Living with and beyond dementia:

A phenomenological investigation of Young People's lived experience with dementia and the transition from pre-diagnosis through diagnosis and beyond to living well with dementia

Jane E Douglas

A thesis submitted in partial fulfilment of the requirement of
Edinburgh Napier University, for the award of Doctor of
Philosophy

October 2017

Declaration

I declare that this thesis is my own work, composed by myself. That no material contained within has been submitted or accepted in any previous application for a higher degree. The work has been performed by myself and all sources of information have been specifically acknowledged.

Signed:

Date:

Acknowledgements

I would like to express my gratitude to Dr Dorothy Horsburgh who when I began my PhD study was my Director of Studies. I would also like to express thanks to Dr Rory MacLean who has supported me throughout this journey over the last six years. I am extremely grateful for the support I have received from Dr Gerri Matthews-Smith who has encouraged and supported me to continue with this journey and without her input I may have faulted at one of the many hurdles I faced on the way.

I am especially grateful to the participants who gave their time and their in depth personal experiences of living with dementia, without whom this study would not have been possible. I was extremely humbled by their honesty. I would also like to thank the Scottish Dementia Working Group who helped me with my search for participants to the study.

My thanks go to Henry Simmons, Chief Executive Alzheimer Scotland, for his support for this study and Alzheimer Scotland for the assistance they provided in funding the research. I am grateful to Scottish Borders Council who also contributed to the funding of this study, both financially and through releasing time.

Thanks go to my long-suffering husband Dr Tony Douglas who has supported me throughout, had to put up with me over the last six years, especially this last year where I have been absent from his life for some of the time due to the commitment of the PhD. My step daughters Alexandra and Rebecca who have continued to take an interest, and although they are residing over waters far and wide have sent encouraging text messages to support me and ask me how it is progressing. Thanks to my two sisters Debbie and Claire and my very good friend Suzanne who have also been supportive through the process. I would like to mention my mum and dad who sadly are no longer here to learn about this study. My mum would have been so interested to hear about the findings of the study. They both would have been so proud to see this achievement. I thank my colleagues and friends who have had to listen to me talk about my PhD findings and act interested.

Abstract

Younger People with Dementia (YPwD) are those who receive a diagnosis of dementia under the age of 65. In Scotland the number of people with dementia who meet this definition is approximately 3200 (Alzheimer Scotland, 2017). The purpose of this study was to explore the human experience of living with dementia at a younger age and to consider interpretations of well-being as defined by the subjective experience of the participants. At the start of this study there was limited quality research available which explored the lives and experiences of YPwD. At that time there was some recognition within professional groups and practitioners that YPwD would benefit from age appropriate services. This study used an Interpretive Phenomenological design to explore the experiences of YPwD and used in-depth qualitative interviews with eight people who were diagnosed with dementia under the age of 65, to capture their journey through pre-diagnosis, diagnosis and beyond. Interpretive Phenomenological Analysis was utilised for the primary analysis. A secondary analysis was then conducted with the initial findings using Self-determination Theory, Basic Psychological Needs Theory, autonomy, competence and relatedness to identify areas of well-being.

The study identified four superordinate themes situated within a four phase transition pathway, which identified how a diagnosis of dementia impacted on the person and the process they underwent following diagnosis. These are: pre-diagnosis phase, living in a changing world, awareness of the changing self, discombobulation; diagnostic phase, anger and relief, the fragmented self, consideration; post diagnostic phase, the challenge of learning to live with dementia as a younger person, the evolving self, assimilation; and the phase living well beyond dementia, consolidated self, consolidation. The study highlighted that while having a diagnosis of dementia at a younger age is a challenging and devastating experience, it is possible to live a good and productive life beyond the diagnosis of dementia.

The secondary analysis using Self-determination Theory, Basic Psychological Needs Theory identified that where the basic psychological needs were supported, this enabled participants to embrace their lives living with and beyond dementia with improved wellbeing. The findings suggest that the basic psychological needs were thwarted in the pre-diagnostic phase and during and immediately after diagnosis, creating feelings of ill-being.

The study acknowledges the strong sense of identity around the younger person with dementia and suggests that this group perceive their dementia, and the support they need to live with the condition to be a different experience to that of older people. The ability of a number of the participants to live an active life within a supported community cannot be underestimated, and suggests that this area of care and support needs to be evaluated in light of the changing needs of people living with dementia, particularly those who are diagnosed at such an early part of their lifecycle.

Table of contents

List of Tables and Diagrams

Glossary of terms and Abbreviations

AS – Alzheimer Scotland, Scottish Strategy supporting people with dementia.

