ethical opinion only. You must not start your research project until all appropriate approvals are in place.

Amendments
Any substantial amendments to documents previously reviewed by the Committee must be submitted to the Committee via HCAREethics@cardiff.ac.uk for consideration and cannot be implemented until the Committee has confirmed it is satisfied with the proposed amendments. You are permitted to implement non-substantial amendments to the documents previously reviewed by the Committee but you must provide a copy of any updated documents to the Committee via HCAREethics@cardiff.ac.uk for its records.

Monitoring requirements
The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.

The Committee must be informed when your research project has ended. This notification should be made to HCAREethics@cardiff.ac.uk within three months of research project completion.

Appendix 4: Young Dementia Newsletter

This is an email from the Young Dementia Network sharing Network and young onset dementia related news and information.

January 2021

Has your family member moved from a psychiatric ward to a care home?

Francisca (Fran) Mada is a Professional Doctorate Student in Advanced Healthcare Practice student at Cardiff University and is also an Admiral Nurse. She is carrying out a study as part of her doctoral degree to explore how we can improve the care and support of families of people with young onset dementia who have transitioned from a psychiatric ward to a care home.

She would like to learn about your experiences from the time the decision was made to make the move to a care home and the move itself. It is hoped your experiences will help professionals to better understand what this is like and to identify where, and how, services might be improved.

If you are interested in taking part, or in finding out more, please email **MadaF@cardiff.ac.uk**

Young Dementia Network resources survey findings

A big thank you to everyone who took the time to complete our recent Young Dementia Network resources survey. It provided us with lots of useful information about how people access our resources, who they obtained them for and whether they have shared them with others.

We were thrilled to discover that 100% of respondents found the Network resources informative. 69% had heard about the resources via the website, and 1/4 had recommended them to a family member, friend or colleague.

Feedback on the **Personal Checklist** symptom checker included, 'Validates concerns and persuades people to seek professional help' and 'I wish I had this two years ago, very handy.'

You can view and download the Young Dementia Network resources **here**.

Young Dementia Network

Join here

You have been sent this email because you joined the Young Dementia Network.
You can leave the Network or unsubscribe from any of our mailings
by completing this form

The Young Dementia Network is hosted by Dementia UK

Dementia UK One Aldgate London EC3N 1RE Charity No 1085595

Unsubscribe

YoungDementia UK

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Appendix 5: Participant Information Sheet.

Experiences of families of people with young onset Dementia.

Francisca Mada: Chief Investigator /Doctoral Student/Researcher.

Telephone: xxxxxxxxxxx

Email: xxxxxxxxxxx

Research Supervisors: Dr Tessa Watts

Email: xxxxxxxxxxxxxxxxxx

Dr Jane Harden

Email: xxxxxxxxxxxxxxx

Dr Anna Jones

Email: xxxxxxxxxxxxxxxxxxx

Please may I introduce myself? My name is Francisca (Fran) Mada. I am a Registered Nurse and a Professional Doctorate Student in Advanced Healthcare Practice student at Cardiff University. I am carrying out this study as part of my doctoral degree. The study is supervised by Doctors Tessa Watts, Jane Harden and Anna Jones.

We are exploring how we can improve the care and support of families of people with young onset dementia and who are moving from a hospital to a care home. We would be grateful if you would read this information sheet and consider helping us by taking part in the study.

What is the study about?

We are interested in learning about the experiences of families or people important to people affected by young onset dementia and who are moving from a hospital to a care home setting. We would like to learn about your experiences from the time the decision was made to make the move to a care home and the move itself. It is hoped your experiences will help professionals to better understand what this is like and to identify where, and how, we might improve our services.

Why have I been asked to take part?

We are inviting you to take part because you are a family member, or you are important to a person with young onset dementia who has recently moved from a hospital ward to a care home.

Do I have to take part?

No, it is up to you to decide whether or not to take part. I would like to assure you that if you decide not to, it will not have any consequence for you.

What will happen if I decide to take part in the study?

