Making sense of young onset dementia: A qualitative exploration of childhood experiences.

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A dissertation submitted in fulfilment of the requirements for the degree of Doctor of Philosophy (PhD)
School of Psychology
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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctor of Philosophy (PhD) is entirely my own work, and that I have exercised reasonable care to ensure that the work is original and does not to the best of my knowledge breach any law of copyright and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

Signed: Cathal Blake

ID No.: 19215355

Date: 08/12/2023

This thesis is dedicated to Linda.

Thank you for your unwavering love, support, and guidance.

Without your encouragement, none of this would have been possible.

You are the reason I am here today.

List of Publications & Presentations

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8) Blake, C., Hopper, L. *Childhood perspectives of parental young onset dementia*: *A qualitative data synthesis*. Irish Gerontological Society 69th Annual & Scientific Meeting, 2022. Slieve Russell Hotel, Cavan, Ireland.
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10) Blake, C., Hopper, L. *Young Onset Dementia*: *Examining the experience through Family Systems Theory*. 5th Annual Liverpool Dementia & Ageing Research Conference, 2023, The Liner Hotel, Liverpool, United Kingdom.
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13) Blake, C., Hopper, L. *Young Onset Dementia*: *Examining the experience through Family Systems Theory*. Dementia Research Network Ireland (DRNI) Early Career Researcher Day, 2023. St James's Hospital, Dublin, Ireland.

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List of Abbreviations

AD – Alzheimer's Disease.
ALS - Amyotrophic Lateral Sclerosis.
bvFTD – Behavioural Variant Frontotemporal dementia.
BPSD – Behavioural and Psychological Symptoms of Dementia.
CADASIL – Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy.
CBD – Corticobasilar Degeneration.
CDT – Clock-Drawing Test.
CJD – Creutzfeldt-Jakob Disease.
CSO – Central Statistics Office.
CT – Computed Tomography.
DSiDC – Dementia Services Information and Development Centre.
DCU – Dublin City University.
EU – European Union.
FHS – Framingham Heart Study.
FTD – Frontotemporal dementia.
fvAD – Frontal Variant Alzheimer's disease.
FUS/TLP – Fused in Sarcoma/Translated in Liposarcoma Protein.
GDP – Gross Domestic Product.
GP – General Practitioner.
GPCOG – General Practitioner Assessment of Cognition.
H-AND – HIV-Associated Neurocognitive Disorder.
ICGP – Irish College of General Practitioners
IQCODE – Informant Questionnaire on Cognitive Decline in the Elderly.
INTRA – INtegrated TRAining.
LOD – Late Onset Dementia.
MIS – Memory Impairment Screen.
MMSE – Mini-Mental State Examination.
MND – Motor Neuron Disease.
MRI – Magnetic Resonance Imaging.
MS – Multiple Sclerosis.
NDO – National Dementia Office.
NHLBI – National Heart, Lung, and Blood Institute.
NICE – National Institute for Health and Care Excellence
NPH – Normal Pressure Hydrocephalus.
PCA – Posterior Cortical Atrophy.
PD – Parkinson's Disease.
PDD – Parkinson's Disease Dementia.
PPA – Primary Progressive Aphasia.
PPI – Public and Patient Involvement.
PSP – Progressive Supranuclear Palsy.
PwYOD – Person with Young Onset Dementia.
QOF – Quality and Outcomes Framework.
TDP-43 – Tau binding protein.
UK – United Kingdom.
UNCRC – The United Nations Convention on the Rights of the Child.
US – United States.
WHO – World Health Organisation.
YOD – Young Onset Dementia.
YO-AD – Young Onset Alzheimer's Disease.
YO-FTD – Young Onset Frontotemporal Dementia.

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Thesis Abstract

Author: Cathal Blake
Thesis Title: Making sense of young onset dementia: A qualitative exploration of childhood experiences.

Introduction: Research into young onset dementia (YOD) tends to focus on the experience from the perspective of the person with the condition or that of their primary carer, typically a spouse or partner. However, many people diagnosed with YOD are part of a wider family system that may include children, yet the experiences of children are consistently absent from the literature. The aim of this research was to investigate the impact of parental YOD on the family system with specific emphasis on the experiences of children and young adults in an Irish context.

Methods: A qualitative research approach was utilised that allowed the exploration of the attitudes, opinions, behaviours and interactions of individuals taking account of the environment in which they occur. Firstly, participatory workshops with members of the Alzheimer Society of Ireland (ASI) Dementia Research Advisory Team (DRAT) were conducted. Members of DRAT are people living with YOD residing in the community. The participatory workshops assisted in the development of research topics of relevance to people living with YOD and their families and guided the research questions addressed in this thesis. Stemming from the participatory workshops, a qualitative systematic literature review was conducted to synthesise the relevant literature in relation to children and young adults experiences of parental YOD. Following this, individual studies employed focus group and one-to-one semi structured interviews with family members including people with YOD (n = 13), spouses/partners (n = 25) and children (n = 36). Data were analysed using thematic analysis in order to recognise, analyse, detail and describe recurring patterns, underpinned by the theoretical framework of Family Systems Theory and Cultural Transmission Theory.

Findings: Across the individual studies, participants reported being significantly impacted by parental YOD leading to considerable adversity. Children and young adults outlined how parental YOD has led to pronounced challenges such as learning to adapt to a new and arduous situation. Consequently, participants reported heighten levels of fear, anxiety, anger, guilt, shame and loneliness. Additionally, the stereotypical view of dementia combined with the general lack of awareness and understanding about YOD can lead to pronounced stigma both at a familial and societal level. Participants highlighted the difficulties when attempting to access formal health and social care support, citing the lack of service provision for younger people combined with poor communication with providers. Furthermore, due to stigma, many children and young adults do not turn to friends for psycho-social support, relying instead on their "*well parent*" putting a further strain on the family system.

Conclusion: Children and young adults with a parent with YOD face significant and unique challenges and therefore require unique psycho-social support(s). However, support must be tailored and stratified by age as one size may not fit all. Any intervention must be a collaborative approach between children and health care providers, with substantial input from children at all stages. Peer-to-peer support is presented as a possible intervention. Peer support has been shown to be an effective tool in the area of youth mental health and as a psycho-social support for children facing other serious parental illnesses. Combined with education and awareness programmes, peer-to-peer support may assist children and young adults facing parental YOD.

1. General Introduction

The research presented in this thesis is an exploration of the impact of YOD on the wider family system. In particular, the studies presented examine the experiences of children and young adults living with (or have lived with) a parent diagnosed with YOD. There is a paucity of information both in the national and international literature in relation to childhood experiences of parental YOD leaving a significant gap in the research. Therefore, my aim was to collaborate with children's and young adults in order to give voice to their lived experiences of the condition.

Accordingly, the importance of this research is presented accompanied by the aims and objectives followed by a summary of the ensuing chapters. I made the decision to explore this topic using the qualitative research method, specifically thematic analysis which allowed me to immerse myself in the participant narratives in order to gain a better understanding of the research topic. Gatekeeper organisations were approached to facilitate participant recruitment using purposeful sampling methods and participants were then interviewed either as part of a focus group or a one-to-one interview.

The findings from the participant interviews are presented in chapters three, five, and six while the results from a qualitative evidence synthesis are presented in chapter four. Initially, I intended to examine the impact of YOD from the perspective of people living with the condition and their primary carers – i.e., spouse or partner. However, following participatory workshops with people living with the condition and their family members, I decided to change the emphasis of this research and focus on the impact on the wider family system. It became obvious from the participatory workshops that children's voices are rarely, if ever, heard in relation to their experiences of YOD.

Consequently, the emphasis of this research was honed further to explore the effect of parental YOD on children and young adults. My interest in YOD began during my undergraduate psychology degree in Dublin City University (DCU). As part of the degree, DCU organise work placements through the INTRA (INtegrated TRAining) programme. While I was interested in dementia, I had limited knowledge of YOD and, similar to a vast majority of the population, assumed dementia was only associated with older adults. I received a clinical placement in a memory clinic within James Connolly Hospital in Dublin. It was here that I met a family living with YOD.

That placement changed my entire research perspective and I decided to examine YOD for my final year project as part of my undergraduate degree. However, I wanted to investigate the topic further and chose to work with families facing YOD for my PhD.

1.1 Chapter Introduction

This chapter provides a definition of the term dementia and the prevalence rates of the condition. The chapter then outlines the most common subtypes of the dementia followed by their clinical manifestation and the brain regions affected. Also outlined are some rarer forms of dementia, again accompanied by their clinical manifestation and the brain regions affected. Following this, the risk factors associated with dementia are illustrated together with the cost of dementia care and the diagnostic process both at an Irish and nationally and international level. The chapter then proceeds to define and describe YOD, outlining its prevalence rates, subtypes, associated risk factors and diagnostic process. Finally, the psycho-social issues associated with care giving in YOD and the lack of services are highlighted followed by the importance, the aims and objectives and structure of this thesis.

1.2 Defining Dementia

Dementia is an umbrella term used to describe a syndrome that progressively affects the brain resulting in cognitive dysfunction. It is most commonly associated with the elderly population, creating difficulties with the management of the activities of daily living (Hughes, Louw & Sabat, 2006). It can result in deficits in memory, language, speech, emotion, and behaviour with the trajectory and rate of decline of the condition often being unpredictable. The prevalence rates of dementia are estimated at 50 million people worldwide (WHO, 2019) with numbers in Europe projected to significantly increase from 9·8 million in 2019 to 18·8 million by 2050 (Alzheimer Europe, 2019).

1.3 Types of dementia

As outlined, rather than being a single disease, dementia is a clinical syndrome. In other words, dementia may be described as a collection of symptoms and features that can combine together to form a recognisable pattern. Dementia may take several forms and have several causes; however, some causes are more common than others (Dening & Thomas, 2013).

The most common types of dementia are Alzheimer's Disease, Vascular Dementia, Dementia with Lewy Bodies, Frontotemporal Dementia, Mixed Dementia and Parkinson's Disease Dementia (see figure 1).

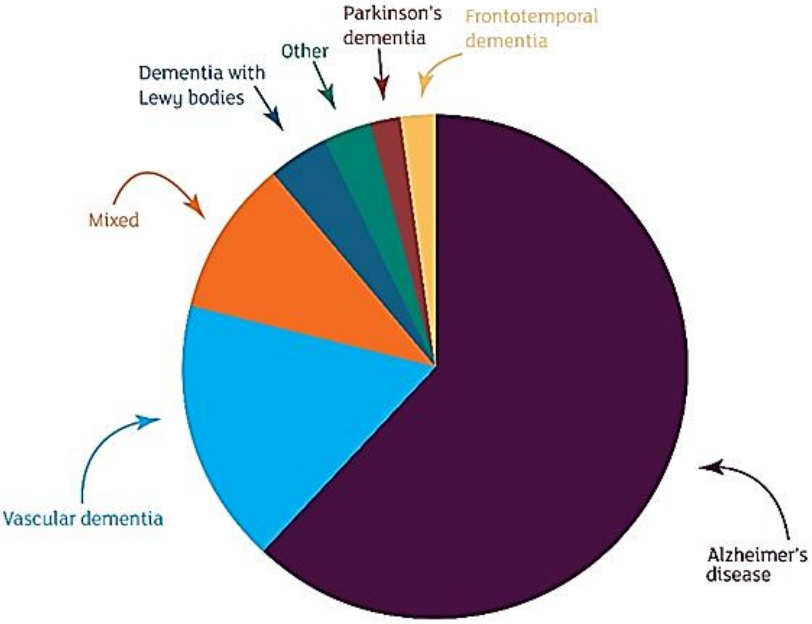

Figure 1: Common types of dementias (Alzheimer`s Resesrch UK, 2020).

1.3.1 Alzheimer's disease

Across all age cohorts, Alzheimer's Disease (AD) is the most prevalent subtype of dementia. AD accounts for approximately seventy – eighty percent of dementia diagnoses globally. In 1906 Alois Alzheimer (1864-1915), a neuropathologist and psychiatrist from Germany, was the first person to describe the symptoms of AD. In fact, what Alzheimer was describing was the first case of young onset Alzheimer's dementia in a patient aged 51 years called Auguste Deter. Deter presented with significant impairment in language and changes in behaviour, and subsequently Alzheimer discovered severe neuropathology in the form of amyloid plaque deposits combined with neurofibrillary tangles and brain atrophy.

Clinical Manifestation

Progressive deficits in memory are one of the primary characteristics of AD, however, impairments may also be observed in language, emotional processing, orientation and behaviour (Taylor & Thomas, 2013). Other notable symptoms may include a reduction in motivation and anxiety disorder. As the disease progresses individuals may have difficulty with everyday tasks such as going shopping, issues with money and problems with wayfinding, ultimately resulting in individuals being unable to selfcare (Steinberg et al., 2008).

Brain Region Affected

The combination of insoluble amyloid plaques and neurofibrillary tangles has been illustrated as a key characteristic in both young onset and late onset AD. More often than not, atrophy begins in brain regions such as the hippocampus (memory), entorhinal cortex and the amygdala (emotions and fear), progressively spreading to other brain regions. This neuropathology causes difficulties in normal brain functioning, with deficits also noted in certain neurotransmitters such as acetylcholine, an important neurotransmitter involved in memory and learning (Vieira et al., 2013).

1.3.2 Vascular dementia

After Alzheimer's disease, vascular dementia is the second most prevalent dementia type accounting for approximately eighteen – twenty percent of cases. Vascular dementia can be caused by interruptions to the brains blood supply, resulting in a reduction in neuronal function and eventual brain cell death.

There are several factors that may lead to an increased risk of vascular dementia including hypertension (high blood pressure), hyperlipidaemia (high fat deposits in the blood), diabetes, smoking, poor diet and excessive weight (obesity). Interestingly, people living with diabetes may be at an increased risk developing dementia (not only vascular dementia) as a result of deposits in the brain from the hormone amylin (Jackson et al., 2013).

Clinical Manifestation

In thirty percent of cases, the development of vascular dementia may occur following a stroke with deficits to memory processing, language difficulties and higher cognitive problems with constructs such as thinking, reasoning and planning. Furthermore, other symptoms may include lack of motivation or apathy, anxiety and depression (O'Brien et al., 2003).

Brain Regions Affected

Both haemorrhagic stroke (bleeding due to a burst blood vessel) or ischaemic stoke (a blockage to blood supply due to clotting) can cause disruption to brain regions resulting in vascular dementia. Furthermore, damage to cells found in the white matter may also be a causal factor, often referred to as subcortical vascular dementia. As numerous brain regions may be affected, individuals will experience a range of symptoms as a result. For example, if the haemorrhagic or clotting occurs in regions of the brain associated with movement and speech, deficits will be pronounced in these functions (Alzheimer's Research UK, 2020).

1.3.3 Dementia with Lewy bodies

The third most prevalent form of dementia is dementia with Lewy bodies, which accounts for approximately ten – fifteen percent of cases (Matsui et al., 2009). The name derives from a German neurologist Dr. Friederich Lewy, when in 1912, he discovered abnormal deposits of a protein that can cause a disruption to the brain's normal functioning in individuals living with Parkinson's disease. Dementia with Lewy bodies shares several features, not only with Parkinson's disease, but also with Alzheimer's disease (Aarsland et al., 2009). A key characteristic dementia with Lewy bodies are small deposits/clusters of alpha-synuclein protein occurring in various brain regions.

Clinical Manifestation

Individuals may have memory deficits, similar to the deficits observed in Alzheimer's disease. Other symptoms may include issues with maintaining alertness, visuospatial difficulties and problems with reasoning and planning. Similar to the characteristics of Parkinson's disease, individuals may observe tremors in the limbs, a shuffling gait and a reduction in facial expressions. Other marked features may include visual hallucinations, sleep disturbances (including nightmares/terrors) and impairment in the levels of conscious awareness (McKeith et al., 2005).

Brain Regions Affected

Areas of the cerebral cortex involved in perception, information processing, language and thought are affected by dementia with Lewy bodies. Furthermore, regions such as the limbic system (responsible for emotional regulation), the hippocampus (memory), the midbrain and basal ganglia (movement) and regions of the brain stem are also affected. In some cases, the olfactory pathways responsible for the recognition of smells may be impaired (Attems & Jellinger, 2013).

1.3.4 Frontotemporal dementia

A relatively less common form of dementia is called frontotemporal dementia (FTD). This dementia, which affects the frontal lobe regions of the brain, includes several different types. Originally known as Pick's disease, first reported by Arnold Pick (1892), frontotemporal dementia can be characterised by behavioural variant frontotemporal dementia (bvFTD), semantic dementia, progressive non-fluent aphasia (deficits in speech and writing) and FTD associated with motor neuron disease (MND) (Warren et al., 2013).

Clinical Manifestation

Approximately fifty percent of cases show behavioural changes that affect personality, with the remainder presenting with deficits in both speech, language and issues with the meaning of words and concepts. The behavioural component can be significantly altered with individuals lacking inhibitory control (inappropriate behaviours), exhibiting a lack of empathy, rigidity in thinking (lack of flexibility/overly obsessive) and issues with memory, planning, reasoning and decision making. A lack of interest in others and deficits in emotional regulation may also be observed. Difficulty with awareness and recognition, as well as problems with movement can also be present. Individuals may alter their eating habits by either overeating or developing a preference for sweet foods (Alzheimer's Disease International, 2015).

Brain Regions Affected

Damage to cells in the frontal and temporal lobes of the brain is evident in FTD which are regions responsible for personality, behaviour and emotional regulation. The frontal regions of the brain are also involved in the understanding of speech and language. A build-up of protein deposits, which form clumps, is a causal factor.

Proteins such as tau, TDP-43 (TAR DNA-binding protein) and FUS/TLP (Fused in Sarcoma/Translated in Liposarcoma Protein) are implicated, forming clumps that damage brain cells in the affected regions. Reasons for the build-up of these proteins are not fully understood (Alzheimer's Disease International, 2015).

1.3.5 Mixed dementia

When an individual is living with more than one subtype of dementia, this is referred to as mixed dementia. The most prevalent subtypes are Alzheimer's disease and vascular dementia, with the clinical manifestations and brain regions affected are similar in both subtypes. Mixed dementia can become more prevalent with advancing age, typically in individuals eighty years and older where the mix of vascular and Alzheimer pathology is uncovered following post-mortem examination (Brayne et al., 2009).

Clinical Manifestation

Similar to the symptomology observed in Alzheimer's disease, individuals living with mixed dementia often display a decline in abilities gradually. However, this manifestation may be accompanied by mild/mini strokes which also contribute to deficits in cognition. Individuals with a clinical history of vascular diseases or associated risk factors such as ischaemic heart disease, diabetes, high blood pressure (hypertension) and elevated lipid levels may be at an increased risk of developing mixed dementia (Dening & Thomas, 2013).

Brain Regions Affected

The brain regions affected in mixed dementia depend on the subtypes involved. For example, in the most prevalent clinical manifestation which includes a combination of Alzheimer's disease and vascular dementia, the brain regions affected would include areas such as the hippocampus (memory), entorhinal cortex and the amygdala (emotions and fear), progressively spreading to other brain regions. Similarly, haemorrhagic or ischaemic stoke can cause disruption to numerous brain regions damaging cells found in white matter (Dening & Thomas, 2013).

1.3.6 Parkinson’s Disease Dementia

Parkinson’s disease dementia (PDD) can develop in individuals living with Parkinson’s disease (PD) approximately one year after diagnosis. It can result in deficits with thinking, reasoning and planning. Changes in the brain brought about by Parkinson’s disease begin in a region that plays a key role in movement and may stem from abnormal microscopic deposits comprised of alpha-synuclein, a protein which is found widely in a normally functioning brain. Theses deposits are called “Lewy bodies”, similar to those found in individuals living with Lewy Body Dementia (Singer et al., 1992). Clinically, the main difference between dementia with Lewy Bodies and Parkinson’s Disease dementia is time. In Dementia with Lewy Bodies the dementia presents first before the Parkinson’s symptoms. In Parkinson’s Disease Dementia the dementia symptoms develop later following a diagnosis of Parkinson’s Disease (Foley, Jennings & Swanwick, 2019).

Clinical Manifestation

The early and most frequent symptoms in Parkinson’s Disease Dementia are observed as impairments in motor function. These symptoms can manifest as shakiness and/or tremors, muscle stiffness, shuffling gait, difficulties maintaining posture, akinesia and bradykinesia (poverty and slowness of movement) and lack of facial expression. As the condition progresses, other deficits can include difficulties with speech, depression, disturbances with sleep and bladder dysfunction. Approximately one year after the first symptoms of Parkinson’s Disease, cognitive impairments can be observed with deficits in mental acuity including memory, attention, difficulty with planning, thinking and reasoning and issues with task completion (Churchyard & Lees, 1997).

Brain Regions Affected

In the human brain there are 220,000 dopaminergic neurons approximately located in a both hemispheres in an area known as the substantia nigra (Graybiel et al., 1990). Individuals with significant neuronal loss (> 50%) in this region begin to develop symptoms of the condition such as deficits in motor function (Singer et al., 1992). While deficits in dopamine lead to significant neurophysiological difficulties, other neurotransmitter abnormalities may also be involved in the development of Parkinson’s Disease Dementia.

For example, there is evidence outlining the role played by the locus coeruleus catecholaminergic system, the raphe nuclei serotonergic system, and the cholinergic neurons from the nucleus basalis. Other brain regions implicated include the cortex, sympathetic ganglia, olfactory bulb, and the central sympathetic nervous system (Wolters, 2000).

1.4 Rarer forms of dementia

1.4.1 Huntington’s disease

Huntington’s disease is a progressive inherited autosomal disease that can cause difficulties with an individual’s coordination and movement. Huntington’s usually manifests in middle age, and together with the difficulties in movement, cognitive deficits can also be observed (Ho et al., 2003). Issues with cognition can often occur at the early stages after onset of the disease with dementia being prevalent in approximately half (50%) of individuals in the advanced stages of the condition (Zarowitz et al., 2014).

Clinical Manifestation

Huntington’s disease results from a genetic fault in certain nerve cells responsible for protein production in the brain, and usually develops while in the womb. Consequently, protein produced by the faulty gene damages, rather than develops, the nerve cells causing a reduced functionality and a reduction in the cells over time. The condition may affect individuals differently, with symptoms varying between patients. For example, some of the symptoms may include loss of weight despite normal appetite, difficulties with swallowing and/or chewing food, an increase in the frequency of body movements and muscle atrophy/rigidity (hda.org.uk)

Brain Regions Affected

Damage often occurs to cells in the basal ganglia area and in the cerebral cortex. These brain regions are highly interconnected and are responsible for various types of both physical and psychological processes including, movement, thinking, planning and reasoning, motivation and emotion. The reduction in the cells in these brain regions results in alterations in their functionality, subsequently the various symptoms associated with Huntington’s disease may be observed (Ho et al., 2003).

1.4.2 Creutzfeldt-Jakob disease

Creutzfeldt-Jakob disease (CJD) occurs as a result of an abnormally shaped protein, known as a “prion” which infects the brain. CJD is extremely rare, with prevalence rates of one in one million. Individuals may be living with the condition for several years before the onset of symptoms. Sporadic CJD is the most common form of the condition usually affecting individuals over forty years of age (Abudy et al., 2014).

Clinical Manifestation

Early symptoms of CJD can include changes in mood, minor memory problems and lethargy, leading to increased confusion and clumsiness, jerky or shaky movements, stiffness in the limbs and incontinence. As the condition progresses, loss of movement, balance and speech can result. CJD progresses rapidly from the initial onset of symptoms, with psychological problems combining with the physical deficits, ultimately resulting in death within six-eight months (Abudy et al., 2014).

Brain Regions Affected

In general, cortical thickness is typically reduced in individuals with CJD when compared to healthy controls. For example, a multitude of brain regions and structures were observed to have significantly less volume in CJD patients including the fusiform gyrus, precentral gyrus, praecuneus and superior temporal gyrus (bilaterally) the caudal middle frontal gyrus, superior frontal gyrus, postcentral gyrus, inferior temporal gyrus and transverse temporal gyrus in the left hemisphere, and the superior parietal lobule in the right hemisphere (Navid et al., 2019). Spongiform encephalopathies (appearance of tiny holes) may also occur in areas of grey matter followed by gliosis (scar formation) in the neo-cortex resulting in neuronal loss (Parchi et al., 1999; Iwasaki et al., 2006; 2014).

1.4.3 Korsakoff's syndrome

Korsakoff’s syndrome is a disorder stemming from deficits in thiamine (vitamin B1) that can cause significant neuropsychiatric difficulties. The condition is most prevalent in individuals with a problematic alcohol misuse resulting in issues of self-neglect and malnutrition. Korsakoff’s syndrome can also manifest from acute Wernicke encephalopathy that may have gone untreated (Isenberg-Grzeda et al., 2016).

Clinical Manifestation

Korsakoff’s syndrome typically manifests as significant deficits in cognitive functioning. For example, individuals can have problems with memory function – i.e., severe anterograde amnesia, and difficulty recalling previous life events. Other symptoms can include issues with working memory and impaired social cognition (Arts, Walvoort & Kessels, 2017; Drost, Postma & Oudman, 2018). A further manifestation that can be observed is confabulation, in other words individuals may recall false or misleading (erroneous) memories resulting from neurological amnesia (Kopelman, 2015). Nearly all individuals living with Korsakoff’s syndrome will exhibit some difficulties with executive functioning causing issues with planning, reasoning and thinking and related higher order cognitive functions (Moerman-van den Brink et al., 2019; Thomson, Guerrini & Marshall, 2012).

Brain Regions Affected

Individuals living with Korsakoff’s syndrome can sustain damage to several regions of the brain. For example, atrophy has been illustrated in the thalamus, the putamen, the hippocampus and the amygdala with a significant reduction in volume in these areas. Furthermore, a reduction in cortical thickness may be found in both the rostral and caudal anterior cingulate gyrus and the fusiform gyrus. Other regions impacted can include the inferior temporal and frontal lobes including the regions surrounding the parahippocampal and posterior cingulate cortex (Navarri et al., 2020).

1.4.4 Posterior cortical atrophy

Individuals with posterior cortical atrophy (PCA) typically present with impairments in both visuo-spatial and visuo-motor abilities (McMonagle et al., 2006). PCA has been classified as an atypical type of Alzheimer's disease as underlying Alzheimer’s pathology is involved in many cases (Warren et al., 2012). However, there is evidence illustrating the association of other pathologies including Lewy bodies, prion disease, gliosis and corticobasal degeneration (Giunta et al., 2021).

Clinical Manifestation

Individuals can appear disoriented and present with simultanagnosia (inability to perceive more than one object at a time) optic ataxia (incapacity to direct limb motions) and oculomotor apraxia (deficits in controlled, voluntary, and purposeful eye movement).

Furthermore, there may be an impairment in global cognition with particular deficits in executive functioning, working memory, dyscalculia (difficulty learning or comprehending arithmetic, such as difficulty in understanding numbers) and a reduced verbal fluency (Giunta et al., 2021).

Brain Regions Affected

The symptoms are consistent with pathology in the brain regions in the posterior lobes, including the primary visual occipital, occipitotemporal and biparietal cortices with significant atrophy in the parieto-occipital lobes (Crutch et al., 2012).

1.4.5 Corticobasilar Degeneration & Progressive Supranuclear Palsy

Another rare subtype of dementia, corticobasilar degeneration (CBD) is a progressive rare condition associated with deposits of the tau protein with similar symptomology to Parkinson’s disease including motor dysfunction and, parkinsonism and limb apraxia. Similarly, progressive supranuclear palsy (PSP) often first presents with parkinsonism. Another clinical feature of PSP is the reduction in vertical gaze as the pathology affects the mid-brain region. Individuals with PSP rarely have the same manifestations observed in Parkinson’s disease (i.e., unilateral tremor or hand bradykinesia-slowness of movement) however, they can present with marked truncal rigidity, with the dementia becoming more apparent with time (Foley, Jennings & Swanwick, 2019).

Other rare subtypes of dementia include:

- Atypical Alzheimer’s disease.
- Frontal variant Alzheimer’s disease (fvAD).
- CADASIL (Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy).
- HIV-Associated Neurocognitive Disorder (HAND).
- Normal Pressure Hydrocephalus (NPH).
- Primary Progressive Aphasia (PPA).

1.5 Risk factors associated with Dementia

The most moderating risk factor associated with dementia is age (Medina et al., 2017; Li et al., 2018). However, there are other mediating factors associated with developing the condition. For example, diabetes, hypertension, sedentary lifestyle, smoking, poor educational attainment and depression have been identified as risk factors. Moreover, some individuals may develop late-stage dementia as a result of hearing loss (Livingston et al., 2017). According to the National Heart, Lung, and Blood Institute (NHLBI) the lack of social and emotional support has also been identified as a potential risk factor, as data form the Framingham Heart Study (FHS) in Massachusetts illustrated that individuals who had lost a loved one were at risk (Li et al., 2018).

Similarly, social isolation may reduce individual's participation in physical and leisure activities leading to a reduction in cognitive stimulation, thus increasing cognitive inactivity, another potential risk factor for developing dementia (Fratiglioni et al, 2000; Livingston et al., 2017). Evidence has outlined the protective nature of cognitive and physical activity through the enhancement of resilience in the brain, therefore, combating the effects of neuropathology through cognitive reserve (Stern, 2012).According to the Lancet Commissions, such risk factors are modifiable and preventative measures could reduce the prevalence of dementia globally by as much as thirty-five percent (Livingston et al., 2017).

For example, reducing the risks associated with vascular disease and an increase in educational attainment may result in a decrease in dementia cases. Moreover, reducing vascular disease will assist in decreasing the prevalence of both cardiovascular disease and stroke. The risks associated with many vascular diseases are similar to the risk factors associated with dementia Therefore, it may be reasonable to assume that a reduction in vascular diseases, may not only prolong the development of, but may also prevent the onset of dementia (Jorgensen et al., 2015).

1.6 The Global Cost of Dementia

According to a report by the World Health Organisation (WHO, 2015) dementia is a major cause of both disability and dependency among the older age cohort globally. Moreover, there is also a significant impact on family members, communities and wider society. Furthermore, the condition is associated with approximately twelve percent of the years lived with a disability due to noncommunicable disease, and with improved life expectancy, this figure set to increase significantly in the future (Prince et al., 2015).

Dementia represents increased financial costs for governments and societies due to care needs and the significant loss of productivity to the economy. For example, in the United States (US) the financial cost of dementia in 2015 was estimated to be in excess of $818billion US dollars. This equated to 1·1% of the country's gross domestic product (GDP). Similarly, for other nations, the cost of dementia ranges between 0·2% for low to middle income economies to 1·4% for higher income economies. Forecasts estimate that the worldwide cost of dementia will reach as high as two trillion US dollars by 2030, a figure that has the potential to cause widespread problems for social, economic and healthcare systems (Prince et al., 2015). People living with dementia, and their families, are faced with a twofold impact on their finances. Firstly, they are faced with the cost of health and social care and secondly, there may be a loss of income due to the condition.

In many Western societies, these costs may be shared between informal care (45%) and social care (40%), while in developing countries social care costs are significantly lower (15%) compared to the cost of informal care (Prince et al., 2015). For example, the Actifcare study examined the costs of dementia care across eight European countries including Germany, Ireland, Italy, Netherlands, Norway, Portugal, Sweden and the United Kingdom (UK). Participants in the study were people living with dementia (mean age-78) and their informal carers (mean age-66), with almost all participants (94%) residing in their own homes.

The average annual cost of dementia across the eight countries was €17,296 with the main cost being informal care at €9,497 (see figure 2). The cost of care varied between the eight countries with Portugal at €6,222 being the lowest and Ireland at €23,737 being the highest (Handels et al., 2018). In a similar study conducted by Gustavsson and colleagues (2010), regional European comparisons across twelve European countries illustrated that dementia costs in Northern Europe were €6,063, Southern Europe were €7,049 while Western Europe were €8,279 annually. Moreover, evidence provided by Wimo and colleagues (2013) assessed the annual average cost of dementia care across three Western European countries to be €20, 376.

In the England, research by Wittenberg and colleagues (2019) has outlined the financial implications of dementia. According to the research, the total cost of dementia is approximately £24·2 billion annually. Of this, over ten billion (£10·1billion) is attributed to unpaid or informal care. The cost of social care at £10·2 billion is almost three time greater than that of healthcare costs (£3·8 billion).

Over half of social care costs (£6·2 billion) are funded by people living with dementia and their families, with the remainder (£4 billion) funded by the exchequer. Further evidence for the study outlines how the severity of dementia can impact on the cost of health and social care with annual costs varying between mild impairment (£3·2 billion), moderate impairment (£6·9 billion) and severe impairment (£14·1 billion) a year.

These figures equate to £24,400, £27,450, and £46,050 for mild, moderate and severe dementia per person respectively (Wittenberg et al., 2019). According to the WHO and the World Bank, up to forty million new roles in both health and social care are needed in order to meet the needs of the exponential growth in dementia. Specifically, these roles are required in primary care settings with additional support in social care settings in the community. These roles require specially trained health care staff who are proficient in addressing the needs in dementia care combined with interventions designed to cater for people living with dementia and their families (WHO, 2017).

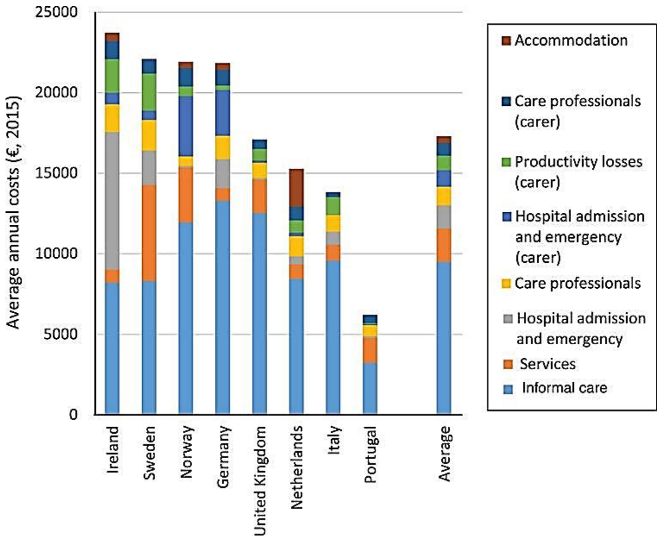

Figure 2: Mean annual cost of dementia in eight European countries in 2015 (Handels et al., 2018).

1.7 The Cost of Dementia in Ireland

Estimating the cost of dementia care in Ireland is difficult due to the lack of epidemiological data in relation to prevalence rates. Ireland does not have a specific dementia registry; therefore, prevalence rates of the condition are frequently approximated.

Research by Pierse and colleagues (2020) utilised international epidemiological data to produce a simulation of prevalence rates for Ireland. Employing a multi-state Markov illness-death model (Commenges et al., 2004), the research calibrated the relationship between dementia, aging and mortality in the population in order to calculate the number of cases of dementia in the country (see table 1). The simulations generated revealed that the estimated number of dementia cases in Ireland averaged from 54,887 in 2016 to a projected number of 98,946 in 2036 representing an annual increase of three percent (Pierse et al., 2020).

Table 1: Weighted mean number of people with dementia from all simulations for 2016 and projected census years.

Year	2016	2021	2026	2031	2036
Weighted mean	54,877	64,888	75,287	87,023	98,946
Weighted SD	(9,804)	(11,769)	(13,763)	(16,020)	(18,320)

Annual growth rate 3·0% (Pierse et al., 2020).

Research conducted by Connolly and colleagues (2014) reported that the estimated cost of dementia in Ireland was €1·69 billion (see figure 3). However, this estimate was based on census figures from 2010 which reported 41,470 people living with dementia.

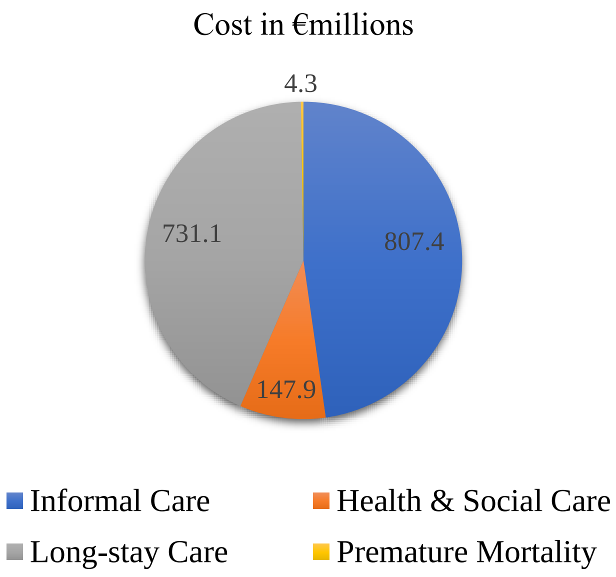

Figure 3: Estimated cost of dementia in Ireland 2010 (Connolly et al., 2014).

According to O’Shea and Monaghan (2017) a more contemporary estimate of dementia costs may be closer to €2billion annually. However, as more recent census figures report approximately 65,000 people living with dementia in Ireland (Pierse et al., 2020) the cost may be significantly higher. For example, Walsh and colleagues (2021) reported that the combined monthly cost of dementia care (both formal and informal) in Ireland may be €3,240 per individual with dementia.

This represents an annual cost of €38,880 per person with dementia. Extrapolated this figure out to account for the estimated number of people currently living with dementia in Ireland, then the total cost may be over two-and-a-half-billion (€2,527,200,000) rising to almost four billion (€3,849,120,000) by 2036.

1.8 Diagnosing dementia

In 2018, the National Institute for Health and Care Excellence (NICE) published a set of guidelines for diagnosing dementia. The guidelines report that the initial assessment should be carried out in a non-specialist setting, typically in the offices of a general practitioner (GP). The initial assessment is utilised to investigate and evaluate other potentially reversible causes of cognitive impairment such as delirium, depression, hypothyroidism, sensory impairment and the negative side effects of prescribed medications (NICE, 2018).

Once other cause are ruled out, patients can then be referred to specialist services such as a memory clinic, neurology clinic or other geriatric services in order to officially diagnose dementia. According to Connor (2020), assessing individuals for dementia includes several factors such as the persons history (provided by themselves or a proxy) and the use of standardised assessment tools including the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE). Other assessment tools include the Mini-Cog Test (Borson et al., 2000) which uses a three-item recall test for memory and a simply scored clock-drawing test (CDT), the Memory Impairment Screen (MIS) (Buschke et al., 1999), the Mini-Mental State Examination (MMSE) tool (Folstein et al., 1975) and the General Practitioner Assessment of Cognition (GPCOG) score (Brodaty et al., 2002). Diagnosis typically follows after six months of declining cognitive function resulting in deficits in daily functioning (Roman, 2002).

Medical examination including blood tests and imaging of the brain using computed tomography (CT) and magnetic resonance imaging (MRI) may also be required to rule out reversible causes or to map atrophy in the brain (NICE, 2018). Some individuals may require a more detailed examination that may include attaining cerebral spinal fluid (CSF) through a lumbar puncture (e.g., investigating Prion disease) if initial assessments are inconclusive (NICE, 2018).

GP’s are typically the first healthcare professionals a family will turn to when a loved one is exhibiting cognitive deficits. In the UK general practitioners utilise the Quality and Outcomes Framework (QOF) in order to assist with the diagnosis of dementia and improve disease management. However, in Ireland GP ’s are often under resourced in relation to dementia care and chronic disease management (Foley, Jennings & Swanwick, 2019). For example, Cahill and colleagues (2006) surveyed Irish general practitioners in relation to dementia.

GP’s reported significant difficulties with diagnosing dementia and issues with disclosing the diagnosis to the individual and their family. In particular, there appeared to be problems distinguishing dementia from the normal symptoms experienced in aging. Other problems reported by Irish GP’s included a lack of confidence and their concerns in relation to the impact the diagnosis may have on the individual. Furthermore, GP’s outlined the need for dementia specific training around diagnosis and in areas including the needs of the family/carer (Cahill et al., 2006).

In a more recent study, Irish GP’s also reported this need for specific training in relation to diagnosis coupled with training on disclosing a diagnosis and disease management, particularly the psychological and behavioural symptoms that may accompany dementia (Foley et al., 2017). Findings from the same research also outlined that families require their GP to signpost them to additional dementia specific social care services and supports.

As an early diagnosis may be difficult due to the variety of symptoms at onset, confirmation of dementia can take a significant period of time. Therefore, the initial consultation with the general practitioner is crucial. For example, the Irish National Dementia Strategy, which was published in 2014 and amended in 2019, outlines the critical role that GP’s play in the management of people living with dementia.

For example, the strategy places the GP at the heart of the process in relation to areas such as a timely diagnosis, proposed interventions and signposting to further multidisciplinary care and social service provision. Other areas include the management of the behavioural and psychological symptoms of dementia (BPSD) and palliative care where appropriate (Foley et al., 2019).

1.9 Young-Onset Dementia (YOD)

Alois Alzheimer reported on a patient named Auguste D., an individual who was living with a progressive condition that resulted in cognitive impairment, delusional behaviour, hallucinations and several other psychosocial issues. Auguste D. died at fifty-five years of age and may be the first documented case of young onset Alzheimer's disease (Maurer, Volk & Gerbaldo, 1997).

Many health services, including the Irish system, define "*older adult*" as age sixty-five and over. This is purely arbitrary as it is based on society's view of age and has its origins in the life phases, or specific changes, people pass through on their way to retirement (Koopmans, & Rosness, 2014). While dementia is typically associated with advancing age some people develop symptoms considerably younger than sixty-five. This form of dementia is referred to as young-onset-dementia (YOD; Roach et al, 2008). Consensus on the terminology often differs among health and social care providers, with some referring to the condition as early onset dementia (EOD) or presenile dementia (Koopmans, & Rosness, 2014).

Basing the distinction between YOD and late onset dementia (LOD) on society's view of age may be convenient, however, it does not take into consideration the underlying pathology or neurobiology of the condition. Furthermore, as dementia is a disease of the brain, both YOD and LOD may be characterised as clinically and pathologically separate (Kemp et al., 2003; Smits et al., 2012; Tellechea et al., 2015). While Auguste D. was only fifty-five years old at time of death, the symptoms met the many of the criteria for dementia.

Specifically, there was a significant deterioration in cognition which progressively affected modalities such as memory, thinking, planning, spatial orientation, speech and language, judgement, emotional control and social behaviour (Maurer, Volk & Gerbaldo, 1997). With such devastating symptoms, YOD represents a significant health and social issue for many individuals and their family members (Bangash & Saad, 2015).

YOD can be insidious and more often than not, many of the early signs or symptoms can go unrecognised or be mistakenly attributed to other conditions such as depression, stress, burn-out, employment difficulties or issues with a relationship.

As a result, a definitive diagnosis may be delayed due to the perception that dementia is a disease of old age (Werner, Stein-Shvachman & Korczyn, 2009; van Vliet et al., 2013; Draper et al., 2016). Compared to LOD, obtaining a diagnosis of YOD can take as long as four years, with LOD being less than three (2·8 years) on average (van Vliet et al., 2013; Kvello-Alme et al., 2019).

1.9.1 Prevalence of YOD

Prevalence rates of dementia are estimated at 50 million people worldwide (WHO, 2019) with numbers in Europe projected to significantly increase from 9·8 million in 2019 to 18·8 million by 2050 (Alzheimer Europe, 2019) However, estimating the prevalence rates for YOD is problematic due to the paucity of epidemiologic evidence (Lambert et al., 2014). When compared to LOD, YOD is a rarer condition accounting for approximately 5-9% of dementia cases worldwide (Engedal & Laks, 2017; Mendez, 2012; van Vliet et al., 2010; World Health Organization, 2017a).

For example, a meta-analysis by Zhu and colleagues (2015) examined research from eight countries found that YOD accounted for approximately 5·5% of the total cases of Alzheimer’s dementia, a finding that was significantly more than previous estimations of 1-2%. Incidence rates for YOD vary greatly, ranging from 11 to 27 people per 100,000 of the population aged between forty-five to six-four. Incidence rates also appear to increase as this cohort ages, with no significant differences between the genders (Garre-Olmo et al., 2010; Abraham et al., 2015).

Differences in the methodologies utilised in the collection of epidemiological data can also add to the variability across studies and standardisation of the methods may assist with gaining correct prevalence rates (Harvey et al., 2003; Lambert et al., 2014). Data from specialised memory clinics also varies widely with the prevalence rate of YOD between 7% and 47% of all dementia cases observed (Vieira et al., 2013).

1.9.2 Types of YOD

Similar to the epidemiological data, there are also differences among the data as to the most common types of YOD. According to Devineni and Onyike (2015) the most common types of YOD are young onset Alzheimer’s disease (YO-AD) and frontotemporal dementia (FTD) with YO-AD accounting for between 30%-40% of cases observed in younger people. This is a significantly lower when compared with the prevalence of Alzheimer’s disease observed in LOD (Harvey et al., 2003; Kelley et al., 2008).

Conversely, FTD is more prevalent in YOD when compared with LOD, with the incidence rate of FTD being higher the younger the age (Davies, Doran, & Larner, 2011). However, Rossor and colleagues (2010) report that vascular dementia is more prevalent than FTD with rates of 18% and 12% respectively highlighting the disparity between researchers and the difficulty with the accuracy of the data. One reason for the disparity in the data may be that the diagnosis in YOD is generally characterised as being broader when compared to LOD with rarer subtypes (see table 2) of the condition more prevalent in YOD (Rossor et al., 2010).

Table 2: Rarer subtypes of dementia

Huntington’s disease	Normal Pressure Hydrocephalus (NPH)	HIV-Associated Neurocognitive Disorder (HAND)
Creutzfeldt-Jakob disease (CJD)		
Korsakoff's syndrome	Corticobasilar Degeneration & Progressive Supranuclear Palsy	CADASIL (Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy)
Primary Progressive Aphasia (PPA)		
Atypical Alzheimer’s disease	Frontal variant Alzheimer’s disease (fvAD)	
Posterior cortical atrophy		

(adapted from Alzheimer’s Research UK, 2020).

1.9.3 Diagnosing YOD

For people with young onset dementia (PwYOD) and their families, the diagnostic process can be significantly problematic. Younger people who may be experiencing issues with memory, cognition or behaviour more often than not are diagnosed with other problems such as depression, anxiety, stress or burn-out (Draper et al., 2016). Typically, deficits in executive functioning are not associated with dementia due to the individuals younger age (van Vliet et al., 2011).

Unfortunately, PwYOD are often diagnosed with a psychiatric disorder due to the neuropsychiatric and behavioural symptomatology which further delays an accurate diagnosis and can also result in the prescribing of inappropriate medications (Bakker & de Vugt, 2010). Furthermore, PwYOD and their families have reported that attempting to obtain a timely diagnosis can be a stress filled and protracted process (Millenaar et al., 2018; van Vliet et al., 2011). Research has outlined that the average waiting time from onset of symptoms to definitive diagnosis can be between 2·8 and 4·4 years for PwYOD, a significantly longer time period when compared to diagnosing LOD (Draper et al., 2016; Novek, Shooshtari, & Menec, 2016; van Vliet et al., 2013).

Almost three-quarters (71%) of family members of PwYOD report significant issues with the diagnostic process citing healthcare professionals lack of knowledge, misdiagnosis and poor referral from general practitioners (GPs) as just some of the problems encountered. These issues appear to be more prevalent when the PwYOD was diagnosed with a subtype other than YO-AD, suggesting that deficits other than memory problems are less likely to be attributed to YOD (Luscombe et al., 1998; Mendez et al., 2007).

Rarer subtypes appear to be particularly problematic, and younger age combined with comorbid conditions, such as depression, muddy the diagnostic waters and can lead to substantial delays with gaining a diagnosis (Draper et al., 2016; van Vliet et al., 2013). In one study by Rosness and colleagues (2008) evidence outlined that the length of time from onset of symptoms to accurate diagnosis in young people with FTD was almost double that compared to YO-AD (4 years, 11 months and 3 years, 3 months respectively).

Participants in the study included fifty-two young people FTD, of which thirty-seven (71%) were wrongly diagnosed with a non-dementia compared to eleven (30%) diagnosed with YO-AD (Rosness et al., 2008).

In another study by Johannessen and Moller (2013) young people with FTD were misdiagnosed with alcohol misuse, relationship issues, midlife crises and psychiatric disorders. Those with YO-AD who received a wrong diagnosis were thought to have atypical depression, work-related stress or symptoms of burn-out. According to Harris and Keady (2009) many individuals with YOD are often still in full employment when symptoms first surface, which is in stark contrast to those with LOD.

For example, research from Norway illustrates that as many as two-thirds of people diagnosed with YOD were in paid employment at symptom onset, however, by the time a definitive diagnosis was achieved the individuals had already ceased employment (Haugen, 2012). The cessation of employment at a relatively young age is another complication of YOD when compared to LOD. For many people with YOD ceasing employment can lead to feelings of loss of autonomy and selfhood, particularly if employment cessation is attributed to psychiatric issues, and not associated with dementia (Beard, 2004; Johannessen, 2017).

Employment is not just a source of income, for many individuals employment is associated with their sense of identity (Rabanal et al., 2018). Cessation of employment can lead to issues with self-esteem and self-efficacy and can also have a negative effect on relationships within the family (Clemerson, Walsh, & Isaac, 2014; Johannessen & Moller, 2013; Roach & Drummond, 2014). Therefore, PwYOD should be consulted at every stage of the diagnostic process in order to allow them to be actively involved in every aspect of their future while they still have the cognitive ability to do so.

Unfortunately, as well as individuals being relatively young, YOD often presents with atypical symptomology making the diagnosis even more problematic. Research by Scheltens and colleagues (2017) illustrated that in a third of cases (30%) individuals showed no signs of amnesia when compared to only 6% in LOD. This may be due to different neuropathology's between YOD and LOD in relation to Alzheimer's disease instead of the age profile of the individual, however, evidence still remains unclear (Smits et al., 2012; Medina et al., 2017).

For example, evidence has shown pathology in the posterior occipital lobe (posterior cortical atrophy-PCA) which significantly impairs visuo-spatial functioning, with difficulties also observed with reading, writing and language (logopenic aphasia) in patients with YOD. However, vision and memory remains largely unaffected (Devineni & Onyike, 2015; Scheltens et al., 2017). In order to improve the diagnostic process for PwYOD, it is suggested that a comprehensive analysis of both cognitive and neurological issues should be conducted in specialist memory clinics (Rossor et al., 2010).

For instance, the Florence centre in the Netherlands is a specialist YOD Knowledge Centre in which young people who are suspected of having YOD are assessed for behavioural and cognitive symptoms in order to assure a timely diagnosis (www.florence.nl).

1.9.4 Risk factors associated with YOD

While LOD is mostly associated with age, YOD is typically attributed to genetics, autoimmune deficiencies, nutritional or metabolic problems and potential modifiable lifestyle factors. Moreover, traumatic brain injury may also be a prelude to YOD, particularly in individuals younger than forty-five years of age (Devineni & Onyike, 2015; Fujihara et al., 2004). McMurtray and colleagues (2006) reported a significant number of cases of YOD due to traumatic brain injury, alcohol misuse and HIV in clients from the United States Veterans Affairs Memory Disorder Clinic.

Similarly, Picard and colleagues (2011) outlined that traumatic brain injury and alcohol misuse resulted in higher instances of YOD, particularly young onset FTD and Huntington’s disease. In two European studies modifiable factors were reported as possible causes of YOD-AD and FTD in both Spain and Greece (Papageorgiou et al., 2009; Garre-Olmo et al., 2010). There is also similar evidence from other research illustrating the role of modifiable causes of YOD (Nordstrom et al., 2013; 2014).

Furthermore, research by the Mayo Clinic examined clients with YOD aged between seventeen and forty-five. Findings outlined that there was varied aetiology attributed to age, however, for people under thirty years of age metabolic issues were the most common cause of YOD. In almost a third of cases (31%) neurodegenerative conditions were reported as the cause for people aged over thirty, with FTD (42%), Huntington’s disease (25%) being the most prevalent subtypes. Autoimmune conditions and various inflammatory disorders accounted for 21% of cases (Kelley et al., 2008).

An allele known as the apolipoprotein-E4 (apo-E4) is the most common factor associated with inheriting both YOD and LOD (Molinuevo et al., 2014). The risk increases significantly for individuals who inherit this gene from both parents, and the age of onset of symptoms can also be much lower as a result. In other words, genetic inheritance of apo-E4 heightens the chances of developing YOD (Breitner et al., 1998). This is a correlational relationship, not a causal one. Therefore, individuals with the allele may only be predisposed to YOD and may not go on to develop the condition (Medina et al., 2017).

However, individuals who have a family history of the condition are at a significantly higher risk, with evidence outlining almost 66% of PwYOD reporting a positive family history (Hodges et al., 2004). Similar findings from a study by Rosness and colleagues (2008) outlined a significant increase in cases due to family history in young people with AD when compared to young people with FTD.

1.9.5 Is Young Onset Dementia (YOD) more a more aggressive condition?

There is evidence to suggest that YOD may be a more aggressive form of dementia when compared to LOD. A meta-analysis of research carried out by Tellechea and colleagues (2015) found that PwYOD had significantly more neurofibrillary tangles and plaques and neuronal destruction occurred more rapidly in comparison to LOD. Similar findings were reported research by Panegyres and Chen (2013) and van der Vlies and colleagues (2009).

In one large cohort study, Koedam and colleagues (2008) found faster disease progression and a higher mortality rate in over twelve hundred participants with YOD when compared to the mortality rate with individuals with LOD. Conversely, research has also illustrated that there is no significant difference in disease progression and mortality rates between YOD and LOD (Shinagawa et al., 2007; Rhodius-Meester et al., 2019). According to Scheltens and colleagues (2017) reasons outlined for perceived differences may be due to atypical presentations, for example, non-amnesia symptoms observed in YO-AD.

1.9.6 Does Cognitive Reserve Play a Role?

One reason for PwYOD having a more aggressive form of dementia may be due to a reduced capacity in cognitive reserve. There is evidence outlining the role that cognitive reserve can play in protecting older people from the rapid onset of dementia. Studies have reported how some older people did not display any dementia symptoms despite autopsy data showing extensive neuropathology (Marshall et al., 2007).

1.9.7 PwYOD – Social issues due to life stage

YOD manifests during the active stage of an individual’s life and as a result significantly affects every aspect of living. The condition has an impact on employment, relationships with a spouse/partner and children, various social obligations and often leaves PwYOD with feelings of inadequacy and the lack of autonomy (Svanberg, Spector & Stott, 2010; Greenwood & Smith, 2016).

Ceasing employment can cause significant financial hardship for PwYOD and their family and can serve to lower an individual's sense of belonging, purpose and engagement in daily life (Harris & Keady, 2009). A loss of selfhood combined with the cognitive, behavioural and functional symptoms experienced by PwYOD has been found to severely affect their sense of quality of life and general wellbeing (Teng et al., 2012). Many PwYOD report feeling "*to young*" to have dementia leading to fears about the future (Clemerson et al., 2014).

PwYOD often have to revise their life expectations and make forced changes and adjustments to their future plans. This revision is paramount if they are to cope physically and emotionally with these new challenges and in order to function adequately in daily life (Huber et al., 2011). Moreover, the perception of dementia as a disease of older age leaves many PwYOD feeling atypical in their own communities which places significant psychological strain on them (Rabanal et al., 2018).

PwYOD, more often than not, are stigmatised due to the condition. Stigma may arise due to the lack of understanding in the general public about dementia in general and YOD in particular. Given the effects of YOD on factors such as memory, judgement and behaviour, many people may view it as a mental health condition leading to fear and misunderstanding that is often associated with other mental illnesses (Morgan et al., 2002). Unfortunately, individuals living with a mental health condition are sometimes viewed as dangerous, have poor outcomes and have difficulties with social engagement (Hayward & Bright, 1997) and similar misunderstandings may be held in relation to PwYOD.

A further significant challenge for PwYOD can be the changes in the relationships with a spouse/partner and other family members including children (Wawrziczny et al., 2016). Shinagawa and colleagues (2006) reported that behavioural changes resulted in issues with affection towards a spouse/partner in almost two-thirds (63%) of people with young onset FTD. Such psychosocial issues can undermine PwYOD's sense of self-identity, as being able to be an active individual who contributes to society is vitally important (Clemerson et al., 2014).

1.9.8 Defining Stigma

In Greek society, *stizein* was a mark placed on slaves to identify their position in the social hierarchy and to indicate that they were of less value. The modern derivative, *stigma,* is therefore understood to mean a social construction whereby a distinguishing mark of social disgrace is attached to others in order to identify and to devalue them (Arboleda-Flórez, 2003). Stigma is a complex concept and may occur at an individual, interpersonal, familial, societal, and institutional level. Erving Goffman often considered the originator of the modern conceptualisation of stigma, defined stigma as "*the situation of the individual who is disqualified from full social acceptance*" who is then "*reduced in our minds from a whole and usual person to a tainted, discounted one*" due to a mark or attribute (Goffman, 1963 pp.3).