AWIA – Adults with Incapacity (Scotland) Act

BPNT – Basic Psychological Needs Theory, sometimes referred to as BPN, a mini theory of Self Determination Theory

Carer(s) – refers to unpaid carer, family or spouse caring for a younger person with dementia or an older person with dementia

CPN – Community Psychiatric Nurse

DPA – Data Protection Act

ENU – Edinburgh Napier University

Health and Social Care – refers to Health and Social Care Partnerships, includes social work, social care, and health

LA – Local Authority, Council

Late onset dementia – refers to people diagnosed with dementia over the age of 65

NHS – National Health Service

OPwD – Older People with Dementia, people over the age of 65 with a diagnosis of dementia

SDT – Self-determination Theory

SDWG - Scottish Dementia Working Group, an action group that is run by people with dementia, for people with dementia

TPO - Talking Point Outcomes

WHO – World Health Organisation

YPwD – Younger People with Dementia, people with a diagnosis of dementia under the age of 65

Younger onset dementia – another term used to refer to people who are diagnosed with dementia under the age of 65

1 Chapter 1 Introduction

1.1 Introduction

This chapter provides the rationale for this study of which the purpose was to explore the human experience of living with dementia at a younger age, to consider interpretations of well-being as defined by the subjective experience of the participants. The chapter also presents the national policy context and prevalence rates of dementia in younger people together with an outline of the structure of the thesis.

1.2 Stimulus for study

As the strategic lead for dementia with a Scottish local authority working in Health and Social Care, part of my role was lead commissioner for adults in need of care and support. Additionally, prior to commencing the study I had been leading on a local joint strategy for dementia with the National Health Service (NHS) and the local authority. The consultation of the strategy highlighted concerns about the needs of younger people with dementia and how their needs were not being met within the area of partnership. As the lead commissioner, I became aware of the concern that perhaps this group were at risk since there were no identified services to meet the needs of a younger person with dementia. This concern stimulated my interest in exploring the area from the perspective of the client to ensure that their needs and support could be accommodated; to understand what the views of Younger People with Dementia were; how Younger People with Dementia felt about living with dementia as a younger person; to explore the support needs of Younger People with Dementia from their viewpoint, all of which became part of the rational for conducting this study.

1.3 National Policy and Context

The Scottish Government launched Scotland's National Dementia Strategy in June 2010 and this was updated in 2013 and further updates are planned for 2017 (at the time of writing the updated strategy had not been launched). The Scottish Dementia Strategy is seen as a 'national priority' for the Scottish Government (Scottish Government 2010, p.1). One of the key aims of the strategy was to:

> 'Ensure that people receiving care in all settings get access to treatment and support that is appropriate…' (Scottish Government, 2010, p.7)

There were a number of key outcomes identified in the 2013 Dementia Strategy such as: an aim to improve quality of life and support people living with dementia to remain at home for longer; to work with communities to ensure that they are dementia friendly and reduce stigma; timely diagnosis; to provide post-diagnostic support; to involve all those living with dementia, including carers of people with dementia as equal partners in their care and support; to promote a rights based approach in all care settings including being treated with dignity and respect (Scottish Government, 2013-2016).

The National Dementia Strategy was an important step towards improving the care for people living with dementia and those who care for them. However, there were severe budget pressures across Health and Social Care and there was no budget attached to the strategy to support the strategic aims. Therefore, there appeared to be a disconnect between the strategic aims of health and social care partnerships and the availability of funds. Younger People with Dementia are a minority group who exist within an expanding group of people with dementia, therefore, there is the potential for them to get lost amongst the demands of other service user groups.

1.4 Dementia definition and prevalence in Younger People

Dementia is the collective term used to describe a range of symptoms that include increasing memory impairment, decreasing communication skills and reasoning (Alzheimer's Society, 2011). It has been defined by the World Health Organisation as:

> 'a syndrome due to disease of the brain – usually of a chronic or progressive nature – in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in a large number of conditions primarily or secondarily affecting the brain'
>
> (World Health Organisation (WHO), 1992 in WHO, 2012 p.7)

The condition affects older people with the potential for incidence of dementia to increase with age. However, there is a growing awareness of the increasing numbers of younger people with dementia. A younger person with dementia is one who receives a diagnosis of dementia who is under the age of 65 (Cox and Keady, 1999; Woodburn, 1999). Other terms evident in the literature include 'young onset dementia' or 'early onset dementia'. For clarity, within this study the term younger people with dementia (YPwD) is used when referring to people who were diagnosed with dementia under the age of 65, and the term older people with dementia (OPwD) when referring to people diagnosed after the age of 65. The terms young onset dementia and late onset dementia are referred to in this study when required.