In view of the COVID-19 physical distancing requirements to reduce infection risk, and following HRA guidance [46], if you are interested, I will email all documents, or I will post the documents to you. Consent will be accepted via electronic completion and signature, or you can sign a paper copy and post it to me. I will enclose a self-addressed envelope for you to return the signed consent form.

What will happen if I take part?

If you feel satisfied that you have been given enough information about the study and would like to take part, please call me on 07824801669 during office hours or email me. We will have to agree on, a mutually convenient day, time and format (by telephone or via a secure video conferencing platform (e.g. Microsoft Teams), for the interview.

You are welcome to have a companion with you at the interviews for support if you wish. It is anticipated that the interview will be no longer than an hour and a half during a working day. With your permission the interview will be audio recorded and subsequently typed up. We will ensure that you will not be identified in the typed-up notes.

What if I change my mind?

Taking part in this study is completely voluntary. Even if you agree to take part, you are free to withdraw at any time without giving a reason and with no negative consequences.

Are there any disadvantages if I do not take part?

There are no disadvantages to you if you do not take part.

What are the possible disadvantages and risks of taking part?

There are no physical risks of taking part in the study. It is possible that you may find it upsetting to discuss your experiences. If you get upset at any point during the interview, you can stop. The researcher can support you and is able to give you advice on who to contact with any problems. With your permission, the researcher will also contact your family members' mental health care coordinator.

Will my taking part in the study be kept confidential?

Yes, any information obtained from you throughout the duration of your participation in the study will remain confidential. Cardiff University is the sponsor for this study based in the United Kingdom. We, the research team, will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information by storing it securely and using it properly. Cardiff University will keep identifiable information about you, that is to say personal data, for 6-12 months after the study has finished. Data collected during your interview will be anonymised during transcription and stored for 15 years after the study has finished until the year 2036.

Your rights to access change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. You can find out more about how we use your information at

https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection or by contacting the University Data Protection Officer: inforequest@cardiff.ac.uk

If you withdraw from the study, we will keep the information about you that we have already obtained if you consent to this or you may request that we destroy this information.

Your name will only appear on the consent form, which will be securely stored in a locked office with restricted access within my workplace office. The audio recordings of your interview will be kept on an encrypted password-protected server at Cardiff University that only the research team can access. Your interview will be transcribed verbatim and the interview transcripts will be anonymised. Once your interview has been transcribed, the audio recording of your interview will be destroyed. Transcripts will be stored on the password-protected server at Cardiff University.

When the researcher writes up the results of the research for publication, brief direct quotations from your interview transcript may be included in our reports. However, all personal details will be removed (such as the names of people and places) so that no one will know who you are, and you will be given a pseudonym.

During the interviews, if you describe poor practice which puts residents at risk as a Registered Nurse the Chief Investigator has a professional obligation and responsibility to bring this to the attention of a senior member of staff within the clinical setting, as it may require further investigation by the appropriate person. The data will not be included in the research.

What will happen to the results of the research study?

The study will be written up as part of a doctoral degree in advanced healthcare practice. The results may be presented at meetings and will also be written up for publication in an academic journal. No individual will be identified in any publication or meeting. On the day of the interview, you will be asked if you wish to be sent a summary of the findings.

Has this study received ethical approval?

This study has been reviewed by The School of Healthcare Sciences Research Ethics Committee and given a favorable opinion by the [REC708] on 10 March 2020.

Who do I contact about this study?

If you would like further information, please feel free to contact Francisca Mada.

Telephone: xxxxxxxxxxxxx

Email: xxxxxxxxxxxxxxxxx

What if I have a concern?

If you have any concerns or queries about any aspect of this study, please contact the research team (details above) who will do their best to answer your questions. If you wish to complain formally about the way you have been treated or any other aspect of the study, please contact Dr Kate Button, Director of Research Governance, School of Healthcare Sciences: Email: xxxxxxxxxxxxxxxx Telephone: 0292 xxxxxxxx.