Dudley (2000), taking from Goffman's initial conceptualisation, defines stigma as stereotypes or negative views attributed to a person or groups of people when their characteristics or behaviours are viewed as different from or inferior to societal norms. Thus, stigma and the process of stigmatisation consist of two fundamental elements: the recognition of the differentiating "mark" and the subsequent devaluation of the person. For example, throughout history and in practically every culture, groups of people, including people living with mental health issues, have been stigmatised. Although the Greeks did not appear to have stigmatised people living with mental illness as such, they nevertheless thought that being mentally ill carried an undertone of shame and weakness of character.

These beliefs are still found in many contemporary societies that consider mental illness as a condition associated with shame that causes the individual or their family to lose the respect of society (Arboleda-Flórez, 2003). Interpretations relating to stigma have developed over time. More recent evolutions suggest a theoretical framework to understand stigma comprising of six interrelated concepts. For instance, in the case of YOD:

i) the labelling of differences (i.e., person living with YOD versus "normal person").
ii) linking these differences to stereotypes (dementia is a disease of old age).
iii) cognitive separation into the categories of "us" (people whose cognition is affected by normal aging) and "them," (person living with YOD).
iv) emergence of emotional responses (i.e., loss of identity and status when living with YOD).
v) prejudice and discrimination.
vi) leading to an unequal power situation (Link & Phelan, 2001).

Given some of the behavioural similarities between YOD and mental ill-health, more often than not, YOD is mistaken for a mental illness. Accordingly, people living with YOD can face stigma that is associated with mental illness (Morgan et al., 2002). Figure 4 illustrates some of the interconnected factors that can result in the stigmatisation of a person or group of people. For example, the use of specific "*in-group*" language can reinforce the sense of belonging to the in-group, while at the same time promote the differences with members of the "*out-group*" (Brashers, 2008).

Utilising language in this way can lead to the labelling of members of the out-group. According to Link and Phelan (2001) stigma typically involves the coexistence of several factors including labelling. The use of language to label the out-group can then lead to stereotyping, prejudice, discrimination, social exclusion and the loss of power/status. Moreover, labelling allows for the easy identification and categorisation of individuals into various groups in society and can also associate an individual, or group, to a set of displeasing attributes, which can then be stereotyped and discriminated against (Link & Phelan, 2001).

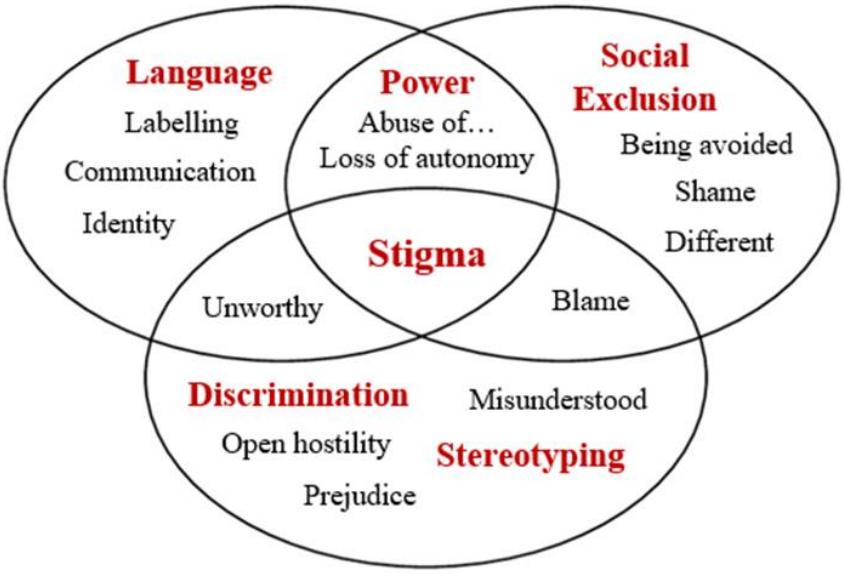

Figure 4: Illustration of the interconnected factors that can be a prelude to stigma.

1.9.9 Family Carers – Spouse and Partners

A diagnosis of YOD, not only effects the diagnosed individual, but can also have a significant negative effect on the family members. Research has outlined that many PwYOD live at home for an average of nine years post diagnosis when compared to four years for people with LOD (Withall, 2013). This can represent a dramatic change for their families (Allen et al., 2009; Cabote et al., 2015; Flynn & Mulcahy, 2013) as many family members become the primary carer and are faced with significant challenges (Pang & Lee, 2019).

Behavioural problems, loss of communication, lack of companionship and poorer relationship outcomes are cited by spouse/partners as significant challenges following a diagnosis (Murray et al., 1999; Holdsworth & McCabe, 2018). Many spouses/partners report that there is no longer equity in the relationship, instead it is more akin to a parent and child situation (Ducharme et al., 2013) with little or no intimacy or affection (Dourado et al., 2010).

1.9.10 Family Carers – Children

Due to the life stage associated with YOD, many of those diagnosed are a parent. Similarly, to spouses and partners, children of a parent with YOD are also burdened by the diagnosis. More often than not, children are not included as participants in research studies. However, when children are involved they report that the situation can have a significant negative impact on their physical and emotional wellbeing due to this burden of care. Some report feeling a sense of loss, almost as if the parent had died (Gelman & Greer, 2011). However, despite the emotional toll, family caregivers require their children’s support and children often play a pivotal role in the care of a parent with YOD (Adelman et al., 2014).

1.10 Service Provision

Most, if not all, formal health and social care services provided for people living with dementia are targeted towards older adults with many based in “*older adult settings*”. As a result, such services are wholly inappropriate for PwYOD. However, many families report that they utilise their own informal social networks, without the need for engaging with formal care (Gibson et al., 2014).

Where the need does arise to use formal care services, it typically depends on the carers competency/coping levels (Withall, 2013). Moreover, as PwYOD are cared for at home, carers require more tailored supports such as respite care and home help (Bakker et al., 2013). Engaging care services that visit the home can incur a significant cost and may remain out of reach. Ducharme and colleagues (2016) outlined that many carers of PwYOD may have little choice but to utilise private care services, while carers of people with LOD may not be faced with such a decision as formal services are open to them.

1.11 Young Onset Dementia (YOD) in Ireland

In Ireland, estimates place the prevalence rates of people with dementia between 40,000 and 60,000 individuals approximately. The reliability of the data is questionable as the true number of people with dementia is dependent on the methodology employed to measure prevalence rates (Pierse, O'Shea & Carney, 2019). Prevalence rates of YOD in Ireland are estimated to be between 4,000 and 5,000 people approximately (Pierse et al., 2019).

However, due to the paucity of research in the area, calculating the precise number of people with young onset dementia (PwYOD) in Ireland is problematic. For example, estimates in the report by Alzheimer Europe (2019) state the number of people with dementia in Ireland is set to double by 2050 due to the ageing population. The report relies on figures from a study by Hoffman and colleagues (1991) to predict the number of PwYOD, applying these data to current population trends. Moreover, estimates include only those individuals who have had some interaction with their health and social care providers (Alzheimer's Disease International, 2015).

When compared to LOD, there is significantly less research on the prevalence rates of YOD (Renvoize, Hanson & Dale, 2011; Bakker, 2013; Pierse et al., 2019). According to Lambert and colleagues (2014) the variability in prevalence rates of YOD may be due to study designs, differences in dementia subtypes and issues with age cut-off points for inclusion in research, which combined can significantly skew data.

1.12 Service Provision in Ireland

There is a significant lack of appropriate services in Ireland targeting PwYOD with the traditional models of dementia care (i.e., day care centres) not suitable for younger people (Pierce, Cahill & O'Shea, 2014; Rabanal et al., 2018).

Where relevant services do exist, they are geographically unavailable to the vast majority of PwYOD (Mayrhofer et al., 2018). For example, research by Haase (2005) reported significant challenges for carers of PwYOD in obtaining flexibility with care arrangements, difficulty accessing home help and respite care and issues with clinical care.

1.13 Development of an Irish Dementia Strategy

Prior to the unveiling of the National Dementia Strategy in 2014, several reports were conducted regarding dementia in Ireland. O'Shea and O'Reilly (1999) published An Action Plan for Dementia, in which the unique complexities of YOD were illustrated both for PwYOD and their care givers. In particular, the need for age-appropriate assistance was highlighted with one recommendation stating: "*particular attention should be paid to the needs of people with early onset dementia with appropriate care packages drawn up to reflect the special circumstances of people in this group and their carers*" pp. 38. Eight years later, another report titled Implementing Policy for Dementia Care in Ireland: The Time for Action is Now (O'Shea, 2007) recapitulated the earlier findings.

Further evidence was outlined in a report conducted by Cahill and colleagues (2012) titled Creating Excellence in Dementia Care. Within this report was a section on the prevalence rates and the need for reliable data relating to cases of YOD. Also included were data relating to the specialised needs of PwYOD and the impediments they face with services such as the diagnostic process, home care, day care, respite and residential care. The National Dementia Strategy incorporated the findings from these reports into its overall strategy outlining six priority action areas as follows:

- Better awareness and understanding
- Timely diagnosis and intervention
- Integrated services, supports and care for people with dementia and their carers
- Training and education
- Research and information systems
- Leadership (Department of Health, 2014).

Acknowledgement is given to the crucial role played by general practitioners (GP's) as the first point of contact for PwYOD, and the strategy also confirms the need for specialist healthcare professionals in relation to diagnosing various subtypes of YOD stating: "*a confirmatory definitive diagnosis and identification of the dementia sub-type {this} remains a specialist task*" (pp. 20).

Diagnosing YOD, and its numerous subtypes, remains a difficult and complex issue. According to a literature review of diagnostic services in Ireland, Reves and colleagues (2018) highlight this complexity stating that no one pathway is suitable for every individual, therefore, tailored services may be preferred for PwYOD. Despite the national dementia strategy stating the need for specialism in YOD, the Dementia Services Information and Development Centre (DSiDC) reported that PwYOD remain a marginalised cohort who face discrimination from the health care system in Ireland.

Following multidisciplinary discussions, the DSiDC reported that access to assessment services for PwYOD was regularly restricted due to arbitrary age cut-off points, and the fact that dementia services are typically located in geriatric settings (Fox et al., 2020). The cost of specialist services for PwYOD is also restrictive as many individuals may not meet the requirements for a medical card, therefore, accessing specialist services is financially unattainable. Furthermore, due to the lack of specialists (i.e., neurologists) in Ireland, PwYOD experience significantly longer waiting times.

For example, a survey of Irish clinicians published by the National Dementia Office (NDO) reported that following consultation with their GP, PwYOD had to wait for a significant period before seeing a specialist. In one case, an individual was waiting four years for an "*urgent*" referral to a neurologist, significantly longer than experienced by people with LOD when accessing old age psychiatric services (Fox et al., 2020). Moreover, the report also found that most assessment were carried out in GP offices instead of in specialist memory centres. Clinicians identified several areas that need improvement including timely access to neurologists and multi-disciplinary teams, timely access to appropriate diagnostic tests, full disclosure of results, appropriate post-diagnostic services with proper continuation of care and relevant information/education on YOD.

In total, the majority of clinicians (85%), stated that they regularly see people presenting with cognitive deficits younger than sixty-five, yet this cohort remain restricted to appropriate service provision (Fox et al., 2020). Furthermore, the lack of research with PwYOD and their families in Ireland only adds to the complexities. For example, until recently there was one study relating to YOD conducted by Haase (2005). The research was funded by the Alzheimer Society of Ireland with the overall aim of interviewing PwYOD in order to ascertain their needs. However, according to the authors, attempts to interview PwYOD proved extremely difficult and the research interviewed primary care givers in lieu.

Findings outlined diagnostic issues, communication difficulties, financial problems and issues with adaptive care (Haase, 2005). Despite the use of proxies, the research outlines the specific issues associated with YOD. Similar findings emerged from a more recent report conducted by Fox and colleagues (2020) published by the National Dementia Office specifically examining the pre and post diagnostic pathways in YOD.

Particular emphasis is placed on the requirement for focused interventions and approaches for PwYOD and their families in order to preserve a normal living standard in all aspects of life (Fox et al., 2020). When compared to other national dementia strategies, the Irish National Dementia Strategy only briefly touches on the impact of YOD. For example, the Dutch, German, Welsh and Belgian-Flanders dementia strategies have individual detailed sections on the impact of YOD and policies tackle the issues.

1.14 The Importance of this Research

While the awareness of YOD has grown in recent years, it still remains a relatively under investigated area within dementia research. And within YOD research, studies involving children are almost non-existent, particularly in Ireland. For example, the major piece of research conducted by Fox and colleagues (2020) outlined above has made a significant contribution to the research landscape. The importance of both pre and post diagnostic pathways for PwYOD and their care givers is vital for future policy makers in Ireland.

However, the research does not include children under the age of eighteen. In fact, including children under eighteen in research on parental illness is not always considered in most studies. Instead, research tends to focus on the ill person and/or their primary carer (typically a spouse or partner). Therefore, my goal in conducting this research was to make an innovative, valued and vital contribution to the literature in relation to children’s experiences of parental YOD.

When a parent is diagnosed with YOD, children are often forgotten within the health and social care setting. However, they are faced with the fact that a parent has been diagnosed with a progressive neurodegenerative illness that is terminal, and for many children, they may be required to assist with various caring tasks. Consequently, their lives have been irrevocably changed and I wanted this PhD thesis to be a vehicle that gave a voice to their experiences.

In addition, the trajectory of the prevalence of dementia cases is constantly being revised upwards. This may mean many more children will be faced with the prospect of a parent receiving a diagnosis and they will need the support of health and social care providers. However, if the support needs of children living with a parent with YOD remain unknown then they cannot be adequately addressed. Furthermore, the small amount of literature that does include children's experiences of parental YOD tends to incorporate the views of older adult children (i.e., > 18 years of age).

Such research, while extremely valuable, does not relate to the experiences of much younger children. Given the age profile at which the symptoms of YOD can manifest, it may be reasonable to assume that many family systems include pre-adolescent and adolescent children. Therefore, pre-adolescent, adolescent and older adult children will experience parental illness entirely differently due to their development stage and level of understanding. Furthermore, awareness of YOD is not as widespread as other parental illnesses (or indeed late onset dementia), and the symptoms accompanying the condition can resemble other mental health problems.

Consequently, as well as being an extremely challenging and confusing time for children, they may also be prone to significant societal stigma. Therefore, this thesis is timely in order to elucidate such experiences and to understand the specific needs of children facing parental YOD. This may assist in the development of tailored interventions specifically designed for children and stratified by age and will be an important addition to the Irish National Dementia Strategy.

1.15 Aims of this Thesis

The overall aim of this thesis was to attain substantial knowledge in relation to the impact of parental YOD on children within the family system post diagnosis. In particular, the research was driven by the relevant findings that emerged in chapter 3. Specifically, the main goals of the thesis were:

i. To investigate the psycho-social impact of parental YOD on the family unit from a family systems theoretical perspective.
ii. To synthesise the national and international peer-reviewed qualitative academic literature in relation to childhood experiences of parental YOD.
iii. To explore if the contemporary cultural perspective of dementia influences how children experience parental YOD through social constructivism.

iv. To investigate whether or not there is a need for peer-to-peer support as an intervention to combat the psycho-social issues facing children living with a parent with YOD.
v. To ensure that children's voices and experiences are included in relation to the above goals.

1.16 Structure of this Thesis

The five main goals outlined above are represented in the four individual studies that constitute chapters three to six inclusive (#1 published). These chapters are prefaced by a comprehensive outline of both dementia and YOD in chapter one. The structure of the remaining chapters in this thesis are as follows:

Chapter 2: **Methodology**

This chapter details the methodological approach used in this thesis. The chapter also illustrates the theoretical approaches guiding the research combined with the rationale for employing the qualitative method. Also detailed within this chapter is an additional piece on the philosophy of using public and patient involvement in research. The concluding parts of this chapter outline the ethical considerations involved when working with people living with dementia and children under the age of eighteen as well as a piece on reflexivity. The methodology as well as the procedure utilised are also detailed separately within each of the four subsequent studies.

Chapter 3:

Chapter three contains an original qualitative study that examined the impact of YOD on the family system, guided by Family Systems Theory. The title of this chapter is; "*Young Onset Dementia*: *A focus group study examining the experience from the perspective of Family Systems Theory*". This chapter contains a section that includes the participatory workshops utilising public and patient involvement (PPI) with people living with YOD. Findings from these workshops lead the way for the inclusion of the wider family system, including children in the subsequent study. Furthermore, the inclusion of children in this initial study set the precedent for the studies contained in the ensuing chapters.

Chapter 4:

Findings from chapter three highlighted the significant gap in the research in relation to childhood experiences of parental YOD, and the need to include children in research on the topic. Therefore, chapter four contains a systematic review and synthesis of the qualitative literature relating to children's experiences of parental YOD. The title of the published paper from this chapter is; "*Childhood perspectives of parental young onset dementia*: *A qualitative data synthesis*". Findings from the evidence synthesis outlined the significant lack of data in containing children's voices in relation to the condition. Findings also illustrated that children are faced with substantial psycho-social issues as a result of their parents diagnosis. In particular, both familial and societal stigma was significantly prevalent in the children's narratives.

Chapter 5:

The findings contained in chapter four demonstrated the significant issues that children and young adults face when living with a parent with YOD. In particular, children and young adults reported significant levels of stigma. As a result, chapter five is an original qualitative study that examined the role of the social construct of dementia. The title of this chapter is; "*The influence of Social Constructivism on children and young adults experiences of parental young onset dementia*". Utilising cultural transmission theory, the study explored if the social and cultural perspective of dementia influences the narratives of children and younger adults faced with parental YOD. Findings outlined how children use comparisons with other "*normal*" illnesses such as cancer mainly due to societies lack of awareness of YOD, and as a coping mechanism. Other significant findings illustrate the loneliness felt by children which is made more acute by the lack of adaptive social support(s).

Chapter 6:

Chapter six investigated whether or not there is a need for peer-to-peer support for children living with a parent with YOD. The title of chapter six is; "*Investigating the need for peer support groups for children affected by parental young onset dementia*". Findings from the previous chapters, particularly chapter five, highlight the significant lack of available and adaptive psycho-social support for children dealing with parental YOD. Therefore, chapter six attempted to address this issue.

Findings show that there is an overwhelming appetite for peer support groups for this cohort, endorsed by the children themselves and their parents. It is intended that the findings contained in this chapter will form the basis of an intervention, and to run pilot studies in order to trial the intervention and examine its efficacy in future research.

Chapter 7: General Discussion and Recommendations

Chapter seven synthesises and discusses the main findings of this thesis and sets out any implications and recommendations for policy makers. Also outlined are the strengths and limitations, particularly in relation to the methodology employed. Finally, the overall conclusions of this thesis are outlined.

2 Methodology

2.1 Chapter Introduction

This chapter outlines the methodological approach utilised in this thesis and the philosophy behind the method chosen. Firstly, the theoretical framework guiding this research – i.e., Cultural Transmission Theory and Family Systems Theory are discussed. Secondly, the significant role of public patient involvement (PPI) in research is illustrated. Thirdly, the reasoning as to why a qualitative methodology was employed in this thesis is explained and the qualitative approach, and in particular thematic analysis, is described. Finally, the ethical considerations when involving both people living with dementia and children under the age of eighteen in research are examined.

2.2 Social Constructivism through Cultural Transmission Theory

Cultural transmission theory posits that beliefs and attitudes are learned or constructed through social interaction and they are not only specific of their time, but also transmitted through time (Cavalli-Sforza et al., 1982). As opposed to learning through experience, non-passive engagement is not a prerequisite, as erudition is acquired acquiescently by being a member of a social environment. In other words, certain beliefs, attitudes, behaviours and norms are passed from one generation to the next in a form of enculturation (Grusec & Hastings, 2014). For instance, the movement in relation to the treatment of people living with mental health disorders in the 1970s.

The movement was opposed to the medicalisation of various disorders and subsequently ignited the person-centred care approach. This resulted in a more socially acceptable understanding of such noncommunicable illnesses (Mental Health Foundation-UK, 2015). Dementia is one such topic that has been shaped via social construction through cultural transmission. Views, beliefs and opinions in relation to dementia are depicted, elucidated and either integrated or repudiated through various social and cultural contexts (Kontos & Martin, 2013). Moreover, the formation of views and beliefs around dementia can be shaped by the existence of other social constructs – i.e., how aging is represented (Hulko, 2009).

In other words, depending on the social and cultural climate (*Zeitgeist*) of the time the perception of people living with dementia has been multifarious.

2.2.1 Social construct of cancer, motor neuron disease and multiple sclerosis

There was a time when cancer came with an associated stigma (Sontag, 1989). However, according to Gibson and colleagues (2017) the contemporary perspective of cancer is one that garners universal sympathy. Therefore, disclosing that a parent has been diagnosed with cancer is no longer hidden. In other words, there is a societal level of awareness in relation to cancer. Furthermore, most individuals are cognisant that cancer is not biased towards a person's race, age or wealth and a diagnosis elicits a certain social protocol (Sikes & Hall, 2018). Consequently, although a cancer diagnosis is viewed as life changing, the condition manifests significantly differently to dementia. For example, as well as the physical symptoms cancer is associated with probable psychological issues for both the diagnosed person and their family.

However, society ascribes such psychological issues as a consequence of the condition rather than stemming from the condition itself (Timmermann & Toon, 2012). Interestingly, other conditions such as motor neuron disease and multiple sclerosis follow a similar protocol as societal awareness has significantly increased. In other words, the social construct of cancer, motor neuron disease and multiple sclerosis is one where the disease itself does not affect behaviour or personality directly, but rather as a consequence. Despite some similarities with certain neurodegenerative conditions, this is in stark contrast to the social construct of dementia, specifically young onset dementia (Hall & Sikes, 2017).

2.2.2 Social construct of dementia: A historical perspective

Speculation about dementia can be traced as far back as classical times where the condition was connected to age instead of an illness or disease. This depiction illustrated older age as a time in life when human beings decay, and this decay was linked to issues relating to the mental processes (Cipriani et al., 2011). For example, Pythagoras (570-495 B.C.) posited five life stages in order to understand the ageing process. According to the five life stages, the "*senium*" stage occurs between 63 and 81 years of age, a stage when cognition and mental function begin to erode and decline.

This senium stage may be one of the primary depictions of dementia, as Pythagoras stated that older age was a time when, "*The scene of mortal existence closes... and ... the system returns to the imbecility of the first epoch of the infancy*" (Poulakou-Rebelakou et al., 2012). The union of aging with dementia brought about the social construct relating the condition to the natural aging process, and at the same time generated a societal stigmatisation of aging that was prevalent in varying domains of society (Berchtold & Cotman, 1998). For instance, within the justice system, the laws governing inheritance were altered by judge Solon (638-558 B.C.) to prohibit people who were deemed to be affected by decreased judgement as a result of old age from claiming their benefaction (Leão & Rhodes, 2016). The negative social construct was further endorsed by Hippocrates (460-377 B.C.) by Plato (424-423 BC.) and Aristotle (384–322 B.C.) who used terms such as "*paranoia*" and "*imbecility*" in relation to cognitive decline in old age (Feldman, 2007).

Even one of the most accomplished medical researchers of his time, Galen (129-216 A.D.) referred to dementia as a "*morosis*". Galen described dementia as a condition where, "*the knowledge of letters and other arts are totally obliterated*", with people unable to recall the simplest of information such as their own names (Berchtold & Cotman, 1998). Galen's perspectives on dementia added to the negative social construct in relation to aging, with older members of society regularly being referred to as demented or cognitively/mentally challenged (Boller & Forbes, 1998). Moreover, the great playwright William Shakespeare described the last stage of the seven ages of man as the "*second childishness and mere oblivion, Sans teeth, sans eyes, sans taste, sans everything*" (Holzknecht, 1955).

In the Middle Ages people with dementia have been perceived as sinners or as receiving punishment for previous sins leading to the association of dementia with some form of divine retribution (Beach, 1987; Berrios & Porter, 1995). Cultural transmission of such beliefs were spread by the institution of the church through its powerful theological teachings. One medieval English philosopher and Franciscan friar, Roger Bacon (1214-1294), placed significant emphasis on the need to utilise empirical or scientific methods in order to study natural phenomenon. However, the church authorities pursued an unrelenting attack on Bacon and his views, eventually imprisoning him for the crime of witchcraft (Beach, 1987). Such religious doctrine sustained the stigma already socially constructed around aging with many Western European countries (during the 15th and 16th centuries) jailing people with deficitis in cognition (including people with dementia) as they were deemed unworthy of Gods glory.

Incarceration was viewed as a way of preventing such individuals from "*infecting those who were pure of spirit*" (Gilleard, 2002). Interestingly, this perception of dementia still exists in some cultural and religious contexts presently, legitimised as a Gods anger (Adamson, 2001) as a form of karmic retribution for previous sins (Hinton et al., 2008) or as demonic possession/witchcraft (Jett, 2006).

The era of Enlightenment followed the Middle Ages and science challenged the religious dogma. However, there remained some ignorance in relation to dementia. For instance, the language used to describe dementia included terms such as "*lethargie*", "*stupidity*" and "*insensitivity*". Such terminology only served to prolong the negative societal perspective in relation to dementia and further endorsed the correlation with aging (Berrios, 1987; Foerstl et al., 1991). During the 19th century there was a measured separation between senile dementia and other subtypes. However, aging individuals with dementia continued to be linked with insanity and were routinely institutionalised (Blumer, 1907). This association prevailed in society as a result of the similar symptoms which may manifest in both dementia and psychosis with people with dementia being regularly housed in lunatic asylums (Hill & Laugharne, 2003).

The 20th century heralded the beginning of the medical model with mental illness and cognitive deficits viewed as a brain disease and dementia being referred to as a neuropsychiatric condition (Alzheimer, 1907). However, as the medical/psychiatric professionals categorised and sub-categorised the various symptoms associated with a dementia diagnosis, individual human attributes were overlooked in favour of the symptomology (Busse & Blazer, 1980). A movement against the medical/psychiatric model of mental illness began in the late 20th century with critics citing the impact of social determinants (Szasz, 1997). One such influential theory was posited by Kitwood (1997) which suggested that neurological deficits may be amplified by malevolent social psychology. The theory assisted in the reconfiguration of care through the evolution of a person-centred approach. Fundamental to the new approach was promoting a sense of personhood for people living with dementia with a foundation built on positive care relationships and practice (Kitwood, 1997).

2.2.3 Social construct of dementia: A contemporary perspective

How dementia is presented (and how it is perceived) in the early 21st century occurs in a myriad of differing ways. The socio-cultural perception of dementia is influenced through advocacy campaigns, the work of various charity organisations and active citizenship by people living with dementia in order to initiate more dementia friendly communities (Heese, 2015). The previous clinical focus that outlined neurological degeneration, or a condition marked by functional impairment in memory and cognition (Blessed et al., 1968; Kitwood, 1997), has been replaced by an emphasis on the lived experiences of the condition.

For instance, recent film and television adaptations have included "*Iris*" a biography of writer Iris Murdoch and "*Still Alice*" a fictional depiction of a university language professor (Parker et al., 2021). This shift away from a biomedical model may assist in dispelling the narrative that dementia is associated with loss – loss of agency, loss of selfhood, loss of personhood and loss of the mind. Rather dementia may be perceived as an adaptation to a representation of a new self (Parker et al., 2021). Despite the recent advances, the stigma associated with dementia prevails in many modern societies and cultures. For example, Arabic culture uses the term "*kharaf*" which literally translates to a person having "*lost their mind*" (Berisic & Nesvadba, 2008).

In contemporary Christian culture views on dementia remain unclear, with the doctrine often referring to dementia as a punishment for sins committed prior to diagnosis or as rightful retribution for the sins of Adam (Radde-Antweiler et al., 2018). Religious communication publicising various values and beliefs may be accountable for contemporary representations of dementia. For example, the modern human behaviour of social media use has been associated with developing dementia by some quarters. At a plenary session of the German bishops conference in 2015, Cardinal Reinhard Marx (Archbishop of Munich and Freising) reportedly stated, "*blogging sometimes leads to dementia, doesn't it*?" (Katholisches, 2015).

Christianity is not alone in associating dementia with some form of divine punishment. Sikhism, for instance, requires its member to adhere to a principle known as "*seva*" a type of giving back to the community through selfless acts. For example, there is an expectation on individuals to care for the sick and assist the less fortunate in society. However, if a person is living with dementia, they are exempted from such activities and instead are required to repent for their sins (Khan et al., 2015).

While in some African countries, symptoms such as psychological and behavioural issues associated with dementia are viewed as demonic possession that only affect those individuals who are weak of spirit (Mkhonto & Hanssen, 2018). Such negative, collective socio-culture perceptions and portrayals mean people with dementia and their families continue to fear prejudice and discrimination as a result of the associated stigma. Consequently, this can lead them to concealing their symptoms from family, friends and the wider community resulting in a withdrawal for society (Berisic & Nesvadba, 2008).

People with dementia may choose to remain on the periphery of their communities and disengage from what they perceive as an able-bodied society. Moreover, the perception of loss can be exacerbated through social interactions with other members of society. As the person living with dementia gradually experiences a decline in their ability to communicate, there may also be a decline in their social identity. This can result in the person with dementia being perceived by others as a “sufferer”. This perception can further maintain the sense of loss felt by the person with dementia as they grapple with an already diminishing sense of self (Sabat & Harré, 1992). For example, imagine a person characterised as positive, active and energetic with a bustling work and home life. Following a diagnosis of dementia, the person is not likely to lose that sense of themselves.

However, it is probable that society will re-characterise those very same attributes as illogical, restless rambling (Downs, 2000). This can lead to the creation of intimations that become adopted and taken for granted in relation to the condition (Harding and Palfrey, 1997). Inclusive dialogue is required to realise an effective communal resolution in order to ensure equity and equality to support people, not to just live, but to live well with dementia (Social Care Institute for Excellence, 2013).

2.3 Family System Theory

First introduced by Murray Bowen (sometimes called Bowen Theory) it was one of the original theoretical insights to examine, in depth, the operations of the family system (Bowen, 1966, 1978, Kerr & Bowen, 1988). The theory posits that the family is a group of people who are organised into a close unit living together in the same location. The members of the unit are both related to each other and dependent on one another and members can include parents, children, and others. Primarily, the theory focuses on the various configurations that evolve within the family, and how they can assist in ameliorating anxiety.

According to Bowen (1966) perceptions of the closeness of relationships can be a major cause of anxiety among family members (i.e., either too close or too distant). For instance, if members are unable to contemplate and respond to familial relationship issues, the family may exist in a prolonged and persistent state of anxiousness. Consequently, this internal anxiety can significantly impact on the levels of external stress a family can cope with. Central to the theory are eight interconnected factors that assist in describing and shaping the reason for the existence of the psychological disharmony among family members (see table 3).

2.3.1 Differentiation of self (Emotional fusion)

Differentiation of self refers to an individual's capability to operate autonomously with a sense of agency and the ability to make egocentric decisions. However, the individual maintains the crucial emotional connection to the family system (Kerr & Bowen, 1988). Conversely, lack of differentiation or emotional fusion involves the individual dispensing with their own autonomy and decision making in order to achieve oneness for the entire system (Brown, 1991). In other words, an individual in an emotionally fused relationship may find it difficult to ponder decisions for themselves or speak directly face-to-face about issues. Instead, they may respond instantly to the requests of another in an impulsive (knee-jerk) fashion. Accordingly, the more emotional fusion exists within the family, the less flexible the system is when adjusting to stressors (Brown, 1999).

2.3.2 Triangles

Triangles or "*triangling*" is a central part of the theory and refers to the smallest relationship component, the couple (Kerr & Bowen, 1988). The process of triangling transpires when the inexorable stress and tension between a dyad is alleviated by including another person. This third individual will either align with one perspective or another or furnish a diversion for the stress and tension (Guerin et al., 1996). Anxiety may stem as the dyad attempts to find a balance between the differentiation of self and the initiation of a nurturing relationship. For example, couples may find communication difficult, however, the inclusion of a third party can transfer the anxiety from the relationship to the other person (Haefner, 2014). However, triangling may become troublesome when the third-party acts as a hinderance to the couples ability to resolve the issues on their own (Bowen, 1978).

Table 3: Eight interlocking factors that describe and shape family functioning as part of the Family System.

Factors	**Description**
***Differentiation of self* (*Emotional fusion*)**	Despite the importance of social groups, the family has the primary role in developing a sense of self.
Triangles	A three-person relationship that has the ability to stabilise a two-person system (dyad) experiencing anxiety.
Nuclear family emotional system	The basic patterns of emotional functioning in one generation: marital conflict, dysfunction in one spouse, impairment in one or more children, emotional distance.
Family projection process	The process through which parents may pass their emotional problems to a child.
Emotional cut-off	Family members unable to reduce or manage their unresolved emotional issues
Multi-generational transmission process	The family projection process can continue to the following generations.
Sibling position	Sibling position in a functioning family.
Societal regression (societal emotional process)	An application of the theory to social organisations.

Adapted from (Haefner, 2014).

2.3.3 Nuclear family emotional system

The nuclear family emotional system places the emphasis on the effect that a lack of differentiation can have on one family generation. This dysfunction in emotional fusion is evident in three distinct categories comprising conflict between the couple, spousal antagonism and projecting the discord onto a child or children resulting in emotional anguish (Brown, 1999).

2.3.4 Family projection process

Psychological symptoms can evolve in children due to the family projection process, specifically if the child (ren) get embroiled in the preceding generations stress and tension regarding relationships. In particular, children with the greatest emotional attachment to their parents may be most at risk from the anxiety transfer. The child (rens) anxious reaction may then mean that they are mistakenly pinpointed as a “problem child” and subsequently they attract and need attention. As the child (ren) receives more attention, they may become more difficult and challenging as the spiral of mutual anxiety continues (Bowen, 1978).

2.3.5 Emotional cut-off

Emotional cut-off can occur in two ways, either through actual physical distancing or through emotional distancing. According to Bowen (1978) physical distancing is achieved through breaking away from the family, while emotional distancing is posited as a growing away from the family. Growing away may occur as adult members of the family pursue different life ambitions and objectives while remaining part of the family system. This may also be viewed as part of the differentiation process (Kerr & Bowen, 1988). If individuals decide to be cut off from the family system, they may choose to escape in order to be entirely disparate from their original family. However, while the cut-off may alleviate the initial stress or anxiety, individuals typically return to their archetypal sequences of behaviour in time (Haefner, 2014).

2.3.6 Multi-generational transmission process

The multi-generational transmission process is similar to cultural transmission theory as it posits that various standards, attitudes, concerns and roles within the family system are transmitted from one generation to the next. This transmission occurs as parents transmit to their child (ren) as part of a triangle or triangles (McGoldrick, 1995).

Depending on the intensity of the relationship within the triangle, the effect of transmission will vary for each child (Miller et al., 2004).

2.3.7 Sibling position

Building on a theory posited by Toman (1961), sibling position places an emphasis on the order in which children were born into the family system. Depending on the order of birth, the evolving personality attributes of the growing child may be significantly influenced.

For example, a parent who associates their child’s birth position as similar to their own, it is likely that through triangling the tension felt by the parent dyad will be passed to the child. Another outcome of sibling position may be observed in how the oldest child may adopt a position of authority and duty, while the middle child may feel a sense of freedom to move between duty and reliance on others. The youngest child (ren) are often happy to remain reliant and acquiesce decision making to others (Brown, 1999).

2.3.8 Societal regression (societal emotional process)

Societal regression relates the relevance of Bowen theory to social organisations. The theory posits that the anxiety, stress and tension faced by the family can be paralleled by society. For instance, if a family system encounters greater chronic stressors its functioning may deteriorate. Similarly, if society encounters sustained stress such as a significant rapid growth in population, a decrease in resources or environmental catastrophes, its functioning will also face regression (Bowen, 1978). Just like a family system, society also incorporates the concepts of differentiation and individualism which may manifest in a conflicting manner (Brown, 1999).

2.3.9 Family System and Illness

The family unit works together in a purposeful manner in order to achieve particular goals (Freidman, 2003). As outlined, within the family system there may be "*subsystems*" such as "*parent-parent*", "*parent-child*", "*child-child*" and "*parent-sibling*" with each subsystem influencing the overall system (Bronfenbrenner, 1986). Therefore, an event that affects one part of the system can affect the entire system (Cox & Paley, 1997). When the event is the diagnosis of an illness, the relationships within the system can be negatively impacted. For example, illness such as a parents or child's diagnosis of cancer (Williams, 1997) or a child's diagnosis of autism, can result in marital discord and significantly poorer sibling relationships (Rivers & Stoneman, 2003).

Similarly, a child receiving a diagnosis of spina bifida can result in the breakdown of family functioning and lead to sibling conflict (Bellin & Rice, 2009). While research on dyadic coping strategies has highlighted positive outcomes for couples, many people with young onset dementia are part of a wider family unit that may also be impacted by the condition. For instance, research by Abbeduto and colleagues (2004) outlined the challenges for families who are living with disability, such as the demand of caring and high levels of stress and anxiety. According to Gelman and Greer (2011) children can also be involved in a caring role, with many reporting poor psychosocial outcomes as a result.

Common among children were feelings of grief and loss, however, families often require their children's support and children often play an important role in the care giving tasks (Adelman et al., 2014). Therefore, neurodegenerative conditions that involve significant cognitive impairment such as dementia, represent substantial issues for both the individual and their families.

Due to the nature of dementia and the trajectory of the disease, family relationships may be irrevocably altered (Ablitt et al., 2009) mainly because of the increased intensity and prolonged nature of caregiving demands. For example, the onset of various dementia subtypes varies considerably, and their impact may only appear gradually over time (Kasper et al., 2016). A combination of the deterioration in cognition and the significant demands of caring places the family system at a considerable risk of losing crucial quality time for social activities. Progressive neurodegenerative conditions require a greater degree of stamina and adaptability in order for the family to cope as they may be faced with behavioural as well as physical issues (Weingarten, 2010). Moreover, the stress and tension can be significantly increased for the family as a result of the perceived threat of neurodegenerative issues for other members in the future. In other words, families can perceive dementia as a multi-generational condition (Rolland, 2006).

Furthermore, families who find themselves on the lower end of the income spectrum are at a further risk as a result of their social position and the financial inequality in health and social care systems (Zuelsdorff et al., 2017). Utilising family system theory, the caregiver role broadens to a caregiver system which may assist with successful coping and adaptation to the chronic condition. In other words, an all-encompassing biopsychosocial model based on the family system may positively impact the illness course and the ill persons wellbeing. Traditionally, caregiver and patient roles have been narrow when adapting to and coping with chronic illness with typical gender-based roles including the "*designated*" female caregiver (Rolland, 2003). Widening this narrow approach to include a multigenerational family system (McGoldrick et al., 2011) may be essential to improve coping over time.

2.4 Public Patient Involvement (PPI) in Research

The research questions in this thesis were generated from identifying gaps in the existing literature and through engagement with people living with young onset dementia. Public and PPI is typically defined as research that is conducted "with" or "by" members of the public and patients rather than "on", "to", "about" or "for" them. PPI does not mean that individuals merely serve as passive participants who take part in interviews or focus groups and complete surveys.

PPI means that patients and members of the public collaborate directly with the research team in order to assist with the design, creation and dissemination of research in a true co-production (Brice et al., 2015). The application of co-production can be a flexible process with the public and patients freely engaging in all aspect of the research at any stage during the research. For example, PPI may involve an initial consultation, reviews of protocols or manuscripts, reciprocal feedback, editing documents such as consent forms and information leaflets etc., and assisting during participant recruitment. Moreover, members of the public and patients can commission research and actively look for specific researchers to employ as part of the project (Price et al., 2018).

Public and Patient Involvement (PPI) at the beginning of this research developed specific topics that guided the initial phase of the thesis. Initially participatory workshops with members of the Alzheimer Society of Ireland (ASI) Dementia Research Advisory Team (DRAT) were conducted. Members of DRAT are people living with YOD residing in the community. The participatory workshops assisted in the development of research topics of relevance to people living with YOD and their families and guided the research questions addressed in this thesis.

Members of DRAT who were involved in the PPI are proficient in research literacy and have participated in many research studies both at an advisory level and as participants. Research literacy refers to an ability to access, interpret, and critically evaluate primary research literature. It involves the development of a range of critical thinking skills including being able to search, discover and evaluate relevant information. Research literacy also encompasses knowledge and an understanding of how data is produced and its value as well as the ethical considerations of its production and dissemination. In other words, research literacy actively motivates (actually requires) individuals to be critical thinkers and readers of academic work (Beaudry & Miller, 2016).

While PPI was utilised to generate topics of interest for investigation at the beginning of this research the members of DRAT further consulted throughout the various stages of this research. Given their expertise by experience, the PPI panel were consulted following each individual study to further examine the findings and provide guidance on the next stage(s) of the research and also to advise on the dissemination of the findings.

2.4.1 Why involve patients and members of the public?

As well as the practical benefits of helping to ensure research quality and relevance, the underlying reasons for involving members of the public in research are also informed by broader democratic principles of citizenship, accountability and transparency. The reasons for involvement might not always be clearly defined, and at times will overlap each other. However, understanding the "*why*" of involving members of the public in research will help with the "*who*" to involve and the "*how*" to involve them (Hughes & Duffy, 2018).

2.4.2 Why members of the public and patients get involved?

Members of the public get involved in research for a variety of personal and social reasons. For some, it may be linked to personal experiences of health or social care services and a desire to bring about change in the quality of care or to improve treatments either for themselves or for others with a similar condition. For others it might be a way to have a "voice" and influence the processes that affect people's lives or it might be to influence research by giving something back and helping others through their involvement. Well planned and resourced involvement in research can also be valuable to those involved by increasing their confidence and knowledge and helping them to develop new skills (Crocker et al., 2017).

2.4.3 Providing a different perspective & improve research quality

Members of the public might have personal knowledge and experience of the research topic or be able to provide a more general perspective. Even if you are an expert in your field, your knowledge and experience will be different to the experience of someone who is using the service or living with a health condition. For example, assisting to make the language and content of information provided more appropriate and accessible (i.e., in questionnaires and patient/participant information leaflets, consent forms etc.). PPI can help to ensure that the methods proposed for the study are acceptable and sensitive to the situations of potential research participants and ensure that research outcomes are important to the public. PPI can increase participation in research by making the research more appropriate and acceptable to potential participants, by improving the information provided so people can make informed choices and by helping to include seldom heard groups (Schwartz et al., 2019).

2.4.4 Improve research relevance

PPI can assist in improving the relevance of a research project. For example, through the identification of a wider set of research topics than if researchers had worked alone, therefore giving voice to the suggestion of ideas for new research areas. Moreover, ensuring that research is focused on the public's interests and concerns and that money and resources are used efficiently, PPI can help to reshape, clarify and bring purpose to the research (Rose, 2014).

2.5 Research Paradigm: Post-positivist; Constructivist or Pragmatism.

As a researcher, I had to decide which methodology would be best suited to explore the aims and objectives of this thesis. However, as a human being I understand that I am prone to inherent presuppositions in relation to the essence of reality (ontology) and the processes involved in attaining knowledge about the same (epistemology). Therefore, my presuppositions are the foundations of my beliefs about the world (ideology) and as such inform my choice of methodology to use in research. Thomas Kuhn (1962), the renowned philosopher, would refer to such ideologies as paradigms.

Three paradigms tend to influence the research landscape: post-positivist; constructivist and pragmatic. Both post-positivist and constructivist are viewed as being diametrically opposed to each other (Howe, 1998) while pragmatism emerged and evolved as a counter to the animosity between the first two. Post-positivism, which is entrenched in empiricism, was significantly shaped by philosophers such as Popper, Durkheim and Locke (Creswell, 2009). According to post-positivist epistemology, ontology is singular (one reality) and is understood through measurable or quantifiable objective quantitative measurement (Popper, 1969). Post-positivism has been, and remains, a presiding research paradigm against which other paradigms are typically compared and assessed (Creswell, 2009).

Contrastingly, the constructivist paradigm presumes the existence of several realities that may be socially constructed. Therefore, these realities can be subjectively investigated and understood through qualitative research methodology. In other words, constructivism elucidates the meaning and importance of a phenomenon (or phenomena) compared to post-positivisms purely quantitative measurement (Creswell, 2009).

Pragmatism embodies a practical and problem centric paradigm that does not commit to one ontology or epistemology. Therefore, a pragmatist researcher is not distracted by any deep philosophical discourse. Rather, pragmatist researchers tend to place the emphasis on recognising and utilising the best method to help answer their research questions (Morgan, 2014). Furthermore, pragmatists are aware of the existence of an external realm outside of their own mind. However, pragmatists are acutely aware that their cognisance of this realm is unbalanced by their own circumstances, principles, morals and ideologies (Cherryholmes, 1992; Creswell, 2009; Morgan, 2014).

In other words, according to Duncan and Nicol (2004) pragmatic researchers ideology is guided by a "*subtle realism*". As such, pragmatism can be the rationale behind any chosen research methodology, and is the paradigm that partners with my beliefs, ideas and principles. Specifically, I believe that the procedure involved must be flexible and adaptable to the aims and objectives of the research question in order to gain the appropriate understanding of the research topic. Furthermore, there also must be objectivity, however this objectivity can be clouded by how I discern, analyse and make sense of it.

My knowledge of dementia, as illustrated in chapter one, aligns with the philosophy of pragmatism. For example, I outline that dementia is a neurodegenerative medical condition that has perceptible and quantifiable origins and influences. However, I also outline my belief that environmental factors can also significantly influence the perceptions and experiences of dementia. Therefore, my knowledge of dementia, and in particular YOD, is compatible with the philosophy behind the methodology employed in this thesis.

However, on reflection, despite originally opting for a pragmatic approach to this research the nature of this research shifted and subsequently adopted a social constructionist approach due to a number of factors. Initially the research incorporated a mixed methods design, and the aim was to combine data from several stakeholders – i.e., people living with YOD and their families, health and social care professionals and family doctors (GP's). However, following inaugural ethical approval, the national body representing GP's in Ireland – the Irish College of General Practitioners (ICGP) – stated that their members were not participating in any research projects for the foreseeable future.

Subsequently, the ethical approval was amended to omit GP's and only include health and social care professionals – i.e., specialist staff in memory assessment services such as gerontologists and occupational therapists etc. – together with people living with YOD and their families.

This amendment to the ethics application was approved and the mixed method research design remained possible. Nevertheless, another significant complication was to arise in the shape of a global pandemic. As Covid-19 gripped the country, access to any and all health and social care professionals and settings was strictly prohibited. Furthermore, both professions were inundated due to the pandemic placing considerable constraints on their time. In other words, it became virtually impossible to engage any health and social care professionals in a research project.

Combined, both of these factors threatened to derail the entire research project. Nonetheless, people living with YOD, and their family members remained willing to participate, albeit virtually and not in person due to the Covid-19 restrictions. The project required a complete rethink and we decided to continue with an important new aim – how does a parent being diagnosed with YOD affect their children.

Following an extensive literature review, it was evident that the voices of children and young adults living with parental YOD were absent from the academic literature. Therefore, not only did the research aim completely change, the research design and paradigm also transformed in response. The mixed methods design was rejected in favour of a solely qualitative design while the pragmatic approach morphed into a social constructionist one.

The rationale behind adopting a social constructionist approach stems from the nature of the knowledge (or data) being produced and the individual(s) producing this knowledge – i.e., the researcher(s). The social constructionist approach or constructivism offers an explanation related to how we (humans) generate knowledge and subsequent meaning as an interaction between our experiences and ideas (Abdal-Haqq, 1998; Duffy, 2006). Constructivism, therefore, is a research paradigm proposing that our minds socially construct our reality and that essentially there are as many of these constructions are there are people (Guba & Lincoln, 1989).

The social constructionist approach posits that no theory is right or wrong or that employing a theory will uncover the truth. Instead, theories have utility in the context that they allow us to form connections with other people and, through such connections, the construction of meaningful ways of getting on together. In other words, assist us to solve issues, to create useful procedures and policies and to productively understand our social world (Romaioli & McNamee, 2021). Therefore, according to constructivism attaining the truth in relation to a given phenomenon results from the interaction between object and subject, where the subject utilises their preexisting knowledge, values and beliefs in order to comprehend the object.

Simply put, the truth is the meaning derived from this interaction, however, constructionism states that the truth may be unobtainable outside of our available cognitive schemas at any given moment (Sabnis & Newman, 2023). Positivists (or objectivists) ascertain that researchers must remain remote, separated and disconnected with the aim of uncovering the unbiased veracity about a topic.

Conversely, constructionists and the social constructionist approach assert that the researcher is a conduit during the research process allowing knowledge generation to be a reciprocal process between researcher and participant (Pallas, 2001). The constructionist approach places an emphasis on this interdependence permitting the co-construction of meaning (Hayes & Oppenheim, 1997). Accordingly, the social constructionist approach accepts that findings from research exhibit the signature of both subject and object – i.e., the possibilities open to the researcher and the decisions made by the researcher during the research process can and do mould the findings (Crotty, 1998).

For example, if the same topic was studied by different researchers at differing times and places a diverse interpretation of the truth would emerge. Moreover, it is important for researchers to be cognisant that data does not tell its own story. That is to say data does not have autonomy separate from the individuals involved in its production, but rather data conveys the stamp of those individuals combined with their current contextual and environmental components (Covarrubias & Vélez, 2013).

Consequently, social constructionism is often the paradigm underpinning qualitative enquiry (Bhattacharya, 2017). In summary, the lens of social constructionism allows reality to be considered in an alternative way, one which is informed by the voices, perspectives and opinions of the marginalised and suppressed in society in order to comprehend their social reality. As such, social constructionism fits with the modified aims that were under investigation during this research.

2.6 The Qualitative Approach

There are a myriad number of definitions of what qualitative research is, however, it typically refers to an approach that allows the researcher to describe and attempt to understand various phenomena. The process involves the exploration of the experiences, attitudes, opinions, beliefs and behaviours of participants, combined with the environment in which they occur (Creswell, 2009).

In order to gain an understanding of the experiences of children and young adults living with a parent with YOD, a qualitative approach was used in this thesis. This gave the researcher an appreciation of the complexity of the issues involved and also allowed the participants to be as open and honest as possible.

The qualitative approach has its beginnings in a range of disciplines such as sociology, anthropology and psychology (Lochmiller, 2021). Regardless of the discipline, the emphasis of qualitative research should be centred on the interpretation of subjective meaning, descriptions of the social context and the promotion of non-expert knowledge (Popay, Rogers & Williams, 1998). As such, questions in qualitative research tend to focus on:

- The exploration of communication and interaction among groups through language.
- Describing and interpreting the subjective meaning ascribed to certain contexts and actions within these contexts.
- Utilising the patterns uncovered in the qualitative data to build theory.In other words, the focus of inquiry tends to be broad, rather than specific hypothesis testing, with the aim of attempting to achieve a depth of understanding of a situation (Buston et al., 1998). In order to achieve this aim, information (or data) is gathered that informs the broader questions which in turn can be filtered to gather more information as the research evolves. Qualitative research allows for flexibility and a responsiveness to the context meaning that the initial research question(s) can adapt in response to the context, collected data and the subsequent analysis. Therefore, the sampling criteria, collection of data and the analysis and interpretation of these data are linked to each other in a recursive process rather than being linear (Fossey et al., 2002).

2.6.1 Sampling

According to Kuzel (1992) qualitative sampling is guided by the need for rich information. In order to achieve this, the researcher must keep in mind two key factors: appropriateness and adequacy (Morse & Field, 1995). For instance, qualitative sampling requires the researcher to identify appropriate participants – i.e., people who will beat apprise the research topic. It is also necessary for the adequate sampling of sources of information – i.e., people, places, contexts, types of data) so that the research question can be addressed. These two factors also allow for an evolution and full elucidation of the phenomenon being studied (Morse & Field, 1995; Popay et al., 1998).

Whether qualitative sampling is purposive (purposeful) or theoretical, sampling is recurrent throughout the duration of the research and is associated with the emerging essence of the research (Fossey et al., 2002). Purposive or purposeful sampling refers to the selection of suitable details in order to investigate meanings. While theoretical sampling refers to the selection of suitable people, contexts or systems guided by theory in order to examine nascent ideas to build theory as the research advances (Rice & Ezzy, 1999).

Participant numbers in qualitative sampling can be relatively small, however, the data produced can be extensive. There is no specified lower limit of participants needed to carry out a qualitative enquiry, however, an adequate depth of data is required in order to chronicle the experience being examined. Sampling is maintained until emerging themes evolve completely and no new themes manifest themselves. In other words, when no new information materialises the point of saturation is reached and any further sampling is unnecessary (Kuzel, 1992; MacDougall & Fudge, 2001).

It was decided that purposive sampling would be the best sampling method to address the aims and objectives in this thesis, with sampling continuing until the point of saturation was reached and no new themes emerged from the data. The sample consisted of participants across the three educational stages in Ireland – i.e., primary, secondary and tertiary education. In other words, participants were both under and over eighteen years of age. Research posits that children should be over seven years of age because of their developmental levels (Mauthner, 1997; Morgan et al., 2002).

Despite the fact that the most recent discourse supports interviews with younger children; there are still suggested limitations regarding children’s language competencies (Harcourt & Einarsdottir, 2011). Younger children have a limited vocabulary and are less able to comprehend the meaning of complex, or abstract words or words that have multiple meanings (Fargas-Malet et al., 2010; Wassenberg et al., 2008). Therefore, the cut-off point for this thesis was seven years of age. Specific aspects in relation to participant recruitment such as inclusion/exclusion criteria and gatekeeper organisations are described in detail in each of the individual studies outlined in chapters three, five and six.

2.6.2 Data Collection

The most commonly used methods of data collection in qualitative research are interviews, focus groups and observations. Research interviews are designed to allow participants to speak openly and freely about their lives, experiences, feelings and their social existence (Rice & Ezzy, 1999). Interviews may be either unstructured or semi-structured. Unstructured interviews are typically carried out in an ordinary, flexible and informal style allowing the participant to lead, rather than being orchestrated by the researcher (Minichiello, 1990).

Contrastingly, semi-structured interviews are designed to be led by the researcher in order to allow for a more concentrated investigation of a particular topic. Semi-structured interviews are commonly guided by a list of questions and/or prompts intended to direct the interview in a certain direction, however, the flexibility and informality remain (Minichiello, 1990). Collecting data by using the interview process ensures that the research is sensitive to both participant language and knowledge (Fossey et al., 2002).

Focus groups may be defined as group discussions, enabled by a facilitator, that utilise the interactions of the group as a way of investigating a research topic. It is this interaction between the group members that differentiates focus groups from singular interviews (Rice & Ezzy, 1999).

Participants for focus groups are typically chosen because of a common societal or cultural experience (i.e., shared gender or ethnic origin) or shared experiences related to the research topic (i.e., children facing parental illness). Focus groups have become more popular, particularly in health-related research. Moreover, they are viewed as been especially useful when examining delicate issues or when researching with populations facing marginalisation. The rationale been that people will feel more comfortable speaking in front of others in a similar situation (Rice & Ezzy, 1999; MacDougall & Fudge, 2001).

Furthermore, the richness of data may be strengthened as a result of the group dynamic, however, the opposite may also occur if the group dynamic is toxic. Therefore, the efficient facilitation of focus groups is crucial in order for effective interactions to occur (Buston et al., 1998; MacDougall & Fudge, 2001). Both semi-structured interviews and focus groups were used as a method of data collection in this thesis. Participants chose whether the interview took place onsite at the university, in their own home or at a neutral venue of their choice. However, due to the advent of the Covid-19 pandemic many interviews took place via video conferencing (e.g., Zoom) or via telephone.

Where there was only one child in the family, a one-to-one interview was conducted. However, when there was more than one child in the family, a focus group interview with all the children who agreed to participate was conducted. The questions used in the interviews were formulated as a result of the participatory workshops with people living with dementia outlined in chapter three and the data synthesis detailed in chapter four.

Semi-structured interviews were an effective method of data collection for this research specifically because children were involved. For instance, they allowed for questions to be repeated or reworded to ensure understanding (Burns, 2000), and provided opportunities to clarify responses or seek further information (Graziano & Raulin, 2010). Moreover, interviewing children face-to-face also allows for any non-verbal cues such as body language or facial expressions to be noted (Bell, 2010), which is particularly useful to identify whether children are becoming bored or tired (Griffin et al., 2014).

Small focus group interviews also capitalise on any social interactions (Bell, 2010; Einarsdottir, 2007) and assist in prompting the child’s memory (Graziano & Raulin, 2010) and provide the opportunity for children to lead the discussion (Curtin, 2000). When children are given the freedom to guide the conversation, the researcher discovers what is important to them, placing children’s voices at the forefront of the research (Leeson, 2013). The data analysis process is outlined in the section relating to thematic analysis.