Younger onset dementia has been classed as a rare condition by the World Health Organisation (WHO, 2012). Determining the extent of dementia within a population is referred to in terms of incidence or prevalence. These terms are defined as: 'incidence is the proportion of people in a specific population developing a condition over a fixed period of time… prevalence is the number of people in a specific population suffering from a condition at a fixed time' (Woodburn, 1999, p. 37). The prevalence rate of dementia in younger people in the UK is 1 in 1400 (age 40-64 years) compared to 1 in 100 age 65-69 years (Alzheimer’s Society, 2012). The number of YPwD in the UK was estimated to be 42,325 in 2014 (Alzheimer’s Society, 2014) which is a significant increase from the figures reported in the Dementia UK report 2007 of 15,034.

The explanation for the increase is due to the way the estimates were calculated; the previous report had calculated estimates based on referrals of YPwD to services, whereas the new estimates are based on a Delphi consensus approach. In Scotland the prevalence of people under the age of 65 is 3200 (Alzheimer Scotland, 2017). Alzheimer Scotland applied Harvey (1998) prevalence rates based on the population projections for 2013 from the General Register Office for Scotland.

1.5 Dementia and Younger People

Dementia is situated firmly within the conditions associated with old age, with dementia under the age of 65 considered a much rarer diagnosis (Woodburn, 1999). There are many different types of dementia and younger people are more likely to have more than one type of dementia. The most common types of dementia affecting younger people are shown below in Table 1:

Table 1 Common types of dementia affecting younger people

Alzheimer’s Disease - this is the most common type with around 33% of younger onset dementia being of Alzheimer type
Vascular Dementia - this is the second most common form of dementia, 20%
Frontotemporal Dementia - affects around 12% of young people. This type of dementia commonly occurs between the ages 45-65, and in around 40% of those diagnosed with this type of dementia there is a family history of the condition
Korsakoff’s syndrome (KS) - is related to a lack of vitamin B1 and is associated with alcohol abuse, around 10% of the dementias in younger people are found to be related to KS.
There are rarer forms of the dementia that are found in around 20% of young people, these diseases that can lead to dementia such as Parkinson’s Disease, Huntington’s Disease and Creutzfeld Jakob Disease (CJD)

(Young Dementia UK, 2017)

The signs and symptoms of dementia are caused by a variety of different disease processes, but are primarily due to the death of cells in areas of the brain that affect memory, reduce capacity in judgement, and difficulty with language and abstract thinking. Other symptoms that maybe present are changes in personality, altered mood and changes in behaviour. All these changes affect the person’s daily living and social interaction (McLennan, 1999).

Although the biomedical signs and symptoms of dementia are similar in younger onset dementia and late onset dementia, Table 2 below identifies those symptoms which are particular to YPwD as described by McLennan

(1999, p.18), which are important if identified in a person under the age of 65.

Table 2 Signs and symptoms of dementia in younger people

- Decline in short term memory
- Symptoms of anxiety and depression
- Personality change with blunting of emotional perception and responsiveness
- Lack of interest in and withdrawal from normal activities including family relationships
- Forgetting appointments
- Inability to perform routine tasks to the same standard as previously
- Poor concentration
- Word finding difficulties
- Repetitive conversations
- The development at times of paranoid ideas

1.6 The needs of Younger People with Dementia

Several early researchers, clinicians and practitioners studying the needs of YPwD have identified the differing needs of YPwD when compared to older people with dementia (OPwD) (Cox and Keady, 1999; Harris and Keady, 2009; McLennan, 1999; Williams, Cameron and Dearden, 2001), and that they have unique challenges when compared to the older population (Harris and Keady, 2004; Novek, Shooshtari and Menec, 2015). These specialist needs are identified because of the age and stage of life the person is at. Younger People with Dementia are at a different stage in their life when they start to experience the symptoms of dementia and their lives are likely to be more complex and challenging (Harris, 2004). People within the midlife age group are likely to be in employment and have financial commitments (McLennan, 1999), and younger families (Beattie, Daker-White, Gilliard and Means, 2004). Being presented with a diagnosis of dementia disrupts the life of the person with dementia and their families' lives, spouse/ significant other and children, and impacts on the presumed life course (Gelman and Greer, 2011).

The following table (Table 3) provides the detail of the specific psychosocial needs for YPwD as identified by Cox and Keady (1999, p.293).