Thank you for your time and for considering taking part in this study. This sheet is for you to keep.

Appendix 6: Blank Consent Form

Participant Consent Form

Experiences of families of people with young onset Dementia

Francisca Mada: Chief Investigator /Doctoral Student/Researcher.

Telephone: xxxxxxxxxxx

Email: xxxxxxxxxxx

Research Supervisors: Dr Tessa Watts

Email: xxxxxxxxxxxxxxxxxx

Dr Jane Harden

Email: xxxxxxxxxxxxxxx

Dr Anna Jones

Email:xxxxxxxxxxxxxxxxxxx

Please read the statements below, initial the boxes against each statement and sign and date this page.

Participant Identification Number:

Please initial each box

1 I confirm that I have read and understand the information sheet version V.05 dated 18/02/2021 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2 I agree to take part in the above project as a participant in an audio-recorded interview in a location of my choice. ☐

3 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences or penalty. ☐

4 I understand that the information gathered during the course of the audio-recorded interview will be confidential and anonymised. ☐

5 I understand that information from of the audio-recorded interview will be typed up, rendered anonymous and will be read and analysed by members of the research team. I give permission for the research team members to look at this information. ☐

☐

6 I understand that direct quotes from interviews may be used in publications and reports and that any personally identifiable information will be anonymised to protect my identity. ☐

7 I understand that research data gathered may be used for future research and teaching purposes, and that my name and other identifying information will be removed. ☐

8 I agree to take part in this study ☐

	dd / mm / yyyy	
Name of Participant	Date	Signature

	dd / mm / yyyy	
Researcher	Date	Signature

Appendix 7: Interview schedule

Questions

1.First of all it might be useful if you could tell me about yourself please.

i. GO THROUGH DEMOGRAPHIC DATA. Fill in the gaps.
ii. How long together/ have known person with dementia? Work?
iii. What role do you play in person with dementia's life?).

2. **Could you tell me about receiving the diagnosis?**

i. How old were they when they received diagnosis?
ii. When you first started noticing [memory] changes?
iii. (What changes did you or others notice?
iv. When was diagnosis? How did you feel when you were told? What did you think? What did you do?
v. What processes/services did you go through? What was that like? Who did you meet?).
vi. Do you think anything would be different if [name of person with dementia] were older?)

3. **How did [person living with dementia's name] get admitted in hospital?**

i. Where did they live before admission? With whom? Work?
ii. What were the reasons for admission, any risks identified and by who? Who sought help?
iii. Did they voluntarily go into hospital? Were they sectioned? What did you think of that? What did that mean to you? What did that mean to **[person living with dementia's name]**?
iv. Was this their only admission?

4.Can you tell me more about the hospital stay?

i. What did you think of the hospital, ward?
ii. How long did person with living dementia stay on the ward? Where you expecting it to be this long/short?
iii. Did you feel involved in his/her care? In what way? Any meetings with professionals (MDT)? Updates on day-to-day life on the ward e.g., behaviours, medication changes, activities of daily living?
iv. What could you do with the person on a visit? Anything that you wanted to do on the ward that you couldn't and why?
v. How long was [person living with dementia] in hospital?

5.**Can you tell me about the transition to a care home.**

i. Where there any delays? What caused delays if any?
ii. How did the topic of care homes come about?
iii. Who initiated the discussion? Were you involved in the discussions?
iv. Were you made aware of any options (e.g. live in carers, assisted living)? Where any of these considered? Why were options not taken?
v. Who made the choice of the home?).
vi. How did you feel about the process of transition planning?
vii. How did they get to the care home on discharge? Any escorts from family or ward staff? Is that how you wanted them to go? What was the mode of transport? Ambulance, taxi, family car? Did you feel that was appropriate?

6. **Is there anything we haven’t talked about that you think is important**?

i. What was the hardest thing for you during this process?
ii. How did you manage that? (Any support, in what form and from who/were?