Thematic Analysis

Broadly defined, thematic analysis involves the process of exploring a dataset in order to recognise, analyse, detail, describe and interpret any recurring patterns (Braun & Clarke, 2006; 2012). In this respect, thematic analysis is compatible with the notion of qualitative research posited by Denzin and Lincoln (2011) which states that: “*qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them*” (pp. 3). In relation to interviews and focus groups, thematic analysis assumes that the recollection of participants has value and warrants investigation, amalgamation and elucidation (Lochmiller, 2021).

These assumptions surmise that the researcher views the reported data as cogent, and that these data are reliable and trustworthy. Therefore, the aim of thematic analysis is to weigh up how the reported data speaks to a particular research question(s) and in doing so delves into these data at both the macro and micro levels (Lochmiller, 2021).

Basically, thematic analysis may be viewed as a query driven practice that is reliant on plainly enunciated avenues of exploration to give context to the researchers interpretations of the dataset. As Braun and Clarke (2006) propose: "*thematic analysis reports experiences, meanings and the reality of participants*" (pp. 81). Consequently, the type of questions that a researcher may wish to address typically begin with "*what*" or "*why*" rather than "*how*". If used in this way, thematic analysis simply recapitulates what is valued by participants and illustrates the participants level of comprehension of an experience. On the other hand, according to Braun and Clarke (2006) thematic analysis may also allow for the researcher to interpret this experience through a philosophical or theoretical framework. In other words, the researcher no longer simply describes participant reports, but now attempts to interpret the patterns in the data. Therefore, thematic analysis has the flexibility to be used to either describe, elucidate and/or critique:

- Describe – to outline the participant's reality by using the participants own written or spoken account.
- Elucidate – to interpret the data and infer meaning about the participant experience based on a particular philosophy or theory.
- Critique – to recognise recurring gaps in participant narratives that may indicate the presence of negative factors such as prejudice or discrimination.

As such, I decided that thematic analysis was the best tool to address the research questions outlined in chapter one of this thesis due to the flexibility it offers, and its ability to address the "*what*" and the "*why*". Once I decided that thematic analysis would best suit the research aims and objectives, the next decision was to choose which type of thematic analysis to use. Braun et al. (2019) ascertained that there are three different types of thematic analysis that may be understood as occupying a place on a spectrum from coding reliability to a reflexive approach (see figure 5).

At one end of the spectrum sits coding reliability thematic analysis which typically means the researcher will develop the themes relatively early in the analysis following some acclimatisation with the data. In other words, themes become an input into the coding procedure instead of an output from it. Coding reliability thematic analysis, therefore, is representative of what has been termed "*small q*" qualitative – i.e., an approach, while using qualitative measures is more aligned with post-positivism and quantitative research (Boyatzis, 1998; Guest et al., 2012).

At the other end of the spectrum sits reflexive thematic analysis which typically means the themes emerge much later in the analytical process. In other words, themes are generated from the coding process and viewed as patterns with related meaning by the researcher (Braun et al., 2014). Reflexive thematic analysis represents what has been termed "*Big Q*" qualitative – i.e., an approach where the researcher is required to carry out a significant amount of analysis and interpretation of the data and is considered "fully qualitative" research (Braun & Clarke, 2013).

In reflexive thematic analysis, themes do not live independently from the researcher. Rather, they are created by the researcher through a combination of considerable engagement with the data and the values, skills and experience of the researcher. Thus, coding becomes an organic process that is unstructured allowing the process to unfold naturally as understanding of the data grows, meaning that the process is intrinsically subjective (Braun & Clarke, 2021).

Residing somewhere in the middle of this spectrum sits codebook thematic analysis. Codebook thematic analysis is typically a combination of the fully qualitative approach of reflexive thematic analysis and the more structed approach involved in coding reliability. In other words, through the use of coding frames there may be some themes developed early (in line with small q coding reliability) combined with the values espoused by Big Q reflexive thematic analysis (Ritchie & Spencer, 1994; King & Brooks, 2018).

Given my research skills and experience, I decided that reflexive thematic analysis would be the best approach as an analytical tool for the research in this thesis. The fundamentals of reflexive thematic analysis permitted full recurrent immersion in the participant data, and I also relished the various phases of the approach as outlined in table 4.

2.7.1 Codes and coding

Individual codes may be defined as, "*a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data*" (Saldaña, 2013, pp. 3). These data can be obtained in various ways such as transcripts of interviews, notes from observations, journals or notebooks from either the researcher or participant, responses to surveys, photographic images or drawings, video, websites or blog posts, written correspondence (e.g., emails, letters, etc.), or published academic literature.

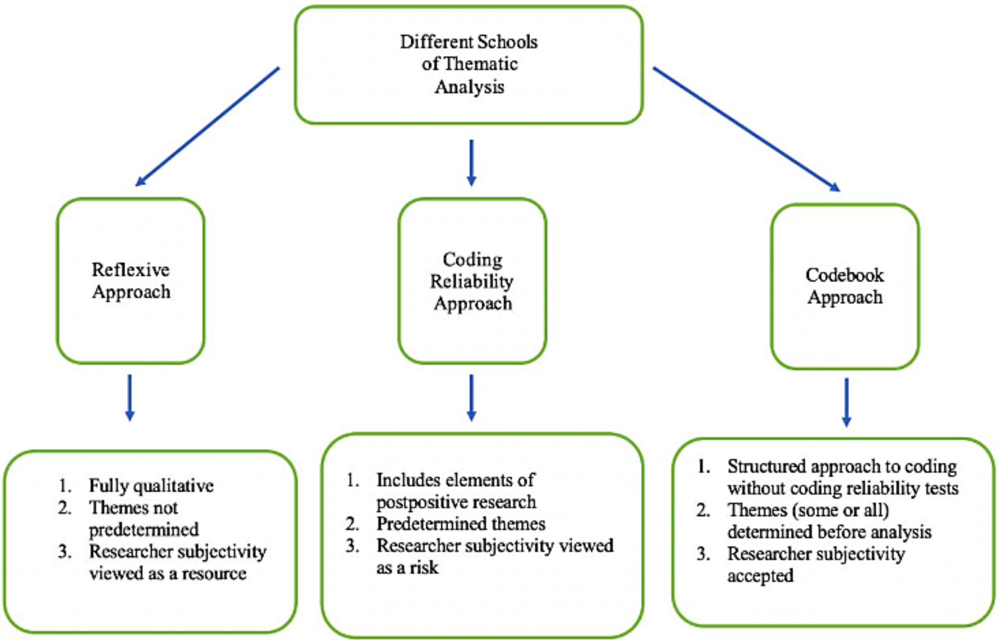

Figure 5: Differences between the three types of thematic analysis (Braun et al., 2019; Braun & Clarke, 2022).

Table 4: Outline of the six-step process involved in thematic analysis (Braun & Clarke, 2006).

Steps	Process	Description
1	Familiarising yourself with the data	Involves repeated and active reading (and rereading) through the data.
2	Generating initial codes	Initial analytical step in the process that helps to organise data at a specific level. Note-taking on data items of interest, questions, connections between data items, and other preliminary ideas.
3	Searching for themes	Scrutiny of the coded and collected data seeking potential themes of broader significance.
4	Reviewing themes	Two-level process. Firstly, the researcher examines the coded data placed within each theme to ensure proper fit. Secondly, the researcher examines the themes in relation to the entire data set to ensure individual themes fit meaningfully within the data.
5	Refining, defining and naming themes	The researcher creates a defines and describes each theme, including why it is important to the broader research question.
6	Producing the report/manuscript	write up of the final analysis and description of findings from the analysis.

Initially, data to be coded can be as small as a single word or as large as a complete page of content, expanding during subsequent coding phases. Most researchers using thematic analysis will code both while collecting these data and following collection.

This can be an effective and efficient strategy as during the coding process the data is being analysed (Miles & Huberman, 1994; Basit, 2003). Coding does not require the researcher to follow a prescribed formula, however, it allows for an exploration and discovery. Coding is crucially important to thematic analysis and has been described as a vital connection between data and their meaning (Charmaz, 2001). This connection allows the researcher to identify patterns in these data from the individually coded sections and single coded units have the ability to enable the researcher to get a sense of these data (Lochmiller, 2021).

In this thesis, as in other research I have conducted, I tended to code larger pieces of text rather than single words. While there are several coding programmes available across various platforms, there is something unique about palpating qualitative data using a pen and paper. I must admit that I am no expert with technology, so I tend to stick to this procedure. Some may find this method old fashioned, however, I find that it gives me more command and jurisdiction over the data. Some examples of coding from this thesis are outlined in table 5.

Table 5: Examples of preliminary and concluding codes and theme generation.

Section of Data	Preliminary codes	Concluding codes	Overarching Theme
"*I think just know that you're not taken seriously. First of all, like, you know, doctors can initially be quite dismissive. And, you know, even the top doctors professor kind of stage, you know. I was trying to tell them that there's certain personality changes, and they kind of just poo-pooed the idea, basically*"	No communication or poor communication with health care professionals. Doctors dismissive. Initial concerns overlooked.	Lack of communication	Obtaining the diagnosis
"*So, the GP* [General Practitioner] *was adamant that it was stress, he was adamant that it was stress, but he did the clock test. You know the clock test, and the GP was shocked and then we were straight away for an MRI. And then it was 18 months from then until we had a diagnosis*"	Poor knowledge or limited awareness of YOD. Similarity with other mental health conditions.	Poorer levels of awareness	
"*…the first GP* [General Practitioner] *told her it was nothing wrong with her. She just needs to focus more*"	GP's are also time poor during initial consultation? GP's overworked?	Difficult GP consultations	
"*And because if you're under 65 they kind of thought, you know, you're automatically sent down that route. And again, he couldn't find anything wrong with her…*"	Age profile Stereotypical view of dementia. Social construct of dementia.	Older persons illness	

2.7.2 Themes

A theme has been defined as a "*patterned response or meaning*" (Braun and Clarke 2006, pp. 82) extracted from the data that enlightens the research question. In other words, a theme could be an inclusive phrase or sentence that assists in identifying what the meaning of a unit of data is. At the very least, a theme can report and classify characteristics of a phenomenon or at the most a theme can elucidate on these characteristics. Furthermore, a theme can be classified at two levels, at the manifest level (i.e., obvious, clear information) or at the latent level (i.e., undiscovered or subconscious information) (Boyatzis, 1998). In some literature, a theme may also be referred to as a category, a domain or unit of analysis. However, DeSantis and Ugarriza (2000) offered a more concrete definition positing that a theme was a theoretical essence that can unify, give sense and recognition to varying manifestations of recursive experiences.

When identifying themes, the researcher can be flexible, however, the identified themes should furnish evidence that speak to the research question. The researcher can pursue either an inductive or deductive approach when identifying themes (Braun & Clarke, 2006; 2012) According to Varpio and colleagues (2020) an inductive approach obtains themes from the data, as observed in grounded theory. With the data driving the themes, they may not reflect exactly what the participant was asked during the earlier interview or focus group. For example, with open ended questions or as part of a focus group study, participants may veer off the initial topic of discussion. Similarly, these data driven themes may not reflect the opinions or preferences of the researcher (Braun and Clarke 2006).

Conversely, in a deductive approach, the identification of themes is driven by existing theory or frameworks or by the researchers' interests (Braun & Clarke, 2012; Varpio et al., 2020). As a result, an inductive approach can deliver a more comprehensive analysis of the whole data set, compared to a deductive approach, which tends to focus on a specific facet that is guided by existing theory (Braun & Clarke, 2006).

2.8 Ethical Considerations

2.8.1 Involving People with Dementia in Qualitative Research – Strategies and Ethics

The ethical process in this thesis involved particular scrutiny due to the inclusion of vulnerable populations in the research. Ethical approval for this research was granted by Dublin City University's Research Ethics Committee. Therefore, it was agreed that the ethos governing this research would represent the ethical principles of non-maleficence and beneficence in order to prevent participant harm (Hellstrom et al., 2007).

All research that involves humans constitutes risk. However, when the research includes people living with dementia, the risk increases greatly. The first vulnerable population included in this research were people living with young onset dementia. People living with dementia have typically not been included in research in the past. Reasons given for non-inclusion centred on their cognitive capacity when proffering informed consent, whether their contribution would be significant or the repercussions of participating in research (Dewing, 2002).

However, ethical committees and researchers must understand that there is a distinction between capacity to supply informed consent and the ability to impart credible personal viewpoints. Furthermore, research has outlined that people living with a mild-to-moderate level of impairment are capable of providing well-grounded perspectives. As an individual's level of capacity can oscillate then that individual should not be labelled incapable to participate (Beattie et al., 2009; 2015). A signed consent form is neither the beginning or the end of the informed consent process, rather it is offering an inclination to take part over time.

Therefore, a more encompassing approach that affords flexibility in the consent process may be more suited to this type of research (Dewing, 2007).

If a person living with dementia has been judged to have challenges with capacity, then the consent process should be adapted appropriately in order to allow participation (O'Connor et al., 2022). The greater risk is to exclude people living with dementia from research purely based on their cognitive ability, as they are the population most experienced to express their specific needs. Only including individuals considered to have capacity places a considerable restriction on dementia research as it does not account for the entire dementia population (Ries et al., 2017).

In other words, research with people living with dementia requires all stages of the condition to be represented (Murphy et al., 2015). Unfortunately, there still remains a significant stigma associated with a diagnosis of dementia, particularly young onset dementia (Garand et al., 2009). As a result, many people living with dementia dislike discussing their condition and refrain from participating in research (Pesonen et al., 2011).

Therefore, specific strategies (outlined in table 6) must be in place to guarantee the safety of people living with dementia who participate in qualitative research (Hellstrom et al., 2007). Using appropriate language when interviewing people living with dementia is crucial. Terminology such as “demented”, “dementia sufferer” or “victim” may strengthen the stigma associated with the condition and lesson the individuals sense of self (Novek & Wilkinson, 2019). A further complication of dementia is that some people may not be aware of their diagnosis at the time of the interview (Pratt, 2002). Researchers may need to remove the term from any research material to avoid potential distress (Bartlett & Martin, 2002).

Table 6: Strategies and ethical considerations to ensure the safety of participants with dementia during the qualitative research process.

Ethical Consideration	**Strategy**
Use of language	Always use respectful terms and avoid language that may be stigmatising or offend
Style of communication	Develop a plan to communicate sensitively with participants who may be unaware of their dementia diagnosis
Identify sources of support	Consult with participants (and/or primary carers where appropriate) to locate sources of support
Time and location of the research	If possible. allow participants to choose the time, location and duration of the interview
Develop a rapport	Take time to develop a rapport with participants and primary carers and also plan to withdraw from the research relationship

Clarify roles	Role ambiguity can be a problem. Take steps to guarantee that participants understand their own and researcher roles
Prepare the research questions	Prepare research questions and interview techniques to suit participants' abilities
When distress arises	Prepare a strategy in case participants become distressed, and attend to both verbal and non-verbal distress cues
Safety of the researcher	Consider researcher safety, and identify strategies and resources to deal with ethical issues and emotional challenges
Sharing the findings	Discuss with participants about their preferences and expectations for disseminating findings, and ensure that findings are shared with relevant parties
Knowledge & skills of the researcher	Novice researchers should seek guidance from more experienced researchers, health & social care professionals or people living with dementia

(Adapted from Novek & Wilkinson, 2019).

There are no easy solutions to avoid this issue, however, some researchers may utilise terminology such as "memory loss" or "memory problems" which may be less stigmatising. One possible answer could be found by meeting primary carers prior to the participant interview in order to determine the participants level of awareness of their diagnosis and how amenable they may be to discuss it (Heggestad et al., 2013).

Another solution may lie in the quality of communication that develops between researcher and participant. For instance, taking the time to grow an affinity with participants is vitally important in qualitative research (Dickson-Swift et al., 2007). This can assist with trust building and help to create a more comfortable atmosphere that promotes conversation and motivates the sharing of personal details. Moreover, a relationship built on trust may enrich the research experience for participants and assist in reducing the often-perceived power imbalance between researcher and participant (Hellstrom et al., 2007).

In this thesis, interviews with people living with young onset dementia were typically conducted using a one-to-one semi-structured interview instead of a focus groups. That is not to say that focus groups were never used with people with young onset dementia. However, with focus groups, there may be an issue with an individual's level of impairment. Focus groups normally contain between six and ten participants and this may not suitable for people with higher levels of cognitive decline.

Furthermore, when working with people living with young onset dementia, an approach based on empathy and compassion is advised. Researchers should actively listen and reply in a calm manner, making participants feel comfortable during the interview process. This approach can promote an in-depth comprehension of participants experiences (Josselson, 2013). Furthermore, the researcher was made aware by the primary carer about any specific needs and/or behavioural issues that may arise prior to the interview. This is consistent with the approach outlined by Sabat and Harré (1992; 1994) which places an emphasis on the researcher being cognisant of the individuals abilities at the time of interview.

2.8.2 Involving Children (< 18) in Qualitative Research – Strategies and Ethics

This thesis also included a second vulnerable population – i.e., children under the age of eighteen years old. Similar to people living with dementia, research with children was viewed as being difficult and significantly different to involving adults (James & Prout, 2015; McLaughlin, 2015; Wilkinson, 2001). When children were involved, they were often seen as an object or a subject of the research (Christensen & Prout, 2002). For example, in the first years of developmental psychology research, children were purely viewed as research objects, completely disregarding them as people with agency.

This opinion was based on the presumption that children are dependent, vulnerable, inept and irresponsible (Barker & Weller, 2003). As a result, children's experiences have been obtained from adults involved in their care such as parents and teachers and not from the children themselves (Bradbury-Jones et al., 2018). This perspective has changed in recent years and children's contributions to research are welcomed. In fact, children are now actively engaged in the development of research from the initial conception stage, through to dissemination of the findings (Clavering & McLaughlin, 2010). This allows for research to adopt a child-centred view on various phenomena as opposed to an adults interpretation of a child's experiences (Coyne & Carter, 2018).

Moreover, the United Nations Convention on the Rights of the Child (UNCRC) stated that the inclusion of children as active participants in research was vitally important, as children are the experts of their own lives (Johnson et al., 2016; Meehan, 2015; Ruland et al., 2008). Despite these advances, there still remains several ethical issues when planning to involve children in research. For instance, the issue of informed consent for a child is entirely different than from an adult.

A further ethical consideration concerns protecting the children from any potential harm that taking part may cause. Then there are the pricinples of confidentiality and anonymity which are crucially important when including children in research (Abrar & Sidik, 2019). Obtaining consent from children can be a complex and timely process, due to the conventions contained in the above-mentioned UNCRC, which outline that consent cannot be legally provided by individuals under eighteen years of age (Noret, 2012). Therefore, in order to include children in research, consent must be obtained from their parents/guardians (Einarsdóttir, 2007). A further issue with consent is estimating whether or not the child (ren) actually wants to take part in the research.

This can prove even more problematic than gaining the initial consent from parents. As children's, cognition, behaviours and characteristics differ altogether from adults, researchers may need to provide more information about the study in an age-appropriate fashion to allow children to come to an informed decision (Einarsdóttir, 2007). It is a necessity that the children understand what is being asked of them, what the risks are and what (if any) the potential consequences could be.

As well as providing this information, children should also be able to understand that they are not being pressured to take part and that they can remove themselves at any time during the research (McLaughlin, 2015). Therefore, in order to overcome the salient ethical considerations, this thesis shadowed a number of strategies (outlined in table 7) to safely involve children in the research. For example, the environment in which children were interviewed was typically in their own home via an online platform (due to the Covid 19 pandemic) with parents/guardians present at all times.

Engaging with children in an environment where they feel safe benefits both the child and the researcher (Montreuil et al., 2021). Group discussions or focus groups, if the child had siblings under eighteen years of age, also feature in this thesis. Focus groups can allow children to participate in brainstorming, in an inclusive and friendly atmosphere, that can lead to several topics that they wish to see addressed.

Focus groups are also a flexible method in qualitative research and can be utilised with various participant cohorts such as healthy adults, hospital patients, health and social care professionals, people with disabilities, adolescence and much younger children (Shaha et al., 2011; Visagie et al., 2017). Furthermore, focus groups via online platforms can assist with the inclusion of vulnerable populations in research. For example, Stover (2012) highlighted how members of the lesbian, gay, bisexual, transgender and queer (LGBTQ) community and adolescence with skin complaints felt empowered and less exposed participating in group conversions while being physically absent.

One of the most important aspects of the research presented in this thesis is that the child's opinion was respected at all times. It is important that researchers understand the legitimacy of the child's voice, and do not attempt to misrepresent children's genuine reflections or manufacture their own perspective of the child's beliefs (Clavering & McLaughlin, 2010).

Table 7: Strategies and ethical considerations to ensure the safety of child participants during the qualitative research process.

Ethical Consideration	Strategy
Power dynamics	Recognise the dynamic and impact of adult-child or child-child relationships on enablement and freedom
Age-appropriate techniques & environment	Include research techniques (e.g., child friendly interviews, focus groups) and environment (e.g., playrooms, open and inclusive spaces) to enable participation
Valid children's voices	Respect the authenticity of children's voices (e.g., do not disparage or undermine the child's experience and respect the child's thoughts)
Engagement & representation	Foster meaningful opportunity for engagement, and representation of children

Protection	Weigh the benefits of participation against the risk of harm
Informed participation	Share knowledge to inform children in relation to the nature of the research
Awareness of capacity	Be cognisant that children’s capabilities may differ from (but are not less) than adults
Vulnerability	Awareness that adult perceptions of vulnerability are different to children’s
Shared expectations	Set reciprocal expectations for the research (e.g., a clear plan and goals etc.)
Reward	How to reward children’s who contribute to the research
Cultural diversity & inclusion	Promote mutual respect and understanding in research with children from marginalised or diverse backgrounds
Motivation	Awareness of children who may have lost interest and wish to withdraw
Privacy	Protection of children’s privacy throughout the research process is paramount

(Adapted from Montreuil et al., 2021).

2.9 Researcher Reflexivity

According to Denscombe (2007) conducting qualitative research is a process of interpretation. The researcher interprets and analyses data according to his or her own perceptions – which, in turn, are influenced by the researchers psyche. In other words, innate biases, ideals, thoughts, beliefs and feelings held by the researcher (whether consciously or not) can not only shape the research but can become part of it. For example, my own constructs of dementia were significantly influenced by society.

As such, my perspective was aligned with the prevailing narrative which promoted the view that people living with dementia were typically older adults who had restricted insight into their own experience and were physically present but cognitively absent (Doka & Aber, 2002). However, having spent time some time on a work placement in a memory clinic this changed. I came into contact with an individual who was not much older than myself and was diagnosed with young onset dementia.

Up to this point, I had never heard the term young onset dementia. As a result, I conducted my final year undergraduate thesis on the topic. Subsequently, this became the main inspiration for my PhD research with the goal of counteracting the typical construct of dementia and to understand, substantiate and give meaning to the participants subjective experiences through coproduction. In order to achieve this, I was conscious of the need to acutely self-reflect with regard to the way my research may be impacted by the factors outlined above (Finlay & Gough, 2008). Therefore, the following paragraphs will reflect on my own personal perspective of my research process using personal contemplation combined with relational reflexivity.

For myself, personal contemplation was crucial at the beginning of the research process at a time when the research objective was in its embryonic stage. I would regularly meet with my supervisor to discuss the intended research subject and I was encouraged to be mindful of my own unique interest and beliefs and how my own personality may impact the subject. Despite having limited research experience with the subject matter, nonetheless I was not a approaching the research in a vacuum. The small amount of exposure I had up to this point had given me an awareness of how complex working with people with a cognitive impairment can be.

Similarly, I was aware that working with children, particularly those facing adversity, could pose problematic. The relational reflexive aspect assisted with finalising the research questions I would attempt to investigate. They originated from meeting(s) with my supervisor and exchanges I've had with people living with young onset dementia and observations I've made over the few short years of my research career to date. The relational aspect of the reflexive process further assisted during the semi-structured interviews with participants during the research – allowing me to be an empathetic listener with the ability to process what I was hearing and to respond in context.

Moreover, it also allowed me to invite participants to reflect on different perspectives to their own. More often than not, this afforded more meaningful discourse and was a crucial component during the analysis of these data. It also assisted with my understanding of how some chances to coproduce meaning were lost. For example, I learned that it was vital to be present as occasionally while I was trying to think of a response that would be considered empathetic, the chance for a genuine connection disappeared. Conversely, when I couldn't conjure a response quickly enough, I tended to try to fill the gap falling foul of impulsiveness and denying the participants an opportunity to reflect.

Another salient point in relation to being overly enthusiastic (or impulsive) is the fact that I have no immediate family members living with dementia. This fact combined with my small amount of research experience meant that I may have been hamstrung when trying to pick up small nuances or inflections when necessary. Silence really can be a useful instrument when utilised appropriately.

To help me during the research process I kept a "research diary" (that's to fancy of a name for it) in order to record my thoughts and feelings post-interview as well as any other information I thought relevant. This allowed me to recreate the context of the interview in my mind – i.e., how the discourse went, what was the mood of the interview, body language cues and how I felt after the interview etc. I found this process useful in several ways as it gave an overview of the participant interviews at the time, and also allowed for a comparison between my first impressions and my more deliberate analysis of these data.

For instance, more often than not, my first impressions tended to include a sense of astonishment and wonder at how the participants appeared so resilient in the face of a life altering situation. This was typically accompanied by an overwhelming feeling of appreciation and thanks for sharing their personal stories. However, deeper analysis of these data revealed that while my initial impressions were not wrong, they tended to lessen the meaning of participant narratives to a simple "*hard luck story/we will prevail/life goes on/happily ever after*" type thing. Keeping the research diary alerted me to this and also to how it could impact my analysis.

This ensured that I constantly consulted with the main transcription to maintain coherence. In other words, by applying reflexivity throughout the research process I was able to preserve the clarity of the analysis (Storey, 2007). I think personal contemplation and reflection was also significantly important for me at the end of the research. While I was feeling extremely elated that the PhD was complete, there were also a myriad of conflicting emotions.

Firstly, I was immensely proud of myself for completing a significant piece of work and proud of being able to adapt to the major modification that was made to the original plan. Despite barrier after barrier blocking my path, I found a way to scale them all. However, there is a big part of me that feels anger, shame and guilt on completion. Anger towards the various obstacles that potholed what I hoping would be a smooth road and anger at myself. Why do I feel this anger? Because sometimes I think to myself, did I just use those participants, use their stories, their lived experiences to further my own needs.

In other words, did I use the participants in order to obtain a doctorate? Such feelings are typically accompanied by guilt and shame. Guilt for using the participants for my own needs and shame for doing so. Similarly, while the interview process with the children and young adults in the current study was a rewarding, it was also an emotional and at times difficult experience. For many of the children it was their first time speaking openly about their experience and while they found it hard to tell their story, I found it difficult to listen.

For example, one young lady said, "*…I didn't want to tell my friends cause it was too hard, they wouldn't know what it's like anyway…*". Such instances were common and made for an extremely emotional process at times, however, the children were adamant that they wanted their voices to be heard. They spoke about having their feelings validated and they outlined that the interview process allowed them to speak about subjects that are often taboo in society. Often participants felt ashamed telling their stories, but they did so with dignity, poise and an unwavering nerve. For myself, I found it challenging to manage these conflicting emotions at the end of such an all-consuming process, and truly I hope that I have done justice to their stories.

2.10 Chapter conclusion

This chapter has given an overview of the methodology used in this thesis. It has also outlined the philosophical reasoning as to why a qualitative method was employed. The chapter then describes the theoretical frameworks guiding this research – i.e., Cultural Transmission Theory and Family Systems. The significant contribution of PPI to this research has been illustrated.

A detailed outline of the qualitative method with specific mention of the three types of thematic analysis – i.e., the coding reliability, the codebook and the reflexive approaches to thematic analysis has been discussed. Finally, the ethical considerations when involving both people living with dementia and children under the age of eighteen in research are examined.

The next chapter will outline an original piece of qualitative research that used PPI and involved people living with YOD and their family members including children. Findings guided the direction of the research in this thesis.

3. Young Onset Dementia: A focus group study examining the experience from the perspective of the Family System.

3.1 Abstract

Introduction

Neurodegenerative conditions resulting in cognitive impairment pose significant challenges to both couples and families. Research tends to focus on the issues couples face – i.e., the dyadic relationship between carers and the affected person. Young onset dementia (YOD) is a neurodegenerative condition that manifests itself during the active stage of the individual's life, resulting in a significant impact on their remaining productive years. However, the condition also significantly effects the individual's family and social circles. This qualitative study examined YOD from the broader family systems approach, focusing on family dynamics following a diagnosis.

Method

Public patient involvement (PPI) was utilised by way of a participatory workshop with members of the Alzheimer Society of Irelands (ASI) Dementia Research Advisory Team (DRAT: *n* = 3). The workshop was designed to uncover specific issues of relevance to people with young onset dementia (PwYOD) and their families that could subsequently be explored through focus group interviews. Focus group interviews involved people with YOD and their family members. The sample (*n* = 44) included people with a formal diagnosis of YOD (with various subtypes) living in the community, and their family members including children.

Findings

The specific issues of relevance that emerged from the participatory workshop, and were explored through the focus group interviews, included: issues relating to the diagnostic process, adjusting to the diagnosis for both PwYOD and their family, post-diagnostic supports and coping mechanisms. Following the focus group interviews, five main themes with related sub-themes emerged including: obtaining the diagnosis; awareness; behavioural and psychological symptoms of dementia; service provision and the changing family relationships.

Discussion

It is clear that a diagnosis of YOD results in significant challenges for the entire family system. Several findings are consistent with prior research; however, novel findings relate to childhood experiences of parental YOD. There is a considerable shift in relationships, with participants reporting a change in their previous roles.

Spousal carers reflected on the physical and emotional strain, while children spoke about future plans being put on hold or scrapped completely. Children also outlined crossing boundaries and assuming more responsibilities, such as managing finances, a role formally undertaken by their parents. There is a significant gap in the literature in relation to childhood experiences of parental YOD in Ireland. Future research should address this gap and assess the impact of YOD on children, in particular children under the age of eighteen, in order to better understand their experiences.

3.2 Chapter Introduction

Typically, the "*normal*" structure of a research thesis would include an evidence synthesis or meta-analysis of relevant data prior to embarking on any investigatory research. However, we decided to undertake an original piece of qualitative research first before we conducted our evidence synthesis. The rationale for approaching the thesis in this way stems our previous work with people living with young onset dementia (YOD).

Although we had various issues and topics that we wished to investigate in relation to YOD, we were also acutely aware that people with young onset dementia (PwYOD) are the experts by experience. Therefore, we decided to hold a participatory workshop with PwYOD in order to uncover relevant topics or issues that they wished to be investigated. Several topics emerged that are consistent with existing research, however novel topics such as children's experiences of living with a parent with YOD also emerged. As a result, we decided to include children as part of the focus group interviews. The six children included in this study were all over eighteen years of age. However, in later chapters in this thesis, the experiences of children under eighteen years of age are explored.

3.3 Introduction

As outlined in chapter one, a diagnosis of YOD is a traumatic and distressing experience for any individual, however, it may not be an individualised experience. Given the relatively young age of onset, many people who receive a diagnosis are typically part of a wider family system. For instance, one or both of their parents may still be alive, or they may be in a relationship, may be married or they may be parents themselves (Millenaar et al., 2016b).

In addition, they may also be part of a wider social system that can include friends, peers and work colleagues (Engedal & Laks, 2017). Again, due mainly to the younger age, many PwYOD have unique and varying challenges when compared, for example, to those diagnosed much later in life.

Similarly, their immediate family members may also have to face these unique, different and difficult challenges (Millenaar et al., 2016a). For instance, some of these unique challenges may stem from the need to remain active (Roach, Drummond, & Keady, 2016) as PwYOD are typically physically healthy (Ducharme & Dickerson, 2015). PwYOD may have important roles and obligations such as employment, financial, parenting or caring for older adults (Chaplin & Davidson, 2016). Attempting to manage the symptoms, to navigate medical care and to plan for an uncertain future all add to the challenge.

Furthermore, coming to terms with a progressive disease with no meaningful treatment or cure can lead to considerable stress and anxiety, for PwYOD and their family (Werner et al., 2009). When these factors are combined with the stigma and the negative stereotypes associated with dementia, and in particular YOD, the quality of life (QoL) for everyone involved can deteriorate rapidly (Baptista et al., 2016). This rapid deterioration can be future exacerbated if the person with YOD, and other family members, decide to withdraw from society in order to avoid stigma (Teng et al., 2012). As social participation is increasingly used as an indicator of health and wellbeing, providing a host of other psychosocial benefits (Ellaway et al., 2003) withdrawal can lead to feelings of isolation and lack of purpose (Harris & Keady, 2009).

As discussed in chapter one, PwYOD can often find this aspect extremely difficult to cope with as they take stock of their lives and look to their future (Huber et al., 2011). Moreover, as daily activities become more difficult to accomplish, assistance from family members is more likely to be required (Harris & Keady, 2009). For family members, moving from being a spouse/partner or son/daughter to an ill-defined caring role brings its own issues (Arai et al., 2007; Freyne et al., 1999; Williams et al., 2001). Compounding these issues further is the lack of age-appropriate service provision for PwYOD. As a consequence, the caring role for family members can be a protracted and difficult period (de Vugt & Verhey, 2013; Svanberg et al., 2010; Withall, 2013).

Other difficulties faced by family members may result from the behavioural and psychological symptoms of dementia (BPSD) associated with the YOD. BPSD are also known as neuropsychiatric symptoms and can manifest due to the complications attributed to the condition (Lawlor, 2004).

According to Kozman and colleagues (2006) BPSD can be characterised as disruptions of perception, thought, mood and behaviour and may consist of delusions, hallucinations, agitation, and depression. The prevalence of BPSD in people living with dementia are relatively high and can significantly affect the entire family (Hersch & Falzgraf, 2007; Selbaek, Kirkevold, & Engedal, 2007; Steinberg et al., 2008).

Incidence rates of BPSD are reported to be similar in both late onset dementia (LOD) and YOD despite varying symptomology (Arai et al., 2007; Bakker et al., 2013). There is evidence to suggest that in some cases people with young onset Alzheimer’s disease exhibit less BPSD when compared to late onset Alzheimer’s (Toyota et al., 2007; van Vliet et al., 2012).

BPSD are typically addressed through pharmacological interventions, however, evidence has outlined poor efficacy for medications with the added risk of unwanted side effects (Hersch & Falzgraf, 2007). Furthermore, family carers report a significantly higher degree of burden when facing BPSD with high levels of stress and anxiety as a result (Hersch & Falzgraf, 2007; Lawlor, 2004) resulting in poorer QoL outcomes (Spreadbury & Kipps, 2019). More often than not, severe BPSD symptoms may mean family members seek to accommodate their loved one in a suitable care setting (Bakker et al., 2013; Gibson et al., 2014). However, as described in chapter one, there is a significant lack of adaptive care settings in Ireland for PwYOD resulting in individuals being accommodated in wholly inappropriate settings.

The significant burden experienced by family members who find themselves in a caring role has been elucidated in several domains. For example, research on carer burden in families experiencing a member with autism or down syndrome has detailed the challenges that may visit the household (Abbeduto et al., 2004). While research on another progressive neurodegenerative condition, amyotrophic lateral sclerosis (ALS) outlines the negative impact on the whole family. ALS is the most common of the motor neuron diseases requiring complex technical and pharmacological management (Calvo et al., 2015; Coupé & Gordon, 2013). ALS can also result in issues with cognition, such as, the loss of recognition and communication which can lead to significant emotional distress and feelings of grief and loss for all family members (Coelho et al., 2018; Anderson et al., 2019).

Similar to YOD, immediate family members often provide assistance with medications, household tasks and emotional support (Kavanaugh et al., 2016; Chen, 2017). Research with families experiencing ALS outlines significant rises in anxiety, depression, social isolation, somatic disorders, extreme worry about getting sick, feeling guilt and self-esteem issues (Harris et al., 2019). Comparable findings have been reported following a parental diagnosis of multiple sclerosis (MS) (De Judicibus & McCabe, 2004) with the entire family being negatively affected (Pakenham & Bursnall, 2006; Gelman & Greer, 2011; Adelman et al., 2014).

Despite the negative connotations related to the caring role outlined above, research has outlined that a common understanding and a willingness to adapt can be beneficial for couples facing significant illness (Berg & Upchurch, 2007; Badr & Acitelli, 2017). For example, research by Vranceanu and colleagues (2020) outlined positive outcomes in conditions such as stroke and traumatic brain injury when couples are united rather than facing the challenge individually. Similarly, when both spouse/partner and the person with YOD adapt to the challenges together, positive outcomes can result (Braun et al., 2009; Hong et al., 2005; Bannon et al., 2021).

While such research has highlighted positive outcomes for couples, solely focusing on the experiences of primary carers and the dyadic relationship with the diagnosed person may be an overly narrow approach. Therefore, broadening the research to include the whole family, guided by Family Systems Theory, may be warranted (Belle et al., 2006; Joling et al., 2012; Mittelman, 2013; Zarit & Talley, 2013). A detailed description of Family systems theory (Bowen, 1978) is given in chapter two of this thesis. Briefly, Family Systems Theory defines the family unit as a group of people who are organised into a close unit living together in the same location.

The members of the unit are both related to each other and dependent on one another and members can include parents, children, and others. The family unit works together in a purposeful manner in order to achieve particular goals (Freidman, 2003). Within the family system there may be "*subsystems*" such as "*parent-parent*", "*parent-child*", "*child-child*" and "*parent-sibling*" with each subsystem influencing the overall system (Bronfenbrenner, 1986). Due to the lack of research into YOD, particularly in Ireland, fully understanding the experiences of PwYOD and their families is problematic.

For example, a literature review of Irish research on YOD conducted in 2020 uncovered just three published articles (Fox et al., 2020). Similarly, as outlined, the majority of research on YOD focuses on the dyadic relationship between the primary carer (spouse/partner) and the person with YOD. Therefore, the overall objective of this study was to examine how YOD effects the entire family system (and subsystems), during and following the diagnosis in an Irish context. Specific aims were:

- To understand the pathway from initial symptom onset through to receiving a definitive diagnosis.
- How do PwYOD and their families adjust and cope with the diagnosis?
- Are adaptive health and social care supports available to people with YOD and their families in Ireland and do they avail of these supports?

It is hoped to translate this knowledge into best-practice strategies to best support people and their families to live well following a diagnosis of YOD.

3.4 Materials and methods

3.4.1 Design

Firstly, using Public Patient Involvement (PPI) a participatory workshop with members of the Alzheimer Society of Irelands (ASI) Dementia Research Advisory Team (DRAT) was held. This workshop included members of DRAT with a formal diagnosis of YOD residing in the community. The workshop was designed to uncover specific issues of relevance to PwYOD and their families, or to identify any gaps in the literature, that could subsequently be explored through focus group interviews (see appendix F) A comprehensive discussion in relation to the efficacy of PPI is included in chapter two of this thesis. Following the participatory workshop, a semi-structured interview schedule was drafted and finalised for the focus group interviews (see appendix G). Secondly, in order to explore perceptions, opinions, and beliefs, in relation to the above aims focus group interviews were conducted with both PwYOD and those close to them (including primary family carers), applying triangulation of data between the groups.

Primary family carers may be defined as any relative, friend or partner who has a significant relationship and provides assistance (physical, social and/or psychological) to a person with a life-threatening, incurable illness (Hudson & Payne, 2009). Focus groups are viewed as an ideal method to reveal various perspectives on various topics and to uncover new insights and unanticipated issues (Hennink, 2007). Interview data were then analysed using inductive thematic analysis. The point of saturation was checked after the fourth focus to ensure that a sufficient number of focus groups had been conducted and no new themes emerged, as per methodological guidelines. Focus groups typically consist of four to eight participants (Krueger, 2014).

3.4.2 Participant recruitment & Inclusion criteria

Purposive sampling was used across groups including PwYOD and their family members with the aim of having a large variation in perspectives. Participants were recruited through gatekeeper organisations. Gatekeeper organisations included the Alzheimer Society of Ireland (ASI), the Dementia Carers Campaign Network (DCCN), Family Carers Ireland, Western Alzheimer's Association, the Dementia Research Advisory Team (DRAT), TeamUp for Dementia, Alzheimer cafes and carer support groups for people caring for people with YOD. It is not clear how PwYOD or family members were approached by these gatekeepers, or how many people refused to participate.

The researcher was contacted by gatekeepers only when participants expressed interest in the study. However, all participants who did express an interest in participating, ultimately took part. In order to be deemed eligible for inclusion in the study, the person with dementia had to have received a formal diagnosis prior to 65 years of age and therefore meets the criteria for YOD. Family members had to reside or have resided with the person with YOD.

Those participants who did express an interest were provided with a plain-language statement and a consent form (see appendices B-E). These documents contained an invitation to participate, further information about the study and contact details for the research team. Those who expressed an interest in taking part were asked to contact the research team to discuss the requirements of the study and the informed consent process in more detail.

On receipt of a completed consent form, the researcher then contacted participants and invited them to complete an online Doodle poll in order to achieve a consensus for of a convenient time for the focus group interviews. When a consensus was reached, the researcher scheduled the interviews via email containing the Zoom link.

3.4.3 Data Collection

Due to the restrictions imposed by the Covid-19 pandemic, cross-sectional semi-structured interview data were collected online via Zoom for all participants. The total number of participants was 44, including the participatory workshop (*n* = 3). The focus groups with people with YOD contained 13 participants (4 focus groups x 3-4 participants).

The focus groups with family members contained 31 participants (4 focus groups x 5-8 participants). Similar methodology was applied by Boots and colleagues (2015) in research exploring the needs and wishes of early-stage dementia caregivers. Materials used during the study included a Dell laptop computer, audio-recording equipment and notebooks. All evaluation material, including recorded material, transcribed data, and participant information, was stored on password protected computer files.

A person-centred approach was taken in managing the data-collection session(s). Focus groups with PwYOD lasted between 30 and 50 minutes depending on individuals' capabilities and plans for that day. Focus groups with family members were longer, lasting between 50 and 90 minutes again depending on the persons plans for the day. If the researcher noticed that a person(s) appeared tired, emotional or if they expressed that they were struggling on the day of the focus group, then the interview was terminated and rescheduled for an alternative time, only if consent was received.

Participants were encouraged to share their expertise (e.g., life experiences) and to view the focus groups as a social event as a means of encouraging open discussion (Patton, 2002). The researcher also ensured that participants had adequate breaks. Focus groups were audio recorded via Zoom and later transcribed intelligent verbatim and anonymised.

3.4.4 Data analysis

Interview data were analysed by applying an inductive qualitative thematic analysis using open coding and categories derived directly from the interview material (Hsieh & Shannon, 2005; Elo & Kyngas, 2008). All narratives were utilised in this analysis. The researcher read the transcripts thoroughly, line by line, to identify meaning units (such as words, sentences or paragraphs that relate to the same meaning), with the aim of condensing the material. Corresponding meaning units were grouped together, and several themes and sub-themes emerged from the data. Transcripts were then reread to ensure goodness of fit of themes and data, and anchor quotes were selected that represented each theme and sub-theme. A detailed outline of the six-step process used, as well as the coding process and theme extraction discussed in chapter two of this thesis.

3.4.5 Ethical considerations

Ethical approval was obtained from Dublin City University Research Ethics Committee (DCUREC/2020/220; see appendix A). Risk associated with participation in the study was moderate, as no deception was involved. Participants were assigned participant numbers to ensure anonymity and confidentiality. The right to withdraw from the study was clearly communicated, and a support pack outlining dementia-specific and more general supports that are available was offered to participants at the end of the interview process (see appendix H).

3.5 Findings

Detailed thematic analysis of the participant narratives uncovered five main themes with related sub-themes including: obtaining the diagnosis; awareness; behavioural and psychological symptoms of dementia; service provision and the changing family relationships. Table 8 outlines participant characteristics, while figure 6 illustrates the main themes with related sub-themes uncovered in the data.

3.5.1 Theme 1: Obtaining the diagnosis

Many participants reported that the diagnostic process can be a stressful and difficult time leading to fear and uncertainty about the future. Diagnosing YOD can be a complex and difficult process, as the overlapping of some symptoms with other mental health conditions across YOD subtypes, appears to make a differential diagnosis difficult. One spouse/partner described how the diagnostic process can be difficult with symptoms being apportioned to other psychological conditions:

> "*So, the GP* [General Practitioner] *was adamant that it was stress, he was adamant that it was stress, but he did the clock test. You know the clock test, and the GP was shocked and then we were straight away for an MRI. And then it was 18 months from then until we had a diagnosis*" [**P18: Spouse/partner**].

While another stated:

> "*…the first GP* [General Practitioner] *told her it was nothing wrong with her. She just needs to focus more*" [**P33: Spouse/partner**].

Such issues can be compounded further by poor communication with health care providers such as the family doctor:

> "*After about six months, he asked me if I would go to the GP with him because he didn't feel the GP was taking it seriously and partly just so that I could help to communicate what the issues were*" [**P42: Son**].

Table 8: Participant (*n* = 44) characteristics of people with young onset dementia (PwYOD) and family members.

Participant number	Gender	Mean Age at Interview (years)	Mean age at diagnosis (years)	Dementia Subtype
PwYOD				
01	Female	**58·4**	**53·2**	Alzheimer’s Dementia
02	Female			Alzheimer’s Dementia
03	Male			Frontotemporal Dementia
04	Male			Dementia with Lewy Bodies
05	Male			Dementia with Lewy Bodies
06	Male			Alzheimer’s Dementia
07	Male			Other
08	Female			Alzheimer’s Dementia
09	Male			Frontotemporal Dementia
10	Male			Dementia with Lewy Bodies
11	Male			Frontotemporal Dementia
12	Female			Other
13	Male			Frontotemporal Dementia
Spouse/Partner				
14	Male	**56·7**	**n/a**	**n/a**
15	Female			
16	Female			
17	Male			
18	Female			
19	Female			
20	Female			
21	Female			
22	Male			
23	Female			
24	Female			
25	Male			
26	Female			
27	Female			
28	Male			
29	Female			
30	Female			
31	Female			
32	Female			
33	Male			
34	Female			
35	Female			
36	Male			
37	Male			
38	Female			
Children				
39	Male	**27·3**	**n/a**	**n/a**
40	Female			
41	Female			
42	Male			
43	Female			
44	Female			

Issues with communication between family members and health care providers may stem from the fact that YOD manifests at a relatively younger age. One family member outlined the difficulty in being taken seriously by medical staff:

> “*I think just know that you're not taken seriously. First of all, like, you know doctors can initially quite dismissive. And, you know, even the top doctors professor kind of stage, you know. I was trying to tell them that there’s certain personality changes, and they kind of just poo-pooed the idea, basically*” [**P43: Daughter**].

> “*you know, there just something in me that thought, this isn't Alzheimer's there’s something else going on here. So, mom had been very depressed and I thought that it was more depression, so we went down the psychologist route as well. And he didn’t think that she had Alzheimer’s either*” [**P39: Son**].

While another participant spoke about the issues with being of a younger age:

> “*And because if you're under 65 they kind of thought you know you're automatically sent down that route. And again, he couldn’t find anything wrong with her. And then just came out with it and said well I can’t find anything wrong with you so it’s probably Alzheimer’s*” [**P42: Son**].

There appears to be a significant length of time between initial onset of symptoms and getting a definitive diagnosis. A participant with YOD highlighted this difficulty:

> “*And so yeah, it took us, I would say about ten doctors and all before we got to the diagnosis*” [**P03: PwYOD**].

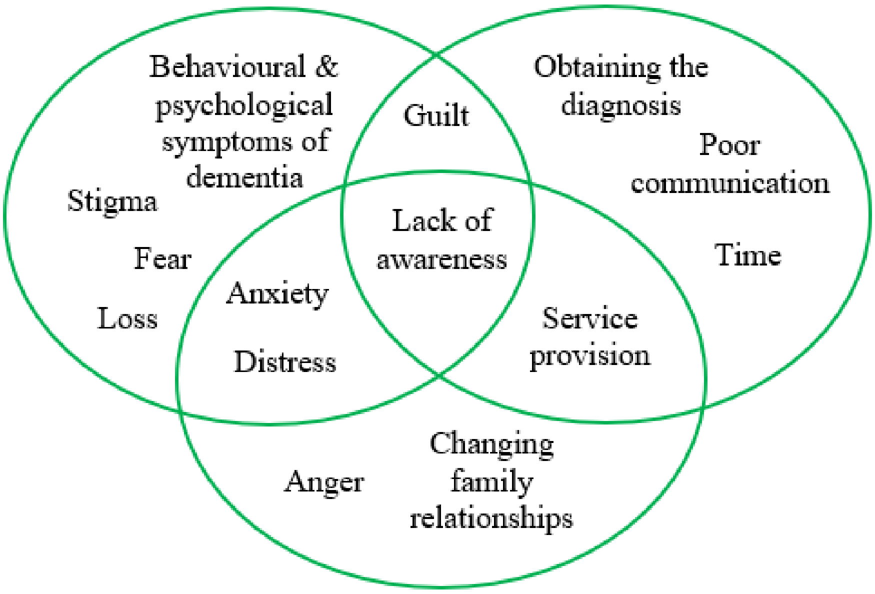

Figure 6: Venn diagram illustrating the main themes with related sub-themes uncovered in the data.

The lengthy diagnostic process may also be as a result of the lack of knowledge among healthcare providers in relation to YOD. One participant stated:

> "*Well, you know be fair, to be fair I think most GP's* [General Practitioners] *will accept they don't know too much about us*" [**P12: PwYOD**].

The difficulties with the diagnostic process can result in the entire family being affected:

> "*You take on a huge fight and nobody could have prepared us for that fight you know, nobody could have prepared me*" [**P19: Spouse/partner**].

3.5.2 Theme 2: Awareness

Both people with YOD and carers outlined how there is a significant lack of awareness among the general public in relation to YOD.

The lack of awareness can maintain the stereotypical view of dementia as a condition of older age which is associated solely with issues with memory:

> "*A lot of people associate dementia, with memory loss. But mom still knows who I am today you know she didn't really have a problem in that department. And so that's something that I'd like you know people to be more aware of that dementia, doesn't necessarily, you know, equal memory loss that there's lots of other areas too*" [**P40: Daughter**].

> "*Again, there's just not that awareness that young people can get dementia. And I want to mention it actually, you know*" [**P38: Spouse/partner**].

This stereotypical view of dementia as a condition of old age can also be perpetuated through various media platforms:

> "*And even though, even though you maybe would have had some insight into dementia or Alzheimer's maybe through TV shows or whatever, you say that you both thought that maybe that Alzheimer's or dementia was something that an older person got*" [**P22: Spouse/partner**].

As a result, many participants reported being faced with stigma as they feared the diagnosis would reflect poorly on them.

> "*I didn't tell anybody. And I think that may have been to do with stigma, you know, partly was because I wanted to protect my work ethic, my reputation, and to keep the show on the road*" [**P14: Spouse/partner**].

As a result of stigma, many participants spoke of the loss of friends:

> "*You definitely find out, you know, who your friends are when you get that kind of diagnosis and yeah I mean, friends just totally disappeared as well. And I think it's because they're scared as well, you know, that they don't know*" [**P08: PwYOD**].

> "*And mom had that thing with the phone as well she lost a lot of friends. And I think that was partially because people didn't know what to say or how to react and even to this day*" [**P43: Daughter**].

> "*…it's our journey like, you know, and you lose friends along the way and you gain a lot of great friends along the way. There's definitely a stigma attached to it, and I think a lot of people don't even know what to say when they meet you*" [**P11: PwYOD**].

Participants reported that the lack of awareness was also event in some health and social care settings:

> "*Yeah, I think it's just not talked about enough, it's, you know, even the nurses, in moms nursing home, you know, they're saying are you sure she's got to dementia*" [**P42: Son**].

3.5.3 Theme 3: Behavioural and Psychological Symptoms of Dementia (BPSD)

Families outlined how the psychological symptoms can be extremely confusing, frightening and can result in significant challenges. YOD can lead to disruptions of perception, thought, mood and behaviour which can result in delusions, hallucinations and agitation:

> "*One particular evening, this is horrific, was about twelve months ago. He had been lying on the couch watching TV, and all of a sudden he got up, and he's a big man, and he was just shouting and roaring and he felt I was deceiving him and I had done this that and the other thing, and it was just horrific*" [**P35: Spouse/partner**].

Families spoke about the distress this can cause and how they sometimes can be subject to verbal abuse as a result:

> "*I also noticed that he'd start to calling me names like tramp, or even worse, names like whore out of the blue*" [**P23: Spouse/partner**].

For some families, however, verbal abuse can lead to physical abuse:

> "*And with that he actually drove made a drive for me like, and grabbed me by the neck, and I went from the front part of the room right back to the end of the room with the force of him pushing me* and *holding his hands around my neck. So, the children did witness this and it was very frightening, and after that violent outburst my son ended up having to pull him of me*" [**P35: Spouse/partner**].

The negative effects of such behavioural issues were also felt by children within the family. Children outlined several occasions when negative behaviours caused issues:

> "*And we're still finding social engagements a big struggle and the slightest thing would irritate And that could cause a major argument*" [**P39: Son**].

The behavioural and psychological symptoms of dementia not only affected the immediate family but can also affect relationships within the extended family circle:

> "*…his family had stopped inviting us places, and their reaction was appalling and this came out, but the reason I found out ages later that they had stopped inviting us to family dinners and things like that they tended to exclude him was because of his behaviour*" [**P30: Spouse/partner**].

3.5.4 Theme 4: Service provision

Many dementia services are situated in older adult settings and are often unsuitable for younger people. In some cases, participants highlighted a complete lack of services for younger people living with dementia, resulting in negative emotional outcomes:

> "*And I just remember going, is there anywhere here to talk in private, you know, there was nowhere even cry, to shed a tear you know, that was the one thing I remember about it*" [**P41: Daughter**].

As a result, many families had to source private dementia services which resulted in significant financial implications. For example, families commented on the cost of accessing private services such as psychological and psychiatric services:

> "*I'd say we went probably about, maybe six times to a psychiatrist, which was quite expensive*" [**P06: PwYOD**].

> "*After paying €400, you know, for, for all this. And so again accepted okay, that's what it is, it is Alzheimer's*" [**P40**: **Daughter**].

Conversely, some families outlined that when and where services were available, the outcome can be positive and can reduce the physical and emotional strain on both the person with YOD and other members of the family:

> "*So, but anyway, I got to hear of them thankfully they're fairly near here, three or four miles away…and they had a day-care center there which I was able to use again because it was only three or four miles and I was able to bring her there and kind of reintroduce her to the place gradually, and I think that was a help then at least and she seemed to kind of seem to enjoy going there*" [**P37: Spouse/partner**].

> "*I have to say in the memory clinic, we were 18 months with the memory clinic they were brilliant, you know, and they were very supportive*" [**P04: PwYOD**].

However, despite some positive narratives, for the majority of families there was a significant lack of appropriate services:

> "*I did not know that services were so limited*" [**P26**: **Spouse/partner**].

3.5.5 Theme 5: Changing family relationships

Following a diagnosis of YOD, there appears to significant relationship changes within the family system as the various subsystems reorientate to the new situation:

> "*I think it can go either way you know it either brings people together or tears them apart sort of thing*" [**P44: Daughter**].

Family members and people with YOD spoke about how the transitions involved can be lengthy, difficult and challenging:

> "*…an evolution, constant evolution. It was a period of seven years really in total but it's kind of a dance between facilitating and overstepping, and, and the line keeps moving as to what the person can do so*" [**P28: Spouse/partner**].

> "*Yeah, I agree there, its, it is an evolution, like, it kind of hits you like a slap in the face, you know, when we got the diagnosis, it's like you get the diagnosis is about like you lose a part of your life to you*" [**P35: Spouse/partner**].

Children, in particular, outlined how transitioning to the role of carer, for example, is fraught with issues. Some of the issues they spoke about included the shifting of boundaries which can affect the various subsystems within the family unit. For example, the evolution from their pre-existing role of /son/daughter within the family system to a new role of carer/financial planner/decision maker:

> "*I mean it's like I had to do her* finances, *so I had to find all the codes had to go through all her emails and that was quite difficult to, you know, read through messages I didn't want to be reading through it, and I found out a lot of stuff that, you know, I'd rather I hadn't. It's all those boundaries like move, you know, that sort of thing happens as well*" [**P41: Daughter**].

Some of the decisions may involve assessing their life stage and can result in changing or forgoing their future plans:

> "*I had plans for the future because, you know, they changed because…it's kind of you just have to try and adapt, you know, things progressed and you just can't plan too far in advance, you know, you kind of learn to sort of just deal with what's in front of you there and then*" [**P39: Son**].

Some family members reported that YOD had affected the dynamics within their family apart as individuals struggle with the changes within the family system:

> "*So, yeah, I mean, yeah, I mean there's a couple. It's not just like moms friends and family like your relationship with family as well, kind of, you know, I became the main carer and I kind of lost the relationship with my brother*" [**P40: Daughter**].