Table 3 Psychosocial need for YPwD

- Point in life stage - life history current roles, responsibilities and concerns
- Changes to lifestyle- what people view as significant and meaningful in their lives
- Retained mobility and physical strength
- The importance of dependent children, from infants to teenagers to grandchildren
- Financial commitments and concerns
- Genetic issues arising from a diagnosis
- Family, friends and wider societal expectations about acceptable behaviour
- Pattern of social contacts and networks
- Attitudes to loss, death and on the meaning of their condition
- Revisions in the expectations of ordinary everyday life e.g. work, money, living arrangements, social and sexual relationships, independence and responsibility for others
- Altered body image

The specific needs identified above indicates the requirement for specialist or age appropriate services and this view is supported in the key literatures by a number of writers: (e.g. Bakker *et al.* 2010; Barber, 1997; Beattie *et al.* 2004; Gibson, Anderson and Ackocks, 2014; Williams *et al.* 2001; Willis *et al.* 2009). However, despite the support for specialist services there are some such as Reed *et al.* (2002) who present an argument against the need for specialist services. They proposed that the disparities identified in their study suggest that the differences in YPwD needs are based on age and as such are socially constructed.

Early discussions around the unique needs of YPwD were being debated in 1999 when Cox and Keady (1999) and colleagues alerted policy makers, service planners and commissioners to ‘an agenda for change for younger people with dementia, their families and support networks’ (p. 292). They described the then service planners and commissioners in Health and Social

Care as ‘ambivalent’, when they sought to try and get the needs of YPwD recognised and onto the health and social care agenda. Yet despite this supported call for change, reinforced by practitioners, specialist clinicians and researchers, little has changed for YPwD over the last seventeen years with only patchy and variable supports available for YPwD (Rayment and Kuruvilla, 2015). The onset of new models of care, such as Self-Directed Support through the Social Care (Self-Directed Support) (Scotland) Act 2013, may perhaps go some way towards assisting YPwD to access the individualised care and support they need. Yet to date within Health and Social Care there is no identified budget for YPwD, which differs to other minority service user groups, such as People with Learning Disabilities and People with Physical Disabilities. With budgets for all service users being stretched further and further, and without the dedicated budget facility, it is difficult to see how this service user group will have equity of access to services compared to other service user groups. However, the question remains about whether the needs of YPwD are different, and if their needs being different, is the view of the younger person? This research study explored the views and experiences of YPwD, to try to understand how they view their lives with dementia and how their needs and wellbeing are maintained.

1.7 Hearing the voice - Experiences of living with dementia as a younger person

Until the early 1990’s people with dementia were excluded from dementia research and were overlooked with a focus on the biomedical model (Hubbard, Downs and Tester 2003; Shlosberg, 2003; Shlosberg, Browne and Knight 2003; Wilkinson, 2002). This was based on the original thought that people with dementia could not be relied upon to give accurate accounts of their experiences (Wilkinson, 2002), and proxy accounts were used in order to understand the experience of living with dementia (Beattie *et al.* 2002). However, it is now recognised that the views of the person’s lived experience provide rich insight into the world of the person with dementia and affords a greater understanding (Phinney, 2002). Early research that focused on the needs of YPwD did not actually include the person with dementia; mainly, it provided the view from the perspective of the carer of the younger person with dementia and clinicians (Phinney, Chaudhury and O'Connor, 2007). Armari, Karmolowicz and Panegyre (2012) note in their study, focused on the needs of people with younger onset dementia, that there continues to be a lack of research that focuses on the perspectives of YPwD. They warn against utilising the perspective of people with late onset dementia as a substitute for younger onset experiences. This current study supports their view that there is a need to hear the perspective of the younger person with dementia in order to ensure that needs are accurately identified, and services adapted to meet that need.

1.8 Structure of the Thesis

The next section provides an overview of the structure of the thesis. The remaining thesis chapters have been organised as follows:

Chapter 2 Literature Review

Whilst Chapter one has provided a context and background to the study Chapter two presents the findings of the comprehensive literature review. The main focus of the literature review was to identify research that had included the voice and experience of YPwD. Research that focused on younger onset dementia and issues associated with younger onset dementia was also included as discussion. This chapter also contains the theoretical underpinning that supports the research with an overview of personhood, self and identity and well-being. Finally, the chapter provides detail about Self-determination Theory which was applied to understand well-being, wellness and ill-being in relation to the lived experience.

Chapter 3 Research Design and Methods

Chapter three presents the research design and methods, identifying the most appropriate approach and methods for this study. The methodology chosen for this research study was a qualitative research approach utilising an Interpretive Phenomenological Analysis.

Chapter 4 Case Studies

In chapter four the reader is introduced to the eight participants in the study. This was considered important in order to provide an overview of the different lifestyles of the group and to provide a more in depth account of the lifestyles of the group, with an outline of the main findings.

Chapter 5 Findings

Chapter five provides the detail of the four themes which were the findings and the findings of the secondary analysis using Self-determination Theory as a framework.

Chapter 6 Discussion

Chapter six presents the discussion in relation to the literature, policy and Self-determination Theory.