7.**Looking back, were you offered formal support** *(e.g. a support group)*?

i. What kind of help did you have in hospital? What was most helpful and why? What was least helpful?
ii. What was most difficult for you?
iii. Was there anything that you would have wanted to be offered or to be available that would have helped you more?
iv. Is there anything you would like to see changed in the process?

7.How would you advise professionals to support people who are going through the same thing as you?

8. **How has COVID impacted on the process**?

i. hospital admission,
ii. hospital visits,
iii. choice of care home, the move itself, and admission to care home?) (IF TRANSITION WAS IN 2020 onwards)

Prompts

Tell me about this [X]....does this [X] mean to you?

How do you feel when you look at this [X]?

Can you tell me a bit more about that?

How have you made sense of that?

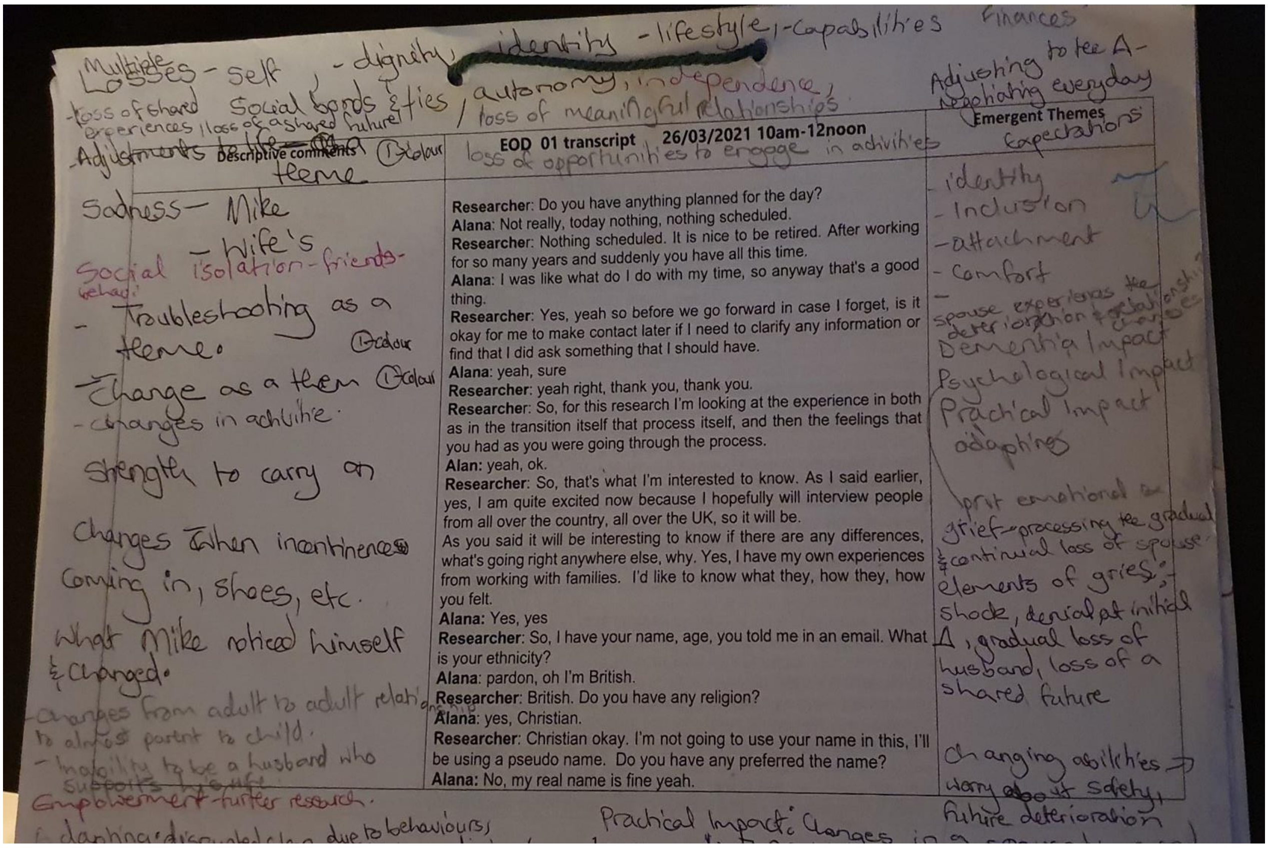
How did that happen?