For others, however, the challenges of YOD brought them closer together, with some participants reporting that they are spending as much time together as possible:

> "*Seven, six or five, I was there on Sunday all day I'd be there all day but I couldn't leave until he was asleep. So, I used to go to sleep with him, you know, and it's something I've never heard people really talk about because we kept that relationship*" [**P32: Spouse/partner**].

It is clear from the narratives, however, that a diagnosis of YOD is a significant transitory period for most family members:

> "*You never get it 100% right, do you know, it was a massive learning, difficult transition, to put it mildly*" [**P37: Spouse/partner**].

> "*I don't think anybody can really prepare you for the role of your husband been diagnosed with dementia at* [so young]. *And again, it's a journey but, yeah its hard being the carer, its hard being the wife, its hard being the mum, because its every day and its every hour of every day*" [**P15: Spouse/partner**].

3.6 Discussion

Using a family systems theory as a guiding framework, the current study uncovered five main themes with related sub-themes including: obtaining the diagnosis; awareness; behavioural and psychological symptoms of dementia; service provision and the changing family relationships. Research posits that obtaining a timely diagnosis is important (Johannessen & Möller, 2013; van Vliet et al., 2013). However, there appears to be significant delays in obtaining a diagnosis of YOD and several factors may account for this.

For instance, there is a greater heritable risk in YOD and a wider array of symptoms (Mendez, 2006) when compared to LOD (Alzheimer's Society, 2015) which can often lead to the condition being misdiagnosed. PwYOD typically present with other subtypes other than Alzheimer's disease (AD) such as frontotemporal dementia (FTD). FTD affects the frontal and temporal lobes and can influence an individual's personality resulting in behavioural and motivational problems (Jefferies & Agrawal, 2018) while memory function may remain intact (Koedam et al., 2010).

In addition, genetic and/or metabolic causes of YOD may be more frequent in younger people resulting in varying symptomology. An illustration of this may be seen in some clinical presentations that can include several neuropsychiatric symptoms such as depression, anxiety, agitation, aggression, apathy, delusions and hallucinations, further complicating diagnosis (Sampson et al., 2004; Mendez, 2006). Therefore, PwYOD may be diagnosed with a psychiatric/psychological disorder rather than a neurodegenerative condition.

In a review by Woolley and colleagues (2011) almost one third (28·2%) of PwYOD were misdiagnosed with a psychiatric disorder prior to a definitive diagnosis of YOD, particularly if the subtype was behavioural variant of frontotemporal dementia (bvFTD).

As a result, obtaining a definitive diagnosis of YOD is significantly more difficult when compared to LOD as symptoms are more likely to be attributed to other causes such as metabolic issues, heritable conditions, infections or psychiatric disorders (Woolley et al., 2011). It is clear from the data in the current study that similar issues exist with the diagnostic process that can have profound consequences for PwYOD and their family members.

Additionally, communicating with health care providers appeared to be a significant challenge for the families adding to the challenges they face. Poor communication can act as a barrier to useful information at a time when such information is important. It is not clear whether poor communication is a result of a failure of the overall health care system or of individuals within it. However, the data obtained in the current research suggests that there is a lack of awareness among health care providers in relation to younger people developing dementia. The finding in relation to lack of awareness about younger people and dementia was not limited to health care providers. Families in the current study outlined that the lack of awareness is endemic in society, thus reinforcing the stereotypical view that dementia is a condition associated purely with advancing age. As a result, people living with YOD, and their family members are subjected to stigma.

Given the effects of dementia on factors such as memory, judgement, and behaviour, it is often primarily viewed as a mental health condition by the general public leading to fear and misunderstanding that is often associated with other mental illnesses (Morgan et al., 2002). Social stigma may also hinder an individual’s willingness to engage with specialised dementia service providers. Such findings highlight the lack of education and understanding associated with dementia and, in particular, YOD. Scrambler (2009) defined stigma as deviating from the perceived social norms.

This is particularly salient in the area of mental health, and more specifically mental ill health. Society, more often than not, views individuals living with mental health conditions as being different or dangerous, and who find normal social roles difficult (Hayward & Bright, 1997). It may be reasonable to assume that individuals living with YOD could be perceived as deviating from society’s view of what is normal, and data from this study illustrates that many families encounter stigma frequently.

Participants spoke of feeling guilt and shame, about the disappearance of family and friends, with some feeling the need to hide their loved ones condition in order to protect themselves. The disappearance of family and friends may be due to the fear brought about by the lack of understanding about mental illness. Some behaviours, as a result of dementia, such as issues with memory and judgement may be associated with mental health issues (Morgan et al., 2002) and as such lead to the stigma uncovered in the current study. This can lead to a negative spiral for people with YOD as stigma may prevent them from engaging fully in society, thus acting as a barrier to service provision (Teng et al., 2012).

Stigma may be further reinforced due to the behavioral and psychological symptoms associated with dementia which may be present prior to a diagnosis (Ducharme et al., 2013). All study participants spoke of cognitive and behavioural symptoms that emerged before the age of 65. Such symptoms were subsequently understood by participants to be the cause of stigma that they and the PwYOD encountered. According to the International Psychogeriatrics Association, people living with dementia may experience a group of heterogeneous clinical phenomena during the normal trajectory of the condition (Finkel et al., 1996).

The phenomena may include disturbances in mood, emotion, perception, motor activity and thought, with some people experiencing changes in personality. Despite variations in the symptoms, rates of the behavioral and psychological symptoms of dementia are similar in both late onset dementia and YOD (Arai et al., 2007; Bakker et al., 2013) and pose a significant challenge to families. Research has outlined that the behavioral and psychological symptoms associated with dementia can result in poorer quality of life outcomes for people living with dementia and their families (Ryu et al., 2011) with family members often being the first to notice the symptoms.

Data from the current study illustrates that the behavioral and psychological symptoms of dementia cause significant distress to family members and PwYOD, adding to the psychological and physical strain. Findings also illustrated both the positive and negative aspects of service provision. Many family members spoke about the challenges of care, and the fact that such challenges are not aided by the lack of appropriate health (and in particular) social care services. Research has shown that PwYOD are usually cared for at home for a significantly longer period (average of nine years) when compared to late onset dementia (average of four years) and care is purely dependent on the carers competency (Withall, 2013).

There appears to be a significant lack of age-appropriate services as most, if not all, services are geared towards older adults. Geriatric settings, therefore, are neither adequate nor desirable to younger people which may heighten the reluctance to utilise them (Morhardt, 2012; Flynn and Mulcahy, 2013; Cations et al., 2017). The lack of appropriate services significantly adds to the burden of care placed on primary caregivers and other family members. Consistent with previous research, participants in this study reported significant burdensome aspects of care. Financial burden was a recurrent theme for caregivers as their family members were diagnosed while they were still in employment resulting in participants struggling to pay for care and support their family with reduced income.

Furthermore, there is limited support from the Irish State as entitlements for individuals who are under sixty-five are lacking (Cahill et al., 2012). Substantial physical and psychological impacts were also associated with caring for a family member with YOD. Families reported the emotional and physical toll caring for their spouse/partner had taken on their lives. Similar findings were outlined in research conducted by Roach et al (2008), which further highlights the complexities involved in caring for individuals with YOD.

Data from the current research complimented such findings, with many family members speaking about the lack of service provision and support which resulted in an increased physical and financial impact on the family system. Specifically, several participants cited the financial strain as particularly worrisome. Conversely, when services and support where available, participants spoke of the positive outcomes on the entire family. The numerous challenges participants cited in this study are all party to the changing relationships within the family system and subsystems.

For both PwYOD and their families, relationship changes appear inevitable (Bakker et al., 2013). As the condition progresses, parent-parent, parent-child, and child-child dynamics shift, and boundaries expand and contract. For example, when a spouse/partner is the primary carer, the parent-parent relationship alters due to a significant role change. Similarly, the parent-child relationship alters for both the primary carer and for the parent with YOD. Subsequently, many child-child (sibling) relationships are also subject to changing dynamics (Nichols & Fam et al., 2013).

3.7 Strengths and limitations

Every measure was put in place in order to ensure the quality of this research. Forty-four participants were included in this study, thirteen people with YOD and thirty-one family members, which is not only in line with, but exceeds the sample size of similar research studies. The breath of the relationship between participants allowed for a number of different perspectives. Taken together, this enabled this research to gain an in-depth view of life with YOD. However, thematic analysis is a subjective process and as a result is susceptible to interpretation and bias. The current research includes individuals perspectives from Ireland, which may be characterised as wealthy Western country.

3.8 Chapter Conclusion

Findings from this study illustrate the shifting relationships and boundaries with participants reporting significant alterations in roles. Spousal carers reflected on the physical and emotional strain, while the older adult children spoke about future plans being put on hold or scrapped completely. Children also outlined crossing boundaries and assuming a more responsible role, such as managing finances, a role formally undertaken by a parent. Several participants referred to the changing situation as an evolution that requires a substantial period of time. While the majority of participants spoke about the challenges, some highlighted that the situation has brought them closer as a couple and as a family.

Family members have stated that they often feel a sense of accomplishment and a gratifying feeling as a deep bond is often formed among them. While other participants reported that transitioning to the new role has allowed for a sense of purpose with life. However, it is clear from the current data that a diagnosis of YOD is a significant challenge for the entire family system. The novel findings related to childhood experiences of parental YOD assisted in guiding the subsequent chapters in this thesis. There is a significant gap in the literature in relation to childhood experiences of parental YOD and in particular, children under the age of eighteen. Therefore, the next chapter will describe a literature review focused on synthesising the qualitative data related to children’s experiences and perspectives of parental YOD.

4. Childhood perspectives of parental young onset dementia: A qualitative data synthesis.

4.1 Abstract

Introduction

While it is less common, young onset dementia (YOD) manifests at a significantly younger age (< 65). Many people with YOD are parents, however, little is known about impact of the condition on children and young adults. A qualitative thematic analysis was conducted to synthesise the literature on the perspectives of children and young adults with a parent living with YOD.

Method

Electronic databases were searched in order to identify all peer reviewed literature in relation to the perspectives of children and young adults with a parent living with YOD. A thematic analysis was conducted on the relevant literature.

Findings

The electronic database search resulted in 15 full texts articles. Four main themes with related sub-themes emerged from the thematic analysis. The four main themes were: changing family dynamics; psychological & physical strain; stigma and coping strategies.

Discussion

The current synthesis outlines the perspectives of children and young adults with a parent living with YOD. There is a significant lack of research in this area which adds to the stereotypical view of dementia as an older persons disease. This can lead to children and young adults being impacted by lack of awareness and stigma resulting in significant psychosocial problems. As the number of people living with dementia (including YOD) is set to increase, future research with children and young adults with a parent with YOD is important in order to better support this cohort.

4.2 Chapter Introduction

The participatory workshop that was conducted with people with young onset dementia (PwYOD) raised several issues of relevance such as, issues relating to the diagnostic process, adjusting to the diagnosis for both PwYOD and their family and post-diagnostic supports. These issues were subsequently investigated using focus group interviews with PwYOD and their family members as described in chapter three. However, while children were included in the focus group interviews, they were older adult children with an average age of twenty-seven and numbered only six participants.

Consequently, there appears to be a considerable lack of research related to children's and younger adults experiences of parental YOD, particularly in Ireland, leading to a significant gap in the literature. Moreover, during the focus group interviews with family members, many of the parents involved enquired whether children's experiences would be included in subsequent studies. There appeared to be a specific emphasis on, and appetite for, an exploration of the experiences of children under the age of eighteen. Furthermore, the six participants who were characterised as older adult children also stated that they would have liked to have had the opportunity to participate in research when they were younger.

Accordingly, we decided to address this gap and investigate the impact of parental YOD on children (under the age of eighteen) and young adults, in order to better understand their experiences. Therefore, this chapter encompasses a systematic review of the qualitative data related to the experiences and perspectives of children and young adults with a parent with YOD. This involved synthesising and expounding the existing qualitative literature, the findings from which significantly influenced the orientation of the remaining chapters in this thesis.

4.3 Introduction

The challenges associated with a diagnosis of YOD are described in detail in the previous chapters of this thesis. While the condition is most prevalent in an older population, a significant cohort of people receive a diagnosis at a relatively younger stage of life (Koopmans & Rosness, 2014). The subsequent deficits in cognition associated with YOD such as memory problems, speech and language issues and emotional and behavioural difficulties can create significant problems for them and their family members (Hughes, Louw & Sabat, 2006; Koopmans & Rosness, 2014).

As outlined in chapter one, despite the relatively recent research focus on YOD, attempting to calculate the prevalence rates of the condition have proven (and remain) quite problematic. This may be as a consequence of a combination of factors. For instance, there is considerably less data related to prevalence rates of YOD in comparison to late onset dementia (LOD) (Renvoize, Hanson & Dale, 2011; Bakker, 2013; Pierse et al., 2019). Furthermore, there may be issues with various study designs, methodologies and inclusion criteria that can all assist in skewing the data (Lambert et al., 2014).

However, Hendriks and colleagues (2021) did conduct a systematic review and meta-analysis in order to assess the prevalence rates of YOD. The findings of which posit that the prevalence of YOD is 119 per 100,000 for people aged between thirty and sixty-four, or four million people approximately. This equates to almost nine percent of diagnosed dementia cases worldwide (WHO, 2019).

Following a diagnosis, the individual and their families may be faced with considerable issues both at a familial and societal level (Rossor et al., 2010). For instance, the majority of PwYOD are usually diagnosed while still in the active phase of life, a phase that may also involve parenting, financial, caring and employment responsibilities (Sansoni et al., 2016). PwYOD may be forced to cease employment, for example, which can lead to significant financial issues for the family. PwYOD may also be required to stop driving which can considerably impact their parenting role and can lead to an individual being excluded socially (Spreadbury & Kipps, 2019). Such factors can have particularly negative consequences on an individual's sense of autonomy and purpose resulting in PwYOD reporting feelings of marginalisation, loss of identity and a reduction in their self-esteem (Harris, 2004; Clemerson et al., 2014; Roach & Drummond, 2014).

As illustrated in previous chapters, the majority of traditional dementia care is situated in older adult settings (Guss et al., 2006; Withall, 2013) particularly in an Irish context. What does this mean for PwYOD and their families? Firstly, it means many families find themselves having to adapt to a new and challenging caring role in the home. Secondly, it reinforces the stereotypical perception that dementia is a disease of old age (Flynn & Mulcahy, 2013). While the specialised and tailored services for PwYOD and their families that are required (Richardson et al., 2016) remain absent, PwYOD will linger on the periphery of tradition dementia care with an increased reliance on family and friends (Ducharme et al., 2013).

Unsurprisingly, PwYOD tend to be cared for in the home for a significantly longer period of time when compared to LOD. Care is typically provided by a primary "*informal carer*" who is usually a family member or close friend (Newbronner et al., 2013). Consequently, family members who provide such care have reported significant levels of burden (Barca et al., 2014) due mainly to the unique challenges posed by YOD (Johannessen et al., 2017). Caring may involve both physical and psychological support, and carers have reported feeling ashamed, guilty, anxious, grief stricken and wholly unprepared for the new situation (de Vugt & Verhey, 2013; Sansoni et al., 2016).

As examined in chapter three, research into caring in YOD usually focuses on the dyadic relationship between PwYOD and their primary informal carer – e.g., a spouse or partner. However, also discussed in chapter three is the fact that many PwYOD may be parents and therefore children may also be impacted by the situation. For instance, research conducted by Wawrziczny and colleagues (2016) report that while spouses and/or partners adopt a caring role, there are also a significant cohort of children and young adults who also provide care.

Interestingly, the issues facing children when a parent is living with an illness have garnered significant attention in recent years, with the exception of YOD (Aldridge, 2018). For example, Cass and colleagues (2011) outlined the negative affect on children's psychological and physical health who experience a parent living with a significant health condition or disability. Similarly, evidence has established the correlation between parental illness and/or disability and negative educational outcomes for children (Sikes & Hall, 2018).

The little research that does exist with children of a parent with YOD details that the physical and emotional toll is significant (Gelman & Greer, 2011) however, families may require their children's support (Adelman et al., 2014). Moreover, evidence from research with spouses and/or partners may not be applicable to children and young adult carers. For instance, Spreadbury and Kipps (2019) suggest that children's responses to caring for a PwYOD may vary considerably when compared to adults. Younger carers may adopt differing coping mechanisms, learn new techniques in order to feel useful and bring a sense of unity to their family (Joseph et al., 2012). Several analyses (van Vliet et al., 2010; Svanberg et al., 2011; Cabote et al., 2015; Baptista et al., 2016; Millenaar et al., 2016; Sansoni et al., 2016; Spreadbury & Kipps, 2019) have include children's experiences of YOD.

However, the findings incorporate the overall family narrative and do not focus solely on children, leading to a significant gap in the research (Richardson et al., 2016). Cabote and colleagues (2015) have examined the experiences of children separately from adults, though the analysis included only two studies exclusively based on younger carers perspectives.

There has been an increased interest in YOD, particularly in the last fifteen to twenty years. Numerous reviews and meta-analyses have focused on the experiences of PwYOD, while others have examined the role of the caring from the experience of spouses or partners. However, children may find that they have to support a parent with a progressive, degenerative disease and assist with certain care giving tasks. It may be applicable to outline the contemporary view of "child carer" or "young carer" as it differs significantly from the archaic or antiquated perspective.

In recent years, significant shifts in society means that it is difficult to gain a consensus on a definition of youth or young age cohort. In other words, in contemporary Western culture, the term youth is a far more fluid construct rather than a fixed aged category (Patton et al., 2016). For instance, according to Walker-Harding and colleagues (2017) there are a considerable number of younger people who remain living in the family home well into their thirties. This is in stark contrast to just a few decades ago, where younger people were expected to leave home at eighteen years of age or even younger in some cases (Walker-Harding et al., 2017).

As a result, there may be far more younger people who experience parental illness or disability as a consequence of being in the family home. In fact, data provided by the Eurocarers Policy Paper on Young Carers (2017) detail that between four and ten percent of younger people provide care for a parent with an illness or disability. Also detailed within these data are the varying levels of care younger people provide. Care can range from simple supervision to physical assistance with mundane household chores to more intimate personal care needs. Some younger carers may also provide psychological and emotional support.

Such tasks, more often than not, are conducted without assistance and are equal to those carried out by adult carers. Moreover, care giving can often be perceived as a natural expansion of family relationships, and as such, younger carers typically do not receive any support from the authorities responsible for health and social care (Moore & McArthur, 2007).

Therefore, younger people providing care for an ill parent particularly those living in the same home, generally report more psychosocial issues when compared to their peers living without an ill parent. For example, issues with their mental health, behavioural problems and difficulties with educational attainment (Becker, 2007).

4.3.1 Rationale and Aims

To the best of our knowledge, there have been six analyses of the literature on children's and young adults experiences of having a parent with YOD (Gelman & Greer, 2011; Poole & Patterson 2020; Wang & Brooke, 2020; Cartwright et al., 2021; Chirico et al., 2021; Grundberg et al., 2021) with one review (Wang & Brooke, 2020) synthesising purely qualitative data. This is likely to lead to a significant gap in the research in relation to the perspectives of children and young adults with a parent with YOD.

The current analysis will focus exclusively on qualitative data and synthesise the evidence utilising thematic analysis to explore this cohorts perspectives of YOD. The specific aim is to critically examine the evidence in order to understand the impact of living with a parent with YOD has on their lives.

4.4 Methodology

Seven electronic databases including PubMed, Medline, Embase, CINAHL Complete, PsychInfo, Scopus and Web of Science were searched in order to identify all contemporary peer reviewed literature in relation to the research aim.

4.4.1 Inclusion Criteria

Inclusion depended on the studies being written in English and published in peer reviewed journals. The electronic search did not include any time/date limit. See table 9 for inclusion and exclusion criteria, databases and search terms used.

4.4.2 Data Collection

Abstracts were screened in the first instance, and subsequently full texts were screened in order to gauge eligibility for inclusion based on the inclusion/exclusion criteria outlined in table 9. Reasons for article rejection were recorded and are outlined in the PRISMA flow chart (figure 7).

Items of data extracted include information in relation to publication (authors, date, country, study aims), eligibility (participant characteristics, methodology, and analysis) and raw data (in the form of participant quotations and relevant themes).

Table 9: Inclusion and exclusion criteria guiding study selection, databases and search terms.

Inclusion Criteria.	
• Primary qualitative studies focused on the perspectives of children, adolescents and young adults with a parent with YOD • Qualitative methodologies such as interviews and focus groups • Included both biological children and stepchildren • Studies with descriptions of the data collection and analysis procedures • PwYOD defined as an individual diagnosed before the age of 65 years • Studies published in English • Studies published in academic peer-reviewed journals	
Exclusion Criteria.	
• Quantitative or mixed method methodologies • Studies that include or are focused on PwYOD • Studies that include or are focused on spouses/partners • Unpublished research – i.e., grey literature, position papers, poster presentations & theses • Studies not reported in English	
Databases and search terms.	
Databases	Search Terms
Scopus Medline PubMed Web of Science Embase PsychInfo CINAHL Complete	“young onset dementia” OR “early onset dementia” OR “presenile dementia” OR “YOD” OR “PwYOD” OR “EOD” “PwEOD” OR “working age” OR “under 65 years” AND “children” OR “child” OR “son” OR “daughter” OR “stepchildren” OR “adolescents” OR “teenager” OR “teen” OR “teens” OR “youth” or “kids” OR “young carer” OR “young adult” AND “parent” OR “parents” OR “parental” OR “mother” OR “father” OR “dad” OR “mom” OR “guardian” OR “legal guardian” OR “stepmother” OR “stepfather” OR “folks”

4.4.3 Data Analysis and Synthesis

Thomas and Harden’s (2008) approach to thematic synthesis was employed, and the synthesis and subsequent analysis were also assisted by contemporary studies in relation to this approach (Soilemezi & Linceviciute, 2018). Thematic analysis is one of a range of methodologies utilised in research synthesis that sits alongside meta-ethnographic and meta-syntheses (Dixon-Woods et al., 2005). According to Boyatzis (1998) thematic analysis is a process that may be utilised with most qualitative methodologies. This approach was used in this paper as it allowed the researcher to immerse fully in the data in order to identify, develop and extract the relevant themes.

Furthermore, this method is increasingly being utilised in health and social science research particularly in relation to the evaluation of participants' experiences (Booth, 2016). The first stage involved reading and re-reading of the included papers in order to identify information pertaining to the context of the paper.

The second stage involved screening data in the "findings/results" section of the included papers to identify themes emerging from the data that related to the research question. The papers were examined in chronological order (from earliest publication date) and were then compared with subsequent papers in order to recognise similar themes across the included papers. This process continued until data saturation was reached, and no new themes emerged from the data. The steps followed during this process are outlined in table 10.

Table 10: Steps followed during the data synthesis.

1	Purposeful reading of the journal articles in order to understand the context, to appraise the quality of the study in order to extract relevant data.
2	Identified themes were extracted from the results/finding's sections, and from the discussion sections of the journal articles.
3	Themes extracted from the results/finding's sections were classed as primary data (i.e., quotes directly from participants).
4	Themes extracted from the discussion sections were classed as secondary data (i.e., the authors' interpretations).
5	Both raw data and secondary data were compared and contrasted within and between journal articles, and subsequently coded for meaning in relation to the research question.
6	Purposeful re-reading of the journal articles in order to ensure coding and thematic analysis was appropriate before final write-up.

4.5 Results

The electronic database search yielded 887 articles. Following the removal of duplicates and those not meeting inclusion criteria, 15 full texts articles were included in the synthesis (see figure 7).

4.5.1 Characteristics of included studies

In total, the current synthesis included 15 articles from six countries (see table 11) representing the narratives of 129 participants. The age of participants ranged from six to thirty-three years with only two articles (Nichols et al., 2013; Baker et al., 2018) focusing solely on participants under the age of eighteen years (age range: 9-18 years).

The studies by Sikes and Hall used the same sample of participants (*n* = 24). Similarly, Hutchinson et al. (2016) used the same sample (*n* = 12) for both studies. Baker and colleagues (2018) interviewed twenty-eight children in total, however, only six had experience of living with an adult with YOD.

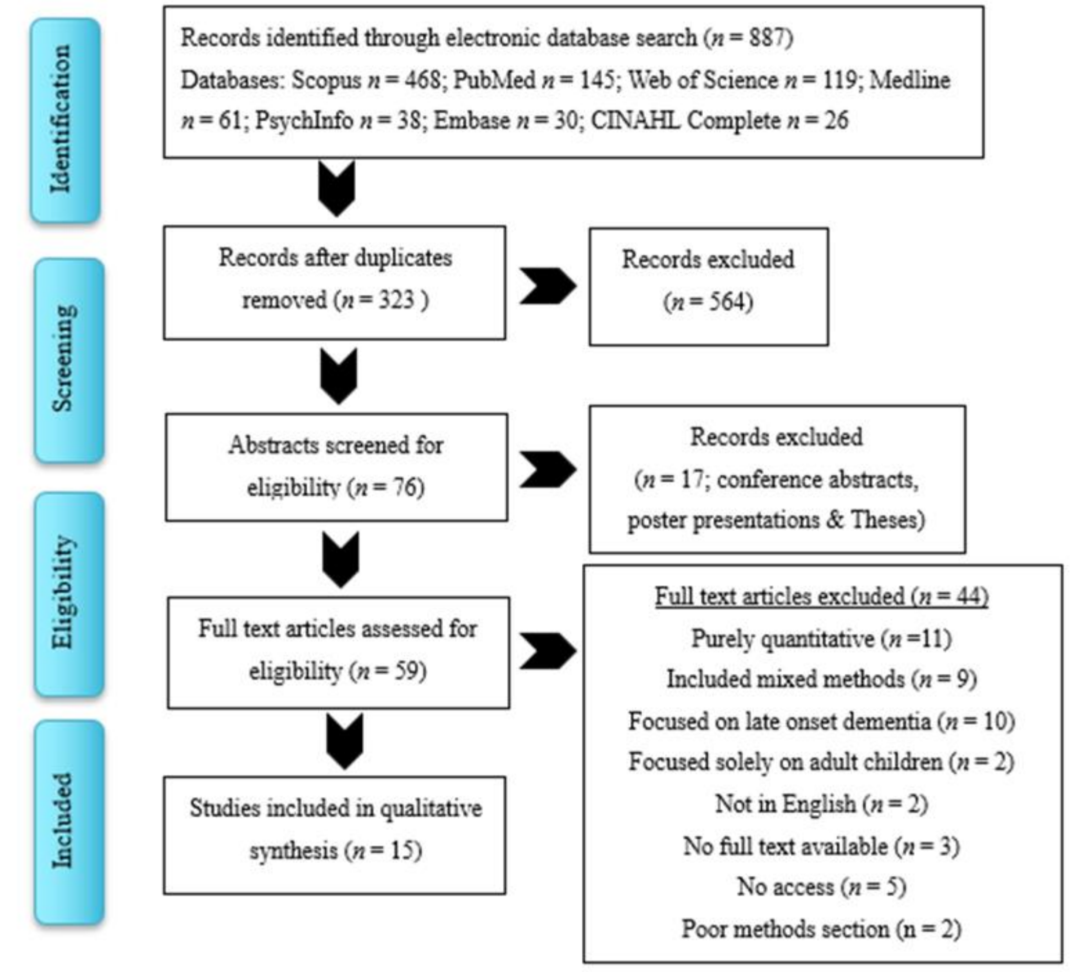

Figure 7: PRISMA flow chart illustrating the study selection process (adapted from Moher et al., 2009).

4.5.2 Quality Appraisal

In order to appraise the quality of the selected studies the Critical Appraisal Skills Programme qualitative checklist was used (Critical Appraisal Skills Programme (CASP, 2018). The CASP assists the review process by providing the reviewer with ten questions to consider in relation to each individual studies validity, value and findings.
The questions require the reviewer to simply answer with either a "*yes*", "*no*" or "*cannot tell*" response. The CASP is the most prevalent tool used to assess the quality of studies during the qualitative synthesis process (Majid & Vanstone, 2018) and as such was used in the current review. Any studies that were deemed to be of poor quality were omitted from the current synthesis (Dixon-Woods et al., 2004).

The aims, methods, participant recruitment and study design were outlined in all cases. The majority of studies utilised one-to-one semi-structured interviews, while focus group interviews and auto-biographical narratives were also used. One study (Nichols et al., 2013) was vague in relation to data collection. A minority of studies recognised the influence the research team may exert on participants. Most studies were cognisant of ethical considerations, however, two studies (Gelman & Greer, 2018; 2020) offered participants monetary reward for participation. Key quotes were used by all studies to illustrate themes and subthemes; therefore, each study was deemed to be of sufficient quality to be included in the synthesis (see table 12).

Table 11: Details of studies included in the qualitative synthesis.

Study/Year/ Country	Aims	Sample	Age at time of interview	Methods	Theoretical Approach	Quality Appraisal
(Szinovacz, 2003) USA	To identify changes in parent–adolescent relationships and in family dynamics when a family member with Alzheimer's or similar dementia moves into the household.	17 participants	12-19 years	One-to-one semi-structured interviews	Family systems theory	Good
(Allen et al., 2009) United Kingdom	To explore the impact on young people's wellbeing of having a parent with younger onset dementia.	12 participants	13-24 years	One-to-one semi-structured interviews	Grounded theory	Good
(Nichols et al., 2013) Canada	To learn more about the needs and experiences of young carers for patients of frontotemporal dementia (FTD) in order to create a relevant support website for young caregivers to dementia patients.	14 participants	11-18 years	Focus group interviews	Thematic analysis	Good
(Millenaar et al., 2014) Netherlands	To explore the experiences of children living with a young parent with dementia with a specific focus on the children's needs.	14 participants	15-27 years	One-to-one semi-structured interviews	Inductive content analysis	Good
(Hutchinson, Roberts & Kurrle, et al., 2016) Australia	To explore the lived experience of young people living with a parent with young onset dementia from the perspective of the social model of disability. Focus on exploring what impact society has on the emotional well-being of the young people.	12 participants	10-33years	One-to-one semi-structured interviews	Social model of disability.	Good
(Hutchinson, Roberts & Daly, et al., 2016) Australia	To explore what are the lived experiences of young people having a parent with younger onset dementia from the perspective of the social model of disability. Secondly we explored influencing factors that could enable these young people to be included and supported within their community	12 participants	10-33 years	One-to-one semi-structured interviews	Social model of disability	Good
(Sikes & Hall, 2017) United Kingdom	To add to the literature by re-presenting the grief-related perceptions and experiences of children and young people who have a parent with a young onset dementia.	22 participants	6-31 years	Auto/biographical: Participants are simply invited to tell their stories of parental dementia	Life historical and narrative approach/thematic analysis	Good
(Hall & Sikes, 2018) United Kingdom	To explore young people's experiences of disruptions to existing family practices, and how they perpetuate a relationship with their parent in the face of dementia.	22 participants	8-31 years	Auto/biographical: Participants are simply invited to tell their stories of parental dementia	Family practices approach	Good

Table 11: (continued)

(Hall & Sikes, 2018) United Kingdom	To examine the implications dementia has for the relationship between children and their parents – specifically, how individuals 'do' and display family when their parent's personality and capacity to function as previously has been undermined.	22 participants	6-31 years	Auto/biographical, one-to-one in-depth interviews	Life historical and narrative approach/thematic analysis	Good
(Sikes & Hall, 2018) United Kingdom	To explore the consequences of parental young onset dementia on children's educational careers.	24 participants	6-31 years	Life historical and narrative approach	Grounded theory/thematic analysis	Good
(Gelman & Rhames, 2018) USA	To explore the impact of children living at home with a parent with YOD in order to better understand their experience and more effectively respond to their unique needs.	10 participants	13-20 years	One-to-one semi-structured interviews	Thematic analysis	Good
(Baker et al., 2018) Australia	To elicit stakeholder priorities for the message content of an education program to improve dementia awareness among youth; specifically, what do children need to know about dementia?	6 participants	9-16 years	One-to-one semi-structured interviews and focus groups	Tripartite framework	Good
(Gelman & Rhames, 2020) USA	How do the parents without YOD understand and negotiate their ever-changing parenting role, and how do their children experience it?	8 participants	15-20 years	One-to-one semi-structured interviews	Thematic analysis	Good
Lövenmark (2020) Sweden	To describe how children, in their own narratives, construct themselves as subjects growing up and caring for a parent with dementia.	12 participants	15-25 years	Discourse analysis of participant blogs	The epistemological perspective	Good
(Hall & Sikes, 2020) United Kingdom	The perceptions and experiences of children and young people who have a parent with young onset dementia, this article explores the ways in which the condition impacted their life courses.	23 participants	6-31 years	Narrative biographical approach with a limited longitudinal element	Life historical and narrative approach/thematic analysis	Good

Table 12: Quality appraisal of included studies using the Critical Appraisal Skills Programme (2018) qualitative checklist.

Study	Aim	Method	Design	Recruitment	Data collection	Relationship	Ethical issues	Analysis	Findings	Value
(Szinovacz, 2003)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
(Allen et al., 2009)	✓	✓	✓	✓	✓	●	✓	✓	✓	✓
(Nichols et al., 2013)	✓	✓	✓	✓	●	●	●	✓	✓	✓
(Millenaar et al., 2014)	✓	✓	✓	✓	✓	✖	●	✓	✓	✓
(Hutchinson, Roberts & Kurrle, et al., 2016)	✓	✓	✓	✓	✓	✖	✓	✓	✓	✓
(Hutchinson, Roberts & Daly, et al., 2016)	✓	✓	✓	✓	✓	✖	✓	✓	✓	✓
(Sikes & Hall, 2017)	✓	✓	✓	✓	✓	✓	✓	●	✓	✓
(Hall & Sikes, 2018)	✓	✓	✓	✓	✓	✖	✓	●	✓	✓
(Hall & Sikes, 2018)	✓	✓	✓	✓	✓	✖	✓	●	✓	✓
(Sikes & Hall, 2018)	✓	✓	✓	✓	✓	✓	✓	●	✓	✓
(Gelman & Rhames, 2018)	✓	✓	✓	✓	✓	✖	✖	✓	✓	✓
(Baker et al., 2018)	✓	✓	✓	✓	✓	✖	✓	✓	✓	✓
(Gelman & Rhames, 2020)	✓	✓	✓	✓	✓	✖	✖	✓	✓	✓
Lövenmark (2020)	✓	✓	✓	✓	✓	✖	✓	✓	✓	✓
(Hall & Sikes, 2020)	✓	✓	✓	✓	✓	✖	✓	✓	✓	✓

Key: ✓ = criteria met ● cannot tell or criteria partially met ✖ = criteria not met.

4.6 Thematic Synthesis

The four main themes with related sub-themes that emerged from the analysis are presented in table 13. To support the analysis, direct participant quotations (primary data) and the authors interpretations (secondary data) were utilised. Primary data are presented in the form of participant quotations in italicised text, and secondary data interpretations are presented in non-italicised text.

4.6.1 Theme 1: Changing Family Dynamics

Relationships and roles within the family are significantly negatively affected following a diagnosis of YOD, however in some instances, the change can also be positive.

Role and relationship change

The changing nature of the roles and relationships within the family was outlined in seven studies (see table 13). Children and young adults, particularly the male participants, reported the need to adopt the role of family protector, specifically if the PwYOD was their father (Allen et al., 2009; Baker et al., 2018; Millenaar et al., 2014). One male participant described how he felt this need:

> "*I am the man of the family, I must be strong. If the family is threatened then, I must protect them*" (Allen et al., 2009, pp. 466).

Another young male participant described how his role changed from student to employee as a result of his father's diagnosis:

> "*Since I was 15, when I knew that dad wasn't going to be bringing in any money for mum, it kind of put me more towards work than university and college*" (Allen et al., 2009, pp. 467).

The sense of the changing relationship with a father with YOD was not restricted to male participants. One nineteen-year-old female described how her relationship with her father had changed significantly:

> "*You miss them being a parent. Normally you are father and child, but now we are on the same level because he does not think like an adult anymore*" (Millenaar et al., 2014).

Young people further outlined how their well parents time was consumed by caregiving tasks leaving little time for their relationships (Szinovacz, 2003; Allen et al., 2009; Gelman & Rhames, 2018; 2020). One young thirteen-year-old female described the loss of time with her mother:

> "*I'm angry at him because it's like my time with my mom… It's like having a brother or sister because I'm an only child. It's like not having them to myself*" (Szinovacz, 2003, pp. 457).

YOD also impacts on normal family life, significantly undermining relationships and the unity of the family:

> "*Every weekend that my father had off from work we'd go on day trips. It was great, it was a great family unit. And then this came in, and we no longer had the flexibility to do that. So, it's like the family, I can't say grew apart, but, you know, the little pleasurable trips that made family life great were no longer allowed*" (Szinovacz, 2003, pp. 461).

Parenting the parent

Evidence of children and young adults having to adopt a parental role was described in six studies (see table 13). Research has illustrated that the situation can have a significant negative impact both physically and emotionally as a result. However, families may require their children's support and children often play a pivotal role in the care of a parent with YOD (Adelman et al., 2014). One nineteen-year-old male described adopting the role of parent for his father in order to assist with caring tasks:

> "*I've had to do some things for him that no kid should ever have to do for their father. I had to wash his clothes after he had an accident and shower him, you know… I had to do that*" (Gelman & Rhames, 2018).

Table 13: Summary of main themes and sub-themes uncovered in the synthesis (*****Behavioral and Psychological Symptoms of Dementia).

Study	**Changing Family Dynamics**				**Psychological & Physical Strain**					**Stigma**		**Coping Strategies**	
	Role & relationship change	Parenting the parent	Chance to bond	Adjusting future plans	Financial worries	Anger & guilt	Grief & loss	Effects of BPSD*****	Care & domestic tasks	Lack of awareness	Familial & societal	Family & peer support	Distraction
(Szinovacz, 2003)	■	■	■	■								■	
(Allen et al., 2009)	■						■	■	■		■	■	■
(Nichols et al., 2013)	■		■					■		■	■	■	
(Millenaar et al., 2014)		■		■				■	■	■	■	■	■
(Hutchinson, Roberts & Kurrle, et al., 2016)					■				■		■	■	■
(Hutchinson, Roberts & Daly, et al., 2016)		■		■		■	■	■	■				■
(Sikes & Hall, 2017)		■		■		■	■	■	■	■	■	■	
(Hall & Sikes, 2018)		■	■	■			■	■			■		
(Hall & Sikes, 2018)			■	■		■	■	■	■		■	■	
(Sikes & Hall, 2018)						■	■	■		■			■
(Gelman & Rhames, 2018)	■			■	■			■		■	■	■	■
(Baker et al., 2018)	■		■							■	■		
(Gelman & Rhames, 2020)	■		■	■	■		■						
Lövenmark (2020)	■			■			■					■	
(Hall & Sikes, 2020)		■		■		■	■			■			■

Participants reported how they were required to help with the needs of their parent with YOD, similar to looking after a child. A girl aged eight had been assisting with her mother needs for almost ten years:

> "*…you'd have to be awake at seven, when she woke up to say hi, good morning, you'd have to prompt her to get up and change her and dress her, put her socks on, it was a pleasure to be able to do that for her*" (Hutchinson, Roberts & Kurrle, et al., 2016).

Another fifteen-year-old male described how the parent/child relationship had completely turned on its head:

> "*But me being in the position that I have with my father, I have to take care of my father; the one who's supposed to be taking care of me, I'm taking care of him*" (Gelman & Rhames, 2018, pp. 343).

The sense of parenting the parent was evident in a quote by a female participant:

> "*After a while I suggested that I wash her hair and make her look nice, so I did. When I had dried her hair and curled it, I gave her a hair clip with rhinestones in and put it in her hair and she was so happy*" (Lövenmark, 2020, pp. 711).

Adjusting future plans

The adjustment of future plans was outlined in ten studies (see table 13). Participants reported how YOD had impacted on their future plans in relation to employment, travel and education (Sikes & Hall, 2017). Participants described feeling stuck as they felt their future plans could no longer progress. A male participant aged twenty-seven illustrated how his future plans for independence were put on hold:

> "*I planned to move out a while ago, but now I feel like I cannot leave anymore since my mother will be alone with him. I did not tell her that because I do not want her to feel guilty*" (Millenaar et al., 2014, pp. 2004).

A twenty-two-year-old female had a similar experience with her future plans being interrupted:

> "*I wasn't entirely sure last summer what I wanted to do…I felt my life had been put on hold and I wasn't getting anywhere*" (Sikes & Hall, 2018, pp. 601).

One twenty-eight-year-old female summed up how future plans are affected:

> "*It affects my life choices as well because I'd probably be looking at having kids soon if it wasn't for this…I think all kind of family plans are gonna be on hold…you don't know how long each stage is gonna last*" (Sikes & Hall, 2017, pp. 331).

Chance to bond

The opportunity for children and young adults to bond with other family members during adversity was outlined in six studies (see table 13). Despite the negative changes to the family, YOD can sometimes bring some positives to familial relationships (Szinovacz, 2003; Millenaar et al., 2014; Gelman & Rhames, 2020). Participants reported that YOD had brought them closer to their parent(s) as they shared their emotions openly. An eighteen-year-old male described bonding with his mother:

> "*We have gotten closer to my mother, who took on the roles of both parents. We're her outlets, people to vent to. We do that, too. We don't keep secrets; we try to be very honest and open*" (Gelman & Rhames, 2020, pp. 685).

Similarly, young people described how they bonded with other siblings, providing emotional support to younger family members. An eighteen-year-old female described providing emotional support to her younger sister which has allowed them to bond:

> "*I think mum will try and cover her emotions up. I'm [sister's name] big sister and she does come to me a lot, like she always talks to me about things so if she has got problems or anything she needs to talk about she'll come and tell me, I don't think she's scared to cry*" (Allen et al., 2009, pp. 471).

4.6.2 Theme 2: Psychological and Physical Strain

A parent diagnosed with YOD can place significant psychological and physical strain on children and young adults.

Financial worries

In three studies (see table 13) children and young adults reported how YOD can impact on them financially, particularly if the PwYOD is the main breadwinner in the family (Gelman & Rhames, 2018; 2020). Children and young adults outlined the psychological strain as a result of worrying about money. A nineteen-year-old female participant described the psychological strain the lack of finances can cause:

> "*So, money's so, so stressful…money is always a problem. Even when we're not talking about the problems, it's hard to do anything because money is really tight*" (Gelman & Rhames, 2018, pp. 347).

Another nineteen-year-old male participant outlined how the lack of money resulted in psychological strain for himself and his siblings:

> "*I essentially support myself financially. I pay for my own tuition, I pay for my car, when I'm at school I pay for my food. I pick myself up and, you know, whenever my sisters need money which, frankly they don't because they have jobs, but whenever they needed money, whenever they needed rides, or whenever they needed whatever, I was there*" (Gelman & Rhames, 2020, pp. 683).

Similarly, a female participant reported how she had to sell contraband in school in order to make ends meet:

> "*With that packet [of cigarettes] I'd sell them to other kids at school and I'd make money… I'd maybe buy a couple of cigarettes and then buy bread and milk and spaghetti and stuff groceries… I guess these are the financial impacts of having a parent with dementia, is that you don't have the things your friends have*" (Hutchinson & Kurrle et al., 2016, pp. 661).

Anger and guilt

Five studies (see table 13) outlined how children and young adults can feel anger and guilt as a result of YOD (Hutchison & Daly et al., 2016; Sikes & Hall, 2017; Hall & Sikes, 2018; 2020). Many participants described feeling significant anger and negativity towards their parent with YOD due to being forced to change future plans. One female participant outlined this anger:

> "*…that made me really angry and just negative towards Mum. But I think she would have died if she knew that I had passed up those scholarships but there was no one else there*" (Hutchison & Daly et al., 2016, pp. 616).

Similar feelings were expressed by another female participant who described constantly feeling angry:

> "*I feel like this big pot of boiling water that's constantly about to overflow so the smallest thing can set me off*" (Hutchison & Daly et al., 2016, pp. 619).

One male participant described feeling angry tinged with grief and sadness for a former life:

> "*I miss my mother as much as I miss my dad. I miss mum's life's spark. I walk around all day and feel angry*" (Lövenmark, 2020, pp. 712).

Feelings of anger can subsequently result in feelings of guilt. One thirty-year-old female described getting angry with her mother, followed by immediately feeling guilty. YOD can be akin to an emotional rollercoaster for young people:

> "*And then I feel guilty because I've told her sometimes… 'Mum I can't do this, I'm not talking about this here. I feel like we spend our whole lives talking about it, I'm out'. I went back and I said to her friends you probably think I'm harsh but I just can't deal with it sometimes*" (Sikes & Hall, 2017, pp. 333).

Another female aged twenty-two described feelings of guilt following an angry outburst:

> "*I know I feel an awful lot of guilt because…when the symptoms were starting to show. . .there was one day she called me four times in an hour and every single time she'd say 'I've just put the washing machine on' and I was in the middle of doing an essay. I had three days to do it and I was like 'Mum you need to stop calling me, you've already told me this three times today' and I got really angry at her*" (Sikes & Hall, 2018, pp. 598).

Grief and loss

In nine studies (see table 13) children and young adults reported significant feelings of grief and loss similar to the death of a parent. Evidence from Nichols and Fam (2013) described feelings of frustration, helplessness and loneliness in children and young adults, subsequently leading to feelings loss and grief. Similar evidence was highlighted by Gelman and Greer (2011) with children and young adults reporting a sense of loss, almost as if their parent were deceased. One eighteen-year-old male described the loss of several life landmarks:

> "*I would be different if dad didn't have FTD. He would have taught me things. Taught me the business, I could have asked him about things – girlfriends. Adult male talk. Working with dad*" (Allen et al., 2009, pp. 466).

A male aged twenty-two outlined the frustration and grief of living with a parent with YOD:

> "*The person is physically there but there's also grief of losing someone… That person is not here anymore. But they are. But I can't reach them. But they're right there…is hard emotional circumstance for anyone to deal with…especially a young person who really doesn't have that emotional framework and faculties to kind of try to process it*" (Hutchinson & Kurrle et al., 2016, pp. 618).

Similarly, a female aged twenty-two also described feeling as if her parent was already gone:

> "*It's like I explained to someone, you start grieving even though they're standing right in front of you…when eventually her body dies, I'm not entirely sure how upset I'll be…*" (Sikes & Hall, 2017, pp.330).

The sense of frustration of the unknown or not knowing was described by a twenty-one-year-old female:

> "*I felt like I was in this long queue waiting for my number to be told that he's died because you know it's coming…you just don't know how long you've got to wait. They have one good day and three bad days and then the bad days outweigh the good days…it's been three years of constant grieving*" (Sikes & Hall, 2017, pp.330).

The insidious nature of YOD can further add to the sense of anger, frustration, loss and grief. A female participant described the anger, frustration and grief she felt in relation to her father:

> "*Please Dad come back! Come back as you are. Not as you have been. I want to talk to you, I want to hug you. I want to have fun with you. I just want one little thing. Come back, alone, without your damn illness that kills you*" (Lövenmark, 2020, pp. 712).

Effects of the behavioural and psychological symptoms of dementia (BPSD)

Behavioural and psychological symptoms of dementia (BPSD) are typically characterised as behavioural symptoms (Finkel et al., 1997) associated with deficits in cognition (Stern et al., 1997) which can significantly impact on the day-to-day activities of PwYOD (Lyketsos et al., 1997). Nine studies (see table 13) outlined the impact of the behavioural and psychological symptoms of dementia (BPSD) on children and young adults with a parent with YOD (Allen et al., 2009; Nichols et al., 2013; Millenaar et al., 2014; Hutchinson & Daly et al., 2016). Several participants described the impact of the behavioural and personality changes a parent with YOD may present.

The effects of BPSD may be slight and subtle. An eighteen-year-old male described witnessing the changes:

> "*... it feels really weird when like someone you know acts a certain way their whole life then all of a sudden they start changing and becoming a different person*" (Nichols et al., 2013, pp. 23).

A nineteen-year-old female outlines subtle changes in her father:

> "*At that moment, I did not think anything was wrong. I just thought he was in a bad mood, which happens to anyone at times*" (Millenaar et al., 2014, pp. 2003).

However, the impact of BPSD may also result in significant changes accompanied by aggression and violence. A twenty-one-year-old female described witnessing aggression:

> "*My dad was getting worse and March was the time when he started to get a lot worse, more aggressive with mum so she was upset and like saying 'What do I do? What do I do?'* (Allen et al., 2009, pp. 469).

Another nineteen-year-old female witnessed similar aggression combined with violence:

> "*I was so scared . . . because he'll freak out at any single moment . . . I'd be up all hours of the night thinking he's going to strangle my mother . . . One day I came out of the shower and he threw a lamp against the wall. I called the police and he got out on the roof with some rope and said he was going to hang himself*" (Gelman & Rhames, 2018, pp. 343).

A seventeen-year-old female recalled an incident in which she had to threaten the use of violence herself to calm the situation:

> "*Another reason that he got took away was because the one night I had actually had enough of it and he hit me so I raised my hand back to him. I was actually going to hit him an' my mum had to get between us and I had to walk out*" (Allen et al., 2009, pp. 464).

The impact of BPSD is not consigned to the household and may also be witnessed in the environment as one female outlined:

> "*I don't care what people think if he's being difficult or even if we get busted by security, he has dementia, he can't help it*" (Hutchinson & Daly et al., 2016, pp. 615).

Care and domestic tasks

Research has illustrated how children and young adults may often find themselves having to support and care for a parent with a progressive, degenerative disease as they assist with certain caregiving tasks and domestic chores (Adelman et al., 2014). In six studies (see table 13) children and young adults reported significant physical strain as a result of caregiving task and extra domestic chores (Allen et al., 2009; Millenaar et al., 2014; Hutchinson & Kurrle et al., 2016; Hutchison & Daly et al., 2016; Sikes & Hall, 2017; Hall & Sikes, 2018). Following a diagnosis of YOD in the family, children and young people often face extra duties in order to assist their well parent. One female described this realisation following her father's diagnosis:

> "*She said like well this is the sort of thing you're going to be dealing from now on and you're your mum's only sort of resource…I just remember thinking like God it's…you're not giving me much options here*" (Hutchinson & Kurrle et al., 2016, pp. 662).

Similarly, younger children also face concerns in relation to their well parent. A thirteen-year-old male outlined this concern:

> "*She is under too much stress. She has to go to work, run the house and everything, she has to clean the house and everything, and she has not got enough time*" (Allen et al., 2009, pp. 470).

A nineteen-year-old male explained how his mother required assistance with the household tasks:

> "*My mom and I have to take over more chores in the household since my father cannot do everything anymore, which causes some friction sometimes*" (Millenaar et al., 2014, pp. 2004).

Assisting with the caregiving and household tasks, not only impacts children and young adults physically, but also psychologically particularly in relation to the effects of BPSD. A sixteen-year-old female described both the physical and psychological strain as she assists with her father resulting in a negative impact on her education and sleep:

> "*He'd be out of bed a lot at night and we'd hear the door go and he'd be out of bed and sometimes mum would fall asleep or mum would be find it hard coss he'd like to have to get up early for work in the morning. And even though I had school I have to help mum and so I'd have to go and try and put him back into bed. But he'd just get out again as soon as I got back into my bed I'd hear the door go again so I ran back down*" (Allen et al., 2009, pp. 467).

4.6.3 Theme 3: Stigma

Stigma may be characterised as deviating from the perceived social norms (Scambler, 2009) and as PwYOD may be impacted by BPSD, they may be perceived as deviating from normal behaviour.

Lack of awareness

In seven studies (see table 13) children and young adults reported the effects of the lack of awareness in relation to YOD (Nichols et al., 2013; Millenaar et al., 2014; Baker et al., 2018; Gelman & Rhames, 2018).

In particular, the perception of dementia as an “older persons” disease can lead to issues for children, as a twenty-three-year-old male outlined:

> “*It was the dementia side of things as well because when you are 14, 15, people who have dementia are normally really old people…*” (Sikes & Hall, 2018, pp. 600).

Similarly, the hidden nature of YOD appear to lead to issues with awareness when compared to visible illnesses. One participant outlined this comparison:

> “*The biggest speed bump for them to get over is the fact that she hasn’t got a broken back, she hasn’t got a broken arm, it’s all in there [point to head], which we don’t understand... when you see somebody who’s physically disabled, you can kind of see people get that instant sympathy and they communicate better with them, they’re a more open to being patient, where when it’s somebody who’s got a mental disability, they don’t see it*” (Baker et al., 2018, pp. 679).

Members of the public seem less aware of a hidden condition. A female aged twenty-three described having difficulty with her employer:

> “*People are given leeway once someone has died but I’ve been dealing with my mum dying for a long time and losing her, continually losing her, and I don’t feel I necessarily get the same breathing space like if someone had lost someone*” (Sikes & Hall, 2017, pp. 332).

Often children and young adults will seek support from their peer, however as a seventeen-year-old female explains, YOD may be difficult for people to comprehend:

> “*I find it really difficult with some of my friends who really don’t get it and it’s not their fault that they don’t get it and that’s what I need to keep telling myself because…they might be coming out with stuff like ‘oh my grandma had it, you know, she wasn’t great, she was a bit forgetful’ and I’m like ‘yeah, hmm*” (Sikes & Hall, 2018, pp. 600).

Familial and societal stigma

The lack of public awareness combined with the erroneous views of people with mental health difficulties can result in fear and subsequent stigmatisation (Hayward & Bright, 1997; Morgan et al., 2002). The stigma associated with mental health conditions (Goffman, 1963; Werner et al., 2010; Gove et al., 2015) may also be associated with YOD. In nine studies (see table 13) children and young adults reported the facing both familial and social stigma in relation to YOD (Allen et al., 2009; Nichols et al., 2013; Millenaar et al., 2014; Gelman & Rhames, 2018). A thirteen-year-old male described social stigma:

> "*Strangers…like stare at you when he's not like acting quite normal. I haven't had any umm friends round while he's been like he is like to see him*" (Allen et al., 2009, pp. 469).

A female participant reported instances of societal stigma:

> "*I get really mad when people treat her not like a citizen and not like a person…it annoys the crap out of me*" (Hutchinson & Daly et al., 2016, pp. 619).

Similarly, another female outlined:

> "*…other people before they knew what he was diagnosed with, their opinion started to change too, because he was acting a different way than what he used to. And that kind of left a lasting impression on the people who don't talk to our family so much*" (Nichols et al., 2013, pp. 23).

Children and young adults spoke about how society perceives other illnesses differently to YOD:

> "*It's so different having a parent sick with something physical like cancer to a parent sick with something like Alzheimer's...there's this real shame around Alzheimer's. No one wants to talk about it. No one wants to acknowledge it. Everyone wants to say she's fine, there's such denial. Where with dad it's much more, how's your dad and how's chemo and oh you poor things*" (Hutchinson & Daly et al., 2016, pp. 618).

As a result of societal stigma, participants reported keeping their parents diagnosis secret. One female aged twenty-three illustrated this:

> "*Not everyone has to know. Maybe if it gets very bad I might tell them because I most likely have to be at home more often, for now, it is fine as it is. Only my boyfriend knows*" (Millenaar et al., 2014, pp. 2005).

Children and young adults also reported facing stigma from within their own extended families. A fifteen-year-old male reported:

> "*My outside family don't really understand and they're not getting it yet and it's people that should. Like my dad's brother hasn't been around*" (Gelman & Rhames, 2018, pp. 345).

Similarly, a participant described divisions in the family:

> "*My dad's sister lives in Florida and she won't even call him anymore. She deleted my mom off her Facebook friends. . .she probably doesn't want to deal with it, but that's horrible*" (Gelman & Rhames, 2018, pp. 345).

4.6.4 Theme 4: Coping strategies

Children and young adults outlined various strategies they use in order to cope with the complex issues that they face following a parent being diagnosed with YOD.

Family and peer support

In nine studies (see table 13) children and young adults outlined the need for support and the use of support from both their family members and peers to help them to cope with the situation (Nichols et al., 2013; Millenaar et al., 2014; Hutchinson & Kurrle et al., 2016; Gelman & Rhames, 2018). A twenty-year-old male described the need for support following the diagnosis:

> "*When they came home and I asked them how it went, they told me it was Alzheimer's. I had no clue what it was, so I went looking for information*" (Millenaar et al., 2014, pp. 2006).

Similarly, a female aged nineteen outlined the need for information and support in order to make the situation easier:

> "*It would be nice to talk to someone who knows what we can expect so that we'll know what we can do for my father to make it easier for him and, at the same time, more bearable for us*" (Millenaar et al., 2014, pp. 2006).

Participants outlined how support from peers and family members can be vital as coping strategy. A male aged nineteen described how a friend can assist:

> "*Fortunately, I have a friend who works with elderly people with dementia who I can talk to. She can also give me advice, which helped me a lot*" (Millenaar et al., 2014, pp. 2006).