Chapter 7 Summary, recommendations and conclusion

Chapter seven presents the summary and conclusions, and discusses contribution to research and practice. Consideration is given in regard to evaluating the credibility, with further consideration given around the limitations of the study.

2 Chapter 2 Literature review

2.1 Introduction

The first part of this chapter focuses on previous research around YPwD. The main literature reviewed focused on the experiences of YPwD and their carers. Other research included in this review also focused on YPwD but did not include the voice of the younger person with dementia. The first section considers the research and the primary focus and identified themes. The sections following this discuss the themes in more detail, drawing on wider research to critique and discuss the themes in depth.

The second part of this chapter provides the theoretical underpinnings that supported the research, including an overview of personhood, self and identity. Self-determination Theory (SDT), Basic Psychological Needs Theory (BPNT) was used as a framework to understand well-being, and this chapter provides a detailed account of SDT as a theoretical model. The second part of this chapter will also provide detail about the Talking Point Outcomes tool, which is used within health and social care to assist people who are requiring support, to identify outcomes to support quality of life and wellbeing. The Talking Point Outcomes are well researched in relation to older people and while they are used across all age groups, there is little research which identifies the outcomes as they relate to younger age groups. This study acknowledges the Talking Point Outcomes and considered these as part of the theoretical underpinning.

2.2 Research identified for this study

The literature search was specifically related to evidence based papers which addressed the needs of YPwD. Although there was a great deal of literature relevant to the older age group this was not included in this review since the focus of the literature was on the sample group being investigated. The literature review included studies that involved carers and family members only where YPwD participated in the study, but excluded research where the primary focus was on the carer or other family members and which did not include the views of the younger person with dementia. However, research which focused on YPwD, but did not include their voice or experiences were utilised to discuss the themes identified in the primary research, which included the voice of YPwD. The reason for this decision was to ensure there was a focus on the research which included the voice of YPwD, and the themes identified by them. Literature reviews and editorials were excluded within this section of the review.

The studies included in the review with the views and experiences of YPwD dated from 1996 to 2016, with prominent researchers in the field still contributing to the studies which focus on YPwD such as, John Keady, Mike Nolan, Phyllis Harris, Pamela Roach and Neil Drummond. Research prior to 1996 was utilised in the supporting discussion sections to demonstrate where there has been a change or a lack of change in support for YPwD over time.

The Table (Table 4) below provides the research articles, numbers and country of origin.

Table 4 Research articles and countries

Country	Number of articles
UK	9
UK/USA	2
Australia	5
Canada	3
USA	2
Norway	1
Sweden	1
Finland	1

Twenty four research papers were selected for inclusion, all of these included YPwD as participants to the study. Out of the 24 selected 21 were qualitative studies, with the remaining three quantitative studies conducted through survey questionnaire. The number of YPwD included in the qualitative studies reviewed ranged from 5 up to 23. Six of the studies had used data collected from the same cohort of participants, which decreases the actual number of YPwD involved in research.

Two qualitative studies were retrieved that identified either one person under the age of 65 or an unspecified number of people under the age of 65: Husband (1999) and Phinney *et al.* (2007), the focus of those studies was not YPwD; however, they have been utilised in the section labelled supporting literature.

2.3 Context of research reviewed

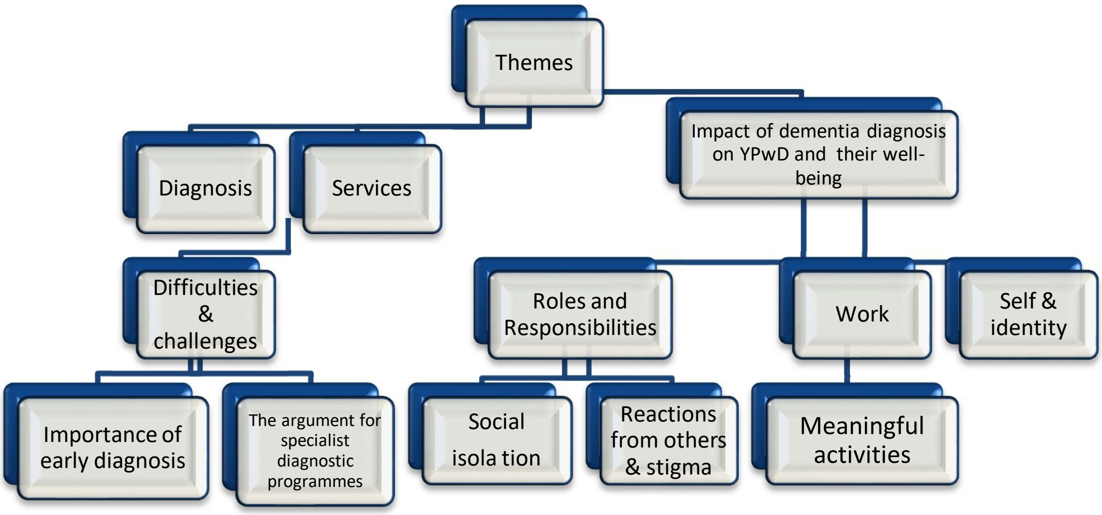
The focus of the studies were varied, a number were generally seeking the subjective experience whereas others were very specific in their focus. The following provides an overview of the focus of the research: exploring the subjective experiences of dementia was the context for nine of the studies, of which only three did not include carers of the person living with dementia; working or leaving work and meaningful activities, were the focus of eight of the studies; two studies focused on services and diagnosis was the main focus for two. The three studies that utilised survey questionnaire focused on needs of YPwD, the second study focused on depression with the third study being a comparison between younger onset dementia and late onset dementia.