How did you feel when that happened?

What do you mean by [participant comment]? Can you give an example….

Do you have a particular example of [participant comment]?

Appendix 8: A picture showing notes and highlighted interesting points.



Multiple LOSSES - self, - dignity, identity - lifestyle, - capabilities Finances

-loss of shared experiences / loss of a shared future Social bonds & ties, autonomy, independence, / loss of meaningful relationships.

~~-Adjustments to life~~

Adjusting to the A- negotiating everyday expectations

loss of opportunities to engage in activities

Descriptive comments ① Colour theme

EOD 01 transcript 26/03/2021 10am-12noon

Emergent Themes

Sadness - Mike - wife's

Social isolation - friends - rehab?

- Troubleshooting as a theme. ① Colour

- Change as a theme ① Colour

- changes in activitie.

Strength to carry on

Changes when incontinence coming in, shoes, etc.

What Mike noticed himself & changed.

- changes from adult to adult relationship to almost parent to child.

- Inability to be a husband who supports his wife

Researcher: Do you have anything planned for the day?
Alana: Not really, today nothing, nothing scheduled.
Researcher: Nothing scheduled. It is nice to be retired. After working for so many years and suddenly you have all this time.
Alana: I was like what do I do with my time, so anyway that's a good thing.
Researcher: Yes, yeah so before we go forward in case I forget, is it okay for me to make contact later if I need to clarify any information or find that I did ask something that I should have.
Alana: yeah, sure
Researcher: yeah right, thank you, thank you.
Researcher: So, for this research I'm looking at the experience in both as in the transition itself that process itself, and then the feelings that you had as you were going through the process.
Alan: yeah, ok.
Researcher: So, that's what I'm interested to know. As I said earlier, yes, I am quite excited now because I hopefully will interview people from all over the country, all over the UK, so it will be.
As you said it will be interesting to know if there are any differences, what's going right anywhere else, why. Yes, I have my own experiences from working with families. I'd like to know what they, how they, how you felt.
Alana: Yes, yes
Researcher: So, I have your name, age, you told me in an email. What is your ethnicity?
Alana: pardon, oh I'm British.
Researcher: British. Do you have any religion?
Alana: yes, Christian.
Researcher: Christian okay. I'm not going to use your name in this, I'll be using a pseudo name. Do you have any preferred the name?
Alana: No, my real name is fine yeah.

- identity
- Inclusion
- attachment
- Comfort
- spouse experiences the deterioration & relationship changes

Dementia Impact

Psychological Impact

Practical Impact

adapting

prit emotional

grief - processing the gradual & continual loss of spouse

elements of grief: shock, denial at initial Δ, gradual loss of husband, loss of a shared future