Similarly, an eleven-year-old female also used her peer group to cope:

> "*I kind of get some support from my friends because they try to imagine what it's like. I think it's good to get support from your friends - just someone else. We get a lot of support from mom, but I think it's good to get support from other people, because sometimes it's just not a good time to talk to my mom about that stuff, or if it's just been a bad day*" (Nichols et al., 2013, pp. 26).

Distraction

In seven studies (see table 13) children and young adults illustrated how they used distraction to assist them with coping. Distraction as a coping mechanism is characterised as coping with a stressful or emotional situation by diverting attention away from it (Cooper et al., 2001). Participants reported utilising a variety of methods to distract them from the psychological strain of a parent with YOD. Several participants described how education was used as a distraction. A male aged fifteen reported:

> "*This happening to my father has inspired me in my academic life to excel [and] to want to be a doctor…to help people like my Dad*" (Gelman & Rhames, 2018, pp. 348).

Similarly, a female aged seventeen outlined how she uses college as an escape:

> "*I can just come in, even on my days off…I can paint, I can draw, I can make a mess, I can make things, I can tear things apart, break things. And you can get away with everything being an art student because it's art…I've thrown myself into my work. I love art, it's my therapy…College is my stability*" (Sikes & Hall, 2018, pp. 599).

Another female aged twenty-two added in relation to college:

> "*I needed to give myself some sort of direction, a distraction, something to focus on that I could work towards*" (Hall & Sikes, 2020, pp. 249).

A male participant aged twenty-two described how postgraduate education helped to bring some normalcy to life:

> "*This Masters is the last piece of the jigsaw, and one of the reasons I did it was so I wasn't at home…it's given me normality in all of this…it's given me something to focus on…I've got friends here…that you can just do normal things with, go to the pub, go to lectures, normality, structure and routine in all of this and it's probably the one thing that's keeping me going*" (Sikes & Hall, 2018, pp. 599/600).

Other participants described using friends as a distraction. A female participant outlined:

> "*Friends provide me with relief precisely because they are not going through the same thing as me and they can provide distraction or they cannot remind me of it*" (Hutchinson & Kurrle et al, 2016, pp. 662).

Similarly, a male aged seventeen described utilising his friends:

> "*Most of the time when something happens, I just want to go outside so I will not have to think about it. Usually, I call some friends or I go to my girlfriend, and then it just disappears*" (Millenaar et al., 2014, pp. 2005).

However, due to the psychological strain faced by many children and young adults, some participants reported using harmful distraction mechanisms. One male aged twenty-three described using alcohol:

> "*Depending what time, I get off and then evenings it's always drink loads of drinking*" (Allen et al., 2009, pp. 471).

Another male aged twenty-two described self-harm:

> "*A brilliant distraction that I made for myself, just to kind of give me a bit of a mental distance, or something, from having to think about it. I stabbed myself in the thigh with the fork, just because I didn't understand what was happening and I just was I guess just really gritting my teeth against freak out and depression and anxiety and dealing with the whole situation. I couldn't quite comprehend what was happening. But I knew something was bad. Something was very bad*" (Hutchinson & Daly et al., 2016, pp. 620).

Similarly, the psychological strain can lead to some participants to contemplate the ultimate distraction of suicide. A male aged nineteen outlined how self-harm may lead to a significantly worse outcome:

> "*I was self-harming, I was going to take my own life as well*" (Allen et al., 2009, pp. 471).

4.7 Discussion

The current synthesis analysed the qualitative literature in order to understand the perspectives of children and young adults with a parent living with YOD. Qualitative data form a total of fifteen studies met the criteria for inclusion and were appraised for quality using the CASP checklist. The current synthesis uncovered four main themes with related subthemes which highlighted the perspectives of children and young adults including; changing family dynamics; psychological and physical strain; stigma and coping strategies.

Participants reported how a parent receiving a diagnosis of YOD can affect the whole family, with normal family roles and future plans impacted (Nichols et al., 2013; Millenaar et al., 2014; Hutchinson & Daly et al., 2016). In particular, participants described how they may have to take on a parental role as the condition progresses (Hall & Sikes, 2020) and shoulder more responsibilities in the household (Gelman & Rhames, 2018; 2020).

Participants reported that the changing family dynamic can have a significantly negative impact on their physical and psychological health with many reporting feelings of anger, guilt, grief and loss (Hutchinson & Daly et al., 2016; Hutchinson & Kurrle et al., 2016). Specifically, participants outlined how the effects of BPSD can be damaging (Hall & Sikes, 2018; Gelman & Rhames, 2018). The perception of dementia as a disease of “old age” prevails and there is a significant lack of awareness in relation to YOD. As a result, children and young adults described facing stigma from both family members and wider society (Allen et al., 2009; Nichols et al., 2013; Millenaar et al., 2014; Hutchinson & Kurrle et al., 2016).

A parental diagnosis of YOD can severely affect the family’s finances, particularly if the PwYOD is the main bread winner, and participants described the impact that financial instability can have (Hutchinson & Kurrle et al., 2016; Gelman & Rhames, 2018). Conversely, a parent receiving a diagnosis of YOD can present the opportunity for the family to become closer. Participants described bonding with family members as a result of the new situation (Hall & Sikes, 2018; Baker et al., 2018) which may also be used as a type of coping strategy (Sikes & Hall, 2017).

According to Lazarus and Folkman (1984) coping strategies may focus on either the problem (managing the stressor) or the emotion (changing ones thinking about the stressor) through cognitive reappraisal or disengagement. Children and young adults described how they use various coping strategies, with many using distraction (Millenaar et al., 2014; Hutchinson & Kurrle et al., 2016; Hutchinson & Daly et al., 2016). Using distraction as a coping strategy typically involves the diversion of attention (Cooper et al., 2001) and has being used during medical procedures with some efficacy (Diette et al., 2003). Participants outlined several coping strategies including consulting with peers and the immersion in education (Gelman & Rhames, 2018; Hall & Sikes, 2020). However, some participants reported that they found the situation particularly overwhelming and resorted to using distractors such as alcohol and self-harm as a way of coping (Allen et al., 2009; Hutchinson & Daly et al., 2016).

The themes described in this synthesis may be specifically related to children and young adults for a number of reasons. For instance, despite children and young adults shouldering a comparable amount of care giving tasks as their adult counterparts, they may be at considerably more risk due to their developmental phase (Erikson, 1958; 1963). In particular, children in the early adolescent phase of development may miss out on important interaction(s) with their ill parent. As the disease takes hold, the parent they once knew gradually “cognitively disappears” while still being physically present, underlining the hidden or invisible nature of YOD.

Additionally, pre-adolescent children are especially vulnerable as their cognitive abilities, due to their early developmental phase, are significantly less than older children (Hutchinson & Kurrle et al., 2016). Furthermore, this hidden aspect of YOD, combined with their parent mentally diminishing little by little, has left children and young adults reporting feelings of unexpressed grief as their ill parent progressively worsens. (Nichols et al., 2013).

Another common factor among children and young adults following a parent being diagnosed with YOD was the sense of turmoil and upheaval wreaked by the prognosis. Due to the uniqueness of YOD, the disease trajectory is extremely difficult to predict leaving children and young adults fearing for the future with feelings of foreboding (Allen et al., 2009). Children and young adults reported that they felt their once stable homelife may descend into a state of disarray as they struggled to make sense of, and accept the diagnosis (Gelman & Rhames, 2018; 2020).

Added to this, many children and young adults assume a further burden, taking on the responsibility for keeping the home and family together. As well as caring for their ill parent, they may also try to provide emotional and practical support for their well parent and other siblings. This can help children and young adults to combat the sense of disarray they feel and also act as a type of coping mechanism through distraction and “keeping busy” (Sikes & Hall, 2018; Hall & Sikes, 2020).

However, assuming this extra burden can see children and young adults experiencing higher levels of psychological distress which can be comparable to the levels experienced by adult carers (Allen et al., 2009; Hutchison et al., 2016). Besides, in order to fully commit to this extra burden, children and young adults may be required to completely restructure their lives and postpone or abandon their existing plans. Typically, educational plans may be terminated, however, career development can also significantly suffer (Sikes & Hall, 2018). Another reason for children and young adults to contemplate abandoning their education may be due to the stigma associated with YOD.

Many participants in the current synthesis cited experiencing significant levels of stigma following their parents' diagnosis. This experience, combined with the adoption of a caring role, strongly influenced their decision to discontinue or postpone school, college or work commitments. Many children and young adults reported feeling marginalised as a result of stigma as the stereotypical view of dementia relates to older people (Nichols et al., 2013).

Therefore, as the wider public have little or no understanding of YOD, participants referenced being treated as if their parent had a "mental illness" or "mental disorder" further pushing them to the periphery of society (Millenaar et al., 2014). This lack of understanding was not limited to wider society only, it was also observed in extended family members such as aunts, uncles and cousins (Baker et al., 2018; Gelman & Rhames, 2018).

It is necessary to point out that some children and young adults enjoy their new situation and appreciate their new caring role. They have reported that it presents an opportunity to give back and provides an opening for both the immediate and extended family to unite and bond (Millenaar et al., 2014; Gelman & Rhames, 2020). Unifying the family can also provide a significantly stronger approach to tackling the issues accompanying a diagnosis of YOD (Johannessen et al., 2015).

A further positive aspect of caring may be observed in children and young adults who report higher levels of self-esteem, self-worth and empathy. However, these benefits are moderated by the degree of external support younger carers receive. In other words, if adequate support is available, positive outcomes can mitigate the negativity associated with caring (Becker, 2007). Moreover, mutual cooperation between family members can also present a united front to health and social care providers and assist with obtaining a systemic approach to care, one of the core recommendations of this thesis.

4.8 Conclusion

The current synthesis outlines the perspectives of children and young adults with a parent living with YOD. There is a significant lack of research in this area which compounds the stereotypical view of dementia as an older persons disease. This can lead to children and young adults being impacted by lack of awareness and stigma resulting in significant psychosocial problems. As the number of people living with dementia (including YOD) is set to increase, future research with children and young adults with a parent with YOD is important in order to better support this cohort.

4.8.1 Strengths and Limitations

Every measure was put in place in order to enhance the quality of the current synthesis. However, quality appraisal is a subjective process and as a result is susceptible to interpretation and bias. According to Majid and Vanstone (2018) the CASP qualitative checklist is not without criticism. Much of the critique centres around the articles extracted using the method, which may comply, but not necessarily contribute to the development of the literature (Dixon-Woods et al., 2007). Similarly, the authors interpretation of the primary and secondary data is also subject to bias. Five articles from the United Kingdom utilised the same sample across their studies (Sikes & Hall, 2017; 2018; Hall & Sikes, 2018a; 2018b; 2020) while two articles from Australia also used the same sample across both studies (Hutchinson & Kurrle et al., 2016; Hutchinson & Daly et al., 2016). However, these articles were included in the synthesis as they varied in their focus and sources.

The current synthesis includes individuals perspectives from six countries; Australia, Canada, Netherlands, Sweden, United Kingdom and USA. These countries may be characterised as wealthy Western countries. It may be reasonable to assume that perspectives of parental YOD may differ significantly in countries with different cultural, social and economic norms. Similarly, included articles were published in English and may not be representative of non-English speaking countries. Therefore, findings from the current synthesis may not be panoptic.

There is a significant lack of qualitative research specifically examining children and young adults perspectives. In particular, research with children and adolescents under the age of eighteen is extremely rare. The current synthesis only found two studies examining the perspectives of children under eighteen years of age (Nichols et al., 2013; Baker et al., 2018). This presents a significant problem as many participants views are retrospective, relying on autobiographical memory, with data is not being gathered in “real time”. Typically, emotionally arousing stimuli are better consolidated in memory and are more easily recalled (Kang et al., 2014). Moreover, recent research by Schümann and colleagues (2020) outlines that temporal delay (over three and a half years) significantly affects recall and memories may not remain stable after this period.

4.8.2 Implications and Recommendations

Children and young adults face significant issues when a parent is diagnosed with YOD. The emotional & physical toll were reported with feelings of anxiety, anger, guilt and grief. Many children and young adults have illustrated resilience in the coping strategies employed. However, for some participants the situation may lead to negative consequences for both physical and psychological health. Following a diagnosis, counselling specifically for children and young adults may help alleviate the psychological strain.

Similarly, the formation of peer support groups where children and young adults can share their experiences with those in a similar position would be advantageous. Education and awareness programmes about neurodegenerative conditions in relation to younger people being affected may assist in dispelling the current stereotypical perception of dementia. Similarly, education and awareness programmes about general brain health may also be beneficial.

4.9 Chapter Conclusion

As a result of the findings uncovered in chapter three of this thesis, we decided to address the significant gap that exists in the literature in relation to children’s and young adults experiences of parental YOD. Specifically, we wanted to gather evidence on the experiences of children under eighteen years of age. Therefore, we conducted a systematic review in order to examine and synthesise the qualitative data related to the experiences and perspectives of children and young adults with a parent with YOD.

We included the voices of 129 participants, whose ages ranged from six to thirty-three years, uncovering four main themes: changing family dynamics; psychological & physical strain; stigma and coping strategies. However, there is a paucity of research with younger carers and none of the studies included the experiences of children and young adults in an Irish context. Therefore, we decided to address this gap with our next piece of research. Amongst other factors, we were interested in whether the social construct of dementia has an impact on children’s experiences of parental YOD, with a specific interest on the stigma that children have reported in this chapter. Accordingly, the next chapter of this thesis explored the social construct of dementia through the lens of Cultural Transmission Theory and examined if this affects children’s and young adults experiences of parental YOD.

5. The influence of social constructivism on children and young adults perspectives of parental young onset dementia: A thematic analysis of the narratives.

5.1 Abstract

Background

Western countries have a significant cohort of children (≤ 18) and young adults who live with a parent with a life limiting condition**.** Children and young adults perspectives of certain parental illnesses have been well documented. However, the perspectives of children and younger adults of parents living with young onset dementia (YOD) tend to be absent from the academic literature. Recently, this gap is beginning to be addressed and research with children in relation to parental YOD is starting to materialise. Older adult children have reported on the impact parental YOD, however, there is a necessity for research with younger adult children and children under the age of eighteen in relation to their perspectives of the condition.

Aims

Utilising cultural transmission theory, the current research explored if the social and cultural perspective influences the narratives of children and younger adults in relation to parental YOD.

Methods

One-to-one interviews were held with children and younger adults (*n* = 17: 29·41% male) who currently live with (or have lived with) a parent with a formal diagnosis of YOD (with various subtypes). Interviews included children from the same family (i.e., siblings) as well as strangers. The participants ranged in age from 14 to 33 years old (*mean* = 21·18 years) with *n* = 6 eighteen years of age or younger (*mean* = 16·17 years). Participant narratives were analysed using inductive qualitative thematic analysis.

Findings

Five main themes (with related subthemes) emerged; making sense; lack of representation; threat to the family system; life has completely changed; systemic psycho-social support and education.

Conclusion

It is clear from the current data that the social and cultural perspective can significantly influence the narratives of children and younger adults in relation to parental YOD. Children are faced with more responsibility, shifting roles, changing relationships, and may be forced to postpone educational or employment plans. Furthermore, the social perception of dementia as can act as a barrier to children and young adults accessing and using health and social care providers.

5.2 Chapter Introduction

Findings from the research described in chapters three and four of this thesis have illustrated the significant toll a diagnosis of parental YOD can have on the entire family system. However, the findings uncovered following the synthesis of qualitative data related to childhood experiences of parental YOD in chapter four elucidate the unique challenges faced by this cohort, a cohort that are relatively forgotten in dementia research. Children and young adults have reported significant issues following their parents diagnosis, issues such as the change in family dynamics, the toll of the physical and emotional burden and the stigma associated with the condition.

Children cited that they experienced stigma at both a familial and societal level and that stigma may be due to the lack of awareness in relation to YOD combined with the stereotypical perception that dementia is an older persons disease. Interestingly, children and young adults also reported that the societal perception of other illnesses is markedly different to YOD.

5.2.1 Does YOD carry greater stigma compared to other illnesses

For example, recent research conducted by Kane and Murphy (2020) outlined that young adults (aged between 18 and 25) held significant negative perspectives towards people with YOD. Similarly, Crisp and colleagues (2005) and Herrmann and colleagues (2017) found comparable findings in relation to dementia and also across diagnoses of mental illness and addiction. One possible explanation for greater dementia-stigma in this age cohort may be a lack of knowledge about dementia compounded by a lack of motivation to learn about the disease. This deficit in both information and knowledge can typically perpetuate the associated stigma (Batsch & Mittelman, 2012).

However, these findings may also be related to ageism. Research by Cullen and colleagues (2009) found that there was a negative bias towards older people held by a sample of university students. Coupled with the societal perception that dementia is an older persons illness this can lead to stigma for people living with YOD.

Interestingly this dementia associated stigma is not solely observed in younger cohorts. In one study conducted in Ireland, GP's reported that they did not like to disclose a diagnosis of dementia to patients with over 40% stating that they never or rarely would (Cahill et al., 2006). Conversely, in Sweden a similar number of GP's (39%) reported they would often or always disclose a dementia diagnosis. Such low disclosure rates for dementia are in stark contrast to the 95% disclosure rate in cases of terminal cancer (Ólafsdóttir et al., 2000).

According Johannessen and colleagues (2016) as many as one in four people living with YOD have a child or children under the age of 18 years. For these children growing up in a household facing parental YOD is a radically different experience when compared to children facing parental cancer or another chronic illness. This may be a result of a better understanding of other serious conditions, such as cancer. Moreover, such illness may be void of the unpredictable nature of YOD making it somewhat easier to explain to a child(ren) (Johannessen et al., 2016a). Why then is it easier to disclose and speak about a diagnosis of cancer compared to dementia, and specifically YOD?

This may be due to the significantly large amount of research conducted on cancer and cancer patients leading to a greater understand of the illness and its effects. Despite dementia being a serious global health issue that touches the lives of many older adults and a significant number of people in early to middle adulthood, there is relatively little research by comparison. Greater awareness, therefore, may mean cancer is socially constructed diversely to dementia resulting in a decrease in associated stigma. It may be reasonable to assume that if this trend continues then the stigma associated with dementia will endure (Garand et al., 2009).

Furthermore, the cognitive deficits observed in YOD may also see the favourable narratives cited in cancer research, such as united against the disease, enrichment, and growing stronger by being together are not replicated in the context of dementia (Li & Loke, 2013). This aspect of living with chronic illness was noticeable in relation to significantly more depressive symptoms in carers of people with YOD (Bruvik et al., 2012).

The occurrence of higher levels carer depression in dementia care may also be exacerbated by the social construct of dementia. Typically, people living with dementia are portrayed as losing (or having lost) their sense of self. As explained by Davis (2004, pp. 375) "*dementia, even in the early stages*, *represents a fraying of the self*". Cognitive deficits such as issues with memory, usually part of the biomedical narrative, characterise the disease as the long goodbye regardless of people living well with dementia (Beard & Fox, 2008; Beard et al., 2009; MacRae, 2010).

People living with dementia have been characterised as the living dead (Aquilina & Hughes, 2006) and zombies (Behuniak, 2011), with these perceptions pointing to what Agamben (1998) refers to as a space without rights located between life and death. The stigma and nihilism associated with dementia, and its social framing as the worst of all diseases (Cahill, 2018) all contribute to the narrative.

In order to address the lack of research with children in relation to parental YOD, particularly in Ireland, we decided to conduct an original and novel piece of qualitative research in order to understand their experiences of the condition. Additionally, we were particularly interested in whether the social construct of YOD influences children and young adults experiences of their parents illness. We also discuss and compare society's perception of "normal" illnesses such as cancer, as well as other neurodegenerative conditions such as motor neuron disease and multiple sclerosis. Therefore, the theoretical framework guiding the research study detailed in this chapter is cultural transmission theory.

5.3 Background

Many Western countries have a significant cohort of children (≤ 18) and young adults who live with (or have lived with) a parent with a life limiting condition (Sieh et al., 2010; 2013). There is an increasing body of research outlining the impact associated with parental life limiting illness on children and young adults. For example, as a result of the changing nature of the parent-child relationship, children and young adults are at risk of developing significant psychosocial issues such as emotional and behavioural problems (Barkmann et al., 2007; Cass et al., 2011; Payler et al., 2020). There is also evidence of the correlation between childrens poor educational attainment and parental illness and disability (Sikes & Hall, 2018).

Parents can also find the situation overwhelming as they grapple with contradictory advice from family and friends, wrestle with their own emotional issues and attempt to find the confidence to best assist their child (MacPherson, 2005; Semple & McCance, 2010). Additionally, assistance and guidance from professionals may be absent as healthcare providers may believe that they are ill-equipped and unsuitable to dispense advice to children (Fearnley & Boland, 2017; Franklin et al., 2019). From the child's perspective, hitherto family dynamics and future plans are distorted as the condition progresses with every feature of normalcy spiraling from the predicable to the unpredictable (Aamotsmo & Bugge, 2014).

5.3.1 Parental Cancer

Parental cancer has an impact on the entire family unit; however, pre-adolescent and adolescent children can be significantly affected. Research conducted with adolescents by Pfeffer and colleagues (2000) posits that following a diagnosis of cancer adolescent children face several losses. For instance, the likelihood of losing a parent to the disease is often accompanied by the feeling that their parents emotional and physical support may become unattainable. Furthermore, adolescents acknowledge that their lives lack the normality that they once knew (Grabiak et al., 2007; Philips, 2014; Melcher et al., 2015) as they are overwhelmed by feelings of anxiety and stress as a consequence of their parents illness (Phillips & Lewis, 2015).

Jansson and Anderzén-Carlsson (2017) conducted focus groups with adolescents in order to obtain their perspectives following a parent being diagnosed with cancer. Themes that emerged included apprehension in relation to the impediment on parents physical health, anticipation of medical emergencies, worry about disease reoccurrence, contemplation about the impending death of their parent and concern for a future without their parent (Jansson & Anderzén-Carlsson, 2017).

Adolescents further reported that they frequently handled the impact of the diagnosis individually, making sense of the condition by noticing and understanding subtle changes in their ill parent. Feelings of isolation were also reported together with the belief that nobody else could appreciate their circumstances, except for other teenagers who were experiencing a similar situation (Philips, 2014; Melcher et al., 2015). The perception of their peers was one reason adolescents gave for tackling such issues on their own. They feared that being overtly emotional, crying and requesting assistance may be negatively perceived, preferring instead to seek comfort from their parents (Melcher et al., 2015).

Conversely, in order to safeguard their children, parents may conceal important information regarding their illness particularly if the information is ambiguous (Visser et al., 2004; Turner et al., 2007; 2008; Asbury et al., 2014). Even pre-adolescent children perceive cancer as an illness that has the potential to be a threat to life (Forrest et al., 2006) impacting both their emotions and behaviour (Osborn, 2007; Krattenmacher et al., 2012; Huang et al., 2014). In particular, pre-adolescent children report significant adverse consequences following a diagnosis of breast cancer (Hilton & Gustavson, 2002; Al-Zaben et al., 2014). Statistically, breast cancer is one of the most prevalent types of the disease globally, is one of the pre-eminent causes of mortality and the most frequent type of cancer affecting females (Ferlay et al., 2015).

Mothers have outlined how the behaviour of their pre-adolescent children has changed. Behavioural changes included alterations in speech and language; attempts to “hide” from the disease; habitually inspecting their mother; assuming the mothers role; constantly seeking reassurance; attachment issues/overly clingy; social disengagement; lowering of inhibitions/acting out and poor educational attainment (Al-Zaben et al., 2014; Zahlis & Lewis, 1999).

Further psychological difficulties manifested in feelings of stress, anxiety, distress/fear, anguish, trauma, and guilt (Foran-Tuller et al., 2012) bouts of depressive-like symptoms (Brown et al., 2007) and similar psychosomatic problems (Watson et al., 2006). Moreover, Niemelä and colleagues (2012) examined data from a sample of over 60,000 children and young adults who participated in a Finnish study. Findings highlighted that the younger a child was when a parent was diagnosed with cancer correlated with a significant increase in the use of psychological/psychiatric services by those children when compared to children of healthy parents.

5.3.2 Parental Neurodegenerative Conditions

Amyotrophic Lateral Sclerosis

Amyotrophic lateral sclerosis (ALS), primary lateral sclerosis and progressive muscular atrophy are terminal progressive conditions identified by degeneration of motor neurons (Van Es et al., 2017). The burden of care faced by families in ALS is briefly mentioned in chapter three of this thesis, however, a more detailed examination is discussed here. Data have outlined the negative impact of the condition (s) on the whole family, including children (Cipolletta & Amicucci, 2015).

ALS is the most prevalent of the motor neuron diseases, the management of which is complex. People living with ALS may require both therapeutic and pharmacological input in order to maintain their quality of life (Coupé & Gordon, 2013). Families have reported how the routine of daily living can be considerably altered following a diagnosis (Calvo et al., 2015).

Moreover, cross sectional research by Burke and colleagues (2015) illustrated how every family member may become involved in caring, representing major lifestyle changes which can effect familial and social relationships. Typically, the person living with ALS is cared for by a spouse or partner, however, children are frequently required to assist with caregiving which may result in heightened stress in this cohort (Kavanaugh, 2016). Research has also highlighted the impact that this responsibility may have on children's sense of identity as they may feel overwhelmed by the situation (Chen, 2017). Indeed, Coelho and colleagues (2018) outlined the negative emotional impact on children who assist with caring for a parent living with a life limiting condition resulting in feelings of grief and loss.

Anderson and colleagues (2019) reported that the functional loss of recognition and communication ability by the ill parent, as the condition progresses, is one of the most troubling aspects of ALS. This one aspect can lead to significant emotional distress for the child(ren). For instance, children have reported experiencing significant psychological and behavioural problems including depressive episodes; bouts of anxiety; social isolation; somatic disorders; feelings of guilt, self-esteem issues; avoidance; aggressive behaviour; rule breaking and extreme worry about developing the condition (Guidry et al., 2013; Foley et al., 2014; Harris et al., 2019).

Multiple Sclerosis

Similarly, research with children who have a parent living with multiple sclerosis (MS) further illustrates the negative impact of the condition. MS affects the central nervous system and is one of the most common progressive neurological conditions affecting younger people – typically between the ages of 20 and 40 – and the condition can display a wide range of clinical symptoms (Leary et al., 2005). The varied symptomology and the resulting disability can significantly impair the activities of daily living and onset of symptoms can often occur as individuals are childrearing. Similar to ALS, much of the care in MS is provided by family members (De Judicibus & McCabe, 2004).

Consequently, children can be impacted by parental MS as they may be required to assist with caring tasks as roles within the family shift and realign (Yahav, Vosburgh & Miller, 2005). For example, comparative research between children of parents with MS and children with "healthy" parents outlined the former reporting higher levels of stress, more responsibility, issues with social adjustment and negative assessment of self (Pakenham & Bursnall, 2006; Turpin et al., 2008; Bogosian et al., 2010). Specifically, as the condition progressed children reported feelings of confusion and "non-normalcy" as demands on them significantly increased (Pakenham & Bursnall, 2006).

Huntington's Disease

Huntington's disease is a progressive neurodegenerative condition responsible for profound deficits in physical, cognitive, and psychological functions (Roos, 2010) and has a detrimental effect on those living with the condition and their families (McColgan & Tabrizi, 2018). Symptoms in Huntington's disease typically appear between the ages of 30 and 50 years approximately, a period in which many individuals may have child dependents. Moreover, Huntington's disease may progress slowly effecting functioning for a significant period of time (mean 17 – 20 years) with little or no available remedies (McColgan & Tabrizi, 2018).

Observable symptoms can involve uncontrolled movement (s) and alterations in motor function. However, the condition can also bring about psychological/psychiatric symptoms such as changes in personality; aggressive behaviour; apathy/lack of compassion; psychotic episodes/mania and deficits in affability (Eddy & Rickards, 2015). Despite such symptoms being unobservable, they can represent the some of the most significant challenges.

For instance, children and young adults living with a parent with Huntington's disease may be faced with a range of unpleasant occurrences in the home such as aggression/violence, a parent who is impulsive and inconsistent (Kavanaugh, 2014) and a parent who may be suicidal (Forrest Keenan et al., 2007; Kjoelaas, Jensen, & Feragen, 2021; van der Meer et al., 2012). While facing such unpleasantness, children and young adults may also be constantly worried about the possibility of developing the condition as they move toward adulthood (Lewit-Mendes et al., 2018; Tillerås et al., 2020).

As a result, many children wrestle with their mental wellbeing and are prone to developing anxiety and depression (Ciriegio et al., 2020). Childrens physical wellbeing may also be threatened as they take on more and more domestic tasks such as washing, grooming and toileting their ill parent, with reports of exhaustion, lack of sleep and poor diet maintenance (Williams et al., 2009). Furthermore, the societal view of mental illness combined with the symptoms exhibited in Huntington’s disease can make the situation worse as children often face stigmatisation (Sparbel et al., 2008).

Young Onset Dementia (YOD)

A detailed description of YOD, its subtypes and associated symptoms are contained in chapter one of this thesis. In essence, YOD refers to individuals diagnosed before 65 years of age, or younger in many cases. While symptoms can include deficits in memory function, YOD can also include impairment of physical function(s); difficulties with communication and aphasia; hallucinations and disturbances in vision; impairment in judgment and planning; lack or loss of empathy; partial/full withdrawal from society; poor temperament and/or aggression; impulsivity/disinhibition/exhibitionism; lasciviousness and obsessive-compulsive tendencies (Garre-Olmo et al., 2010; Gelman & Rhames, 2018; Hall & Sikes, 2017; Sikes & Hall, 2018).

Therefore, a diagnosis of YOD represents a significant challenge to everyone involved. However, what sets YOD apart from late onset dementia (LOD) is the life stage at which it manifests. As explored in chapter four, many individuals diagnosed with YOD are parents and as a result children are faced with the consequences of their parents progressive illness. For example, research conducted by Haugen and colleagues (2012) in Norway reported that approximately 25% of people living with YOD were parents.

As symptom onset occurs at an inopportune time, YOD is often perceived as discrepant with the normal life course (Allen et al., 2009; Aslett et al., 2019) and can be viewed with scepticism by an ill-informed public making this an uneasy time for the entire family (Hoppe, 2018). Moreover, developing children may experience this period with higher degrees of anxiety compared to adult children as they are neither cognitively nor emotionally mature (Gelman & Rhames, 2020) and may turn expectantly to their healthy parent for solace. However, their healthy parent may be unable to supersede as their workload increases (Hutchinson et al., 2016) therefore, the child (s) typical development may be impeded leading to problems later in life (Johannessen et al., 2016).

Typical daily family activities such as assisting with schoolwork, involvement in sporting activities, the provision of sustenance, reassurance and consolation may all be lost to the condition (Gelman & Rhames, 2018; Hall & Sikes, 2020).

To synopsise, despite some characteristics being similar in both young onset and late onset dementia (e.g., observing the progressive degeneration of a loved one) other characteristics are temporally and symptomatically conditional. For instance, a child (ren) who is confronted by an amnesic parent may be far less traumatised than a child (ren) who is confronted by an aggressive one (Hall & Sikes, 2017). Therefore, children facing parental YOD may be more comparable to children whose parents develop ALS, MS or Huntington's Disease rather than being compared to older adult children whose parents may develop late onset dementia.

Another similarity to ALS, MS and Huntington's disease is that people living with YOD are usually cared for at home by a primary informal carer, typically a spouse or partner. A definition of the term primary is given in chapter three. This may be due to any number of factors, however, as discussed in previous chapters, it may also be out of necessity as most dementia services in Ireland are sited within older adults services.

However, not all care in YOD is carried out by a spouse or partner and children and young adults often find that they are required to provide assistance with care including; dispensing medication, assisting with household tasks and providing emotional support (Kavanaugh et al., 2016; Chen, 2017). As the findings from earlier chapters of this thesis substantiate, research with spouses/partners and older adult children may not be conversant to younger children. Specifically, in chapter four of this thesis, the findings in relation to childhood experiences of YOD indicate that children and younger adults adapt to the role of carer differently when compared to older adults.

For example, children may find contrasting methods in order to make sense of the situation and to get a handle on exactly how they can assist their parents and family (Joseph et al., 2012; Spreadbury & Kipps, 2019). Despite children being involved in many aspects of care, the perspectives and experiences of children and young adults with a parent who is living with YOD tend to be absent from the academic literature. There has been a shift recently to address this deficiency and the literature is beginning to include research with children.

For instance, older adult children have reported on the impact a parental diagnosis of YOD can have, with narratives including themes on emotional wellbeing, coping mechanisms and resilience (Allen et al., 2009; Svanberg et al., 2010; 2011; Gelman & Greer, 2011; Barca et al., 2014; Millenaar et al., 2014; Johannessen et al., 2015; 2016; Hutchinson et al. 2016; Aslett et al., 2019; Sikes & Hall, 2018; Gelman & Rhames, 2018; Hall & Sikes, 2017, 2018, 2020).

Nevertheless, there is scant research with younger adult children in relation to their perspectives of parental YOD, while the narratives of children under the age of eighteen are almost non-existent. Green and Kleissen (2013) and Roach and colleagues (2008) highlighted the necessity for firsthand qualitative research with children (≤ 18) and younger adults. Furthermore, there appears to be a necessity to diverge from the narratives typically provided by spouses and/or partners, older adult children, and grandchildren of people with dementia, who tend to be considerably older than sixty-five (Celdron, Triadó, & Villar, 2011; 2012).

The current study attempted to tackle this necessity and augment the existing literature in relation to the repercussions of parental YOD on children and young adults in an Irish context. Utilising Cultural Transmission Theory as a guiding framework, this research explored if the social construct of dementia influences the narratives of children and young adults in relation to their parents condition. Chapter two of this thesis provides a comprehensive discussion on Cultural Transmission Theory and the social construct of dementia (and other illnesses – both similar and differing) from both an historical and contemporary perspective.

Therefore, specific aims of this research were:

- Investigate whether the social construct of dementia, and in particular YOD, has an influence on children and young adults whose parents have developed the condition.
- Do children and young adults compare parental YOD to other illnesses?
- If so, do the comparisons involve similar conditions – i.e., other neurodegenerative conditions or different conditions – i.e., cancer?
- Does the social construct of these other illnesses effect children's perceptions of YOD?

It is hoped that any knowledge gained as a result of this research will assist in supporting children and young adults who may be experiencing parental YOD.

5.4 Materials and methods

5.4.1 Design

To achieve the above aims, one-to-one semi structured interviews were conducted with children and younger adults living with (or who had lived with) a parent with YOD. Interviews included children from the same family (i.e., siblings) as well as strangers. The interview schedule (see appendix P) was drafted using a combination of relevant literature (Joseph et al., 2009) and findings from the research described in the earlier chapters of this thesis.

5.4.2 Participants Recruitment & Inclusion Criteria

Purposive sampling was used across all groups. Participants, and where applicable, their parents or guardians were recruited through gatekeeper organisations. Gatekeeper organisations included the Alzheimer Society of Ireland (ASI), Dementia Northern Ireland, the Dementia Carers Campaign Network (DCCN), Family Carers Ireland, Western Alzheimer's Association, the Dementia Research Advisory Team (DRAT), TeamUp for Dementia, Memory clinics, Alzheimer cafes and carer support groups for people with young onset dementia. It is not clear how participants were approached by the gatekeeper organisations, or how many people refused to participate.

The researcher was contacted by gatekeeper organisations only when participants or parents/guardians expressed an interest in the study. However, all participants who did express an interest in participating did end up taking part. Eligibility for the study meant that the child or young adult must live (or have lived with) their parent with YOD and their parent received the formal diagnosis before 65 years of age meeting the criteria for YOD. Participants over the age of eighteen who expressed an interest in taking part were provided with a plain-language statement containing information about the aims of the study, the methodology to be used and a consent form (see appendices J-K).

Participants who were aged between fifteen and eighteen years of age who expressed an interest in participating were provided with a plain language statement (see appendix L) and their parents/guardians were also provided with a plain language statement and a parental consent form (see appendices M-N). Participants under the fifteen years of age who expressed an interest in participating were provided with a combined plain language statement and consent form (see appendix O) while their parents/guardians were provided with a parental consent form (see appendix N).

These documents contained an invitation to participate, further information about the study and contact details for the research team. Those who expressed an interest in taking part were asked to contact the research team to discuss the requirements of the study and the informed consent process in more detail. On receipt of a completed consent form, the researcher then contacted participants in order to schedule a convenient time for the interview.

5.4.3 Data Collection

Due to the restrictions imposed by the Covid-19 pandemic, interview data were collected online via Zoom for all participants. Participants (*n* = 17; see table 14) were encouraged to share their experiences. A person-centred approach was adopted in relation to the data-collection session(s). One-to-one interviews with participants lasted between 30 and 60 minutes, depending on the persons plans for the day.

However, interviews with younger children were considerably shorter and a parent/guardian was present at all times during the interview process. If the researcher noticed that a participant (s) appeared tired, emotional or if they expressed that they were struggling on the day, then the interview was terminated and rescheduled for an alternative time, only if consent was received. The researcher also ensured that participants had adequate breaks. All interviews were audio recorded via Zoom and later transcribed intelligent verbatim and anonymised. The intention was for the sample to cover a wide range of perspectives, with different ages and different relationships to the person with YOD (Green & Thorogood, 2018).

Narratives were appraised in their entirety in order to catalogue events both temporally and contextually and to extract salient themes (Riessman, 2008) and participants were encouraged to share their perspectives openly as a means of encouraging open discussion (Patton, 2002).

The narrative approach allowed participants to talk openly and freely and to express their feelings. Participants were enthusiastic in their responses and eagerly recounted the history of their families, parents condition and future plans. Typically, the narrative approach is not used with children and young adults. However, this method permits younger participants to speak candidly about their past, their current situation and their future plans and dreams (James, 2005). For instance, the use of the narrative approach with young participants has uncovered concerns in relation to wellbeing, mental health, and social initiatives (Goodley & Clough, 2004; McNamara, 2013).

Table 14: Participant (*n* = 17) characteristics.

Participant number	Gender	Age at interview	Childs age when symptoms first appeared	Parents age when symptoms first appeared	Parents age when diagnosed	Dementia subtype
01	Female	33	16	56	64	Alzheimer’s dementia
02	Female	29	15	50	56	Mixed dementia
03	Female	14	10	40	45	Frontotemporal dementia
04	Male	17	13	40	45	Frontotemporal dementia
05	Male	18	14	43	50	Dementia with Lewy Bodies
06	Female	19	15	42	47	Alzheimer’s dementia
07	Female	24	17	45	48	Vascular dementia
08	Male	16	12	41	46	Alzheimer’s dementia
09	Female	27	18	46	50	Alzheimer’s dementia
10	Male	24	16	44	49	Frontotemporal dementia
11	Female	26	15	42	47	Alzheimer’s dementia
12	Female	22	14	41	44	Frontotemporal dementia
13	Female	20	16	42	45	Vascular dementia
14	Male	19	14	40	43	Dementia with Lewy Bodies
15	Female	16	12	41	48	Frontotemporal dementia
16	Female	17	13	38	41	Dementia with Lewy Bodies
17	Female	19	14	40	47	Vascular dementia

5.4.4 Data Analysis

Interview data were analysed by applying an inductive qualitative thematic analysis using open coding and categories derived directly from the interview material (Hsieh & Shannon, 2005; Elo & Kyngas, 2008). All narratives were utilised in this analysis. A detailed outline of the data analysis, as well as the coding process and theme extraction is provided in chapter two of this thesis.

5.4.5 Ethical considerations

Ethical approval was obtained from Dublin City University Research Ethics Committee (DCUREC/2021/232; see appendix I). Risk associated with participation in the study was moderate, as no deception was involved. Participants were assigned participant numbers to ensure anonymity and confidentiality. The right to withdraw from the study was clearly communicated, and a support pack outlining dementia-specific and more general supports that are available was offered to participants at the end of the interview process (see appendix H).

5.5 Findings

Detailed thematic analysis of the participant narratives uncovered five main themes (with related subthemes); making sense; lack of representation; threat to the family system; life has completely changed; systemic psycho-social support and education (see table 15).

5.5.1 Theme 1: Making sense

Attempting to make sense of a diagnosis of dementia can be an extremely difficult process. However, when the person being diagnosed is relatively young (< 65 years) and the person trying to understand is a child, it can be a daunting time. Children and young adults may look to social and cultural cues surrounding them to help them understand. This will inevitably include their healthy parent (or guardian), their siblings, extended family, friends, and wider social and cultural system.

It’s just easier to deny, dismiss and ignore

However, if a detrimental view of dementia has been socially constructed within this wider system, children and young adults may be influenced by such perceptions. Participant narratives outlined how they looked to their immediate family for help to make sense of the situation and mirrored their reactions which often included denial, dismissal, and an ignoring of the situation.

> “*And, and I would argue, that my family was probably a little bit in denial so it was just never something that you would actually think until it was said to you, but I still wouldn't believe that it was [parent] that had been diagnosed with dementia*” [**P02: Daughter**].

Table 15: Main themes with related sub-themes extracted from the participant narratives.

Making sense	**Lack of representation**	**Threat to the family system**	**Life has completely changed**	**Systemic psycho-social support & education**
Deny, dismiss, and ignore	In society	No clear timeline until death Disease trajectory	Increase in responsibility ◆ assisting with household tasks ◆assisting financially	Support for the family system
Fear, what if I develop it?	In the media ◆ T. V ◆ Radio ◆ Advertising ◆ Social media etc…	Anxiety Stress Financial woes	Relationship change Infantilisation Parenting the parent	Age-appropriate peer to peer support
Lack of a visible illness	In service provision	Stigma ◆BPSD† ◆ grief ◆ anger ◆ guilt	Future plans & dreams change	Support from health & social care providers
Using comparison with ◆ "normal" illness ◆ cancer ◆ late onset dementia			Coping	Support from the community Education & awareness

†BPSD = Behavioural & psychological symptoms of dementia

> "*And so, we kind of just dismissed it we thought well because of the young age, like dementia dismissed immediately, you know what if you're too young. It must be something else…yeah, and like when we heard it first, we were like it's no way this is dementia or Alzheimer's*" [**P14: Son**].

> "*The first signs I dismissed, I guess I dismissed a lot of it, but I think it got to the point where we all realised, we couldn't ignore it, because ignoring it wasn't going to be helpful anymore, I think we were a little bit in denial. I think everybody was trying to process it. It can be tough to tell you know, like is somebody experiencing cognitive decline, or are they experiencing depression, you know these kinds of things. So, it just made it more difficult to tell if there was actually something wrong there*" [**P10: Son**]

Fear, what if I develop it?

The use of denying, dismissing, and ignoring the situation may arise as a result of being afraid, being afraid of the unknow, combined with a fear of what's to come. Some children and young adults outlined that they were afraid that they may develop dementia later in life causing significant levels of fear and anxiety.

> "*…so sometimes I do worry that I will get it. I did suffer with quite a lot of anxiety and still to this day, I suffer with a lot of anxiety…but I would say a lot of it is a fear that something bad is going to happen kind of always lingers in the background. What will be will be*" [**P11: Daughter**].

This had has brought a sense of realism to other participants Narratives illustrated a sense of pre-planning in case a diagnosis of young onset dementia arose in the future.

> "*And I think it's so ingrained in me to be like, we have to be near services, we have to be near hospitals. I think that's what it's just turned me into. I don't know if I'm a pessimist so much as a realist. I don't have any of these wonderful notions of retiring to the country having chickens and goats because I'm like what's going to happen me you know, if I get early onset Alzheimer's as well. So, I think I'm kind of trying to future proof a little bit in the decisions that I make*" [**P01: Daughter**].

Lack of a visible illness

Striving to compare young onset dementia to another illness may also arise from the fact that YOD is a hidden condition, coupled with the societal perception of the medical model of disease and illness. Participants in the current study illustrated the fact that the condition cannot be seen and this can lead to confusion and a lack of understanding.

> "*Oh yeah like a total lack of understanding and I think as well, if that had been in hospital…like confined because of an ailment of some sort I think people would have understood it better, and I think people can grasp the illnesses that they can see an awful lot better…*" [**P07: Daughter**].

> “*I think it's that…the hidden nature of the illness or the fact that it affects the brain that sort of mental health kind of stigma you know, instead of someone say with cancer*” [**P12: Daughter**].

Using comparison to make sense

Comparing YOD to other more recognisable illnesses arose in several participant narratives. Both the children and young adults and wider society appear to use comparative techniques as a way to make sense of situation, particularly if there is a lack of understanding around the condition. It is almost as if having another illness would be more preferable to YOD.

> “*Because I didn't feel that people understood the disease good enough to know this information, I felt like because people have viewed it, not as a physical disability, but as a mental disability. If somebody's got diabetes or a physical disability…are you going to say there's something wrong with them if they become confused, are they mad*” [**P09: Daughter**].

> “*…it's not something that you're going to get over, and you know so, to be honest, I found most of the time, I think, initially I said it to my friends. And then, occasionally, people will check in and say: Oh, how is [parent] but there was always that kind of, they'd ask it in the same way that you might ask somebody who maybe had the flu*” [**P13: Daughter**].

Comparison with cancer

Interestingly in several narratives, when comparing YOD to another illness, cancer appeared to be the illness many participants used. The implication may be that public awareness of cancer and cancer treatments are significantly better when compared to YOD

> “*I used to know somebody who lives down in [place name] and I remember, I was in their house when they phoned me to confirm the diagnosis and I remember they, like they took my hand kinda oh don't worry like. But they kind of implied like a lot of people kind of treated as though, like you know, like a cancer diagnosis, something you can kind of fight or rally around*” [**P06: Daughter**].

Moreover, the comparison with a cancer diagnosis may have arisen as people are aware that for proportion of cancers there is a capacity for successful treatment and in many cases, people can recover fully. In other words, certain cancers are no longer perceived by society as a death sentence (Tritter, 2009). This may be where the perception of "*rallying round*" and "*fighting*" stems from.

Comparison with terminal cancer

Conversely, many participants in the current study appeared to be aware of the terminal nature of young onset dementia, and that currently there is no cure. Therefore, many narratives spoke about comparing young onset dementia to terminal cancer. It may be an indication that participants have a subconscious awareness that death is an inevitability for their parent. Similar themes emerged in research by Hall and Sikes (2017).

It may also reveal that participants wished for a more compassionate and swifter death for their parent. There is no suggestion whatsoever that participants wished for their parent to die; however, it appears as if a condition which attacks bodily functions rather than attacking the functions of the brain would be preferable. This may stem from the significant distress that young onset dementia can cause as participants watch the progression of the condition as their parents cognitive function making it difficult to properly say goodbye.

> "*But yeah for me it was kind of, I mean it is the same as somebody being told they have terminal cancer or something along those lines, and you know it's not I don't want to say it's a death sentence, but you mean it is you're going to say goodbye to a person*" [**P05: Son**].

Comparison with late onset dementia

Several children and young adults in the current study compared young onset to late onset dementia. The prevailing socio-cultural perception of dementia is as disease of old age. Many participants may use this as a reference point as a way to acknowledge the severity of the condition and allow themselves the opportunity to process the situation.

> “*And because I was I’m quite close with this person, they are the same age as me. And when we were younger, I remember her grandmother lived with them. And she was in the late stages of Alzheimer’s so I’d like, I’d seen her go through it and I’d seen what it put their family through and then I’d seen the…decline that happened there*” [**P09: Daughter**].

5.5.2 Theme 2: Lack of Representation

The social construct of dementia as an “*an old age problem*” combined with the lack of representation of younger people living with the condition may add to the difficult experience expressed by participants. The lack of representation in society also arose several narratives.

> “*Yeah, to be honest, the whole like, even now it's really difficult because the whole time I ever tried to speak with anyone about it, like if I mentioned that my [parent] has Alzheimer’s. The response I get from anyone who has had a family member with it is, oh yeah my granny had it, you know or my granddad had it. And I’m like, was your granny 85 when she developed it? And they're like, oh, she was 90. She lived a good life and I’m kind of like, obviously I don't say it to people, but you know, like in your head you're like it's not the same thing*” [**P16: Daughter**].

In society

Some children and young adults in the current study addressed the negativity around dementia, particularly for younger people diagnosed with the condition that appear to be prevalent in society.

> “*People around me were quite ignorant and they would say things like, oh your [parent] is gone mad. Oh, your [parent] is gone senile you know, your [parent] has lost the plot; you know. Your [parent] is a bit crazy, you know, and I didn't want people saying or thinking those things about my own [parent]*” [**P01: Daughter**].

In the media

Children and young adults outlined the fact that many media and advertising campaigns propagate the socio-cultural perception that dementia is an old age condition.

> "*…even on the ads for TV, so [dementia advertising campaign] like you'd always see it'd be people from the age of 65 up is what you'd see explaining their stories and its them walking round a park but it's always, it's never an under 65-year-old*" [**P04: Son**].

> "*A lot of people don't have a very good grasp of it, I suppose, because of how maybe it's portrayed in media or the fact that their own experience of it is, perhaps you know much older relatives, but this is kind of idea yeah like this person is a bit a bit daft you know, like doing like crazy things and like. Or that it's a bit entertaining you know because this idea, you know that people always seem to think that. Like the person just regresses you know and they start to live in the past, you know. So, it's like, oh look what year does your [parent] think it is like*" [**P13: Daughter**].

In service provision

Similarly, the provision of services for people with dementia are typically based around older adults. Again, children and young adults highlighted the lack of representation within service providers for their parents who are considerably younger.

> "*I think, realistically, we didn't know what to do, where to go for those kinds of things. And also, the problem was that you know at the [service provider] we're in cafes and dementia cafes and all those kinds of things. But when we looked into it, it was all for, the average age of those things was about eighty-five. And like you know, we weren't going to send a young, a young fit [person], you know, to hang out with eighty-five-year-olds, I think that that's part of the problem*" [**P02: Daughter**].

5.5.3 Theme 3: Threat to the Family System

Moreover, some narratives illustrated how family harmony can be destroyed as they felt they could neither turn to siblings or their healthy parent for support. It illustrates how YOD can affect the family system, as some members feel as if they are left alone to deal with the current situation.

> "*So then, of course, we're getting this life changing news, and I wanted to shout but I can't talk to my [sibling] about it, and I didn't really feel like I could talk to my [healthy parent] about it, I didn't know what to say*" [**P08: Son**].

> "*But something was happening, and my [parent] had been a fantastic parent. It was the most traumatic thing that happened and I was told by his bedside your [parent] has the brain of a seventy-year-old*" [**P14: Son**].

> "*And I was, I know it's awful, but I was like, you don't get it, it's a life changing illnesses like I'm gonna have to watch my [parent] deteriorate. I think I had the negative connotations of what you know Alzheimer's meant. And so, yeah it was it was tough so probably didn't take it very well, to be honest, but I know like I know my [healthy parent] did not do well with the diagnosis at all*" [**P017: Daughter**].

No clear timeline until death – disease trajectory

The view of dementia as a slow death sentence also adds to the distress felt by participants and appears to be a significantly demanding aspect of YOD. Narratives outlined how this distress unfolds as participants spoke about having to watch their parents deterioration over the course of the disease without any sense of a timeline.

> "*yeah like it was it was very strange that it was kind of like you know so my [parent] was still doing okay, it was you know kind of in the very, very mild stages and then just be sent home with no kind of like I know you can't give somebody a timeline when it comes to*" [**P05: Son**].

> "*…it's different for everybody, somebody could decline very rapidly and I actually had another friend, his [parent] was diagnosed quite young and [person] was gone within five years, which is just you know that's horrific. You wouldn't think that that would happen. But yes, so I think it's just kind of like but there's no there's no sense I know. Because no one can give you a definite answer, but there was no sense given of how long we had with my [parent] and the current stages and those kind of things. And then you can read up on, you know care needs for people with Alzheimer's, but I was like this doesn't apply to where my [parent] is now*" [**P02; Daughter**].

Anxiety, stress & financial woes

Many children and young adults expressed their feelings of anxiety and stress as a result of the diagnosis. Some narratives also outlined that the diagnosis had left the family in financial difficulties.

> "*Because when somebody I would say I'm fine, fine, fine ,fine and then, when somebody asked me in a certain way I couldn't stop crying or I could answer something crazy like, well I think I'm dying*" [**P17: Daughter**].

> "*…I had gotten through five years of, just stress beyond stress and didn't know where it was coming from, or what was going on*" [**P10: Son**].

> "*We saw what was happening, we couldn't get it out of our heads. Basically, we were suddenly bankrupt as well because we had barely been managing money*" [**P06: Daughter**].

Stigma

Stigma may be identified as contravening societies perceived norms (Scambler, 2009) and as people with YOD may be affected by the behavioural and psychological symptoms of dementia, they may be perceived as contravening normal behaviour.

Behavioural & psychological symptoms of dementia

Children and young adults outlined both the positive and negative side of stigma. The negative aspects can be difficult for individuals to confront, particularly if some behaviours are unpleasant.

> "*But you do see the changes like when somebody is diagnosed with dementia and you can see, unfortunately, the illness does take over…I ended up having to pull my [parent] of [healthy parent] I was very shaken*" [**P04: Son**].

> "*And oh yeah he, like he's been he's been very aggressive, to be honest. You know what, what whatever inhibits you normally is gone. So, yeah like there was there's been an awful lot of like physical and verbal aggression*" [**P12: Daughter**].

> "*And we're still finding social engagements a big struggle, the slightest thing…could cause a major argument …his family and had stopped inviting us places and their reaction was appalling and this came out, but the reason I found out ages later that they had stopped inviting us to family dinners and things like that they tended to exclude him was because of his behaviour*"[**P13: Daughter**].

> "*yeah I told* [my friends] *straight away*" Interviewer: *And have they stayed friends with you*?
> "*No*" [visibly emotional and upset – interview is paused] [**P03: Daughter**].

Conversely, some participants highlighted the positive aspects. From initially being fearful of disclosing their parents diagnosis, some children found that there was a favourable reaction, particularly from their friends.

> “*I didn’t tell mine straight away, but then after time I did open up and speak to them about it like, and they’ve been a great support, ever since they’ve been told, none of them backed down or walked away they've always been there. Doesn’t matter if its morning, noon, or night they’re always there*” [**P04: Son**].

Grief

Dementia research has generally recognised that for many families the process of grieving typically begins while their loved one is still living (Sweeting & Gilhooly, 1997). However, some children and young adults found this process extremely emotional.

> “*…because every year that they're alive, you lose a piece of who they are, I don't understand like. I believe that it becomes lost in that person, it's become silence that piece of them becomes silenced it's still there, but it can't be expressed at the time. My understanding was that part of them, you know died, and I said so as a person whose parent is like that you lose them. Slowly but surely and so every year you mourn a new loss*” [**P09: Daughter**].

Anger

Many participants described feeling significant anger and negativity towards their parent with YOD. This may arise as a result of a number of factors. There is an obvious threat to family harmony and social constructions of the family emphasise a harmonious place (Morgan, 1996). On a personal level, children and young adults may be forced to change future hopes and plans.

> “*I was so angry, deep down, I was murderous really angry and I knew it was hurting me more than anybody…*” [**P10: Son**].

> “*I think I suffered more feelings of hatred, which everybody is afraid to mention. Parents with dementia, they're causing sort of divorce situations where they want to protect the children. But in no other circumstances do I know that you allow your children to be damaged on a daily basis and that's okay and it's sanctioned*” [**P13: Daughter**].

Guilt

Several narratives cited feelings of guilt. Participants may feel guilty as a result of the anger felt towards their ill parent. It may also be a consequence of the societal perception of doing what is right. Children and young adults reported confusion and guilt in relation to doing the right thing. It is difficult to know for certain if the guilt arose because of how participants perceived society would perceive them, however, there were significant feeling of guilt among participants.

> “*…but then one of the things that you can live with constantly is guilt. When you know, like it's you know it's guilt like am I doing the right thing for the person, am I doing what they would have done, am I doing what they would do for me, you know. Am I doing the right thing and for me. Like you know, am I completely abandoning my [healthy parent]. I’m leaving my [healthy parent] to you know, suppose shoulder the whole burden*” [**P01: Daughter**].

> “*I knew I had a chance to say goodbye, for me it was well if I leave for two and a half years, is my [parent] going to know who I am when I come back you know, and I think to me that just felt like it was going to be way*” [**P11: Daughter**].

5.5.4 Theme 4: Life has completely changed

The adjustment of future plans was outlined in several narratives. Participants reported how parental YOD had impacted on their future plans in relation to employment, travel and education. Participants described feeling stuck as their future plans were put on hold.

Increase in responsibility

Moreover, children and young adults reported a significant increase in feelings of responsibility as they struggle to manage their personal lives with assisting at home with various household tasks. Some children and young adult also spoke about feeling the need to contribute financially to the household which also added to their sense of responsibility.