The next section provides the detail of themes found in the studies.

2.4 Themes identified

The themes identified have been grouped as: diagnosis – difficulties and challenges; the impact of dementia on wellbeing, which included changes to roles and responsibilities work, selfhood and identity, and finally services for YPwD. Figure 1 below provides a visual overview of the themes discussed:

Figure 1- Overview of research themes identified from literature reviewed



These themes will now be discussed in detail in relation to the research reviewed, and drawing on wider studies to assist with discussion where the research is limited around YPwD.

2.4.1 Diagnosis

Diagnosis was a recurring theme throughout the literature reviewed and provides insight into the difficulty experienced by YPwD in getting an actual accurate diagnosis (Armari *et al.* 2012; Beattie *et al.* 2004; Clare, Rowlands and Quin, 2008; Clemerson Walsh and Isaac, 2014; Harris, 2004; Harris and Keady, 2004; Novek *et al.* 2015) and the reaction to diagnosis (Clare, *et al.* 2008; Pipon-Young *et al*. 2011; Pesonen, Remes and Isola, 2013; Roach, Drummond and Keady, 2016). Roach *et al.* (2016) identified reluctance from health care providers to investigate dementia when the person presented with symptoms when they were younger. Their finding also indicated a lack of information on YPwD for the diagnosed person and their families (Roach *et al.* 2016). Symptoms prior to diagnosis were only identified in Pesonen *et al.* 2013 and were only described in terms of memory loss. Their study identified that there was little or no discussion about changes prior to diagnosis where these were noticeable by the family member; however, the study did not comment on why families did not discuss these changes (Pesonen *et al.* 2013).

Getting a diagnosis was reported as a protracted and drawn out process, identified by Beattie *et al.* (2004) where participants felt that they were subjected to a barrage of investigations and tests, perceived as ‘baffling’ (p.363). Beattie *et al.* (2004) stated that a dedicated approach to diagnosis, such as a specialist resource, would help prevent negative experience. Harris (2004) and Harris and Keady (2004) identified difficulties with getting an accurate diagnosis. They suggested that this was linked to the age of the person, the person’s appearance of looking young and healthy, and that doctors were not too concerned about their symptoms (Harris and Keady, 2004). Clare *et al.* (2008) also identified difficulty with receiving a diagnosis which was described as ‘riding the diagnostic merry-go-round’ (p.16). In regard to diagnosis Pipon-Young *et al.* (2011) did not provide any information about the path to diagnosis nor did they detail any of the symptoms before diagnosis.

When diagnosis was received the reaction was one of shock related to the knowledge that dementia is a condition that affects older people (Pipon-

Young *et al.* 2011). Additionally, feelings of complete devastation were identified which were attributed to dementia being a condition that affects older people (Clemerson *et al.* 2014). Pesonen *et al.* (2013) suggested that the impact of a diagnosis on a younger person is greater than that of an older person, because dementia is perceived as an older person's condition. Where there had been awareness of symptoms prior to diagnosis by the person and their carer, the diagnosis brought a sense of understanding and was said to be a mutual turning point with diagnosis providing an explanation (Pesonen *et al.* 2013).

These findings provide insight into the difficulties experienced by YPwD and their families in obtaining a diagnosis. The issues that were experienced over a decade ago are still being experienced today, as supported in the recent literature, despite an increased awareness of dementia and the implementation of National Dementia Strategies. This suggests that there continues to be a lack of awareness of dementia in younger people, or perhaps a reluctance to diagnose dementia at a younger age.

There was a lack of detail about the time before diagnosis and the symptoms experienced in most of the research reviewed. However, where symptoms prior to diagnosis were identified, memory problems were the first recognised symptoms but these were not associated with dementia; rather, they were attributed to being related to age, depression, burnout or other illnesses (these were not provided) (Pesonen *et al.* 2013). Additionally, in some cases family members were not necessarily aware of any changes (Personen *et al.* 2013). Where there was an awareness of change with the person there was little discussion about this. An avoidance of discussion is perhaps a form of denial that anything is wrong or that the person with the symptoms does not want to worry their spouse or significant other (Husband, 1999).