Changing abilities → worry about safety, future deterioration

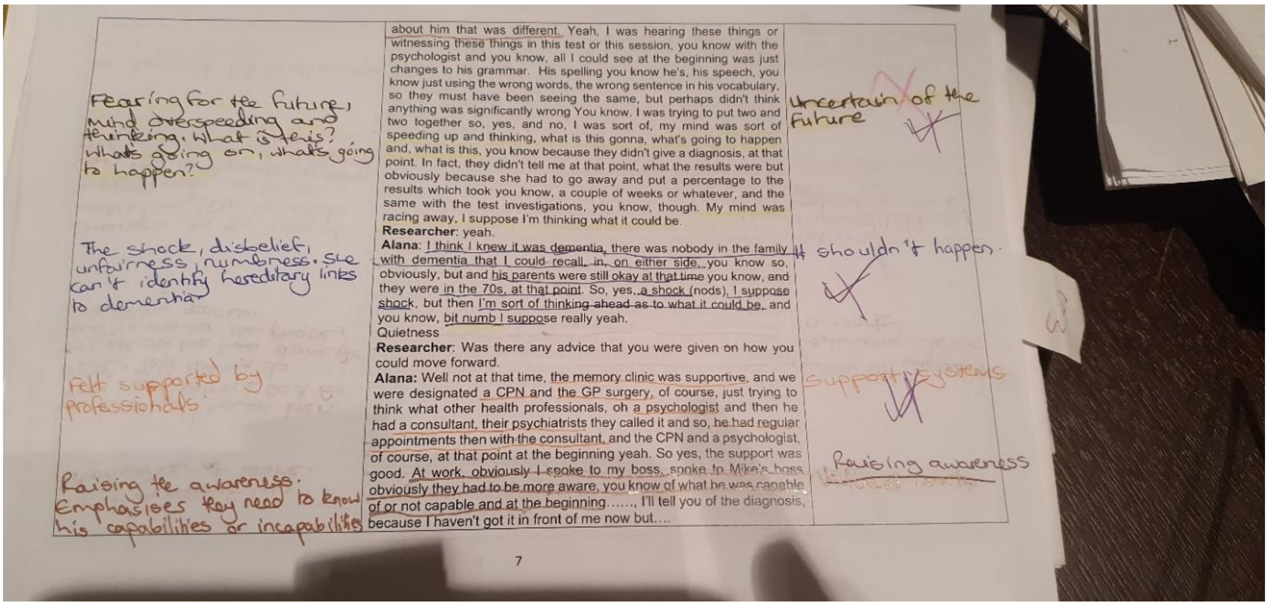
Empowerment - further research.

- changing/disrupted sleep due to behaviours,

Practical Impact: Changes in a

1

Appendix 9: showing Colour coded interesting points and notes.



Fearing for the future, mind overspeeding and thinking. What is this? What's going on, what's going to happen?

The shock, disbelief, unfairness, numbness. She can't identify hereditary links to dementia.

Felt supported by professionals

Raising the awareness. Emphasises they need to know his capabilities or incapabilities

about him that was different. Yeah, I was hearing these things or witnessing these things in this test or this session, you know with the psychologist and you know, all I could see at the beginning was just changes to his grammar. His spelling you know he's, his speech, you know just using the wrong words, the wrong sentence in his vocabulary, so they must have been seeing the same, but perhaps didn't think anything was significantly wrong You know. I was trying to put two and two together so, yes, and no, I was sort of, my mind was sort of speeding up and thinking, what is this gonna, what's going to happen and, what is this, you know because they didn't give a diagnosis, at that point. In fact, they didn't tell me at that point, what the results were but obviously because she had to go away and put a percentage to the results which took you know, a couple of weeks or whatever, and the same with the test investigations, you know, though. My mind was racing away, I suppose I'm thinking what it could be.
Researcher: yeah.
Alana: I think I knew it was dementia, there was nobody in the family with dementia that I could recall, in, on either side, you know so, obviously, but and his parents were still okay at that time you know, and they were in the 70s, at that point. So, yes, a shock (nods), I suppose shock, but then I'm sort of thinking ahead as to what it could be, and you know, bit numb I suppose really yeah.
Quietness
Researcher: Was there any advice that you were given on how you could move forward.
Alana: Well not at that time, the memory clinic was supportive, and we were designated a CPN and the GP surgery, of course, just trying to think what other health professionals, oh a psychologist and then he had a consultant, their psychiatrists they called it and so, he had regular appointments then with the consultant, and the CPN and a psychologist, of course, at that point at the beginning yeah. So yes, the support was good. At work, obviously I spoke to my boss, spoke to Mike's boss obviously they had to be more aware, you know of what he was capable of or not capable and at the beginning……, I'll tell you of the diagnosis, because I haven't got it in front of me now but….