> "*And I was busy [in college] so it was quite challenging because I was still very young. And you know, I was only really a teenager really, and I felt like I had this massive responsibility. Taking on kind of something that most people take on maybe 20 years later*" [**P07: Daughter**].

> "*...yeah, so by this stage, of course, I have to go to work. So, to keep the family right someone's gonna pay the bills right, so I go to work my [healthy parent]gives up his job retire and starts to look after my [parent] but obviously there's some things that my [healthy parent] is not able to do so, it still was a huge load to bear*" [**P02: Daughter**].

Relationship change

Several participants outlined how relationships changed with family, friends, and peers. The increase in responsibilities in the home may be a contributing factor to the changing relationships reported by children and young adults in the current study.

> "*yeah I would say I probably did drift away from a lot of friends, because they just. I think to, lack of understanding and me having to prioritise different things you know. There's only so many invitations you can turn down to things before the invitations stop coming, and I'm sure you know yourself like so just that's kinda the way it was*" [**P14: Son**].

Infantilisation – Parenting the parent

The societal construct of the "normal" parent-child relationship can be turned on its head following a diagnosis of YOD causing disruption to the family unit. Children and young adults often find that they are parenting their parent. This aspect can cause significant physical and psychological strain as many narratives reported in the current study.

> "*And then you don't want to be in infantilising somebody as well you know because it must have been, it must have been so distressing for my [parent] you know. And then you don't want to certainly, don't want to start being that person is like, oh no sorry you can't, you can't do the thing you just did yesterday, because now you've got this diagnosis on you*" [**P02: Daughter**].

> "*I was, I was like sort of begging my [parent] right now it's time to shower, now it's time to eat, now it's time to take me for me to go to [college] you know this kind of a way. Don't forget services coming tomorrow oh you've got an appointment basically doing you know basically being her basic carer*" [**P06: Daughter**].

Future plans & dreams change

Narratives highlighted that future plans and dream are also affected, with many reporting that it was simpler not to make any future plans at all.

> "*And in terms of a you know, even, you know as a young, when you're young you have all these dreams and things for your life, those all got put on hold. Yeah, like it was easier and safer to not have plans*" [**P09: Daughter**].

Participants spoke to feeling the need to be at home more often. This may stem from the increased responsibility with household chores, however, it may also result from a level of understanding in relation to both parent's needs.

> "*…so, even though there were [number of siblings], I was the only I was the only one remaining at home and when my [parent] got sick. So, for me it was maybe just going to [university] a lot less you know, kind of staying home more being more conscious of my parents and their needs and that kind of stuff*" [**P12: Daughter**].

Conversely, one young participant spoke about the positives in relation to the experience. As a result of the increase in household and possible caring tasks, the narrative outlined that their future plans may involve becoming a health care provider.

> Interviewer: *And what do you hope to go on to do*? “*I want to go on to a carers course*” [**P04: Son**].

Coping

Many participants have found that coming to terms with the new situation to be extremely difficult. Subsequently, children and young adults may employ unhealthy coping mechanisms in order to forget about the reality of their lives. The adoption of certain maladaptive coping strategies such as excessive working was illustrated during the interviews.

> “*And I very much I’m one of those people I know it's not healthy, it's not healthy coping mechanism, I work too much. And I was working, seven days a week, and I was, but I mean it was great because I could also be around for a moment I need me to be around but. And I wasn't taking I mean like I wasn't taking a break I wasn't going on holidays I wasn't you know, I was just working from you know, I was working every hour that I could. Realistically, I was probably doing it because I didn't want to stop and think too hard*” [**P01: Daughter**].

5.5.5 Theme 5: The need for systemic psycho-social support & education

A significant number of children and young adults in the current study outlined the need for a systemic approach to both psychological and social supports following a parent being diagnosed with YOD.

Support for the family system

The social and cultural construct of dementia can act as barrier when attempting to access support, in particular age-appropriate support. Narratives pointed to the perceived lack of age-appropriate support for the entire family (including the person with YOD) as a significant factor in exacerbating the negative experience for children and young adults.

> "*...a lot of the people who were around be whose parents did have different kinds of dementias their parents were of a different generation and they themselves were of a different generation, and so I just felt like my problems were not problems that they necessarily identified with. Do you know what I mean. I'm in my 20s but they're in their 50s yeah they were old enough to be my parents*" [**P12: Daughter**].

> "*I think, maybe having access to a network of people who were going through the same thing. And you know I think seeing my [parent] with other people of the same age, you know, with the same illness, could establish a support network on being able to talk to somebody who was under the age of 50. So, the social support in terms of you know communication or a network for people*" [**P09: Daughter**].

> "*…it was just, it was stuff you know that wouldn't have been interesting, if you like. What do you try, you try arts and crafts, try finger painting, try this and we'll try that and I'm like, my [parent] not a baby, you know my [parent] is a fully grown [person] who you know has declined a little bit…*" [**P01: Daughter**].

Age-appropriate peer to peer support

Similarly, children and young adults highlighted the need for age-appropriate peer to peer support for themselves. Narratives reported that participants perceived that older age support services may not necessarily understand the experience from a child's perspective.

> "*You know, and for me that's kind of where the issue came as somebody who looked after my parents with the young onset is that our support groups out there, but they're not necessarily people who are your age your generation they don't necessarily understand your lived experience, it's a different generation and, You know, and maybe their ideas about these kinds of things might be a bit different to my views*" [**P10: Son**].

Support from health & social care providers

Participants also illustrated the need for support from health and social care providers at the time of their parents diagnosis and beyond. As the diagnosis can be life changing for children and young adults, many felt that there was no support for them from the heath service providers.

> "*And one thing that I found really strange as well, so like they were given that diagnosis and they were just sent home from the hospital. You know, there was no here's a support group here somebody you should talk to here is a service to reach it was just nothing, it was here is this, you know this life changing thing and we're going to send you home alone to deal with it*" [**P07: Daughter**].

> "*You need the adults to be on top of their game with support, so they can talk through what's happening …the [dementia organisation] have a family resource therapist, but she's actually a family counsellor, but she doesn't actually accept referrals for under 18`s, again so…you know it's a pity that there's again very little supports offered to children*". [**P12: Daughter**].

Support from the community

Positive aspects of support were reported by several participants. The narratives spoke about support from the wider community such as friends, neighbours and work colleagues. Children and young adults outlined how this support was of crucial importance to them.

> "*I had a lot of support from my peers at work and my friends, that could it be really useful for me when I was younger*" [**P02: Daughter**].

> "*…yeah, like we you know we're in a housing estate with neighbours nearby and you know people, we can call them. If we've been living where my [sibling] is living, she is on the [place name]beautiful spot, but you know her closest town is still a 10-minute drive like. And you know, and all I can think of is if we lived there you know, like my [parent] would have been so isolated*" [**P17: Daughter**].

Education & awareness

Children and young adults also outlined that an increase in educational and awareness campaigns may assist with the wider community becoming more involved in help and support. Younger participants taught that an educational awareness campaign would be a positive for school age children.

> "*transition year is a great year really, yeah that's I think when students mature like that*". [**P04: Son**].

Furthermore, educational and awareness campaigns may increase community level awareness of YOD.

> "*It's only in the last year that were trying to really I suppose ourselves, you know make people more aware of it, and its only in the last twelve months that were talking more about it. Its only now really like that we're hearing other people's stories, who are like the same age as [parent] as well, or younger*" [**P06: Daughter**].

5.6 Discussion

The current study attempted to address the gap in the academic literature in relation to research with children and young adults living with a parent diagnosed with YOD. In particular building on research conducted by Hall and Sikes (2017) the current study explored how the wider socio-cultural construct of dementia may influence the narratives of children and young adults with a parent with the condition in an Irish context. Five themes with related subthemes emerged from the narrative (see table 15). Findings from the current study are consistent with the limited research that has been undertaken with similar participants (Gelman & Rhames, 2018; 2020; Hall & Sikes, 2018; 2020) and are also consistent with the findings uncovered in chapter three of this thesis.

Specifically, in the current study, children and young adults often use comparison as a method of finding meaning and making sense of the situation. Due to the negative social construct of YOD, comparisons were typically made with other illnesses, such as cancer, giving their experience (s) context (Klawiter, 2004; Garro, 2000).

Despite various illnesses being a ubiquitous experience, perceptions of YOD appear to be biased by a lack of awareness amongst society (Cipriani et al., 2011). As a result, there is a significant lack of representation of people living with YOD in society in general. The lack of representation also extends to all forms of media and YOD is also significantly underrepresented among dementia services. For example, recent research conducted by Sm-Rahman, Lo and Jahan (2021) illustrated the power of both print and online media to influence the social perception in relation to dementia. Typically, the media portrays dementia as a disease of old age that is predominantly heterogeneous.

Such portrayals appear to influence the general narrative in relation to dementia. Data from the current study complimented such findings with many participants outlining the underrepresentation of YOD on various media platforms and in service provision. Consequently, the current study extracted data illustrating that children and young adults perceive YOD as a threat to their family system or unit. As described in chapter three, the family system comprises of "*subsystems*" such as "*parent-parent*", "*parent-child*", "*child-child*" and "*parent-sibling*" with each subsystem influencing the overall system (Bronfenbrenner, 1986).

It may be reasonable to assume that an event affecting one part of the system can affect the whole system (Cox & Paley, 1997). For example, a parental or childhood illness can threaten the marriage partnership as well as sibling relationships (Williams, 1997; Rivers & Stoneman, 2003; Bellin & Rice, 2009). Participant narratives in the current study highlighted the fragility of the family system when confronted with YOD from factors such as stigma; behavioral issues; fear; anxiety; guilt and uncertainty as to the amount of time their ill parent has left to live.

The family system is also susceptible to change across the disease trajectory. Research has illustrated how roles, relationships and boundaries can alter within the family system as a result of YOD (Allen et al., 2009; Baker et al., 2013; Millenaar et al., 2014). Findings from this study corroborated this research and outlined the shifting relationships and roles. Participants spoke about the significant increase in responsibility, both in relation to household and caring tasks and financial matters.

Moreover, children and young adults outlined that future plans i.e., educational, travel and employment plans, were put on hold or scrapped completely. As a result of the significant challenges children and young adults experienced in the current study, many narratives reported difficulty with coping.

Previous research has highlighted the need for children to adopt coping mechanisms when coming to terms with the situation (Nichols et al., 2013; Millenaar et al., 2014; Hutchinson, et al., 2016; Gelman & Rhames, 2018). However, data from the current study illustrated that some children may adopt maladaptive coping mechanisms such as working excessively as a mean to hide or ignore their situation.

Engaging with support services may be used as another means of coping. Searching for and using psychological and social supports has been shown to be an important factor for children and young people when faced with adversity. For example, research has posited that fostering strong links with family members, friends and peers is a crucial element of social support (Forrest Keenan et al., 2007; Pakenham, Chiu, Bursnall, & Cannon, 2007; Kjoelaas et al., 2021; Kavanaugh, 2014; Lewit-Mendes et al., 2018). A significant number of children and young adults in the current study outlined the need for a systemic support both socially and from professional health care providers. However, narratives outlined the significant lack of support services as the socially constructed perception of dementia is as a disease of old age. Children and young adults reported of their reluctance to use service providers as a result.

Moreover, the lack of age-appropriate peer to peer support groups appears to be another significant barrier. Participants stated the vital need for such supports and the need for educational and awareness campaigns around YOD in order to dispel the existing social and cultural perceptions in Ireland. For instance, several European countries provide educational, awareness and peer to peer support programmes for children and young adults with a parent living with Huntington’s disease. Children and young adults are encouraged to attend unique camping trips combined with retreats organised by the Huntington’s Disease Youth Organisation (2014) a group committed to supporting families living with Huntington’s disease. Recent research by Hoppe (2022) was conducted with participants in the Netherlands. The sample included sixteen adult children over eighteen years of age (ranging from 19 to 43 years: *mean* = 31·7). However, despite been considerable older than the sample in the current study, similar themes emerged in relation to the social and cultural construct of dementia.

5.7 Strengths and limitations

Every measure was put in place in order to ensure the quality of this research. Seventeen participants (29·41% male) participated in this study ranging in age from 14 to 33 years old (*mean* = 21·18 years) with *n* = 6 eighteen years of age or younger (*mean* = 16·17 years). This represents a significant gender bias within the sample. However, the sample size is not only in line with but exceeds the sample size of similar research studies. The breath of the relationships between participants allowed for a number of different perspectives. Taken together, this enabled the researcher to gain an in-depth view of life with a parent YOD. However, thematic analysis is a subjective process and as a result is susceptible to interpretation and bias.

The current research includes individuals perspectives from Ireland, which may be characterised as wealthy Western country. It may be reasonable to assume that perspectives of YOD may differ significantly in countries with different language, cultural, social, and economic norms. Therefore, findings from the current research may not be panoptic. While the current study did capture the perspectives of children who currently live with a parent with YOD, a proportion of participants no longer did so. Their views of their experiences may be retrospective in nature, relying on autobiographical memory, which may colour somewhat. Furthermore, the current study included children and young adults from typical nuclear families. Therefore, the sample does not include the perspectives of children living in one parent families whose parent may live with YOD.

5.8 Chapter Conclusion

Findings from this study illustrate the influence the social and cultural construct of dementia can have on children and young adults with a parent with YOD. Children are faced with more responsibility and shifting roles leading to significant physical and emotional strain. Future educational or employment plans are being put on hold or scrapped completely. Children and young adults also outlined changes in relationships with family, friends and peers. Moreover, the social perception of dementia as a disease of old age can act as a barrier to children and young adults accessing and using health and social care providers. The novel approach adopted in this chapter with the inclusion of younger children combined with the findings in relation to stigma and the apparent need for peer-to-peer support informed the direction of the research described in the next chapter in this thesis.

Children and young adults readily used comparisons with other illnesses such as ALS, MS and cancer mainly because of how society portrays such illnesses and to give some context to their own experiences. However, while participants may presume that the carer burden in YOD is comparable to these other illnesses, the associated stigma certainly is not. What is clear from data in the current study is that age-appropriate tailored peer to peer support and educational and awareness campaigns would significantly benefit children and young adults. Accordingly, the next chapter of this thesis utilised a piece of qualitative research in order to investigate whether or not there is a need for adaptive peer-to-peer support for this cohort.

6. Investigating the need for peer support groups for children affected by parental young onset dementia.

6.1 Abstract

Background

Dementia diagnosed before the age of 65 is typically referred to as early onset, presenile or young onset dementia (YOD). A diagnosis at such a young age means the individual and their family are faced with a host of significant challenges. From facing up to the diagnosis and the inevitable cognitive decline to navigating employment issues, matrimonial and relationship changes and social isolation. As a result, the wellbeing of the entire family system begins to be negatively affected. Many families who receive a diagnosis may include pre-adolescent, adolescent or young adult children who are reliant on their parents.

Aims

Most research on the challenges of YOD tends to focus on the main or primary carer, usually a spouse or partner. However, if children are part of the family system, they may also be adversely impacted by the new and changeable situation. The use of peer support with children in other domains such as mental health has been well documented. However, little or no research exists with children facing parental YOD. Therefore, the current study examined whether there is a need for peer support groups for children and young adults with a parent with YOD.

Methods

One-to-one interviews were held with children and younger adults (n = 13) who live with (or have lived with) a parent with a formal diagnosis of YOD (with various subtypes) living in the community. Participants ranged in age from 15 to 34 years old (*Median age* = 18 years). Participant narratives were analysed using inductive qualitative thematic analysis.

Findings

3 main themes (with related subthemes); a unique experience; power of communication and support that fits.

Conclusion

Children and young adults face significant difficulty when attempting to access age-appropriate health and social care support. Participants were overwhelming in favour of tailored peer support, stratified by age, as an intervention. Moreover, whether the support was delivered online of face-to-face carried no weight with participants in the current study.

6.2 Chapter Introduction

Findings uncovered in earlier chapters of this thesis, particularly chapters four and five, have described the significant toll a diagnosis of parental young onset dementia (YOD) can have on the children within the family system. Children and young adults have reported considerable problems following their parents diagnosis, problems such as changing relationships within and outside the family, the physical and emotional burden, the stigma they must face and access to adaptive support to name just a few.

Children have also outlined how their future plans and dreams may be postponed or cancelled completely, plans that may involve educational or career goals for example. As described in chapter five, the societal perception of dementia as a disease of old age can exacerbate the issues that families, and specifically children, face when confronted with YOD. Due to the stigma associated with YOD, children have described how they may lose contact with friends, and as a result lose a source of support. Moreover, the stereotypical portrayal of dementia combined with a distinct lack of age-appropriate services can prevent children from seeking support from formal health and social care providers. Children and young adults have also cited that they feel that they do not want to over burden their well parent with any issues they may have. This can leave children in an extremely lonely and isolated place.

However, findings from chapter five also uncovered a need for systemic psycho-social support with participants reporting that peer-to-peer support could be extremely beneficial. While there is extensive literature in relation to the use of peer support with children in other domains such as mental health, there is very little research in relation to its use in YOD. What research does exist typically involves the use of peer support for people living with YOD or their carers – i.e., a spouse or partner. Therefore, we decided to address this gap in the literature and investigate whether or not there is a need for adaptive peer-to-peer support for children and young adults facing parental YOD in Ireland.

6.3 Introduction

Of the estimated 55 million people living with dementia globally (Nichols & Vos, 2021) approximately 25% of cases may be an atypical or vascular subtype. For many individuals who are diagnosed with dementia before the age of 65, aberrant subtypes of dementia may be prototypical (Brotherhood et al., 2020). Dementia diagnosed before the age of 65 is typically referred to as early onset, presenile or young onset dementia (YOD). Approximately 8-10% of worldwide dementia cases are diagnosed in individuals between the ages of 30 and 60 years equating to almost 4 million people (Hendricks et al., 2021).

As discussed in the preceding chapters of this thesis, a diagnosis at such a young age means the individual and their family are faced with a host of significant challenges. From facing up to the diagnosis and the inevitable cognitive decline to navigating employment issues, matrimonial and relationship changes and social isolation resulting from systemic barriers (Mayrhofer et al., 2020; Sonnicksen, 2016). Such psychosocial conditions may be worsened by the abundance of dementia services that cater solely to older adults and are not suitable or flexible enough to serve individual's younger in age (Novek & Menec, 2021).

Findings from the previous chapters illustrate how the wellbeing of the entire family system begins to be negatively affected as the burden of the diagnosis and subsequent care needs take hold (Barca et al., 2014). However, the findings from earlier chapters also demonstrate that atypical subtypes are not the only unique feature of YOD. Many families who receive a diagnosis may include pre-adolescent, adolescent or young adult children who are reliant on their parents. The opposite may be the case in late onset dementia (i.e., a diagnosis after 65 years of age) where the family composition may include older adult children who are relatively independent (Johannessen et al., 2017).

What both young onset and late onset dementia do have in common is the high levels of strain as a result of care giving, with the caring role in YOD bringing unique challenges (Johannessen et al., 2017). As described in chapter three, most research on the challenges of YOD tends to focus on the main or primary carer, usually a spouse or partner (Brodaty et al., 2012). However, if children are part of the family system, they may also be adversely impacted by the new and changeable situation (Johannessen et al., 2016). For example, findings from the study discussed in chapter three show how communal relationships can suffer significantly as a result of a progressive decline in cognitive function(s), effecting the entire family dynamic and in particular children (Groennestad & Malmedal, 2022).

Moreover, adolescent children may become preoccupied with various tasks and responsibilities as a coping mechanism at a time when their developmental trajectory would typically see a separation from their family (Johannessen et al., 2016). According to Erikson's (1958; 1963) influential theory of psychosocial development adolescence is a critical period of transition where teenage children develop a sense of self and personal identity.

Adams and Marshall (1996) expanded on this concept, posting that parents may act as mediators (socialising agents) between developing adolescent children and society in general. Schachter and Ventura (2008) extended this idea further hypothesising that agentic parents who have the capacity to fulfil the role of mediator ultimately assist in their child's autonomous development. In other words, developing children are moulded by their interpersonal relationships with their parents (Pittman et al., 2011). Consequently, child-parent interactions during the adolescent stage are thought to significantly influence the genesis of the child's self-identity and affectivity during the later emerging adult stage (Luyckx et al., 2007; Lichtwarck-Aschoff et al., 2008). Therefore, if the household is beset by serious illness such as YOD, the developing child may lose their mediator thus stunting their developmental progress (Pittman et al., 2011). Furthermore, the unconventional characteristics of YOD may leave children with negligible contact with others in similar situation outside the family unit, consequently increasing the likelihood for anguish (Groennestad & Malmedal, 2022). Peer-to-peer support may be one option to assist children and young adults through this challenging period.

6.3.1 Peer Support – Theory and Practice

Health promotion can include championing healthy lifestyle behaviours such as exercise, good sleep management and nutrition, for example, and is crucial in preventing illness instead of treating it. However, health promotion may also include building and maintaining positive social networks and relationships (Stewart & Tilden, 1995). For instance, the World Health Organisation (2009) recognises the importance of social connections as a strategy to promote positive health. Social relationships, therefore, are extremely important for the preservation of health and well-being both prior to and after disease treatment. Evidence illustrates that strong social relationships can offer protection and assist with recovery from both physical and psychological illness.

In fact, interventions that can change an individual's social circumstances have been effective in promoting emotional transformation, helping to aide recovery from trauma and prolonging life expectancy in chronic illness (Cohen, 2004). Encapsulated within the social relationship paradigm is the concept of peer support (see figure 8) which has been recognised for a number of years as beneficial to positive health outcomes (Lackey & Cohen, 2000) and can also be used to promote health and prevent disease (Stewart & Tilden, 1995). Peer support hinges on six social and behavioural theories including social support (Sarason et al., 1983), verifiable knowledge (Borkman, 1999), helper-therapy concept (Skovholt, 1974), social learning theory (Bandura & Ramachaudran, 1994), social comparison theory (Festinger, 1954), and self-determination theory (Ryan & Deci, 2000).

While there have been various definitions of peer support, there is general consensus that peer support refers to, "*a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful*" (Mead et al., 2001; pp. 135). Moreover, peer support has been growing as a way of acquiring and receiving effective social and emotional mutual support (DH, 2010; HM Government, 2012). In other words, the growing use of peer support in health and social care settings may represent a move away from "*advice from on high to support from next door*" (DH, 2004; pp. 103).

When attempting to define peer support, it is crucial to understand the meaning of the term peers as well as the type of support that may be available. To that end, an investigation of the use of peer support with various groups and within a variety of settings assists with the comprehension of the concept (Keyes et al., 2016). For instance, peer support appears to contain five core features as follows:

i) It is a mutual interaction grounded in common experiences.

ii) It is, more often than not, based on an exchange of support.

iii) It may have a positive social and emotional impact.

iv) It includes shared learning based on direct experience.

v) It challenges a medical/deficit model of illness/disability (Keyes et al., 2016).

These five core features give peer support the latitude to be applied in an assortment of health and social care settings. For example, the use of peer support with individuals who share a homogeneous diagnosis or life circumstance is based on the first core feature of common experience.

As a result, individuals can relate to the mutual experience(s) and any challenges that they may face. Research conducted with individuals diagnosed with cancer or diabetes, for example, or with primary carers of individuals with mental health difficulties illustrates this commonality of experience (Ussher et al., 2006; Fisher et al., 2012; Chien & Norman, 2009).

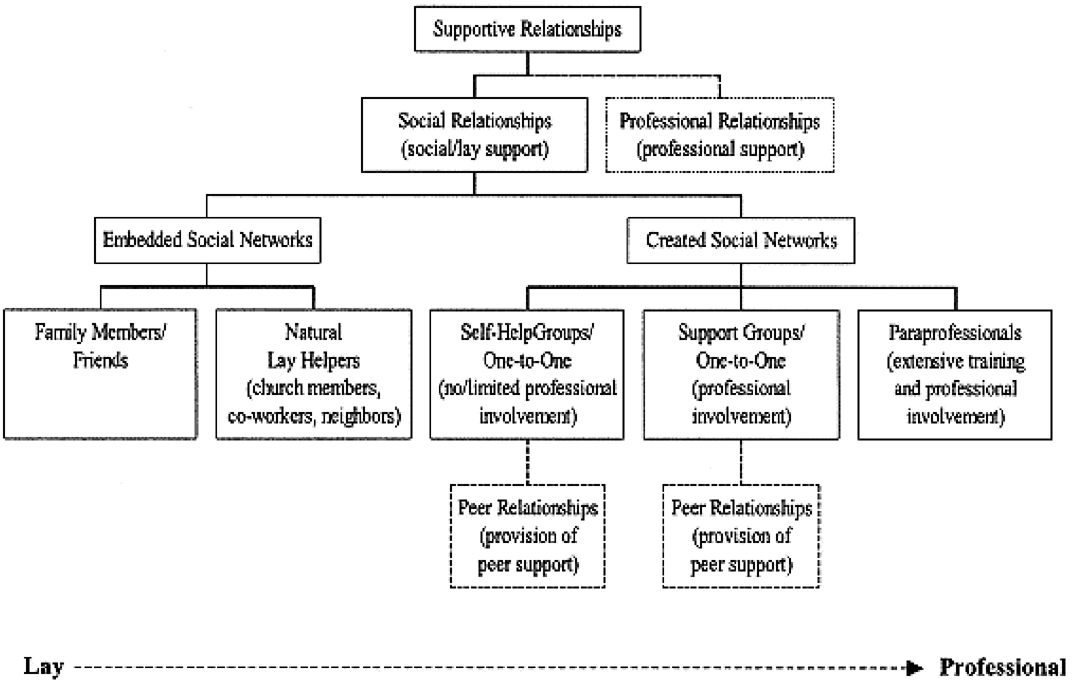

Figure 8: Illustration of the classification of social relationships from lay to professional support (Dennis, 2003).

In these examples, the term "peer" or "peers" is understood to mean people who associate with each other based on their experiences of a particular diagnosis, or life challenge, in which there is an equivalence (Keyes et al., 2016). The second core feature is based on support being reciprocal within any relationship(s) in which support is both offered and accepted. This reciprocity can be either informal – i.e., some peer support relationships can become lifelong friendships, or formal – i.e., designated peer support workers or counselling/mentorship programmes (Repper & Carter, 2011: Ho, 2007).

The third core feature of peer support relates to the positive outcomes from both an emotion and social level. For instance, research with older adults who feel marginalised or isolated outlines the efficacy of peer support in assisting them to regain a sense of belonging through social interaction (MacKean & Abbott-Chapman, 2012).

Furthermore, peer support has proven advantageous in the prevention of any future distress, for example, when working with women who may be at risk of developing postpartum depression (Dennis et al., 2009). The fourth core feature centers on the mutual learning that can be experienced during peer support (Hartley-Brewer, 2003).

Research in the area of addiction and specifically addiction recovery highlights how peer support can be utilised to share information and advice about behavioural change techniques as well as various coping strategies (Boisvert et al., 2008; Klatt et al., 2008; Thomson et al., 2012). Furthermore, people may experience two distinct types of learning which can vary in both quality and content. For example, practical knowledge and advice can come from professional peer support workers while emotional support can be entrenched in the shared lived experience(s) (Bassett et al., 2010).

Finally, the fifth core feature of peer support can assist with refocusing away from the purely medical model of illness and/or disability towards a more psychosocial understanding (Keyes & Brandon, 2012). In other words, peer support may help to address more of what a person needs, through a social awareness of the environmental barriers, rather than focusing solely on what is physically wrong with them. The commonality of experience, therefore, means that people with shared experiences can help each other to challenge and break down such barriers (Barnes & Mercer, 2006). Peer support has been an effective intervention in the areas of mental health and disability, including neurodegenerative conditions.

6.3.2 Peer Support in the area of Mental Health

Peer support has long been established in the area of mental health where evidence has outlined that it has been welcomed by both clients and providers alike (Mackay et al., 2022) and are an integral part of a person-centred model of care (Solomon, 2004). For example, people living with serious mental illness can access human support as a result of their shared experiences and understanding.

Through peer support individuals can gain unique personal insights that can aide in the recovery process (Mead & MacNeil, 2006). What seems to separate peer-to-peer support from professional support is the enhanced bond between individuals that is grounded in expertise and reciprocity and appears to lead to a superior therapeutic alliance (Horvath et al. 2011; Melau et al. 2015).

In the area of serious mental illness, evidence suggests that peer support can improve several outcomes such as increasing levels of hope, empowerment and sense of autonomy, improved personal care and a notable decrease in symptoms of depression and psychosis (Davidson et al. 2012). The sense of autonomy gained from peer support is a vital part of the process for people living with serious mental illnesses. For instance, self-determination theory posits that people are more likely to engage in behaviours if they have made decisions for themselves rather than being co-opted or forced by a third party (Deci & Ryan, 1985).

Individuals living with serious mental health difficulties, more often than not, are not given much choice about treatment interventions or options (Wright, 1997). In other words, if individuals experiencing mental health issues perceive that their goals are being set by health care professionals, they may be less inclined to try to achieve these goals (Brehm & Brehm, 2013; Ordóñez et al. 2009). Contrastingly, if the same goals are perceived to be set by other people with lived experiences of mental health issues, then they result in significantly better engagement (Fortuna et al., 2018).

A further benefit for people with mental health issues stems from the sense of belonging achieved through peer support. The need to belong is an innate human requirement whether we are experiencing adversity or not (Baumeister & Leary, 1995; Maslow1954). This sense of belonging is strengthened through a shared sense of identity and shared experiences with strong emotional bonds formed with other members of the group. Interestingly, the sense of belonging is reached significantly sooner between peers when compared to individuals working solely with health professionals (Hagborg, 1998). This may result from the fact that people experiencing mental health issues often struggle with building trust and connections with conventional health providers due in part to feelings of stigma (Dixon et al., 2016).

6.3.3 Peer Support in the area of Neurodegenerative Diseases and Disability

Evidence of the efficacy of peer support was reported by carers in amyotrophic lateral sclerosis (ALS), the most common of the motor neuron diseases. For example, research conducted by Ugalde and colleagues (2018) examined the efficacy of a self-care, problem-solving and mindfulness intervention for informal cares of people living with ALS by means of a pilot study. The authors decided to run the pilot study as part of a group session rather than an individual session specifically to allow for peer support between participants.

Similar findings emerged in a qualitative study examining the experience of two peer support groups for family cares of people with ALS that was conducted by Cipolletta and colleagues (2018). Participants reported that they agreed to use support groups because they believed that such groups would offer them the possibility to converse with people similar to themselves. Furthermore, participants cited that the sharing of comparable experiences with others and the giving and receiving of advice were also mitigating factors (Cipolletta et al., 2018).

In an exploratory study, de Wit and colleagues (2019) carried out qualitative semi-structured interviews with carers of people with ALS. Findings illustrated overwhelming support for some form of peer-to-peer intervention to assist with the care burden. For instance, half of the participants interviewed outlined that they would appreciate the opportunity to talk to other carers in order to share experiences because other carers would understand their situation. The giving and receiving of care tips and advice was perceived as a further significant factor in favour of peer support groups (de Wit et al., 2019).

The mechanism of the peer support delivery does not appear to impair its efficacy. In other words, whether it is delivered online or in person, peer support appears to be just as effective. For example, a recent systematic review by Wallace and colleagues (2021) examined online peer-support interventions for carers in conditions such as stroke, traumatic brain injury, post-traumatic stress disorder, Parkinson disease and multiple sclerosis (MS). The review included eighteen studies that all incorporated some component of peer-to-peer support as part of an intervention, with fifteen incorporating both psychosocial and educational aspects.

The authors reported statistically significant improvements for participants in factors such as knowledge acquisition, carer burden, autonomy and self-efficacy. Further benefits were observed in mental health with reductions in stress levels, depression and distress. The authors also outlined positive qualitative results such as the perception of stress reduction and an increase in both emotional and informational support. Interestingly, of the eighteen studies examined, over seventy percent (n = 13) were peer support interventions for carers of people living with dementia (Wallace et al., 2021). While the evidence for the efficacy of peer support for carers is abundant, much of the research is conducted with older adults. For example, in the studies outlined above the age of carers ranges from twenty-two to eighty-eighty with only two participants under twenty-nine years of age.

6.3.4 Peer Support in the area of Dementia

Peer support for people living with dementia and their carers is less extensive, however, many dementia organisations and charities do provide opportunities for clients to socialise (Kimura et al., 2015). Evidence illustrates that peer support interventions in dementia care provide an assortment of positive results, for both family members and the person living with dementia (Brotherhood et al., 2020).

For instance, carers have cited significant improvements in the understanding of dementia, an enhanced feeling of belonging, reductions in loneliness, a decrease in anxiety and stress and a sense of sharing (Lauritzen et al., 2015). Similar findings were reported in research conducted by Smith and colleagues (2018) and Willis and colleagues (2018) with participants also outlining a heightened sense of empathy and an improvement in general well-being.

In a recent study conducted by Bamford and colleagues (2021) findings outlined the emotional and psychological benefits of peer support for carers. Participants reported that peer support was a valuable asset as it assisted with the validation of their experiences and also was a source of knowledge. Despite these positives, several reviews of such interventions have uncovered numerous shortcomings within the literature, in particular shortcomings in relation to the methodology applied (Dam et al., 2016; Carter et al., 2020).

Moreover, the way some peer support interventions in dementia care are delivered make it challenging to elucidate whether or not the positive outcomes are meaningful. Additionally, many interventions are tailored for older adults and are delivered in older adult settings (Sullivan et al., 2022). Similar to the evidence discussed in relation to ALS above, the studies related to peer support in the area of dementia also cater for older adult carers. For example, in the study by Bamford and colleagues (2021) the age range of carers is forty-two to eighty-seven. Similarly, the research by Smith and colleagues (2018) included carers whose ages ranged from thirty-four to eighty-five.

Consequently, for families impacted by an atypical subtype of the condition, such as YOD opportunities to engage with peers remain scarce, particularly for children and young adults (Brotherhood et al., 2020). As such, there remains a considerable evidential gap in relation to the need for, and implementation of, peer support interventions for children and young adults impacted by parental YOD.

Therefore, the current study attempted to tackle this evidential gap and examine whether there is a need for peer support groups for children and young adults with a parent with YOD in an Irish context.
Specific aims include:

- Would peer support groups assist children and young adults face the unique challenges posed by parental YOD?
- If there is a need for peer support groups, would it be beneficial to stratify such groups by age?
- How would children and young adults like the peer support to be delivered: face-to-face or online?

6.4 Materials and methods

6.4.1 Design

To achieve the above aims, one-to-one semi structured interviews were conducted with children and younger adults living with (or who had lived with) a parent with YOD. Three participants who participated in this research also took part in previous research described in chapter 5. The interview schedule (see appendix Q) was drafted using a combination of relevant literature (Joseph et al., 2009) and findings derived from the research described in the earlier chapters of this thesis.

6.4.2 Participants Recruitment & Inclusion Criteria

Purposive sampling was used in this study. Participants, and where applicable, their parents or guardians were recruited through gatekeeper organisations. The gatekeeper organisations contacted are outlined elsewhere in this thesis. It is not clear how participants were approached by the gatekeeper organisations, or how many people refused to participate. The researcher was contacted by gatekeeper organisations only when participants or parents/guardians expressed an interest in the study. However, all participants who did express an interest in participating did end up taking part.

Eligibility for the study meant that the child or young adult must live (or have lived with) their parent with YOD and their parent received the formal diagnosis before 65 years of age meeting the criteria for YOD. Participants over the age of eighteen who expressed an interest in taking part were provided with a plain-language statement containing information about the aims of the study, the methodology to be used and a consent form (see appendices R-S).

Participants who were aged under eighteen years of age who expressed an interest in participating were provided with a combined plain language statement and consent form (see appendix T) and their parents/guardians were also provided with a combined plain language statement and parental consent form (see appendix U).

These documents contained an invitation to participate, further information about the study and contact details for the research team. Those who expressed an interest in taking part were asked to contact the research team to discuss the requirements of the study and the informed consent process in more detail. On receipt of a completed consent form, the researcher then contacted participants in order to schedule a convenient time for the interview.

6.4.3 Data Collection

Due to the restrictions imposed by the Covid-19 pandemic, interview data were collected online via Zoom for all participants. Participants (*n* = 13; see table 16) were encouraged to share their experiences. A person-centred approach was adopted in relation to the data-collection session(s). One-to-one interviews with participants lasted between 30 and 60 minutes, depending on the persons plans for the day.

However, interviews with younger children were considerably shorter and a parent/guardian was present at all times during the interview process. If the researcher noticed that a participant (s) appeared tired, emotional or if they expressed that they were struggling on the day, then the interview was terminated and rescheduled for an alternative time, only if consent was received. The researcher also ensured that participants had adequate breaks. All interviews were audio recorded via Zoom and later transcribed intelligent verbatim and anonymised.

The intention was for the sample to cover a wide range of perspectives, with different ages and different relationships to the person with YOD (Green & Thorogood, 2018). Narratives were appraised in their entirety in order to catalogue events both temporally and contextually and to extract salient themes (Riessman, 2008) and participants were encouraged to share their perspectives openly as a means of encouraging open discussion (Patton, 2002).

The narrative approach allowed participants to talk openly and freely and to express their feelings. Participants were passionate in their responses and eagerly recounted the history of their families, parents condition and future plans. Typically, the narrative approach is not used with children and young adults. However, this method permits younger participants to speak candidly about their past, their current situation and their future plans and dreams (James, 2005). For instance, the use of the narrative approach with young participants has uncovered concerns in relation to wellbeing, mental health, and social initiatives (Goodley & Clough, 2004; McNamara, 2013).

Data were then analysed using inductive thematic analysis. Narratives were appraised in their entirety in order to catalogue events both temporally and contextually and to extract salient themes (Riessman, 2008). Methodological guidelines suggest that most issues around a research topic will be captured when the point of saturation is reached, and no new themes emerge (Braun & Clarke, 2006). Focus groups are viewed as an ideal method to reveal differing perspectives on various topics and to uncover new insights and unanticipated issues (Hennink, 2007; Krueger, 2014).

6.4.4 Data Analysis

Interview data were analysed by applying an inductive qualitative thematic analysis using open coding and categories derived directly from the interview material (Hsieh & Shannon, 2005; Elo & Kyngas, 2008). All narratives were utilised in this analysis. A detailed outline of the data analysis, as well as the coding process and theme extraction is provided in chapter two of this thesis.

6.4.5 Ethical considerations

Ethical approval was obtained from Dublin City University Research Ethics Committee (DCUREC/2022/249; see appendix V). Risk associated with participation in the study was moderate, as no deception was involved. Participants were assigned participant numbers to ensure anonymity and confidentiality.

The right to withdraw from the study was clearly communicated, and a support pack outlining dementia-specific and more general supports that are available was offered to participants at the end of the interview process (see appendix H).

Table 16: Participants (*n* = 13) characteristics.

Participant number	Gender	Age at interview	Childs age when symptoms first appeared	Parents age when symptoms first appeared	Dementia subtype
01	Female	34	16	56	Alzheimer’s disease
02	Female	30	15	50	Vascular dementia
03	Female	15	10	40	Lewy body dementia
04	Male	18	13	40	Alzheimer’s disease
05	Male	22	16	41	Frontotemporal dementia
06	Female	17	14	44	Vascular dementia
07	Female	18	12	45	Vascular dementia
08	Male	17	13	42	Lewy body dementia
09	Female	25	17	45	Alzheimer’s dementia
10	Male	18	12	43	Frontotemporal dementia
11	Female	21	16	46	Alzheimer’s dementia
12	Female	18	14	39	Lewy body dementia
13	Female	19	13	41	Alzheimer’s dementia

6.5 Findings

Detailed thematic analysis of the participant narratives uncovered 3 main themes (with related subthemes); a unique experience; power of communication and finding support that fits (see table 17). Analysis is presented including participant anchor quotes in italicised text (identified by participant number).

6.5.1 Theme 1: A unique experience – *What makes YOD such a unique experience?*

During the current study, many children and young adults spoke about how having a parent with YOD is a unique experience. One unique aspect stems from the age profile of people when diagnosed with the condition. Typically, dementia is associated with a much older cohort who are at a much later stage of life. However, YOD manifests at a much younger life stage and several of the participant narratives referenced this. Specifically, the narratives reported that because of their parent(s) relatively young age, it made it extremely difficult to comprehend that the diagnosis was dementia:

> "*I had no idea was going on really, I was only just a teenager...but I knew something was wrong and that* [parent] *was sick, like. That's kinda all I was aware of...*" [**P10: Son**].

Correspondingly, the young age of participants in the current study also added to the sense of bewilderment as they grappled with the news that their parent(s) diagnosis. Moreover, the lack of awareness in relation to YOD further confounded the issue:

> "*...like, I was trying to understand what* [well parent] *was telling me, but I really had no clue what young onset dementia was. I knew dementia was something to do with memory, but my* [parent] *wasn't old...*" [**P11: Daughter**].

Table 17: Main themes with related sub-themes.

Themes	**1. A unique experience**	**2. Power of Communication**	**3. Support that fits**
Sub-themes	• Lack of representation. • Little or no suitable services. • Can impact on developmental stage.	• Need for simple, open and honest communication. • Good communication could: ➢ build confidence. ➢ help with knowledge acquisition ➢ educate others. ➢ combat anxiety/stress.	• Help to tackle stigma could: ➢ relieve feelings of guilt, shame and loneliness. • Age-appropriate support could: ➢ offer safe space to share experiences. • Mode of delivery could vary.

For some participants, this made the period following the diagnosis an exceptionally tough and challenging time:

> "*I remember it was such a confusing time, I felt so alone…it was just so hard to come to terms with was I was being told*" [**P02: Daughter**].

Much of the confusion cited by participants seems to have its origins in the societal portrayal or the stereotypical view of dementia as a disease representing older age. Several children and young adults referenced that dementia is usually representative of a much older cohort:

> "*I don't think it's portrayed enough like when people think of dementia, they think of like old people and grandparents and stuff*" [**P03: Daughter**].

Even when availing of health and social care supports participants cited that the services are designed for a significantly older cohort of people adding to the lack of representation of YOD:

> "*…to be honest its aimed a lot at the older people. Even when the healthcare professionals gave us books, they gave us books about information about dementia, picture books as well. But the pictures were all of old people, like there was no younger people like, at all. And even it was, like, the information that they gave in the books was all. it's usually aimed from 60 onwards, so it wasn't for anyone younger*" [**P07: Daughter**].

Another unique aspect of YOD stems from the fact that family systems may include pre-adolescent, adolescent or older adult children. This offers a particularly distinctive set of circumstances as the children cope with adversity differently at various stages of their development. Some of the participants in the current study outlined how being older, or at a different developmental stage, offered more insights into their parents condition and allowed them to cope. In other words, the more mature the participants were, the more understanding and less anxious they appeared about the situation:

> "*No, like when you start to mature, you realise that no one really like, takes any notice anymore*" [**P09: Daughter**].

Moreover, the stage of development or level of maturity appears to bring a certain degree of openness combined with a lack of fear when facing the situation and when sharing with others. In other words, maturity brings appears to come with confidence:

> "*No, it's just as you get older. Really, it's just so…You feel more confident, maybe as well, and talking to people more about it and being open about it*" [**P02: Daughter**].

Participants reported that feeling more open and confident in the face of adversity also helped them to talk with friends and share their experience. However, while sharing with friends is a positive factor, it may stem from the negative consequences of stigma. For example, participants reported that, in some cases, extended family seemed to disappear following their parents diagnosis:

> "*Yeah to be honest, there's been a few good friends that you could talk to about it, yeah 100%, yeah friends more than family like we didn't really have a family around*" [**P04: Son**].

A further unique factor for children and young adults living with a parent with YOD is the threat the condition poses to the child's sense of identity or the child's sense of self. As a consequence of their parents condition, children often are required to take on more responsibility within the family system. For some children and young adults, this role reversal may mean that they have to grow up much sooner than normal. Furthermore, they may feel as if they are now the adult as they begin to parent their parent. This sense of change and threat to their identity was illustrated in several participant narratives:

> "*So much has changed, I feel that my* [parent] *isn't my* [parent] *now. I'm looking after her, like. It's not the way it should be, I shouldn't be the parent, I'm way to young like, you know*" [**P13: Daughter**].

For other participants, they felt as if they had to take on the responsibility of seeking and providing information about YOD. As their ill parents condition deteriorated, many reported that they also had to step into their well parents shoes in order to gain the relevant knowledge in relation to the condition:

> "*It was left to me to talk to the* [health care provider] *as my* [parent] *wasn't able to speak with them. It was the same with researching what was happening, I had to do all that, but we needed to know what to expect* " [**P05: Son**].

The sense that children and young adults have to "*grow up*" quickly when faced with parental YOD was apparent in the narratives. Participants reported how the deterioration of cognitive function(s) combined with the other symptoms associated with a neurodegenerative condition can lead to children witnessing distressing episodes:

> "*… being so young and seeing things like your* [parent] *being so angry and confused. It was so upsetting, my* [parent] *would say and do things and have no recollection afterwards. Me and my* [sibling] *just had to help my* [well parent] *you know*" [**P01: Daughter**].

6.5.2 Theme 2: Power of Communication

Communication is a crucial component in order to combat some of the negative factors following their parents formal diagnosis. Whether its communication with their well parent or health and social care providers, children in the current study reported the importance of open, honest, and simple communication:

> "*I think they* [health care professionals] *mainly talked to mum, and then she like told us what was going on, but like there's a few of them that would like, sit down and talk to us about us*" [**P01: Daughter**].

When health and social care professionals spoke with children in a calm and open manner, participants reported that they felt less ignored or forgotten.

Interestingly, when the health and social care professional(s) were younger, or closer to the child’s age, this appears to have helped the situation:

> “*…it was, yeah, it was good to talk to* [health care professional]. *I suppose, I felt that cause* [health care professional] *was younger than the others, like cause she not too much older than I was…*” [**P07: Daughter**].

Communication with other children and young adults in a similar situation was viewed as a positive factor. Several narratives referenced the benefits of sharing in order to give and receive help. Therefore, as an intervention, peer-to-peer support could be a crucial component:

> “*Yeah, I would think that would be a great idea, 100% yeah, because you might be able to help out another person who is living with it, and you might be able to take home advice about how they are coping…what helps them at home as well. You would both be, maybe helping each other out in one way*” [**P04: Son**].

Moreover, peer-to-peer support could also be utilised by children and young adults to increase their education and awareness about YOD. Participants in the current study outlined how knowledge acquisition could then be passed on to siblings, extended family members and the wider community in order to increase awareness and tackle the typical portrayal of dementia:

> “*…even if you do sit down and tell person a person that's our* [parent] *has been, like, diagnosed with dementia, their first reactions shock. Because they can't believe how, they're like, how did he get it at such a young age is the first question. That’s the first thing they’d say to you*” [**P03: Daughter**].

Peer-to-peer support could also alleviate the load on the well parent. Participants reported how their well parent was under significant pressure, not only as a primary carer, but also as a source of comfort and information for their children. Peer support groups may assist in dispersing this pressure as children and young adults could lean on the group as a source of information and consolation instead of their well parent:

> “*You need the adults to be on top of their game with support, so they can talk through what's happening. It’s only in the last year that were trying to really to make people more aware of it, and its only in the last twelve months that were talking more about it. Its only now really like that we're hearing other people's stories, who are like the same age as my* [parent] *as well, or younger*” [**P11: Daughter**].

If children and young adult do utilise peer support as a source of consolation and solace, it may also help to ease some of the stress, anxiety and anger that children and young adults experience as a result of their parents diagnosis. Several participants referenced this in the current study:

> “*… because I find it so hard to get used to my* [parent] *being, like the way they are, ill like, I do get mad, really mad. And sometimes I’ll lose the head and go off on one...but I think if I was able to talk to other people going through the same thing, I think it might, like, help me to keep the head, like …*” [**P08: Son**].

Similarly, some children and young adults talked about how communicating with those in a similar situation could make them feel more comfortable. Participants reported that if they were in a situation, such as a peer support group, were others were sharing their stories, it may help them to open up and also share:

> “*...I don’t know. But I do think that if I was in a group were they were all sharing, it might help me to share to, like I’d say, I’d feel happy to do that. That’d be a big deal for me like, if others opened up, I would too*” [**P12: Daughter**].

However, the significance of communication being reciprocal was also outlined in the narratives. Participants illustrated the importance of sharing with somebody who is experiencing the same situation, rather than somebody who is not:

> "*...no, no, someone lecturing to me about something they know nothing about, I wouldn't like that at all, like. I wouldn't last long in that group* [laughs] *for me it would have to be someone going through the same thing, who knows the story like...*" [**P10: Son**].

6.5.3 Theme 3: Support that fits

Finding a support network that fits appears to be an extremely important factor. Participants cited that a suitable support network could help them to tackle issues such stigma and taboo that appears to accompany YOD. For several participants in the current study, the stigma associated with YOD was an ongoing issue. Children and young adults reported that they faced stigma regularly, mainly as a result of societal ignorance in relation to YOD. However, when the opportunity arose to speak with others in the same, or similar situation, participants felt much more at ease:

> "*…nobody wants to know about it* [young onset dementia] *or asks how you're doing. So, people just avoid me, and I avoid them too, probably cause it's just easier. But when I speak with others who know parental young onset, I feel it's so much easier, you know, just to talk...*" [**P05: Son**].

One of the salient reasons why children and young adults feel it easier to avoid other members of society may be due to the sense of guilt and shame felt by some. Various participants referred to feeling guilty or ashamed following their parents diagnosis and also admit that they did not know why. Interestingly, individuals appear to have no issues speaking about other illnesses or even late onset dementia, however, YOD seems to remain a taboo subject:

> "*...yeah, guilty and ashamed, and I have no idea why. Friends will often talk openly about other illness, like cancer for example. Some of my friends even talk about their older relatives having dementia, so why it is so hard for me to talk about my* [parents] *diagnosis?* [**P02: Daughter**].

The taboo surrounding YOD was especially noticeable for some children and young adults who reported that they would never speak about it outside of their immediate family unit:

> "*What happens in our house stays in the house, and there's no chance that I'll talk about it with anyone. Its cause of the shame that comes with the diagnosis*" [**P10: Son**].

Therefore, peer support may be an extremely important tool to break the taboo and tackle the stigma associated with YOD. This may also assist children and young adults feel less guilt, shame and isolation following their parents diagnosis:

> "*... to help me to stop feeling so alone and isolated, and feeling guilty all the time. It kinda helps when I talk to somebody who is sharing the exact same experience as me*" [**P01: Daughter**].

> "*... just somebody the same age to talk to and to maybe…just see that I am not the only one who's going through this*" [**P13: Daughter**].

Participants outlined that if an intervention involving peer-to-peer support was made available, it must be age appropriate. Several participants reported that they had attended various support groups on offer, typically by a dementia charity. However, these support groups were routinely designed for older adults, both older adults with dementia and their carers:

> "*You know, that's kinda something that annoys me so much. I help to look after my* [parent] *and yeah, there are some groups we've gone to, but they're not for us. They're not our generation, so how would they understand?*" [**P02: Daughter**].

Other children and young adults reported finding themselves in a similar situation. Attending a support group, only to find it was tailored to older adults and their family members, that in some instances were spouses or partners:

> "*A lot of the people who were around be whose parents did have different kinds of dementias. Their parents were of a different generation and they themselves were of a different generation, and so I just felt like my problems were not problems that they necessarily identified with. Do you know what I mean. I'm in my 20s but they're in their 50s, yeah they were old enough to be my parents*" [**P09: Daughter**].

> "*…and as a daughter, there's no support for me at all. I went to a peer-support group once in* [dementia organisation], *but everyone there was a wife or partner, you know. Like, how was I expected to relate to them, like, and sure they couldn't relate to me either…*" [**P12: Daughter**].

Likewise, when a child's well parent attempted to obtain practical assistance for their children, it can be a baffling and frustrating experience:

> "*…my* [well parent] *called the* [dementia organisation] *cause they have a family resource therapist, but she's actually a family counsellor. But like, she doesn't actually accept referrals for under 18`s, again so like, you know, it's a pity that there's again very little supports for us*" [**P11: Daughter**].

When children and young adults find support that fits, whether formal or informal, it can have a significantly positive effect. For example, participants spoke about how a suitable support network can be a crucial tool to assist them to cope:

> "*…yeah, like we you know we're in a housing estate with friend and neighbours nearby and you know people, we can call them, its brilliant to be able to do that, you know*" [**P02: Daughter**].

Similarly, several participant highlighted the role that their work colleagues had played in helping them following their parent(s) diagnosis. However, while having work colleagues to speak with is a positive, younger children do not have this facility:

> "*Actually, I didn't need to do a lot, I mean, I had a lot of support from my peers at work, and d'you know, that could it be really useful for me when I was younger*" [**P01: Daughter**].

When asked whether a suitable peer support intervention would work best either face-to-face or online, some participants stated that they would prefer an online based method of delivery:

> "*I'd say that an online support group would work well, yeah. I'd be happy with online*" [**P10: Son**].

> "*... yeah, something to do with* social *media could be a good space, like I feel like, maybe if there's someone else experiencing this, and they can feel a little less alone*" [**P01: Daughter**].

While for other participants, a face-to-face or group type intervention would be the preferable method:

> "*A group session probably like, like face-to-face, yeah*" [**P06: Daughter**].

6.6 Discussion

The current study examined whether there is a need for peer-to-peer support for children and young adults impacted by parental YOD. Three themes with related subthemes emerged from the narratives (see table 17). All the participants interviewed in the current study agreed that there is a need for peer-to-peer support. The line of argument (Noblit & Hare, 1988) was situated in the fact that meeting with other young people affected by parental YOD would be extremely beneficial. Likewise, evidence from those participants who had previously experienced peer support also reported the benefits, specifically, the sense of shared understanding that comes from a shared experience (Johannessen et al., 2016).

Participants in the current study reported that they had experienced significant changes in their relationships with their ill parent and subsequently this can have an impact on their relationship with their well parent. As a result, children and young adults struggle with their emotional and psychological well-being as they attempt to cope with the changing situation. Furthermore, the emotional consequences can also impact on how children and young adults feel about themselves, particularly as the changing situation may force them to re-evaluate their daily routine, their life plans and future goals. Such emotions can also effect children in different ways depending on the child's stage of development. In other words, the older and more mature the child is when parental YOD enters the family, the better their ability to cope (Erikson, 1958; 1963). Therefore, children and young adults have unique and specific needs for different types of support at different stages of their lives during their parent's illness.

However, these specific needs related to the child's developmental stage may not be instinctively apparent to health and social care providers. In fact, children and young adults in the current study report feeling a disconnect from health and social care providers. In particular, participants cited poor communication and a lack of recognition and reciprocity as significant factors that can prevent them from engaging with health professionals. Therefore, children and young adults in the current study stated that they rely on their well parent for information, however, they also realise that this adds to the stress and anxiety felt by their well parent. As a result, this makes children and young adults feel guilty adding to their negative emotions in an extremely negative spiral.

Although research on the impact of parental YOD on children is scarce, similar findings have emerged in research conducted by Nichols and colleagues (2013). The authors conducted semi-structured interviews with fourteen young children under eighteen years of age who were living with a parent diagnosed with YOD. Findings reported factors such as the lack of familiarity with health and social care providers combined with little or no guidance as reasons for the disconnect. As a result, the majority of children admitted that they relied on their well parent as a means of information and support, followed by siblings, extended family and friends.

The healthy parent's role included providing information, emotional support, and a sense of stability. However, feelings of anxiety and guilt were common among children as they feared that this reliance may significantly overburden their healthy parent, resulting in overcompensation and a compulsive need to care. Moreover, children who may have difficulties in communication with their healthy parent, and wider family members, may find a lack of commonality and unity within the family (Nichols et al., 2013).

Such emotional upheaval at a relatively young age can have lifelong consequence for children and young adults. For example, in a retrospective study conducted by Charles and colleagues (2010) the authors outlined how the effects of psychological strain in early childhood can led individuals to act as carers in all future relationships. As a result of the responsibility, they felt as children and young adults, individuals reported that they grew up to soon which led to being isolated from friends and peers (Charles et al., 2010).

For instance, a synthesis of the literature on young carers' experiences found that caring became an important part of adolescents' emerging identity, which helped to reduce feelings of guilt and anxiety (Rose & Cohen, 2010). This may therefore be one way in which some adolescents resolve the impact on their identity associated with caring for a parent with YOD. Adolescents may have particular needs for emotional support in order to safely explore their identity and independence in the context of their caring role. It may be this group for whom peer support, possibly through collaboration between young carer and dementia services, would be most beneficial.

Children and young adults in the current study outlined how they felt that parental YOD was a unique illness and experience. This seems to stem from the age profile of those diagnosed with the condition and the societal construct of dementia.

Typically, dementia is portrayed in society as being a disease of old age or is associated with a much older cohort who are at a much later stage of life. However, as YOD develops at a much younger age participants reported that how this aspect made their parents diagnosis unique and difficult to comprehend. Children and young adults in the current study reported how they felt that they had to grow up quickly in order to feel useful and help in the home. As their stress levels increase, participants also reported that they did not want to overburden their well parent. As a result, participants may turn to friends, peers and school or work colleagues for solace.