Supporting research – difficulties and challenges

The need for a timely and accurate diagnosis was identified by a number of the authors including difficulties in receiving a diagnosis (Bakker *et al.* 2010; Draper *et al.* 2016; Luscombe, Brodarty, Freeth, 1998; Sperlinger and Furst, 1994); symptoms prior to diagnosis (Husband, 1999; McLennon, 1999; Innes, Symczynska and Stark, 2014) and complications in getting a diagnosis (Mendez, 2006; Panegyres and Frencham, 2007; Rossor *et al.* 2010).

Difficulties in reaching an accurate diagnosis is not a new theme, a small early UK study with carers of YPwD found the diagnosis timescales to be between one month and three years. However, that study was limited to one area in England (Sperlinger and Furst, 1994). An Australian study conducted by Luscombe *et al.* (1998) also identified difficulties in getting a diagnosis for YPwD. While their research was conducted via carers of YPwD utilising a questionnaire, it provided useful statistics. They identified that 71% of carers experienced problems obtaining a diagnosis, with 11% of people being misdiagnosed and that diagnosis was finally confirmed 3.4 years after consulting. This very early research also identified that YPwD were likely to be underprepared for diagnosis compared to older people. Another Australian study by Armari *et al.* (2012) found timely diagnosis to be a high level need in their research which focused on the needs of YPwD and their carers. They found that 88% of the YPwD said timely diagnosis was the main priority, but this priority differed from the carers who felt treatment was a higher priority, indicating the disparity of needs between the person with dementia and the carer of the person with dementia. While treatment is important it is necessary to receive diagnosis in order to access treatment since a diagnosis is considered to be a gateway to care and support (Knapp, *et al*. 2007).

Linked to issues around diagnosis is the length of time that younger people wait in order to receive an accurate diagnosis. A recent Australian study by Draper *et al*. (2016) found that people with younger onset dementia waited significantly longer for a diagnosis compared to people with late onset dementia. Their study, which included 88 people with younger onset dementia, found the median time from onset of symptoms to first consultation was 2.3 years, and that it could take up to 4.7 years to receive a confirmed diagnosis. Similarly, a recent Canadian study by Novek *et al.* (2015) found that YPwD waited three times longer to get a diagnosis compared to older people. Their data also found that YPwD wait 4.4 years compared to older people who waited around 1.3 years (Novek *et al.* 2015). These studies indicate that younger people continue to be at risk of not receiving a timely and accurate diagnosis, which was one of the outcomes of the Scotland 2013-2016 Dementia Strategy. Although the strategy did not specifically identify younger people it is assumed that the outcomes of the strategy apply to all people with dementia regardless of their age of onset.

Linked to the theme of diagnosis there was limited information about the time prior to diagnosis and the presentation of symptoms. While Bakker *et al.'s* (2010) study focused on the carer rather than the younger person with dementia, it did provide a summary of the problems that presented for the individual prior to diagnosis. They found that there were issues with memory problems, with the person forgetting appointments, further, there were difficulties in managing finances and changes in behaviour. There was a decrease in functional ability which resulted in the person losing their job; however, the symptoms experienced were initially diagnosed as problems with concentration and marital issues. Husband's (1999) study which included one person under the age 65 also reported symptoms of memory loss, but no other clinical symptoms prior to diagnosis. A study by Innes *et al.* (2014) focused on post-diagnostic support, included twelve carers and six people with dementia with an age range of 58 – 82 years. Their study acknowledged pre-diagnostic memory problems identified by the person with dementia. Issues in the workplace and issues with memory and driving were identified by the carer of the person with dementia. Innes *et al.* (2014) reflected on the views of the carer in the pre-diagnostic phase and noted that there was a sense of denial and a refusal to accept that changes were happening, suggesting a reason for the lack of discussion.

Diagnosis in YPwD can be more complicated because of the presentation of symptoms, and these symptoms will differ from those presented by older people, which has the potential to lead to misdiagnosis (Mendez, 2006). Rossor *et al.* (2010) described it as a 'diagnostic challenge' (p.793) with multiple aetiologies (Panegyres and Frencham, 2007). As identified by McLennon (1999) the presentation of symptoms of dementia in younger people are subtly different to people presenting with late onset dementia, which was also reported in 1994 by Keady and Nolan, with the first symptoms being behavioural or changes in personality. The findings identified in the studies reviewed suggest that there is a need for raised awareness in the subtle differences in the presentation of symptoms since there appears to be a difficulty in diagnosis.