Uncertain of the Future

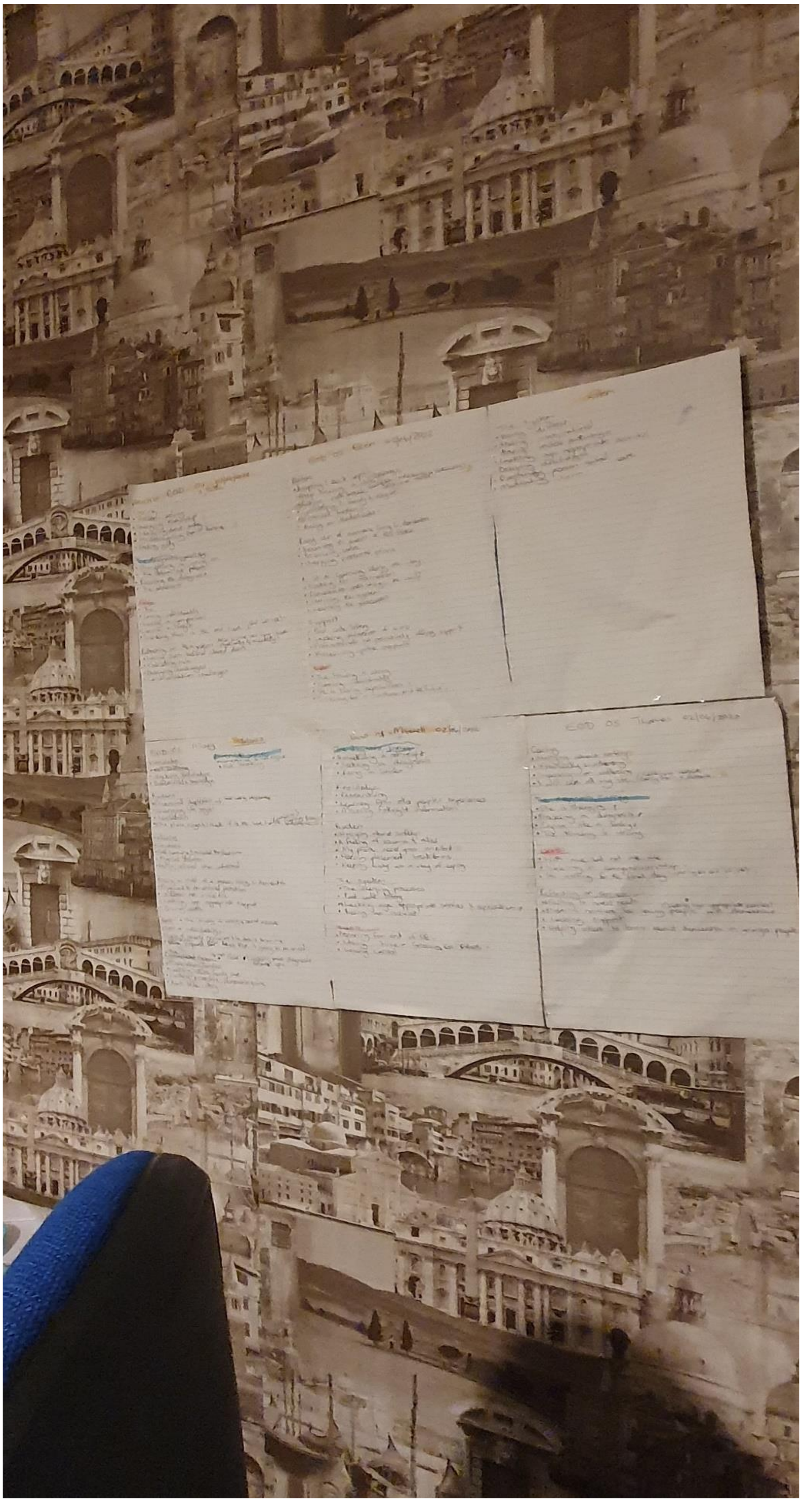
It shouldn't happen.

Support systems

Raising awareness

7

Appendix 10: *A Picture showing GETs on the wall.*



Appendix 11: GETs with similarities marked in highlight pens.