However, for some participants the stigma associated with dementia, and in particular, YOD may mean this avenue of support can be problematic. The stigma appears to result from a significant lack of knowledge and awareness of YOD among the general public. This can have a detrimental effect on children and young adults who rely on friends and peers for support. For example, while friends and colleagues may be willing to help, many lack the understanding and knowledge in relation to YOD to be an effective support system (Nichols et al., 2013). When research has been conducted with children living with a parent with YOD in relation to peer support, participants agreed that peer support groups would beneficial. However, participants cited that such groups should be small in size and organised by age in order to allow for relaxed discussion (Nichols et al., 2013).

Participants in the current study were aware that both charitable organisations working in the area of dementia support and certain health and social care providers do provide peer support interventions. However, participants also cited the need for tailored support specifically accounting for age. Many of the supports currently available are unsuitable for use by a younger cohort and need be more age adaptive to function for children and young adults.

There is a consensus within the literature that peer support for people caring for someone with dementia is of crucial importance. However, a vast quantity of the literature focuses on people with YOD themselves, spouses and partners, and children over the age of eighteen (Carter et al., 2020; Queluz et al., 2020) with little or no evidence with pre-adolescent and adolescent children leading to significant gaps in our understanding of peer support for this cohort (Roach et al., 2016).

There needs to be a greater recognition of the diversity in dementia, particularly within the largely homogenous dementia care sector. Acknowledging this diversity may afford pre-adolescent and adolescent children affected by parental YOD the opportunity to partake in tailored peer support. There is a growing body of literature on living with an atypical subtype of dementia such as YOD that is illustrating the need for adaptive peer support models specifically aimed at those previously overlooked (Sullivan et al., 2022). Adapting and tailoring peer support to include this cohort can build on the strength of the social similarity they share.

6.7 Strengths and limitations

There are a number of strengths and limitations associated with this study. For example, the sample size is relatively small (*n* = 13), however it is similar to sample sizes used in similar research. The gender bias in the sample must also be acknowledged as almost seventy percent (69.23%) of participants were female. Similarly, only seven participants (53.8%) were aged eighteen or younger at the time of interview. Future research could address both issues by including younger children in a more gender balanced sample. Other strengths and limitations in relation to the use of a qualitative methodology and the generalisability of the findings are addressed elsewhere in this thesis.

6.8 Chapter conclusion

The novel approach adopted in this chapter with the inclusion of younger children combined with the findings in relation to the need for peer-to-peer support will inform the direction of any future research. All of the participants in this study stated that they thought a group experience could be extremely beneficial. In particular participants cited how it was difficult to talk to friends, extended family members or health and social care providers who, they felt, would not understand their particular set of circumstances.

Participants reported that a peer-to-peer setting could give them the space to share their feelings with others who are in a similar situation. Such a setting could allow children and young adults to unmask feelings of anxiety, stress, fear and anger in a safe space. Importantly, peer-to-peer support groups could be extremely useful in tackling the loneliness felt by some children and assist with building comradery and trust.

Consequently, peer support groups could help with reinforcing of self-efficacy and self-esteem in children and young adults. Practical aspects of peer support groups for children could be in relation to the acquisition and sharing of knowledge, thus improving their both their understanding and management of YOD. Specifically, children could have the opportunity to share experiences with others who may be facing atypical types of dementia.

Similarly, children and young adults may also learn new ways to communicate with their both ill and well parents. Additionally, providing a peer support intervention may assist with the psychological adjustment needed when a parent is diagnosed with dementia at a relatively younger age. Given the difficulty in accessing professional psychological support and mental health services, particularly in Ireland, a peer support network for children may be invaluable.

7. General Discussion

7.1 Chapter Introduction

The overall aim of this thesis was to gain an in depth understanding of the experience(s) of children and younger adults who are affected by parental young onset dementia (YOD). Specifically, it was envisaged that this thesis would serve as a vehicle that gives a voice to their experiences. This chapter will synthesise the research presented in this thesis within the wider context of relevant literature. In particular, this chapter will unify the findings uncovered across the four empirical studies included in this thesis, and present them under the following headings:

- 7.2 Summary of the main findings.
- 7.3 How Public Patient Involvement (PPI) shaped this thesis.
- 7.4 Understanding YOD from the perspective of the family system.
- 7.5 Children live here too.
- 7.6 Could peer-to-peer support help?
- 7.7 Why the social construct of dementia matters.
- 7.8 Recommendations
- 7.9 Unique contribution of this thesis – Strengths & limitations.
- 7.10 Conclusion
- 7.11 Research output from this thesis.

7.2 Summary of the main findings

A number of common themes linked the findings that emerged from the four individual research studies. For instance, the stereotypical view of dementia combined with the general lack of awareness and understanding about YOD can lead to pronounced stigma at both a familial and societal level. However, this thesis adds a significant contribution to current literature due to the novel insights obtained from children and young adults who live with (or have lived with) a parent diagnosed with YOD. Children and young adults face significant and unique challenges and therefore require unique and tailored psycho-social support(s).

Chapter 3 – Study 1: Young Onset Dementia: A focus group study examining the experience from the perspective of Family Systems Theory.

Objective: To understand the pathway from initial symptom onset through to receiving a definitive diagnosis.

Questions considered:

- How do PwYOD and their families adjust and cope with the diagnosis?
- Are adaptive health and social care supports available to people with YOD and their families in Ireland and do they avail of these supports?

Utilising Public Patient Involvement (PPI) a participatory workshop with people living with young onset dementia (PwYOD) was held in order to uncover specific issues of relevance to PwYOD and their families, or to identify any gaps in the literature, that could subsequently be explored. Findings from the workshop lead the way for the inclusion of the wider family in the research. Employing Family Systems Theory as the theoretical framework established that the entire family system experiences significant challenges as a result of a diagnosis of YOD. Several findings are consistent with current and prior research; however, novel findings related to children and younger adults experiences of parental YOD.

Chapter 4 – Study 2: Childhood perspectives of parental young onset dementia: A qualitative data synthesis.

Objective: Examine the current qualitative literature relating to children and younger adults experiences of parental YOD by means of a systematic review and synthesis.

Questions considered:

- Does empirical evidence exist that illustrates the impact that living with a parent with YOD has on children and younger adults?
- How does the existing qualitative data assist with our understanding of this cohorts experiences of parental YOD?

Findings from chapter three highlighted the significant gap in the literature in relation to children and younger adults experiences of parental YOD, and the need to include children in research on the topic. What research does exist details how children and younger adults are faced with substantial psycho-social issues as a result of their parents diagnosis. In particular, stigma was significantly prevalent in the children’s narratives. Children also described issues such as changing relationships; physical strain and coping strategies.

Chapter 5 – Study 3: The influence of Social Constructivism on children and young adults experiences of parental YOD.

Objective: Investigate whether the social construct of dementia, and in particular YOD, has an influence on children and young adults whose parents have developed the condition.

Questions considered:

- Do children and young adults compare parental YOD to other illnesses?
- If so, do the comparisons involve similar conditions – i.e., other neurodegenerative conditions or different conditions – i.e., cancer?
- Does the social construct of these other illnesses effect children's perceptions of YOD?

Society can and does contribute to the psychological anguish of children and younger adults due to the social construct of dementia. Children and young adults use comparisons with other perceived "*more normal*" illnesses such as cancer as a form of coping mechanism. Children and young adults feel isolated and alone as a result of their caring role at a time when they are experiencing considerable developmental challenges. The inadequacy of available age-adaptive support is a further contributing factor compounding the loneliness felt by children. Children and young adults face significant losses in comparison with their peers. For example, lost friendships and lost educational and/or career attainment as a result of their association with their ill parent can be explained by social constructivism and cultural transmission.

The novel approach adopted in this study with the inclusion of younger children combined with the findings illustrate the significant need for age-adaptive support and educational and awareness campaigns that would significantly benefit children, young adults and the entire family system. Shifting the focus to ensure that support services are tailored may assist to keep the family system better connected resulting in an acknowledgement of all needs within the system and improvements in emotional wellbeing.

Chapter 6 – Study 4: Investigating the need for peer support groups for children affected by parental YOD.

Objective: Investigate whether or not there is a need for peer-to-peer support for children and young adults affected by parental YOD.

Questions considered:

- Is there a need for peer support groups for children and young adults living with a parent with YOD?
- Would peer support groups assist children and young adults with knowledge acquisition and knowledge sharing in relation to YOD?
- Would peer support groups assist in alleviating the anxiety and stress felt by children and young adults living with a parent with YOD?
- If there is a need for peer support groups, would it be beneficial to stratify such groups by age?
- How would children and young adults like the peer support to be delivered: face-to-face or online?

Children and young adults expressed an overwhelming appetite for age-adaptive peer-to-peer support. The use of such a strategy as a coping mechanism was further endorsed by the children's well-parents. All of the participants in this study stated that they thought a group experience could be extremely beneficial. In particular children and young adults cited how it was difficult to talk to friends, extended family members or health and social care providers who, they felt, would not understand their particular set of circumstances. A peer-to-peer setting could give them the space to share their feelings with others who are in a similar situation.

Such a setting could allow children and young adults to unmask feelings of anxiety, stress, fear and anger in a safe space. Importantly, peer-to-peer support groups could be extremely useful in tackling the loneliness felt by some children and assist with building comradery and trust. Consequently, peer support groups could help with reinforcing of self-efficacy and self-esteem in children and young adults.

Practical aspects of peer support groups for children could be in relation to the acquisition and sharing of knowledge, thus improving their both their understanding and management of YOD. Specifically, children could have the opportunity to share experiences with others who may be facing atypical types of dementia. Given the difficulty in accessing professional psychological support and mental health services, particularly in Ireland, a peer support network for children may be invaluable.

7.3 How Public Patient Involvement (PPI) shaped this thesis.

In recent years, there has been a growing recognition of the importance of the views and opinions of patients in relation to health and social care research. Including such views and opinions can considerably improve the quality and relevance of the research and, as a result, has increased the profile of public and patient involvement (Tinetti & Basch, 2013; Mockford et al., 2016). Subsequently, public and patient involvement (PPI) has helped to improve the influence and scope of health and social care research, as PPI can assist in ensuring that the research question(s), researcher conduct and research outcomes are relevant and meaningful to both patients and the public (Boote et al., 2015).

Moreover, PPI contributors can be involved as co-producers during every stage of the research from identifying and prioritising the research topic(s) or question(s) to disseminating the research findings (Staniszewska et al., 2018). Therefore, PPI allows patients and members of the public to collaborate directly with the research team in order to assist with the design, creation and dissemination of research in a true co-production (Brice et al., 2015). The application of co-production can be a flexible process with the public and patients freely engaging in all aspects of the research at any stage during the research process.

For example, PPI may involve an initial consultation, reviews of protocols or manuscripts, reciprocal feedback, editing documents such as consent forms and information leaflets etc., and assisting during participant recruitment. Moreover, members of the public and patients can commission research and actively look for specific researchers to employ as part of the project (Price et al., 2018).

In relation to involving people with dementia and/or family members/carers in PPI, Miah and colleagues (2020) outlined the benefits to both the quality and relevance of the research and the benefits to the clients themselves. For instance, clients cited how working as part of a group during the PPI process was like receiving peer support in an environment that fostered mutual understanding. Clients also reported that they had gained new knowledge during the PPI process, and praised the benefits of receiving research awareness training that helped them to make a meaningful contribution to the research (Miah et al., 2020).

Similarly, Alzheimer Europe actively promotes the benefits of including people living with dementia in health and social care research, not just as participants, but as active advocates through PPI. The organisation readily acknowledges that people with dementia can advise the researchers, prioritise research topics and influence the research direction through PPI, as they are experts by experience (Gove et al., 2018).

PPI can involve people living with dementia in a range of activities, from being consulted at the beginning and at specific stages throughout the research project to being significantly involved as co-researchers with key responsibilities such as the collection, analysis and dissemination of data (McNichol & Grimshaw, 2014).

Therefore, while gaps in the existing literature did help to generate relevant research questions/topics for this thesis, the use of PPI was a major contributing factor. As detailed in chapters two and three, there was significant involvement from people living with YOD through of PPI at the beginning of this research. PPI assisted to developed specific research topics that guided the initial (and subsequent) phase(s) of this thesis. Although we had various issues and topics that we wished to investigate in relation to YOD, we were also acutely aware that people with YOD are the experts of their own experience.

Therefore, we decided to hold a participatory workshop with people with YOD in order to uncover relevant topics or issues that they wished to be investigated. Several topics emerged that are consistent with existing research, however novel topics such as children's experiences of living with a parent with YOD also emerged.

As a result, we decided to include children as part of the focus group interviews for the initial research study. Children who were included in opening study were all over eighteen years of age, however in the subsequent studies the experiences of children under eighteen years of age were also explored. Without the use of PPI during the initial phases of this thesis, childhood experiences of living with a parent with YOD would not have been explored. As such, it is fair to say that PPI changed the entire focus and direction of the research presented in this thesis and was responsible for the rationale to investigate children's experiences of YOD.

7.4 Understanding YOD from the perspective of the family system.

As detailed in the study described in chapter three and following the impact of PPI, the experience of YOD was examined through the lens of family systems theory in order to capture the perspectives of all members of the family at varying stages of their lives. Gaining a wide and varying range of perspectives from family members living with by YOD is essential in order to understand the impact of the condition. As far as I am aware, the perspectives of the entire family system are typically lacking in the academic literature in relation to YOD.

Research tends to focus on the dyadic relationship between the person with YOD and their primary carer, usually a spouse or partner. This thesis has brought the experiences of all family members, and especially the experiences of children and younger adults, to the fore. Furthermore, the significant lack of research with children and younger adults can negatively reinforce their sense of unimportance in relation to their parents condition, something that I hope this thesis has addressed. Each individual family member has to confront the challenge(s) that a diagnosis of YOD brings into the home, challenges that can influence the quality of relationships across the entire family system.

Therefore, it is crucial when exploring the impact of YOD to recognise the circumstances that affect the individual also affect the entire family. Utilising family systems theory can significantly help with our understanding of how families cope when faced with adversity such as a members illness. As detailed in chapter two and three, families are comprised a group of people who are organised into a close unit living together in the same location. The members of the unit are both related to each other and dependent on one another and members can include parents, children, and others.

Family system theory focuses on the various groupings that can evolve within the family, and how they can assist in alleviating anxiety (Bowen, 1966, 1978, Kerr & Bowen, 1988). According to Bowen (1966) the perceived closeness of inter-familial relationships can be a major cause of anxiety among family members (i.e., either too close or too distant). For instance, if members are unable to consider and acknowledge internal relationship issues, then the family risks living with constant levels of anxiety. Consequently, this internal anxiety can considerably limit the families ability to deal with any external stressors, for example, a diagnosis of a progressive neurodegenerative disease such as YOD.

The insight(s) and understanding(s) attained through the use of family system theory can be used to tailor relevant health and social care supports for the entire family unit and the individual members within it. Most importantly however, family system theory demonstrates that children and younger adults are also part of the family unit.

Therefore, any health and social care supports need to be age-adaptive to cater for the differing developmental stages within the family, and this aspect is examined in chapter six of this thesis. Moreover, health and social care providers need to understand that a family living with YOD may not just be a dyad of husband/wife or partner/partner but can also include children.

Findings from the study described in chapter three illustrate the impact on the entire family system including shifting relationships and boundaries with participants reporting significant alterations in roles. Spousal carers reflected on the physical and emotional strain, while children spoke about future plans being put on hold or scrapped completely. Children also outlined how they were forced to cross traditional familial boundaries and assume a more responsible role, such as managing finances, running the household and caring for their ill parent.

Participants referred to this situation as an evolution that requires a substantial period of adjustment. While there were many challenges reported that face the family system, some participants stated that the situation had brought the family closer together as a unit. For example, some participants reported that they often felt a sense of accomplishment and gratification as a deep bond was formed by the family. While others cited that the transition to new roles allowed for a sense of purpose. However, it is clear that a diagnosis of YOD is a significant challenge for the entire family system.

7.5 Children live here too

As outlined above and elsewhere in this thesis, children and younger adults may be faced with the effects of YOD as part of the family system. However, the consequences of this typically receives little, or no attention in the academic literature. The research presented in this thesis has attempted to address this. Through the use of family systems theory and social construct theory, chapters three and five of this thesis solely focus on children's and younger adults experiences of parental YOD.

A common thread running through this thesis is that there is a complete lack of awareness and understanding in relation to YOD from society in general leading to considerable unpleasantness for the entire family. In particular, there is no recognition that young people, who are parents and who have children living in the home, can be diagnosed with a disease such as dementia. In other words, the stereotypical perception of dementia prevails, where the majority of society regards the condition as only afflicting the older population. This impression is extremely difficult to jettison with YOD being perceived as a deviation from "*the normal*" aging process.

Therefore, many families may attempt to hide the diagnosis from their community as the fear of stigma is ever present (Hutchinson et al., 2016) another common theme that was uncovered in this thesis. This may explain why so many children are assumed to be grandchildren if they disclose that dementia has visited the family (Gelman & Rhames, 2018).

However, it is an impression that urgently needs to be discarded by society, and the health and social care sectors within it, in order that we can acknowledge and assist children within families who are impacted by parental YOD (Gelman & Greer, 2011). Furthermore, the problems that children can encounter when faced with parental YOD are not the sole preserve of the dementia sector, as they can extend into other settings such as education, employment and health. Moreover, there appears to be the possibility for appreciable connection and cooperation among various sectors throughout society (Gelman & Greer, 2011).

While this lack of awareness can increase the detrimental effect on the entire family system, increasing the levels of distress and anxiety, it has considerable ramifications for children and younger adults facing YOD. For example, as family relationships become increasingly strained, children can feel isolated and forgotten within their family and community with very little options for help (Gelman & Rhames, 2018).

For instance, evidence presented in chapters four, five and six of this thesis demonstrates the lack of both formal and informal support for families facing YOD. As parents grapple with a life changing diagnosis and are forced to fight for assistance from the health and social care sector, children (particularly young children) typically go unnoticed. Participants in this research recalled being completed ignored by the health and social care professionals, and when they were acknowledged, communication was extremely poor. Such experiences only augment children's sense of exclusion from the situation and reinforces their beliefs about staying silent (Gelman & Rhames, 2018).

One reason why health professionals may choose not to communicate with children stems from the child's developmental stage at the time of their parents diagnosis. In other words, some children may be perceived as "*too young to understand*". Despite this perception, many children in this research reported that they have (or had) significant caring roles and responsibilities that disregard their age profile. Children are frequently required to assist their well parent with care giving tasks and household chores, particularly when other members of the family may be preoccupied and agitated by the situation (Allen et al., 2009).

This can, and has, resulted in significant distress for children and younger adults. Evidence proffered in chapter four and five of this thesis cites that children sometimes feel as if they have absolutely no control over the situation and find it difficult to cope. Some children reported that they would rather leave the family altogether. However, if they cannot flee physically, children may employ risky behaviours as a substitute in order to "*get out*" mentally and emotionally (Barca et al., 2014). Such difficult psychological and emotional circumstances could be alleviated by providing an opportunity or intervention for children to express their feelings and emotions in a secure and non-critical way.

7.6 Could peer-to-peer support help?

Chapter six of this thesis proposes such an opportunity – the utilisation of peer-to-peer support as an intervention for children and younger adults facing parental YOD. The rationale for peer-to-peer support stems from the knowledge that children and younger adults range in their developmental stage. We must understand that children's cognitive abilities significantly differ from adults, and as such they cannot be expected to react to extreme stressors as maturely (Johannessen et al., 2016).

Moreover, children's development can be stunted by shouldering caring responsibilities, as well as attempting to deal with grief and loss as they anticipate the death of their ill parent (Roach et al., 2016; Rolland, 2006). As children are confronted with an uncertain future as a consequence of parental YOD, their fears and anxieties are real as they face the unknown. For many children their parents diagnosis comes at a developmental stage when they are attempting to discover who they are. They may be trying to find their own independence and explore the world away from the family system and their parents diagnosis may curtail this exploration.

Children may also feel that the protection and support typically associated with their family system suddenly ceases as other family members deal with the illness. Without this support presently and for the foreseeable future, children may be unprotected in the face of the challenges that life may bring (Allen et al., 2009; Sikes & Hall, 2017). A similar scenario is reported in research with adolescent children whose parents have been diagnosed with cancer (Maynard et al., 2013). For example, the importance of a positive parent/child relationship can act as a bulwark against life's stressors, boosting both the child's self-esteem and their adjustment to their parents illness (Lewis & Darby, 2003).

Interestingly, participants reported similar feelings in chapter six of this thesis. For example, children spoke about feeling that they had to grow up too soon as they took on more of an adult role. As a result, they felt that their sense of identity was lost as they were forced to postpone or cancel future hopes, plans and dreams. Participants also compared YOD to other illnesses in an attempt to make sense of the situation. Something that was also observed in the research presented in chapter five of this thesis.

However, children and younger adults also stated that YOD was a unique experience, due mainly to the age profile of their ill parent. It appears that this uniqueness combined with the lack of awareness and stigma associated with YOD prohibits children from opening up about their experiences. They further cited that they did not want to place any extra burden on their well parent and as a result felt as if they had nowhere or no one to turn to.

Therefore, peer-to-peer support may be a crucial intervention to help children facing parental YOD share their feelings about their experience. A detailed definition and explanation of peer support is presented in chapter six, however, it basically refers to a way of giving and receiving mutual emotional support and comfort (Mead et al., 2001). Peer support has long been established in other fields such as mental health where it has been welcomed by both clients and providers (Mackay et al., 2022) and is a vital cog in the wheel of a person-centred care (Solomon, 2004).

Peer-to-peer support has proven efficacious in other neurodegenerative conditions such as motor neuron disease. Ugalde and colleagues (2018) examined if a self-care, problem-solving and mindfulness intervention for informal carers of people living with ALS would be accepted by participants. Findings outlined that participants liked the intervention, particularly valuing the group format, and would recommend it to others.

Similarly, Cipolletta and colleagues (2018) recorded the experiences of family cares of people with motor neuron disease who took part in two peer support groups. Participants were unanimous in agreement that peer support would offer them the opportunity to share their experiences and advice with people similar to themselves. It must be stated that in both studies referenced above, all the participants were adults and over eighteen years of age.

In relation to peer-to-peer support interventions for people living with or caring for someone with dementia, this thesis is not attempting to reinvent the wheel. On the contrary, we are well aware that peer support interventions have been (and are being used) with family carers in YOD for several years. For example, in a recent integrative review, Sullivan and colleagues (2022) identified and synthesised the literature on peer support interventions for people living with or caring for individuals with a rare form of dementia or YOD.

The synthesis spanned almost twenty years of research with the results reporting several peer-to-peer interventions that were either community or hospital based. Findings also outlined the valuable contribution of such interventions and of peer support in general. However, similar to the evidence outlined above about peer support in motor neuron disease, Sullivan and colleagues (2022) recent analysis only examined interventions for people over eighteen years of age.

Therefore, while we stated that we do not want to reinvent the wheel, we do want to include young children – i.e., pre-adolescent and adolescent children in any proposed intervention. Our rationale for the inclusion of young children stems from the research presented in this thesis as many of the participants in this research were under the age of eighteen when they faced parental YOD.

7.7 Why the social construct of dementia matters.

All of the children and young adults who participated in this research were carers during some part of their pre-adolescent, adolescent or young adult lives. For some participants, this was a willing choice, for others though it resulted from some sense of obligation to their family, specifically their well parent.

For those participants who were in their late twenties of earlier thirties when interviewed, participation gave them an opportunity to reflect on the difficulties that being a young carer brought to their earlier lives. Some became emotional upset when recalling their own behaviour, particularly when the behaviour was negative and not conducive to a harmonious household. When asked about the reasons for the negative behaviour, many participants cited the stigma associated with dementia, and particularly YOD. Typically, they reported that they did not want to be seen as different from their peers or draw attention to themselves or their family. Consequentially, they kept any needs or concerns to themselves, however, as the stress built their behaviour sometimes deteriorated.

One significant reason why children and young adults may have felt (and still feel) the need to keep their feelings about parental YOD bottled up is the stereotypical perception of dementia combined with the stigma associated with the condition. As detailed in chapter five of this thesis, the perception of dementia has been socially constructed and culturally transmitted across the generations. Briefly, cultural transmission theory hypothesises that beliefs and attitudes are learned or constructed through social interaction and they are not only specific of their time, but also transmitted through time (Cavalli-Sforza et al., 1982).

As opposed to learning through experience, active engagement is not essential, as learning is gained freely by being a member of a social environment. In other words, certain beliefs, attitudes, behaviours and norms are passed from one generation to the next in a form of socialisation (Grusec & Hastings, 2014). The problem with the social construct of dementia is that it has been, and still is, associated with ageing and decay. Older age is viewed as a time in life when human beings begin to deteriorate and decline, with this deterioration linked to deficits with our mental processes (Cipriani et al., 2011).

Consequently, dementia has been negatively socially constructed as being related solely to aging, rather than being a disease of the brain, with older members of society regularly being referred to as demented or cognitively/mentally challenged (Boller & Forbes, 1998). Even the language used is problematic as the word dementia or demented can conjure up images of madness or insanity (Feldman, 2007).

So, if dementia is perceived as a disease of older age, manifesting as we begin to decay, then YOD completely contradicts this view as symptom onset occurs at a much younger age. Therefore, YOD is often perceived as discrepant with the normal life course (Allen et al., 2009; Aslett et al., 2019) and can be viewed with scepticism and mistrust by an ill-informed public as a result (Hoppe, 2018).

As outlined above, and elsewhere in this thesis, participants in this research stated numerous times that they did not want to be seen as different from their peers or draw attention to themselves or their family. In other words, they did not want to be seen as different from their society. However, despite this society automatically marks them as different because of YOD and the social construct of the same. As described in chapter five this can be extremely difficult, particularly for developing children, who do not see families like their own represented in society which can lead to issues in later life (Johannessen et al., 2016).

As described throughout this thesis YOD is significantly more than a medical diagnosis for just one individual and effects the entire family system. As a result, the social construct of dementia does not just inhibit children and young adults but reaches the entire family. In other words, the entire family system may face the barriers erected through social construction. As a result, the person living with YOD and their family may feel that they are excluded from engaging fully in society because they have been associated with YOD, labelled, categorised and face prejudice and discrimination (Hutchinson et al., 2018).

These types of discriminatory practices may represent a type of "*social disablement*" and can manifest through the lack of equity in the provision of health and social care for example. Interestingly, the children and young adults in this research often cited comparisons with other "*more normal illnesses*" noticing how their peers were treated differently in the case of cancer for instance. For others, their frustrations lay in being compared to children who may have grandparents living with dementia. Such factors contributed to the participants sense of being different, negatively affecting their confidence and ability to ask questions particularly of health professionals.

Another reason for person living with YOD being excluded can stem from the behavioural and psychological symptoms of dementia (BPSD), or more specifically, societies lack of awareness of same. People living with YOD reported, in chapter three of this thesis, how BPSD can result in them being shunned by society as a result of fear, ignorance and stigma. However, while the negative consequences of BPSD impact the person with YOD, they can sometimes go even further. For example, when the person living with YOD exhibits behavioural issues, these behaviours may be viewed by society to be a direct result of the condition. However, they may also be interpreted as an indication of poor relational dynamics and unmet needs within the family that can lead to conflict and crisis (Bakker et al., 2013).

Subsequently, the family system not only has to face the behavioural issues, but they may have to do so without societies assistance. To compound this issue further, linking dementia with old age can see society question the parental abilities of the person with YOD. As dementia is typically associated with grandparents, people who are living with YOD may no longer be regarded as a "*normal parent*" and can be subconsciously and unintentionally excluded from that role (Roach et al., 2014). Questioning the parental ability of a person with YOD can undermine their sense of agency/autonomy resulting in negative outcomes for the whole family (Boyle, 2014).

Individually, ordinary members of society can sometimes be forgiven for this exclusion as they are guided by the way society in general regards dementia. For instance, the way dementia services are designed and delivered for an older cohort adds to this social construct of dementia, particularly in Ireland. The inadequacies in service design and provision for people with YOD is discussed in chapter three, with families members including people with YOD scathing in their opinions in relation to the scarcity of services.

7.8 Recommendations

The findings presented in this thesis challenge the stereotypical view of dementia as a disease of old age. By giving people with YOD and their families a voice, this thesis illuminates how YOD effects the entire family and not just the person who is diagnosed. Furthermore, this thesis voices the experiences of children facing parental YOD, a typically under investigated area within dementia research. As a result of the research presented in this thesis, a number of recommendations have emerged for the health and social care sector in Ireland, as well as society in general.

As described in chapters two and five, the prevailing social construct of dementia stems from the biomedical model of illness and disease. There is a need to move away from this model that purely sees a diagnosis and fails to see the person leading to a loss of agency, loss of selfhood, loss of personhood for the person with YOD (Parker et al., 2021). Given the biomedical dogma within the Health Service Executive in Ireland, moving away from the biomedical perspective may prove difficult.

Could situating dementia within the Social Model help?

Numerous authors have called for dementia to be situated within a social model, similar to disability. This would allow for a contrast to be made between the illness and deficitis observed in dementia and the social exclusion, prejudice and discrimination that people living with dementia experience (Oldman, 2002; Keyes et al., 2019; Thomas & Milligan, 2018; Shakespeare et al., 2019).

Moreover, the consideration of dementia as a disability would also afford greater legislative protection to both the person with dementia and their family members. Another distinct advantage of the social model of disability is that it prompts members of society (i.e., us) to see over the constraining walls of the typical health and social care niche where dementia usually sits and may help us to breakup our existing social constructions about the condition (Shakespeare et al., 2019).

For instance, according to Oldman (2002), the social model could be used to critique and rearrange existing public policies and practices that currently exclude people with dementia and their families. In other words, the social model could be used to tackle our embedded social constructs about dementia and equip the necessary policies to positively change the lives of families living with dementia.

The need for education, awareness and support in YOD

The two major threads that wove their way continuously throughout this research were the need for more inclusive psychosocial supports/interventions for both people with YOD and their family members and a greater awareness of the condition. For instance, if more inclusive psychosocial supports are to be created then there is a considerable need for a greater awareness of YOD amongst both health and social care professionals and the general public. Increased awareness of YOD may lead to improvements in service design and support for families living with the condition. Such findings are also reflected in the recent literature.

For example, evidence around the use of interventions for families living with YOD suggests significantly greater awareness of YOD is crucial in order to provide suitable community based, health and social care supports and/or interventions for families (Shnall, 2015). Furthermore, whether the supports or interventions are outdoor or indoor activities, physical or cognitive activities, and social/supportive interventions, they all hinge upon being age-adaptive. As such, greater awareness of YOD can only be a benefit in relation to this (O'Shea et al., 2017).

Moreover, if and when we finally begin to increase awareness that dementia is a brain disease and can (and does) affect anyone at any age, then we may be in a position to be a more dementia inclusive society. Then the benefits of community-based interventions may be truly noteworthy. Currently, there is ample evidence for community-based support models proffered in the dementia literature.

For example, In Ireland The Community Supports Model for People with Dementia (Genio, 2016) aims to ensure that people living with dementia have access to what they term a "*care and support ecosystem*" (Genio, 2016, pp.10) that would ideally combine conventional health and social care services with both community and voluntary organisations. While this is an extremely laudable sentiment and the evidence backs up the model, the report unfortunately does not mention YOD or children, focusing solely on late onset dementia.

Consequently, there is a scarcity of empirical evidence as to whether or not such social supports are appropriate and appreciated by people living with YOD (Mayrhofer et al. 2018). Regrettably, there is little or no evidence in relation to the ways in which the wider community can be supportive of people with YOD and while there are numerous community-based supports that may be appropriate, people with YOD may not know how they are accessed (Mayrhofer et al. 2018).

However, on the plus side we can take the evidence from the literature and apply it to families living with YOD in order to assist them. For instance, research conducted by Fox and colleagues (2020) specifically examined post-diagnostic supports for people with YOD in Ireland. The authors posit that both voluntary and community organisations have enormous potential to both promote awareness of YOD and facilitate vital social engagement for families living with YOD.

The dementia sector also needs to acknowledge that many people living with YOD are parents and as such their children also need opportunities to access age-adaptive support without pre-judgement. As described in chapter six of this thesis, this could be achieved by way of peer-to-peer support interventions, similar to those already available in areas such youth mental health (Mackay et al., 2022).

Peer-to-peer support can also be harnessed to develop children's and young adults' self-efficacy, resilience, build confidence, leadership and mentoring skills meaning the intervention could become self-sustaining with current participants tutoring the next generation (Mackay et al., 2022).

Several of the participants interviewed as part of this research would welcome peer-to-peer support as an intervention and they also pointed out that geography should no longer be a barrier due to technology. Children and young adults facing parental YOD can therefore make a valued contribution to developing awareness campaigns about YOD and be involved in the necessary changes required in service provision in order to build social inclusion for everyone (Gelman & Rhames, 2018; Hall & Sikes, 2018).

Additionally, children and younger adults could contribute to and receive awareness about YOD through the education sector in Ireland. For instance, the primary and secondary education sectors could be viable avenues to facilitate increased awareness of YOD while also tackling the stigma and social isolation felt by children and families (Chirico et al., 2021: Shnall, 2015). Similarly, the area of third level education could also be an important conduit for education and awareness around YOD, utilising their research and communication centres to distribute relevant information (Bakker et al. 2022).

Implications for Health & Social Care services in dementia care

Considerable implications for the dementia sector in relation to the provision of health and social care services arise from the findings of this thesis. In particular, the need for education and awareness training for all health care staff and volunteers working within dementia services.

Many participants in this research are aware that getting a definitive diagnosis of YOD is a complex and difficult process due to the persons younger age and the overlapping of some symptoms with other mental health conditions across YOD subtypes. As described in chapter three and six of this research, this ultimately results in a stressful and difficult time for the entire family, leading to fear and uncertainty about the future.

However, participants also reported that the lack of awareness of YOD among health and social care providers can add to an already difficult situation. As described in chapter three, the first interaction with a health professional in Ireland is typically the general practitioner (GP) who may not always be fully aware of YOD. Several participants have reported in chapter three how they (or their partners) were initially mis-diagnosed by their GP meaning there was no referral to a neurologist or memory clinic for further tests.

Fox and colleagues (2020) reported similar findings when examining the post-diagnostic pathways in Ireland for people with YOD and their families. For instance, the authors recommend that greater awareness is required across various roles within the health service and health care professionals could benefit greatly from specific training in relation to YOD.

Another area where health and social care professionals could benefit from awareness training about YOD may be related to communication and communication style with families and in particular, children. Participants in chapter six of this research reported that communication is a crucial component in order to combat some of the negative factors following their parents formal diagnosis. Whether its communication with their well parent, work colleagues or peers, children and younger adults in the current study reported the importance of good communication.

In particular, the communication style of various health and social care professionals was cited as an area that needs improvement. Contrastingly, when communication was open, honest and age-appropriate, participants reported that this was extremely beneficial to them and assisted in alleviating their stress and anxiety, particularly as they were not expecting the diagnosis.

Likewise, Fox and colleagues (2020) outlined the importance of good communication when health professionals made sure to impart simple, honest and relevant information that was fully understood by everyone in the family. Discordantly, when communication was perceived as being poor, it added to the participants anxiety and stress levels making the situation considerably worse (Fox et al., 2020).

To synopsise, any education and awareness training must consider that a whole family system exists and not just the dyad of person with YOD and carer. Additionally, compassionate communication is crucial from the beginning to build trustworthy reciprocal relationships. It may be necessary to pursue a policy whereby health care staff continue to receive quality, evidence-based education and training, that will be mutually beneficial, on an ongoing basis.

For instance, findings described in a systematic review conducted by Surr and colleagues (2017) outline several factors that define good quality education and training programmes for health and social care staff. Of most importance are the following:

- relevance to the participants role and/or experience
- face-to-face participation
- practical learning underpinned by theory
- delivered by an experienced teacher/tutor/facilitator
- total duration of at least eight hours (individual sessions of ninety minutes)
- support applied learning

With regard to education and awareness training being mutually beneficial, quality trained health care staff and/or volunteers could subsequently assist families to alleviate the stresses and anxieties through psycho-education. For example, age-adaptive psycho-education could increase family members self-efficacy and resilience giving them the confidence required to face the challenges of caring for their loved one (Surr et al., 2017).

Implications for policy makers

Findings from this thesis mirror previous research in relation to the partiality of dementia services in Ireland. Significant inequalities exist between service provision in young onset and late onset dementia, with most services catering to late onset. There are also inequalities based on geographical location in Ireland, with major cities and towns getting the majority of services while many rural areas have none (O’ Shea et al., 2018; Blake & Hopper, 2021).

Furthermore, as detailed in chapter two of this thesis, these inequalities were not addressed in the Irelands last national dementia strategy (Department of Health, 2014). Moreover, following a review of the national dementia strategy, the Department of Health (2018) published a mid-term report based on progress made.

It must be pointed out that in the four years between the publication of the national dementia strategy and the subsequent review, a significant amount of work had been undertaken. For example, the following funded actions were implemented as part of the strategy:

a) The establishment of the National Dementia Office (NDO) in 2015 which provides leadership around the implementation of the National Dementia Strategy.
b) Education programmes have been developed for both GPs and Primary Care Teams by the PREPARED project (Primary Care Education, Pathways and Research of Dementia). Programmes had been delivered to over 500 GPs, and 150 Primary Care Team members.
c) Intensive Homecare Packages were introduced to provide a higher level of support to people with dementia in their own homes.
d) The Dementia Understand Together public awareness campaign is a national public awareness campaign aimed at raising awareness of dementia and reducing stigma through TV, radio, newsprint and social media ads combined with the www.understandtogether.ie website.
e) An external international independent consortium is evaluating how the National Dementia Strategy has been implemented.
f) An evaluation of the Alzheimer Society of Ireland Dementia Adviser Service (Department of Health, 2018; pp.06).

As well as the actions outlined above, a number of non-funded actions were also implemented (Department of Health, 2018; pp. 06-08). While such actions can only be beneficial for everyone who is living with dementia and their families, there is scant reference to YOD specifically. I could only find three entries that refer to YOD directly with one that refers to YOD as a consequence of Down Syndrome (Department of Health, 2018; pp.17 & pp.33).

Furthermore, the understand together public awareness campaign has to be commended on bring dementia to the attention of the public. However, it may also have negatively reinforced the stereotypical view of dementia as a condition associated with older age, as a result. For instance, participants in both chapter five and six of this research have reported they felt that YOD is not represented in any advertising campaigns at all with one participant stating; "*...even on the ads for TV, so* [dementia advertising campaign] *like you'd always see it'd be people from the age of 65 up is what you'd see explaining their stories, and its them walking round a park but it's always, it's never an under 65-year-old*" [**P04: Son**].

Therefore, any future dementia policy or strategy will need to address such issues and place a significant emphasis on YOD and the need for age-adaptive services for people living with YOD and their family members. As outlined earlier in this chapter, it may be time to consider dementia under the social model similar to disability. However, if there is to be a reconsideration, it may not lie solely with the Department of Health and may instead require cooperation across several departments within the Irish Government.

For example, in the last ten years two major healthcare policies namely "*Healthy Ireland*" (Department of Health, 2013) and "*SláinteCare*" (Houses of the Oireachtas, 2017) report that cross-departmental cooperation is vital to the advancement of the populations health and wellbeing. In other words, by including authorities at a local and national level and by involving people from all sections of society it may be possible to move away from the prevailing biomedical model of dementia towards a more social based one.

I should point out that although this research was carried out in Ireland with reference made to Irish dementia policy and the Irish health system, this does not exclude the findings from translating to other jurisdictions. In fact, many of the findings that emerged during this research are reflected in the international literature in relation to children's experiences of parental illnesses and not just YOD. However, what is unique about this research is the novel approach used to include children under the age of eighteen in order to understand their experiences of parental YOD. Therefore, these findings will be relevant to any future research relating to parental YOD or indeed other parental illness in an Irish context and beyond.

7.9 Unique contribution of this thesis – Strengths & limitations.

A fundamental strength of the research presented as part of this thesis is the focus on the meaningful inclusion of the experiences of people living with YOD and their family members including children and young adults. Through the use of public patient involvement (PPI) this thesis was able to explore the issues of relevance to people living with YOD and their families, allowing for the collection of rich data on the experiences of the whole family system following a diagnosis. A further strength of this research was the fact that it was counselled by an expert interdisciplinary supervisory team from the disciplines of psychology and child and family nursing.

The specific interests of the supervisory team include amongst others dementia research (policy, awareness, assistive technologies, psychosocial models of care and ethics), understanding the experiences of children and families living with childhood long-term health conditions (child and family communication, shared self-management responsibilities, and psychosocial wellbeing and illness impact on child and family) and cognitive psychology (cognitive assessment, enhancement, rehabilitation and reserve).

Each individual member of the interdisciplinary team brought a unique perspective to the research process that enlightened me about working with people living with life limiting conditions such as dementia. The different, yet compatible, perspectives obliged me to examine areas that I may have overlooked, such as the family system, while being extremely knowledgeable and supportive throughout the process.

To the best of my knowledge (and at the time of writing) only three significant pieces of research have been conducted in relation to families living with YOD in Ireland. Haase's (2005) "*Early Onset Dementia - The Needs of Younger People in Ireland*", a report by Fox and colleagues (2020) for the National Dementia Office "*Young Onset Dementia: A Review of Diagnostic and Post-Diagnostic Processes and Pathways*" and a qualitative study by Blake and Hopper (2021) "*A qualitative investigation into family carers' experiences of living with/caring for a person with young-onset dementia*".

This thesis builds on and adds to the information and knowledge included in these three pieces of research. However, this thesis contributes a new and novel perspective by focusing solely on the childhood experiences of YOD in Ireland. Utilising a qualitative methodology allowed for a richness in the data resulting in an in-depth exploration of the participants personal experiences.

Gaining an understanding of children's experiences of YOD is crucial if we are to help this cohort to face the challenges in the future. As the voices of children facing parental YOD are typically absent from the academic research particularly in an Irish context, this thesis makes a significant contribution to filling that gap and as such makes a unique and important contribution.

Limitations and Challenges

The initial plan for this research was to recruit children and young adults (and their parents) from across the three educational phases in Ireland – i.e., primary school; post-primary (secondary) and tertiary (college/university) in order to represent a diverse range of experiences. In other words, children and young adults ranging in age from seven years to twenty-four/five years whose primary residence was still the family home. The recruitment process was to involve an advertisement campaign in schools and colleges backed up by recruitment through various gatekeeper organisations.

However, this initial recruitment plan was significantly hamstrung by the arrival of the Covid-19 pandemic to Ireland and the country shut down. As a result, I was unable to place any recruitment advertising in schools and colleges and instead I had to rely solely on the gatekeeper organisations. Unfortunately for this research, there appeared to be an immediate shift away from "typical dementia research" towards research involving some aspect of Covid-19.

Every gatekeeper organisations appeared to be involved in Covid research and attempting to explain that my research had absolutely no relationship to the pandemic proved difficult. Working with gatekeeper organisations can be challenging at the best of times, as they can limit access to participants and their families if they choose to do so (Novek & Wilkinson, 2019). In this research, I do not think that gatekeepers were being intentionally belligerent, however, they were blinkered by the all the "new" research opportunities being offered by the pandemic and its effects on families living with dementia. Furthermore, as the pandemic wore on, the mental health of the cohort that I was interested in appeared to worsen as they were isolated from friends and peers as a result of the numerous lockdowns. This meant that parents were understandably overly protective of their children, particularly as adversity had already visited the home in the guise of YOD.

In retrospect, the authorities through the various lockdowns were attempting to mitigate the significant health risks associated with the pandemic. As a result, they were not initially focused of the psychological impact of such lockdowns on pre-adolescent and adolescent children. However, this population have reported significant emotional and psychological issues as a result such as; social isolation, depression, anxiety, and increases in maladaptive behaviour (O'Sullivan et al., 2021). This was the cohort that I was attempting to engage and it is completely understandable that parents were reluctant to let children be involved.

Additionally, as the number of people living with YOD in Ireland is not fully known, we are forced to work with an approximation of roughly six-thousand individuals. Therefore, we cannot be certain about how many of this population are actually parents making the recruitment process even more complex. The challenges posed by the pandemic and gatekeeper organisations forced me to approach the recruitment process differently. Through the use of academic networks, peers, work colleagues and certain social media channels I was able to recruit enough participants to make this research viable.

However, while there were not as many participants under eighteen years of age as I would have originally envisaged, the differing ways of recruiting participants can only be beneficial going forward. A further benefit of the pandemic was the introduction of so many online communication platforms, such as Zoom and Teams. Despite some drawbacks, I have to acknowledge that without such online platforms this research may not have been carried out at all. Therefore, the use of online technology is something that I will carry into future research projects.

The data analysis procedure adopted in the studies described in this thesis could also be viewed as a limitation, as the data was coded by one person. However, according to Braun and Clarke (2006) double coding as part of a reflexive thematic analysis of qualitative data contradicts the constructivist paradigm due to the notion of inter-rater reliability being rooted in the post-positivist premise that an objective reality can be uncovered. Given that the philosophy guiding this research was pragmatism, my belief is that reality is diluted by the subjectivity of the researchers psyche and several psyches will not invalidate such subjectivity.

7.10 Conclusion

This thesis presents a significant piece of research exploring the experiences of families living with YOD with particular emphasis on the perspectives of children with a view to informing policy and practice in Ireland. The findings have demonstrated that there is a significant shortfall in services for families living with YOD and that supporting the entire family system must be the standard rather than the exception. There has been little, or no research with family members living with YOD in Ireland and in particular there is no research with children under the age of eighteen. Therefore, the policies enacted by the various governmental and health departments do not cater for this cohort, disadvantaging entire families due to the complete lack of age-adaptive support.

Current policies that are based on the biomedical perspective of dementia cause further issues adding to the social construct of a disease that only affects an older population. The elimination of this view may help to acknowledge that dementia, as a brain disease, can affect anyone whatever the age. A further consequence of dementia being associated with old age is that most dementia health and social care services are based in older adult settings, particularly in Ireland. The lack of service provision for people living with YOD has been discussed frequently and regularly by numerous other researchers and is tackled in several chapters of this thesis. As a consequence, many children and younger adults are involved in some aspect of their parents care at some stage of the dementia journey. The participants in this research were no different.

There must be a greater acknowledgement that children and young adults involved in this care may face adverse effects on their physical, psychological and emotional health. However, there appears an unwillingness to discuss such issues outside the family mainly due to the stigma associated with the condition and the negative behaviours and attitudes of wider society. Additionally, the situation may not be discussed within the family system either, and it is important to understand that many children feel isolated and alone irrespective of the number of siblings or other family members there are. The association between the deterioration of emotional wellbeing and caring responsibilities was clearly established in this research, particularly in relation to the developmental stage of the child.

For instance, as children are transitioning from pre-adolescence stage to the adolescence stage they typically distance themselves from parents. However, this research illustrated significant levels of frustration as children and young adults feel trapped by the current situation and an uncertain future. Moreover, this research describes how some children and young adults may have to spend a considerable amount of time in this caring role without any formal help or support. Consequently, the longer this situation prevails, the more detrimental it becomes for the child or young adult and for everyone in the home. This research has proposed peer-to-peer support as an intervention for children and young adults in order to help alleviate these issues. Findings from this research also outline a significant need for psycho-education and awareness programmes/training for health and social care professionals and for society in general. Such a programme will help to tackle the social construct of dementia and, by proxy, the stigma associated with the condition.

It has to be acknowledged that participants in this research were Irish in nationality and English speaking and their perspectives may not be representative of non-English speaking people from other nationalities. Furthermore, the research presented in this thesis may not represent certain minority groups such as; the Irish Travelling community, the LGBTQ+ community or other ethnic minority groups. Moreover, the findings here may not represent those people living with YOD who chose not to participate in the research.

Future research may wish to address the lack of minority group representation in this current work. For instance, children who may be living in a single parent family where their parent has been diagnosed with YOD. The concept of the nuclear family within Family System theory may need to be revised in order to account for contemporary family structure(s).

The nuclear family emotional system outlined in the eight interlocking factors that describe and shape family functioning as part of the Family System theory (Brown, 1999) could be questioned in modern society. Traditionally, the nuclear family consisted of a mother, father and their children. However, modern family structure can consist of various different structures from single parents to same sex couples with either biological or non-biological children.

Similarly, another under researched area is the dual role (i.e., being both parent and carer) that is often taken on by the well parent. Balancing a parenting role with a caring role while dealing with all of life's challenges is an area within YOD research that requires more attention. In other words, research can be utilised to identify and illustrate the complexity of the social context(s) of families facing YOD in order to allow policy makers to assist these families to live well with dementia.

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Appendices

Appendix A: REC Approval letter for study 1

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

DCU

Dr. Louise Hopper
School of Psychology

Mr. Cathal Blake
School of Psychology

5th November 2020

REC Reference: **DCUREC/2020/220**

Proposal Title: **Marginalised voices: A mixed-methods study of the needs, experiences and quality of life of people living with younger onset dementia.**

Applicant(s): **Dr. Louise Hopper & Mr. Cathal Blake**

Dear Colleagues,

Further to full committee review, the DCU Research Ethics Committee approves this research proposal.

Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee.

Should substantial modifications to the research protocol be required at a later stage, a further amendment submission should be made to the REC.

Yours sincerely,

Geraldine Scanlon

Dr Geraldine Scanlon
Chairperson
DCU Research Ethics Committee

DCU
Research & Innovation

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Appendix B: Plain Language Statement for people with YOD – study 1

Dublin City University

Title of Research Study:

Marginalised voices: A mixed-methods study of the needs, experiences, and quality of life of people living with younger onset dementia.

Principal Investigator: Mr. Cathal Blake email: cathal.blake25@mail.dcu.ie
Supervisor: Dr Louise Hopper (Tel: +35317008540) email: louise.hopper@dcu.ie

You are being invited to take part in this research study. Before you decide whether to take part or not, it is important that you understand why the study is about. Please read the following information carefully and discuss it with others, if you wish. If you require further information, or would like to ask any questions, contact details for the principal investigator are outlined above.

The main aim of the study is to understand your day-to-day experience of living with young onset dementia. We may ask you about receiving the diagnosis and how you have managed since then. We may also ask you about family members and friends and if you think that your diagnosis has affected them.

It will only take between 20 to 40 minutes to answer the questions. We can take a break if needed, and if you want to stop the interview, we will stop. The interview will be recorded.

You do not have to take part in this study, and you can withdraw your information at any time. All details related to you will be anonymous so nobody will be able to identify you.

Taking part in this study will give you the opportunity to voice your opinions on living with young onset dementia.

This may benefit you directly; however, it is more likely to be of benefit to people in the future who receive a diagnosis of young onset dementia. If you would like to ask any questions or you wish to be involved, you can contact any member of the team. Our details are at the top of the first page.

If you have any concerns about this study and wish to contact an independent person, please contact:

The Secretary
Dublin City University Research Ethics Committee
c/o Research and Innovation Support
Dublin City University
Dublin 9.
Tel: 01-7008000 / E-mail: rec@dcu.ie

Thank you for reading this information leaflet.

Appendix C: Consent Form for people with YOD – study 1

Dublin City University

Title of Research Study:

Marginalised voices: A mixed-methods study of the needs, experiences, and quality of life of people living with younger onset dementia.

- Please read this consent form about your participation in the study.
- Please ask us any questions you have about the study as we want to make sure that you are happy, and that you understand what you are being asked to do.
- You will be asked some questions in relation to your diagnosis of young onset dementia, care needs and quality of life.

If you are happy that you understand the nature of the questions being asked please tick the corresponding symbol.

	👍	👎	?
I understand what I am being asked to do in this study.			
I have had the opportunity to ask questions and they were answered to my satisfaction.			
I understand that my interview with the researcher is being recorded.			
I understand that confidentiality is assured within the limits of the law.			
I understand that I can take a break from the study or withdraw any time.			
I am happy to participate in this study.			

Signature: ________________________________ Date:________________

For any further information please contact:
Cathal Blake
DCU, Glasnevin Campus, Dublin 9.
Email: cathal.blake25@mail.dcu.ie

Thank you so much for your time!

Appendix D: Plain Language Statement for family members – study 1

Dublin City University

Plain Language Statement

Title of Research Study:

Marginalised voices: A mixed-methods study of the needs, experiences and quality of life of people living with younger onset dementia.

Principal Investigator: Mr. Cathal Blake email: cathal.blake25@mail.dcu.ie
Supervisor: Dr Louise Hopper (Tel: +35317008540) email: louise.hopper@dcu.ie

Introduction:

This project titled: "*Marginalised voices: A mixed-methods study of the needs, experiences and quality of life of people living with younger onset dementia*", is a PhD research project in the School of Psychology, Dublin City University. This research project is self-funded.
You are being invited to take part in this research study. Before you decide whether to take part or not, it is important that you understand why the study is being carried out and what it will involve. Please read the following information carefully and discuss it with others, if you wish. If you require further information, or would like to ask any questions, contact details for the principal investigator are outlined above. The main aim of the study is to examine the (un)met needs, experiences, and quality of life of people living with young onset dementia and their families. Secondary aims of this study include seeking and getting a timely diagnosis, adjusting to the diagnosis, the coping strategies employed and access to formal care. It is intended that the information gained from you will help to inform policy and practice in dementia care in Ireland.

Do I have to take part?

If you do not want to take part in the study, you do not have to and you do not have to say why.

What does taking part involve?

If you decide to take part, the principal investigator will ask you some questions as part of a focus group, or a one-to-one interview (via Zoom/Skype/Phone) using a semi-structured interview. These questions will ask about caring role. The questions may also relate to the coping mechanisms you employ, whether you feel anxious, your quality of life and how young onset dementia has impacted on you socially. The researcher may also ask about activities of daily living, and some questions about behaviour, mood, and quality of life. The researcher will also talk to you about the type of dementia-related services used (if any) and why that is. The focus group interview may take between 40 minutes and 80 minutes approximately. Depending on how you feel, you can continue to complete the full interview that day or arrange a second session another day at a suitable time and place. You can also take a break from the interview at any stage. You may withdraw from the process at any time without giving an explanation.

We would like to audio-record the interviews so that we can concentrate on your views and have a full record of your thoughts. You do not have to agree to this. Even if you do agree, you can ask to have the audio-recording stopped at any time and you do not have to say why. If you agree to the audio-recording, it will be kept in a locked cabinet in DCU and destroyed after transcription.

What are the possible benefits of taking part?

Participation in this study will give you the opportunity to voice your opinions on what being a carer is like, what your needs are, and how and when you would like these needs to be met. This may benefit you directly; however, it is more likely to be of benefit to people in the future who receive a diagnosis of young onset dementia and those who care for them. Also, people often find the experience of taking to someone about their needs and experiences enjoyable.

What are the possible risks involved in taking part?

We do not envisage any risks that are greater than those encountered in everyday life. However, if at any stage during the interview you feel uncomfortable or distressed, you can take a break, or you can withdraw from the interview without any consequences. The researcher may also suggest that you talk to the clinical team (if any) who have been managing your family members’ care, and you will be supplied with a support pack outlining dementia specific and more general supports.

How will the information you give be used?

If you agree to take part all information collected will be kept strictly confidential within the limitations of the law. All information will have your name(s) and address(es) removed so as to preserve confidentiality. Any comments you make will be made anonymously. Your name(s) and any other identifying information will be removed and this information will not be used in the report or in any scientific conferences or publications. This will help to make sure that information about you is kept private. All information provided by you will be securely stored at DCU for the duration of the PhD after which it will be destroyed. This study complies with GDPR regulations. If you have any concerns in relation to this, you should contact the DCU Data Protection Officer – Mr. Martin Ward (data.protection@dcu.ie or Ph: 7005118 / 7008257).

Who has approved this research?

This study has received ethics approval from the DCU Research Ethics Committee.

Participation in this research study is voluntary

You have volunteered to take part in this study. You may withdraw your participation at any time. If you decide not to participate or if you withdraw, you will not be penalised. There will be no penalty for withdrawing from the study before all stages of the research study have been completed.

What do I have to do now?

If you would like to ask any questions or you wish to be involved, you can contact any member of the team. Our details are at the top of the first page.

Thank you for reading this information leaflet.

If you have any concerns about this study and wish to contact an independent person, please contact: **The Secretary**
Dublin City University Research Ethics Committee
c/o Research and Innovation Support
Dublin City University
Dublin 9.
Tel: 01-7008000 / E-mail: rec@dcu.ie

Appendix E: Consent Form for family members – study 1

Dublin City University

Title of Research Study:

Marginalised voices: **A mixed-methods study of the needs, experiences, and quality of life of people living with younger onset dementia**.

Principal Investigator: Mr Cathal Blake email: cathal.blake25@mail.dcu.ie
Supervisor: Dr. Louise Hopper (Tel: +35317008540) email: louise.hopper@dcu.ie

Clarification of the purpose of the research:

The main aim of the study is to examine the (un)met needs, experiences and quality of life of people living with young onset dementia. Secondary aims of this study include seeking and getting a timely diagnosis, adjusting to the diagnosis, the coping strategies employed and access to formal care. It is intended that the information gained from you will help to inform policy and practice in dementia care in Ireland.

Confirmation of requirements as highlighted in the Plain Language Statement:

The principal investigator will ask me some questions about care needs, anxiety and stress levels, coping mechanisms, and quality of life as part of a focus group interview. The researcher may also ask about the type of dementia-related services that are used (if any) and why that is. The focus group interview could take between 40 minutes and 80 minutes approximately. If more time is needed, I can decide either to continue or to arrange a second session at a suitable time. I know I can withdraw from the process at any time without giving an explanation. I am also aware that a tape-recording will be made of the interview.

Who has approved this research?

This study has received ethics approval from the DCU Research Ethics Committee.

Participant – please complete the following [circle either Yes or No for each question]

Have you read or had read to you the plain language statement?	*Yes / No*
Do you understand the information provided?	*Yes / No*
Have you had an opportunity to ask questions and discuss this study?	*Yes / No*
Have you received satisfactory answers to all your questions?	*Yes / No*
Are you aware that your interview will be audio recorded?	*Yes / No*

Confirmation that involvement in the research is voluntary

I have read or had read to me this consent form. I have had the opportunity to ask questions about the consent from and all the questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study which respects my legal and ethical rights. I am aware that I may withdraw at any time, without giving reason, and without this decision affecting me in any way. I have received a plain language statement.

Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provide is subject to legal limitations

My identity and other personal information will not be revealed, published or used in further studies. All information will have my name and address removed to protect confidentiality. Any other information that may identify me will also be removed. Confidentiality is assured but I am aware that confidentiality of information provided can only be protected within the limitations of the law. It is possible for data to be subject to subpoena, freedom of information claim, or mandated reporting by some professions. This study complies with GDPR regulations. If you have any concerns in relation to this, you should contact the DCU Data Protection Officer – Mr. Martin Ward (data.protection@dcu.ie or Ph: 7005118 / 7008257).

Signature

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project.

I confirm that I am over eighteen years of age: ☐ (*please place a tick in the box provided*).

Signature: ____________________ **Name in Block Capitals:** ________________________

Witness: ______________________ **Date:** ______________________

Appendix F: Topics that emerged from the PPI participatory workshop

Topics to be investigated using Focus Groups Interviews

- Period before diagnosis.
- Experiences around the diagnosis (assessment and disclosure of the diagnosis).
- Post-diagnosis.
- Dementia specific questions in relation to subtype, service use and supports.
- How children and the wider family experience each of the above.

Appendix G: Interview Schedule – study 1

I am going to ask you a number of questions about the time that your spouse/partner received his/her initial diagnosis of young onset dementia.

Period before diagnosis

1. When did you first notice that something was going on?
   - What did you notice?
2. How was the period before the diagnosis?
   - What did you think was the matter?
   - What problems did you experience? (What problems did the children experience?)
   - When did you seek help? Where did you seek help?
   - How did they help you?

The diagnosis

1. When was the diagnosis determined?
2. What was your reaction to the diagnosis?
   - What did it mean to you and your children?
   - How did you handle it? (How did your children handle it?)
   - Did you tell other people about the diagnosis? Who did you tell?
   - What were the reactions?
   - How did you handle it?
   - If the caregiver has children: Did your children tell other people? What were the reactions? How did your children handle that?
3. What kind of help did you receive after the diagnosis?
   - What do you think about the help that you received?
   - Was the information/support/treatment that you received sufficient?

After diagnosis

1. Did the dementia change your relationship? In what way?
   - Communication?
   - Intimacy?
2. What else has changed for you?
   - Family/Social life
   - Work? Financially?

If the caregiver has children:

3. How did the relationship between your significant other and your children change?

4. Did the relationship between you and your children change?

5. What else has changed for your children?

6. What do you miss the most?

7. How do you try to manage the disease?

- How do you try to manage the problems, such as changes in behavior?
- (How do the children manage?)
- Do you talk about the dementia with each other? How do you talk about it?
- (How do your children react to that?)

Care

8. What do you think is most important in your care for your spouse?

9. What do you miss the most?

10. What are your needs?

- What kind of support do you need for yourself?
- What care do you want for your spouse?
- Do you experience problems in communication with care professionals?

Future

11. What do you think about the future?

- What do you think about day-care in the future?
- What do you think about nursing home admission in the future? (Time, place, reason?).

Appendix H: Support Pack

Mental health support services for participants

If you are looking to access additional supports and services, you may find the information below useful.

Organisation	**Website**	**Phone or Text**
Mental Health Ireland	www.mentalhealthireland.ie	01 284 1166
Childline	www.childline.ie	1800 66 66 66 Free text 50101
Jigsaw	www.jigsaw.ie	Contact email service on the website.
	https://jigsaw.ie/find-a-jigsaw/	Link to Jigsaw branches across Ireland
	https://jigsaw.ie/talk-online/	Talk online
Pieta House	www.pieta.ie	1800 247 247 Text HELP to 51444
Crisis Text Line	https://text50808.ie	Text HELLO to 50808
Barnardos	Family Support (barnardos.ie)	01 453 0355

Dementia Specific Support Services

Where do I start?

Often the first step to accessing support is to make an appointment with your General Practitioner (GP). Your GP will assess your situation and may refer you on to a specialist. Below are some of the healthcare professionals your GP may suggest:

- The Public Health Nurse (PHN) is a qualified general nurse who is based in the community. The PHN visits people in their own homes, assesses their needs and coordinates supports and services. The PHN can also link into local community and voluntary supports by making referrals to facilities such as day care and home care or supports such as home-help, meals on wheels and respite care.

- The PHN can also advise on incontinence wear and other products and performs basic nursing duties such as changing dressings.
- The Psychiatrist is a medical doctor who specialises in diagnosing and treating a wide range of mental health problems. Persons under 65 may be referred to a psychiatrist.
- The Occupational Therapist often visits people in their own homes to help them remain physically active and independent in their daily activities. Examples of areas an occupational therapist may look at include cooking, washing, managing stairs, and other activities that you do every day or every week. They can advise on practical aspects such as alterations to the home or specialised equipment.
- The Social Worker provides psychological and social support. They have an advocacy role, ensuring that people’s needs are highlighted and met by coordinating supports and services.
- Memory Clinics provide information and support to people experiencing problems with their memory. The services provided by memory clinics include information about how to improve and maintain cognitive health, clarification of memory problem symptoms, diagnosis, advice for managing memory problems and treatment information. Information about memory clinics in Ireland can be found at http://www.dementia.ie/images/uploads/site-images/mem.pdf

Where else can I go for information?

There are also a number of voluntary organisations which offer supports and services. Details of some of these organisations are listed below:

THE ALZHEIMER SOCIETY of IRELAND

The **Alzheimer Society of Ireland (ASI)** is the leading dementia specific service provider in Ireland. They offer a range of specialist services throughout Ireland such as social clubs, Alzheimer cafés, home care, day centers, and respite care and support groups.

- Information about available supports can be found at: www.alzheimer.ie.
- Helpline Advisers are available to people living anywhere in Ireland and can help you to contact local supports and services in your community. Contact Una Fogarty or Tina Hannan by calling 1800 341 341 or email helpline@alzheimer.ie.

- The ASI also offers a Dementia Advisor service which provides individualised information and signposting to local supports and services. Details of how to contact your local dementia advisor in the Dublin area are:

  North Dublin: Joanne Brennan - 086 3808 492 (jbrennan@alzheimer.ie).
  or Ana Dalton - 086 7826312 (adalton@alzheimer.ie).
  South Dublin: Jean Scanlan - 086 045 4703 (jscanlan@alzheimer.ie).

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. If you are a family carer in need of support you can contact Care Alliance Ireland using the following details:

- Care Alliance Head Office Coleraine House, Coleraine Street, Dublin 7.
- Phone: 01 874 7776 or email: info@carealliance.ie

Family Carers Ireland is a registered charity which emerged from the coming together of The Carers Association and Caring for Carers. They provide training, information and support services to carers across Ireland. If you are a family carer in need of support you can contact Family Carers Ireland using the following details:

- Phone; 1800 240724 or http://familycarers.ie/

If you have any queries relating to the study or the information provided above, please contact:

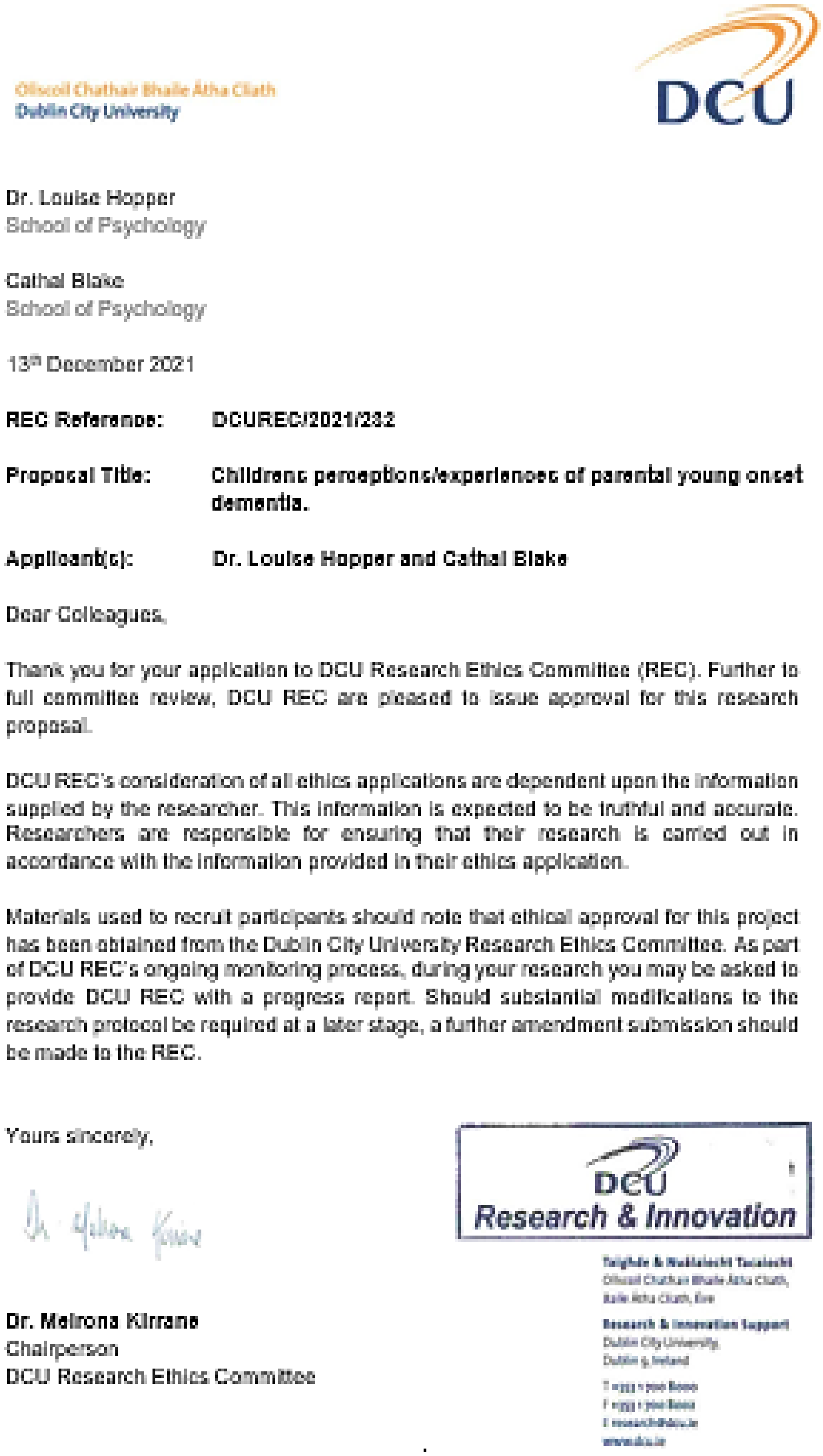
Dr Louise Hopper

Telephone: 01-7008540

Email: louise.hopper@dcu.ie

Cathal Blake
Email: cathal.blake25@mail.dcu.ie

Appendix I: REC Approval letter – study 2



Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

Dr. Louise Hopper
School of Psychology

Cathal Blake
School of Psychology

13th December 2021

REC Reference: **DCUREC/2021/232**

Proposal Title: **Childrens perceptions/experiences of parental young onset dementia.**

Applicant(s): **Dr. Louise Hopper and Cathal Blake**

Dear Colleagues,

Thank you for your application to DCU Research Ethics Committee (REC). Further to full committee review, DCU REC are pleased to issue approval for this research proposal.

DCU REC's consideration of all ethics applications are dependent upon the information supplied by the researcher. This information is expected to be truthful and accurate. Researchers are responsible for ensuring that their research is carried out in accordance with the information provided in their ethics application.

Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee. As part of DCU REC's ongoing monitoring process, during your research you may be asked to provide DCU REC with a progress report. Should substantial modifications to the research protocol be required at a later stage, a further amendment submission should be made to the REC.

Yours sincerely,

DCU
Research & Innovation

Dr. Melrona Kirrane
Chairperson
DCU Research Ethics Committee

Appendix J: Plain language statement for participants over 18 – study 2

Dublin City University

Plain Language Statement

Title of Research Study: Childrens perceptions/experiences of parental young onset dementia (YOD).

Principal Investigator: Mr. Cathal Blake email: cathal.blake25@mail.dcu.ie

Supervisor: Dr Louise Hopper (Tel: +35317008540) email: louise.hopper@dcu.ie

Introduction:

You are being invited to take part in this research study titled: "*Childrens perceptions and experiences of parental young onset dementia (YOD)*", which is part of a PhD research project in the School of Psychology, Dublin City University (DCU). This research project is self-funded. Before you decide whether to take part or not, it is important that you understand why the study is being carried out and what it will involve. Please read the following information carefully and discuss it with others if you wish. If you require further information, or would like to ask any questions, contact details for both the principal investigator and supervisor are outlined above. The main aim of the study is to examine the perspectives and experiences of children and young adults living with (or who have lived with) a parent diagnosed with young onset dementia (YOD). It is intended that the information gained from you will help to inform policy and practice in dementia care in Ireland.

Do I have to take part?

If you do not want to take part in the study, you do not have to and you do not have to say why.

What does taking part involve?

If you decide to take part, the principal investigator will ask you some questions either in a one-to-one interview, or in a group interview with your siblings. The questions will be semi-structured in nature and due to the current pandemic restrictions the interviews will be conducted via Zoom/Skype/Phone. The one-to-one interview will ask about your experiences of parental YOD.

The questions may also relate to the coping mechanisms you employ, whether you feel anxious, your quality of life and how YOD has impacted on you socially. The researcher may also ask about daily life with your family and friends. Both the one-to-one or group interview may take between 30 and 60 minutes approximately. Depending on how you feel, you can continue to complete the full interview that day or arrange a second session another day at a suitable time and place. You can also take a break from the interview at any stage and you can withdraw from the process at any time without giving an explanation.

We would like to audio-record the interviews so that we can concentrate on your views and have a full record of your thoughts. You do not have to agree to this. Even if you do agree, you can ask to have the audio-recording stopped at any time and you do not have to say why. If you agree to the audio-recording, it will be kept in a locked cabinet in DCU and destroyed after transcription.

What are the possible benefits of taking part?

Participation in this study will give you the opportunity to voice your perspectives and experiences of living with a parent with YOD. This may benefit you directly; however, it is more likely to be of benefit to people in the future who receive a diagnosis of young onset dementia and those who care for them. Also, people often find the experience of taking to someone about their needs and experiences enjoyable.

What are the possible risks involved in taking part?

We do not envisage any risks that are greater than those encountered in everyday life. However, if at any stage during the interview you feel uncomfortable or distressed, you can take a break, or you can withdraw from the interview without any consequences. A support pack outlining dementia specific and more general supports will be provided if necessary.

How will the information you give be used?

If you agree to take part all information collected will be kept strictly confidential within the limitations of the law. All information will have your name(s) and address(es) removed so as to preserve confidentiality. Any comments you make will be made anonymously. Your name(s) and any other identifying information will be removed, and this information will not be used in the report or in any scientific conferences or publications. This will help to make sure that information about you is kept private. All information provided by you will be securely stored at DCU for the duration of the PhD after which it will be destroyed. This study complies with GDPR regulations. If you have any concerns in relation to this, you should contact the DCU Data Protection Officer – Mr. Martin Ward (data.protection@dcu.ie or Ph: 7005118 / 7008257).

Who has approved this research?

This study has received ethics approval from the DCU Research Ethics Committee.

Participation in this research study is voluntary

You have volunteered to take part in this study. You may withdraw your participation at any time. If you decide not to participate or if you withdraw, you will not be penalised. There will be no penalty for withdrawing from the study before all stages of the research study have been completed.

What do I have to do now?

If you would like to ask any questions or you wish to be involved, you can contact any member of the team. Our details are at the top of the first page.

Thank you for reading this information leaflet.

If you have any concerns about this study and wish to contact an independent person, please contact: **The Secretary**
Dublin City University Research Ethics Committee
c/o Research and Innovation Support
Dublin City University
Dublin 9.
Tel 01-7008000: E-mail: rec@dcu.ie

Appendix K: Consent form for participants over 18 – study 2

Dublin City University

Plain Language Statement

Title of Research Study: Childrens perceptions/experiences of parental young onset dementia (YOD).

Principal Investigator: Mr. Cathal Blake email: cathal.blake25@mail.dcu.ie
Supervisor: Dr Louise Hopper (Tel: +35317008540) email: louise.hopper@dcu.ie

Clarification of the purpose of the research:

The main aim of the study is to explore the experiences and perspectives of children and young adults living with (or who have lived with) a parent with a diagnosis of young onset dementia (YOD). It is intended that the information gained from you will help to inform policy and practice in dementia care in Ireland.

Confirmation of requirements as highlighted in the Plain Language Statement:

A researcher from Dublin City University (DCU) will ask me some questions about the coping mechanisms I employ, whether I feel anxious, my quality of life and how YOD has impacted on me socially. The researcher may also ask about daily life with my family and friends. The one-to-one or group interview (if siblings share the same household) may take between 30 and 60 minutes approximately. If more time is needed, I can decide either to continue or to arrange a second session at a suitable time. I know I can withdraw from the process at any time without giving an explanation. I am also aware that a tape-recording will be made of the interview.

Who has approved this research?

This study has received ethics approval from the DCU Research Ethics Committee.

Participant – please complete the following [circle either Yes or No for each question]

Have you read or had read to you the plain language statement?	*Yes / No*
Do you understand the information provided?	*Yes / No*
Have you had an opportunity to ask questions and discuss this study?	*Yes / No*
Have you received satisfactory answers to all your questions?	*Yes / No*
Are you aware that your interview will be audio recorded?	*Yes / No*
Do you agree that your interview will be audio recorded?	*Yes / No*

Confirmation that involvement in the research is voluntary

I have read or had read to me this consent form. I have had the opportunity to ask questions about the consent from and all the questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study which respects my legal and ethical rights. I am aware that I may withdraw at any time, without giving reason, and without this decision affecting me in any way. I have received a plain language statement. If I decide to withdraw from the study, there are two options: 1) No additional data will be provided, however, the data already collected can be used in the study; 2) None of the data already given will be used in the study. However, once data has been anonymised, it will NOT be possible to remove it from the study.

Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provide is subject to legal limitations

My identity and other personal information will not be revealed, published or used in further studies. All information will have my name and address removed to protect confidentiality. Any other information that may identify me will also be removed. Confidentiality is assured but I am aware that confidentiality of information provided can only be protected within the limitations of the law. It is possible for data to be subject to subpoena, freedom of information claim, or mandated reporting by some professions. This study complies with GDPR regulations. If I have any concerns in relation to this, you should contact the DCU Data Protection Officer – Mr. Martin Ward (data.protection@dcu.ie or Ph: 7005118 / 7008257).

Signature

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project.

I confirm that I am over eighteen years of age: ☐ (please place a tick in the box provided).

Participant’s signature: __________________Name in Block Capitals: ____________________

Witness: __________________________ Date: ___________________________

Appendix L: Plain language statement for participants aged 15+ - study 2

Dublin City University
Plain Language Statement
Title of Research Study: Childrens perceptions/experiences of parental young onset dementia (YOD).

Principal Investigator: Mr. Cathal Blake email: cathal.blake25@mail.dcu.ie
Supervisor: Dr Louise Hopper (Tel: +35317008540) email: louise.hopper@dcu.ie

Introduction:

You are being invited to take part in this research study titled: "*Childrens perceptions and experiences of parental young onset dementia (YOD)*", which is part of a PhD research project in the School of Psychology, Dublin City University (DCU). This research project is self-funded. Before you decide whether to take part or not, it is important that you understand why the study is being carried out and what it will involve. Please read the following information carefully and discuss it with others if you wish. If you require further information, or would like to ask any questions, contact details for both the principal investigator and supervisor are outlined above. The main aim of the study is to examine the perspectives and experiences of children living with a parent diagnosed with young onset dementia (YOD). It is intended that the information gained from you will help to inform policy and practice in dementia care in Ireland.

Do I have to take part?

If you do not want to take part in the study, you do not have to and you do not have to say why.

What does taking part involve?

If you decide to take part, the researcher will ask you some questions as part of a one-to-one interview, or a group interview with your siblings. The interview will take place online (via Zoom/Skype/Phone). The questions will be about your experience of YOD. The questions may also ask about how you feel about your parent being unwell, and if it has affected you in any way. The researcher may also ask about daily life with your family and friends. Both the one-to-one or group interview may take between 30 and 60 minutes approximately. Depending on how you feel, you can continue to complete the full interview that day or arrange a second session another day at a suitable time and place. You can also take a break from the interview at any stage. You may withdraw from the process at any time without giving an explanation. We would like to audio-record the interviews so that we can concentrate on your views and have a full record of your thoughts. You do not have to agree to this. Even if you do agree, you can ask to have the audio-recording stopped at any time and you do not have to say why. If you agree to the audio-recording, it will be kept in a locked cabinet in DCU and destroyed after transcription.

What are the possible benefits of taking part?

Participation in this study will give you the opportunity to voice your perspectives and experiences of living with a parent with YOD. This may benefit you directly; however, it is more likely to be of benefit to people in the future who receive a diagnosis of YOD and those who care for them. Also, people often find the experience of talking to someone about their needs and experiences enjoyable.

What are the possible risks involved in taking part?

We do not envisage any risks that are greater than those encountered in everyday life. However, if at any stage during the interview you feel uncomfortable or distressed, you can take a break, or you can withdraw from the interview without any consequences. A support pack outlining dementia specific and more general supports will be provided if necessary.

How will the information you give be used?

If you agree to take part all information collected will be kept strictly confidential within the limitations of the law. All information will have your name(s) and address(es) removed so as to preserve confidentiality. Any comments you make will be made anonymously.

Your name(s) and any other identifying information will be removed, and this information will not be used in the report or in any scientific conferences or publications. This will help to make sure that information about you is kept private. Confidentiality of the information provided to the researcher(s) cannot always be guaranteed. Information can only be protected within the limitations of the law, i.e., it is possible for data to be subject to subpoena, freedom of information request or mandated reporting by some professions. All information provided by you will be securely stored at DCU for the duration of the PhD after which it will be destroyed. This study complies with GDPR regulations. If I have any concerns in relation to this, you should contact the DCU Data Protection Officer – Mr. Martin Ward (data.protection@dcu.ie or Ph: 7005118 / 7008257).

Who has approved this research?

This study has received ethics approval from the DCU Research Ethics Committee.

Participation in this research study is voluntary

You have volunteered to take part in this study. You may withdraw your participation from the study process at any time. For example, you may decide not to participate or withdraw before all stages of the research have been completed. You do NOT have to give an explanation for withdrawing. If I decide to withdraw from the study, there are two options: 1) No additional data will be provided, however, the data already collected can be used in the study; 2) None of the data already given will be used in the study. However, once data has been anonymised, it will NOT be possible to remove it from the study.

What do I have to do now?

If you would like to ask any questions or you wish to be involved, you can contact any member of the team. Our details are at the top of the first page.

Thank you for reading this information leaflet.

If you have any concerns about this study and wish to contact an independent person, please contact: **The Secretary Dublin City University Research Ethics Committee**
c/o Research and Innovation Support Dublin City University
Dublin 9. Tel 01-7008000
E-mail: rec@dcu.ie

Appendix M: Plain language statement for parents – study 2

Dublin City University

Title of Research Study: Childrens perceptions/experiences of parental young onset dementia (YOD).

Principal Investigator: Mr. Cathal Blake email: cathal.blake25@mail.dcu.ie
Supervisor: Dr Louise Hopper (Tel: +35317008540) email: louise.hopper@dcu.ie

Your child(ren) are invited to take part in a research study being conducted by Cathal Blake who is a PhD student at Dublin City University (DCU), as part of his research into the lived experiences of young onset dementia (YOD). The study, as well as your rights are described below.

Description:

This project titled: "*Childrens perceptions and experiences of parental young onset dementia (YOD)*", is part of a PhD research project in the School of Psychology, DCU. This research project is self-funded. Before you decide whether your child (ren) wish to take part or not, it is important that you understand why the study is being carried out and what it will involve. Please read the following information carefully and discuss it with others if you wish. If you require further information, or would like to ask any questions, contact details for both the principal investigator and supervisor are outlined above. The main aim of the study is to examine the perspectives and experiences of children living with a parent diagnosed with YOD.

It is intended that the information gained will help to inform policy and practice in dementia care in Ireland. If you agree, your child (ren) will be asked some questions online (e.g., via Zoom/Skype/or phone) using a semi-structured interview. These questions will ask about how YOD has impacted on the family, and whether the family's quality of life has been affected. It is envisaged that the interview with your child (ren) may take between 30 – 60 minutes approximately.

You can be present with your child (ren) at all times. We would like to audio-record the interviews so that we can concentrate on your child (ren's) views and have a full record of their thoughts. You do not have to agree to this. Even if you do agree, your child (ren) can ask to have the audio-recording stopped at any time without saying why. If you agree to the audio-recording, it will be kept securely on a password protected computer and destroyed after transcription.

Confidentiality:
Your child (ren's) identity will not be revealed to anyone but the principal researcher(s) and his designated research associates. Your child (ren's) answers will not be associated with their name. Rather, each child will be given an identification number or pseudonym. The audio recording of your child (ren's) participation will be destroyed after it has been transcribed. Confidentiality of the information provided to the researcher(s) cannot always be guaranteed. Information can only be protected within the limitations of the law, i.e., it is possible for data to be subject to subpoena, freedom of information request or mandated reporting by some professions.

Risks & Benefits:
There are no risks to your child (ren's) safety. However, if at any stage during the interview your child (ren) feel uncomfortable or distressed, they can take a break, or can withdraw from the interview without any consequences. I understand that my child (ren) has the right to end the audio recording at any time, or to refuse to answer any of the interviewer's questions without any prejudice or consequences from the researcher. If you or your children decide to withdraw from the study, there are two options: 1) No additional data will be provided, however, the data already collected can be used in the study; 2) None of the data already given will be used in the study. However, once data has been anonymised, it will NOT be possible to remove it from the study.

Grievance Procedure:
This study has received ethics approval from the DCU Research Ethics Committee. If I have any concerns about this study and wish to contact an independent person, please contact:
The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9.
[(Tel 01-7008000) or (E-mail: rec@dcu.ie)].

Please feel free to ask the researcher(s) any questions before, during or after the study.

What do I have to do now?

If you would like to ask any questions or your child wishes to be involved, you can contact any member of the team. Our details are at the top of the first page.

Thank you for reading this information leaflet.

If you have any concerns about this study and wish to contact an independent person, please contact: **The Secretary**
Dublin City University Research Ethics Committee
c/o Research and Innovation Support
Dublin City University
Dublin 9.
Tel 01-7008000 E-mail: rec@dcu.ie

Appendix N: Parental consent form for children under 18 – study 2

Dublin City University

Title of Research Study: Childrens perceptions/experiences of parental young onset dementia (YOD).

Principal Investigator: Mr. Cathal Blake email: cathal.blake25@mail.dcu.ie
Supervisor: Dr Louise Hopper (Tel: +35317008540) email: louise.hopper@dcu.ie

Your child (ren) are invited to take part in a research study being conducted by Cathal Blake who is a PhD student at Dublin City University (DCU), as part of his research into the lived experiences of young onset dementia (YOD). The study, as well as your rights as a participant, are described below.

Description:
This project titled: "*Childrens perceptions and experiences of parental young onset dementia (YOD)*", is part of a PhD research project in the School of Psychology, DCU. This research project is self-funded. Before you decide whether your child (ren) wish to take part or not, it is important that you understand why the study is being carried out and what it will involve. Please read the following information carefully and discuss it with others if you wish. If you require further information, or would like to ask any questions, contact details for both the principal investigator and supervisor are outlined above.
The main aim of the study is to examine the perspectives and experiences of children living with a parent diagnosed with YOD. It is intended that the information gained will help to inform policy and practice in dementia care in Ireland. If you agree, your child (ren) will be asked some questions online (e.g., via Zoom/Skype/or phone) using a semi-structured interview. These questions will ask about how YOD has impacted on the family, and whether the family's quality of life has been affected. It is envisaged that the interview with your child (ren) may take between 30 – 60 minutes approximately. You can be present with your child (ren) at all times.

We would like to audio-record the interviews so that we can concentrate on your child (ren's) views and have a full record of their thoughts. You do not have to agree to this. Even if you do agree, your child (ren) can ask to have the audio-recording stopped at any time without saying why. If you agree to the audio-recording, it will be kept in a locked cabinet in DCU and destroyed after transcription.

Confidentiality:

Your child (ren's) identity will not be revealed to anyone but the principal researcher(s) and his designated research associates. Your child (ren's) answers will not be associated with their name. Rather, each child will be given an identification number or pseudonym. Confidentiality of the information provided to the researcher(s) cannot always be guaranteed. Information can only be protected within the limitations of the law, i.e., it is possible for data to be subject to subpoena, freedom of information request or mandated reporting by some professions. The audio recording of your child (ren's) participation will be destroyed after it has been transcribed. I agree to have you audio record my child (ren) during this study. I understand this audio recording will only be used for the purposes of research (e.g., analysis of responses, transcriptions of responses, etc.) and will not be available to anyone aside from the research team:

___________________________________ [Parent/Guardian Signature]

Please complete the following [circle either Yes or No for each question]

Have you read or had read to you the plain language statement?	*Yes / No*
Do you understand the information provided?	*Yes / No*
Have you had an opportunity to ask questions and discuss this study?	*Yes / No*
Have you received satisfactory answers to all your questions?	*Yes / No*
Do you agree that your interview will be audio recorded?	*Yes / No*

Risks & Benefits:

There are no risks to your child (ren's) safety. However, if at any stage during the interview your child (ren) feel uncomfortable or distressed, they can take a break, or can withdraw from the interview at any time. I understand that my child (ren) has the right to end the audio recording at any time, or to refuse to answer any of the interviewer's questions without any prejudice or consequences from the researcher.

If you or your children decide to withdraw from the study, there are two options: 1) No additional data will be provided, however, the data already collected can be used in the study; 2) None of the data already given will be used in the study. However, once data has been anonymised, it will NOT be possible to remove it from the study.

Grievance Procedure:

This study has received ethics approval from the DCU Research Ethics Committee. If I have any concerns about this study and wish to contact an independent person, please contact:
The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9.
[(Tel 01-7008000) or (E-mail: rec@dcu.ie)].

Please feel free to ask the researcher(s) any questions before signing the consent form or at any time during or after the study.

Informed Consent Statement

I, ________________________________ [Parent/Guardian Signature] give permission for my child (ren) to participate in the research project. The study has been explained to me and my questions answered to my satisfaction. I understand that my child (ren's) right to withdraw from participating or refuse to participate will be respected and that their responses and identity will be kept confidential. I give this consent voluntarily.

_________________________________ [Parent/Guardian Name in Block Capitals]

_________________________________ [Parent/Guardian Signature]

_________________________________ [Witness Signature]

______________________ [Date]

Appendix O: Combined plain language statement and consent form for children under 18 – study 2

Project Title: Childrens perceptions/experiences of parental young onset dementia (YOD).

Researcher: Cathal Blake

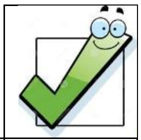
Hi, my name is Cathal, and I work in Dublin City University.

I have asked your parents and they said it is okay for you to talk to me. I am doing research about what it’s like to live with (or have lived with) someone who has dementia. Dementia is a disease that can affect how a person’s brain works. Research is a way to learn more about people. If you would like to help me with this research, I will ask you some questions about your day.

It will only take between 30 to 60 minutes to answer the questions. Your Mam or Dad or older brother or sister are going to be with you during the interview. We can take a break, and if you want to stop, just say “Stop” and we can finish up. I will use a recorder to record our voices. I will listen to them again to help me do my work. You do not have to be in this research if you do not want to be. If you decide to stop after we begin, that’s okay too. When we are finished with this research we will write a report about what was learned.

This report will NOT include your name, or that you were in the research. You can also decide NOT to be part of the report.

If you are happy to take part in this research, please put a tick in the boxes:

		
The research has been explained to me.		
I understand what I will have to do.		
I understand we are going to meet for 30 to 60 minutes.		
I am happy for my voice to be recorded.		
I understand that I can ask questions at any time.		
I can decide to stop and finish whenever I want to.		
My name will never be used in any essays written about the research.		
My information will be kept in a locked drawer, which no one else can open.		

My information will be kept for a while in case it is used to write other essays about the research. After this it will be safely deleted.		
If I and/or my parent(s)/guardian(s) have any questions about this research, I can contact the researcher. Name: Cathal Blake Work Address: Dublin City University Tel: 017008540 Email: cathal.blake25@mail.dcu.ie		
<u>Or</u> If I and/or my parent(s)/guardian(s) have concerns about this research and wish to contact an independent person, I can contact: The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel:01-7008000 e-mail: rec@dcu.ie		

If you decide you want to be in this study, please sign your name.

I, ________________________________, want to be in this research.

_________________________________ [Parent/Guardian Signature].

__________________ [Date]

Appendix P: Interview Schedule – study 2

I am going to ask you a number of questions about living with (or when you used to live with) your Mother/Father. Some of the questions will be about the time just before the diagnosis but most of the questions will be about the time afterwards.

Period before diagnosis

1. Did you notice that something was going on, or that something was wrong?
   - What did you notice?
   - What did you think was the matter?
   - At the time, did you ask anyone about it? (Well parent/siblings).

The diagnosis

1. Did you know what the diagnosis meant? What YOD was?
   - If Yes – How did you know?
   - If No – Did anyone explain it to you?
   - Did you find it difficult to understand?
   - Did you tell other people, your friends, about the diagnosis?
   - If Yes – How did they react? Did they know what YOD was?
   - If No – Why not, why did you not tell them?
2. Did any health and social care professionals (doctors, nurses, social workers etc…) help after the diagnosis?
   - If Yes – What did you think about the help? Was it of any benefit?
   - Was the information/support/treatment that you received sufficient?

After diagnosis

1. Has your relationship changed with your ill parent?
   - If Yes – In what way?
2. Has your relationship changed with your well parent?
   - If Yes – In what way?
3. Has your relationship changed with your sibling(s)?
   - If Yes – In what way?

4. What else has changed for you?

- Family life?
- Social life?
- School life? College life? Work life?

<u>Care (use a combination of some or all of the questions)</u>

1. Because of helping to care for your (parent) do you feel:

- That you are doing something good?
- That you are helping?
- That you are closer to your family?
- That you feel good about yourself?
- That you have to do things that make you upset?
- That you feel stressed?
- That you feel that you are learning useful things?
- That your parents are proud of the kind of person you are?
- That you feel like running away?
- That you feel very lonely?
- That you feel like you can’t cope?
- That you can’t stop thinking about what you have to do?
- That you feel so sad you can hardly stand it?
- That you don’t think you matter?
- That you like who you are?
- That life doesn’t seem worth living?
- That you are having trouble staying awake?
- That you feel you are better able to cope with problems?
- That you feel good about helping?
- That you feel you are useful?

<u>Future</u>

11. Do you think about the future much?

- What do you think about it?

Appendix Q: Proposed Interview Schedule – study 3

I am going to ask you a number of questions about living with (or when you used to live with) your Mother/Father. Some of the questions will be about the time just before the diagnosis but most of the questions will be about the time afterwards. I will also ask you whether or not you think peer support would be something that you think might help.

Period before diagnosis

1. Did you notice that something was going on, or that something was wrong?

- What did you notice?
- What did you think was the matter?
- At the time, did you ask anyone about it? (Well parent/siblings).

The diagnosis

1. Did you know what the diagnosis meant? What YOD was?

- If Yes – How did you know?
- If No – Did anyone explain it to you?
- Did you find it difficult to understand?
- Did you tell other people, your friends, about the diagnosis?
- If Yes – How did they react? Did they know what YOD was?
- If No – Why not, why did you not tell them?

2. Did any health and social care professionals (doctors, nurses, social workers etc…) help after the diagnosis?

- If Yes – What did you think about the help? Was it of any benefit?
- Was the information/support/treatment that you received sufficient?

After diagnosis

1. Has your relationship changed with your ill parent?

- If Yes – In what way?

2. Has your relationship changed with your well parent?

- If Yes – In what way?

3. Has your relationship changed with your sibling(s)?

If Yes – In what way?

4. What else has changed for you?

- Family life?
- Social life?
- School life? College life? Work life?

Questions relating to Peer support

1. Do you know what peer support is?

2. How it works and what it involves?

3. In your opinion, do you think peer-to-peer support would be a good idea?

- If either yes of no, ask the participant to explain why.

4. Do you know what stigma is?

5. Have you faced stigma as a result of your parents diagnosis?

- If answer is yes – why do you think this is?

6. How do you think YOD is portrayed in the media – social media, radio, TV etc…?

7. Do you think the general public are aware of YOD and what it is?

8. Have you ever used any resources available from the various dementia charities, such as the Alzheimer Society of Ireland?

9. Do you think you rely on your well parent for information and support?

10. Do you rely on other family members, friends, school/college/work colleagues?

Appendix R: Plain language statement for participants over 18 – study 3

Dublin City University

Plain Language Statement

Title of Research Study:

Investigating the need for peer support groups for children and young adults affected by parental young onset dementia.

Supervisor: Dr. Louise Hopper (Tel: +35317008540) email: louise.hopper@dcu.ie

Principal Investigator: Mr. Cathal Blake – email: cathal.blake25@mail.dcu.ie

Introduction:

You are being invited to take part in this research study titled: "*Investigating the need for peer support groups for children and young adults affected by parental young onset dementia*", which is part of a PhD research project in the School of Psychology, Dublin City University. This research project is self-funded. Before you decide whether to participate, it is important that you understand why the study is being carried out and what it will involve. Please read the following information carefully and discuss it with others if you wish. If you require further information, or would like to ask any questions, contact details for both the principal investigator and supervisor are outlined above. The main aim of the study is to examine whether or not you think a peer support group(s) would be beneficial for children living with (or who have lived with) a parent with young onset dementia. We are also interested in whether parents would like to use peer support groups. It is intended that the information gained from you will help to inform policy and practice in dementia care in Ireland.

Do I have to take part?

If you do not want to take part in the study, you do not have to and you do not have to say why.

What does taking part involve?

If you decide to take part, the researcher will ask you some questions as part of a one-to-one interview, or as part of a focus group interview. The interview will take place at a time and location of your choosing or online (via Zoom). The interview will ask about your experience of young onset dementia and whether or not you think a peer support group(s) would be beneficial. The questions may also relate to the coping mechanisms you employ, whether you feel anxious, your quality of life and how young onset dementia has impacted you. The researcher may also ask about daily life with your family and friends.

Both the one-to-one or focus group interview may take between 30 and 60 minutes approximately. Depending on how you feel, you can continue to complete the full interview that day or arrange a second session another day at a suitable time and place. You can also take a break from the interview at any stage. You may withdraw from the process at any time without giving an explanation. We would like to audio-record the interviews so that we can concentrate on your views and have a full record of your thoughts. You do not have to agree to this. Even if you do agree, you can ask to have the audio-recording stopped at any time and you do not have to say why. If you agree to the audio-recording, it will be kept in a locked cabinet in DCU and destroyed after transcription.

What are the possible benefits of taking part?

Participation in this study will give you the opportunity to voice your perspectives and experiences of living with a person with young onset dementia. This may benefit you directly; however, it is more likely to be of benefit to people in the future who receive a diagnosis of young onset dementia and those who care for them. Also, people often find the experience of talking to someone about their needs and experiences enjoyable.

What are the possible risks involved in taking part?

We do not envisage any risks that are greater than those encountered in everyday life. However, if at any stage during the interview you feel uncomfortable or distressed, you can take a break, or you can withdraw from the interview without any consequences. A support pack outlining dementia specific and more general supports will be provided if necessary.

How will the information you give be used?

If you agree to take part all information collected will be kept strictly confidential within the limitations of the law. All information will have your name(s) and address(es) removed so as to preserve confidentiality. Any comments you make will be made anonymously. Your name(s) and any other identifying information will be removed, and this information will not be used in the report or in any scientific conferences or publications. This will help to make sure that information about you is kept private. Confidentiality of the information provided to the researcher(s) cannot always be guaranteed. Information can only be protected within the limitations of the law, i.e., it is possible for data to be subject to subpoena, freedom of information request or mandated reporting by some professions.

All information provided by you will be securely stored at DCU for a maximum of 1 year after which it will be destroyed. This study complies with GDPR regulations. If you have any concerns in relation to this, you should contact the DCU Data Protection Officer – Mr. Martin Ward (data.protection@dcu.ie or Ph: 7005118 / 7008257).

Who has approved this research?

This study has received ethics approval from the DCU Research Ethics Committee.

Participation in this research study is voluntary

You have volunteered to take part in this study. You may withdraw your participation from the study process at any time. For example, you may decide not to participate or withdraw before all stages of the research have been completed. You do NOT have to give an explanation for withdrawing. If I decide to withdraw from the study, there are two options: 1) No additional data will be provided, however, the data already collected can be used in the study; 2) None of the data already given will be used in the study. However, once data has been anonymised, it will NOT be possible to remove it from the study.

What do I have to do now?

If you would like to ask any questions or you wish to be involved, you can contact any member of the team. Our details are at the top of the first page.

Thank you for reading this information leaflet.

If you have any concerns about this study and wish to contact an independent person, please contact:

The Secretary
Dublin City University Research Ethics Committee
c/o Research and Innovation Support
Dublin City University
Dublin 9.
Tel 01-7008000
E-mail: rec@dcu.ie

Appendix S: Consent form for participants over 18 – study 3

Dublin City University

Consent Form

Title of Research Study:

Investigating the need for peer support groups for children and young adults affected by parental young onset dementia.

Supervisor: Dr. Louise Hopper (Tel: +35317008540) email: louise.hopper@dcu.ie

Principal Investigator: Mr. Cathal Blake – email: cathal.blake25@mail.dcu.ie

Clarification of the purpose of the research:

You are being invited to take part in this research study titled: "*Investigating the need for peer support groups for children and young adults affected by parental young onset dementia*", which is part of a PhD research project in the School of Psychology, Dublin City University (DCU). The main aim of the study is to examine whether or not you think peer support group(s) would be beneficial for children living with (or who have lived with) a parent with young onset dementia. You have been approached in relation to this research because of your knowledge and experience in relation to the psychosocial impact of young onset dementia.

Confirmation of particular requirements as highlighted in the Plain Language Statement:

I will take part in an interview led by a researcher from DCU, during which I will give my opinion regarding peer support groups for children affected by parental young onset dementia. The interview will be approximately 30-60 minutes long, although it may run a little longer if I have more I would like to say. I know that I can take a break from the interview at any stage, and that I may withdraw at any time without giving an explanation. I am also aware that the discussion will be audio recorded.

Participant – please complete the following [circle Yes or No for each question]

I have read the study information sheet	*Yes/No*
I understand the information provided	*Yes/No*
I have had an opportunity to ask questions and discuss this study	*Yes/No*
I have received satisfactory answers to all my questions	*Yes/No*
I consent to having my interview audio recorded	*Yes/No*
I am aware that whilst every effort will be made to protect my identity, anonymity cannot be entirely guaranteed.	*Yes/No*

Confirmation that involvement in the research is voluntary

I have read this consent form. I have had opportunity to ask questions about the consent form and all the questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study which respects my legal and ethical rights. I am aware that I may withdraw at any time right up to publication of the final report without giving reason, and without this decision affecting me in any way.

Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations

I am satisfied that the research team will ensure confidentiality subject to the limitations of the law, and they will ensure, in so far as it is possible, that my identity will not intentionally be revealed to others.

Signature

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project.

I confirm that I am over eighteen years of age: ☐ (*please place a tick in the box provided*).

Participant's signature: ___________________

Name in Block Capitals: ___________________

Witness: _________________________

Date: __________________________

Appendix T: Combined Plain Language Statement & Consent Form for participants under 18 – study 3

Dublin City University – Information Sheet

Project Title: Investigating the need for peer support groups for children and young adults affected by parental young onset dementia.

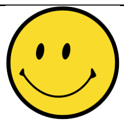
Researcher: Cathal Blake – email: cathal.blake25@mail.dcu.ie

Hi, my name is Cathal, and I work in Dublin City University.

I have asked your parents and they said it is okay for you to talk to me. I am doing research about what it's like to live with (or have lived with) someone who has dementia. Dementia is a disease that can affect how a person's brain works. Research is a way to learn more about people. If you would like to help me with this research, I will ask you some questions about your experience(s) of living with somebody with dementia.

I will also ask you if you think that talking about these experiences with other children, in a similar situation, would help you. It will only take between 30 to 60 minutes to answer the questions. Your Mam or Dad or older brother or sister are going to be with you during the interview.

We can take a break, and if you want to stop, just say “Stop” and we can finish up. I will use a recorder to record our voices. I will listen to them again to help me do my work. You do not have to be in this research if you do not want to be. If you decide to stop after we begin, that’s okay too. When we are finished with this research we will write a report about what was learned. This report will NOT include your name, or that you were in the research. You can also decide NOT to be part of the report. If you are happy to take part in this research, please put a tick in the boxes:

		✓
The research has been explained to me.		
I understand what I will have to do.		
I understand we are going to meet for 30 to 60 minutes.		
I am happy for my voice to be recorded.		
I understand that I can ask questions at any time.		
I can decide to stop and finish whenever I want to.		
My name will never be used in any essays written about the research.		

My information will be kept in a locked drawer, which no one else can open.		
My information will be kept for a while in case it is used to write other essays about the research. After this it will be safely deleted.		
If I and/or my parent(s)/guardian(s) have any questions about this research, I can contact the researcher. **Name: Cathal Blake** **Work Address: Dublin City University** **Email: cathal.blake25@mail.dcu.ie**		
Or **If I and/or my parent(s)/guardian(s) have concerns about this research and wish to contact an independent person, I can contact:** **The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9.** **Tel:01-7008000** **e-mail: rec@dcu.ie**		

If you decide you want to be in this study, please sign your name.

I, ____, want to be in this research.

____ [Parent/Guardian Signature].

_______________________ [Date]

Appendix U: Combined Plain Language Statement and Consent Form for Parents of children under 18.

Dublin City University – Consent Form

Title of Research Study:

Investigating the need for peer support groups for children and young adults affected by parental young onset dementia.

Principle Investigator: Dr. Louise Hopper (Tel: 017008540) email: louise.hopper@dcu.ie
Researcher: Mr. Cathal Blake – email: cathal.blake25@mail.dcu.ie

Your child (ren) are invited to take part in a research study being conducted by Cathal Blake who is a PhD student at Dublin City University (DCU), as part of his research into the lived experiences of young onset dementia. The study, as well as your rights as a participant, are described below.

Description: This project titled: "*Investigating the need for peer support groups for children and young adults affected by parental young onset dementia*", is part of a PhD research project in the School of Psychology, DCU. This research project is self-funded. Before you decide whether your child (ren) wish to take part or not, it is important that you understand why the study is being carried out and what it will involve. Please read the following information carefully and discuss it with others if you wish.

If you require further information, or would like to ask any questions, contact details for both the principal investigator and supervisor are outlined above. The main aim of the study is to examine whether or not you think a peer support group(s) would be beneficial for children living with (or who have lived with) a parent with young onset dementia. It is intended that the information gained will help to inform policy and practice in dementia care in Ireland. If you agree, your child (ren) will be asked some questions either face-to-face of online (e.g., via Zoom/Skype/or phone) using a semi-structured interview. These questions will ask about how young onset dementia has impacted on the family, and whether attending a peer support group would be beneficial.

It is envisaged that the interview with your child (ren) may take between 30 – 60 minutes approximately. You can be present with your child (ren) at all times. We would like to audio-record the interviews so that we can concentrate on your child (ren's) views and have a full record of their thoughts. You do not have to agree to this. Even if you do agree, your child (ren) can ask to have the audio-recording stopped at any time without saying why. If you agree to the audio-recording, it will be kept in a locked cabinet in DCU and destroyed after transcription.

Confidentiality: Your child (ren's) identity will not be revealed to anyone but the principal researcher(s) and his designated research associates. Your child (ren's) answers will not be associated with their name. Rather, each child will be given an identification number or pseudonym. Confidentiality of the information provided to the researcher(s) cannot always be guaranteed. Information can only be protected within the limitations of the law, i.e., it is possible for data to be subject to subpoena, freedom of information request or mandated reporting by some professions. The audio recording of your child (ren's) participation will be destroyed after it has been transcribed. I agree to have you audio record my child (ren) during this study. I understand this audio recording will only be used for the purposes of research (e.g., analysis of responses, transcriptions of responses, etc.) and will not be available to anyone aside from the research team:

____________________________________ [Parent/Guardian Signature]

Please complete the following [circle either Yes or No for each question]

Have you read or had read to you the plain language statement?	*Yes / No*
Do you understand the information provided?	*Yes / No*
Have you had an opportunity to ask questions and discuss this study?	*Yes / No*
Have you received satisfactory answers to all your questions?	*Yes / No*
Do you agree that your interview will be audio recorded?	*Yes / No*
I am aware that whilst every effort will be made to protect my child's identity, anonymity cannot be entirely guaranteed.	*Yes/No*

Risks & Benefits: There are no risks to your child (ren's) safety. However, if at any stage during the interview your child (ren) feel uncomfortable or distressed, they can take a break, or can withdraw from the interview at any time. I understand that my child (ren) has the right to end the audio recording at any time, or to refuse to answer any of the interviewer's questions without any prejudice or consequences from the researcher.

If you or your children decide to withdraw from the study, there are two options: 1) No additional data will be provided, however, the data already collected can be used in the study; 2) None of the data already given will be used in the study. However, once data has been anonymised, it will NOT be possible to remove it from the study.

Grievance Procedure: This study has received ethics approval from the DCU Research Ethics Committee. If I have any concerns about this study and wish to contact an independent person, please contact:

The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9.
[(Tel 01-7008000) or (E-mail: rec@dcu.ie)].

Please feel free to ask the researcher(s) any questions before signing the consent form or at any time during or after the study.

Informed Consent Statement

I, ________________________________ [Parent/Guardian Signature] give permission for my child (ren) to participate in the research project. The study has been explained to me and my questions answered to my satisfaction. I understand that my child (ren's) right to withdraw from participating or refuse to participate will be respected and that their responses and identity will be kept confidential. I give this consent voluntarily.

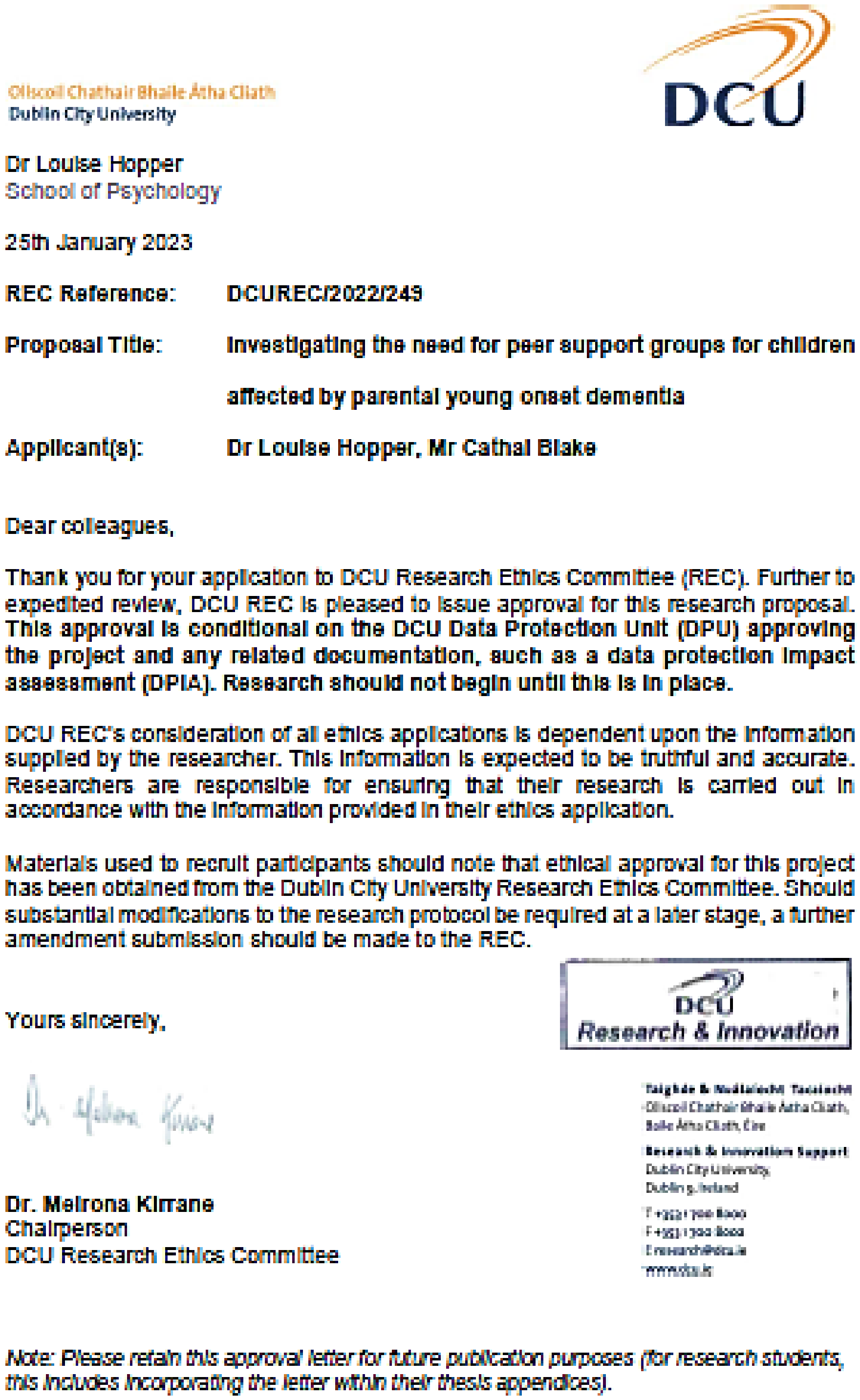
_________________________________ [Parent/Guardian Name in Block Capitals]

_________________________________ [Parent/Guardian Signature]

_________________________________ [Witness Signature]

______________________ [Date]

Appendix V: REC Approval letter – study 3



Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

Dr Louise Hopper
School of Psychology

25th January 2023

REC Reference: DCUREC/2022/249

Proposal Title: Investigating the need for peer support groups for children affected by parental young onset dementia

Applicant(s): Dr Louise Hopper, Mr Cathal Blake

Dear colleagues,

Thank you for your application to DCU Research Ethics Committee (REC). Further to expedited review, DCU REC is pleased to issue approval for this research proposal. **This approval is conditional on the DCU Data Protection Unit (DPU) approving the project and any related documentation, such as a data protection impact assessment (DPIA). Research should not begin until this is in place.**

DCU REC's consideration of all ethics applications is dependent upon the information supplied by the researcher. This information is expected to be truthful and accurate. Researchers are responsible for ensuring that their research is carried out in accordance with the information provided in their ethics application.

Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee. Should substantial modifications to the research protocol be required at a later stage, a further amendment submission should be made to the REC.

DCU
Research & Innovation

Yours sincerely,

Dr. Melrona Kirrane
Chairperson
DCU Research Ethics Committee

Taighde & Nuálaíocht Tacaíocht
Ollscoil Chathair Bhaile Átha Cliath,
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Note: Please retain this approval letter for future publication purposes (for research students, this includes incorporating the letter within their thesis appendices).