Importance of early diagnosis

There is international consensus on the importance of early diagnosis of dementia, regardless of age (Knapp *et al.* 2007). Further, receiving an early diagnosis for dementia is recognised as important to assist with future planning (Weaks *et al.* 2012). It was acknowledged by the Scottish Government with the introduction of HEAT standard (Health, Efficiency, Access to Service, Treatment) as a person's right to have a diagnosis (Scottish Government, 2012/2013). A right to diagnosis is one of the Standards of Care for Dementia Care in Scotland (Scottish Government, 2011) and an objective within Scotland's National Dementia Strategy (Scottish Government, 2010). Diagnosis is important for the person, the carer, the policy makers and planners (Harvey 1998; Werner, Stein-Shvachman and Korczyn*,* 2009). Early diagnosis is important for the person as this will enable them to plan their future and to seek out or commence appropriate treatments (Sampson *et al.* 2004; Weaks *et al.* 2012). Despite the call for early diagnosis, the literature researched indicates that YPwD are not receiving a timely diagnosis, which appears to be due to a lack of awareness about dementia in younger people, or reluctance to diagnose dementia at a younger age. Additionally, the presentation of symptoms and multiple aetiologies could be preventing prompt diagnosis (Panegyres and Frencham, 2007).

The argument for specialist diagnostic programmes

There is a strong argument for the development of specialist diagnostic programmes due to the current difficulties in obtaining an accurate diagnosis for this group (Beattie *et al.* 2004; Harris, 2004; Harris and Keady, 2004; Panegyres and Frencham, 2007), not just from the onset of illness to diagnosis, but also following the first consultation (Draper *et al.* 2016), and because of the challenges identified with diagnosing younger people, specialist diagnostic services have been proposed (Mendez, 2006; Panegyres and Frencham, 2007; Rossor*, et al.* 2010). Evidence of an improved diagnostic process were provided in Beattie *et al.* (2004), where those participants that were part of a specialist service did not raise any issues with the diagnostic procedure. Further support for a collaborative approach to diagnosis was found in Cordery *et al*. (2002) who welcomed the direction of the Royal College of Psychiatrists' recommendation, that old age psychiatry should take the lead in the provision of care and support, including diagnosis with collaboration from a range of specialists including neurologists. However, they were concerned that patients could be missed or get lost in the system where they were referred between specialists, particularly between neurology and old age psychiatry. They undertook a postal questionnaire with neurologists and old age psychiatry and recommended a shared approach which would create a model of excellence where there were a joint lead allocated to younger people, drawing on the skills of both old age psychiatrists and neurologist. The small case study by Husband (1999), where one participant was under 65, described the diagnosis as terrifying. Most importantly and very recently the Younger Dementia Network (2017) have devised a detailed dementia journey for young people, titled 'A young onset dementia journey', which requests 'a clear, collaborative and specialist diagnostic process' (p.2), with clinicians who are expert in the field of younger onset dementia.

2.4.2 Impact of diagnosis for Younger People with Dementia

This section of the review addresses themes that impact on the wellbeing of YPwD. The following areas will be explored:

- Roles and relationships, including social isolation and stigma
- Cessation of work and the need for meaningful activities
- Self and identity including building new networks
- Services

2.4.3 Roles and Relationships

Changes to roles and relationships were identified in the research reviewed (Harris, 2004; Harris and Keady, 2004; Harris and Keady, 2009; Pesonen *et al.* 2013; Roach *et al.* 2016). Social isolation through loss of friends and connections was also identified (Clemerson *et al.* 2014; Harris and Keady, 2009). It is suggested that YPwD found that leaving work had a detrimental effect on family relationships, with a consequential impact on finances contributing to some of the issues (Chaplin and Davidson, 2016). These themes are linked to self and identity, the role one has: wife, husband, mother, father, employee, and social identity the groups that the person associates with: family group, worker, social groups.

A change and impact of role were identified by Harris (2004) where a diagnosis of dementia brought changing roles within the family structure; participants were struck by the impact of dementia on their role identity. Dramatic changes had to be made, such as retiring from an executive position and living abroad, to moving back home to live with older parents. They also found that their participants suffered from a loss of their role as spouse, and mother or father. However, Harris (2004) does not relate this to impact on the person's identity compared to Harris and Keady (2009) where the focus of the study was to explore the psychosocial impact of dementia on self, referred to as selfhoods. Harris and Keady (2009) identified this as loss of identity as worker, loss of family identity and loss of sexual identity. This suggests that their findings identify an impact on role identities (Burke and Stets, 2009) of a younger person with dementia. Pesonen *et al.* (2013) identified similar changes and that a restructuring of roles was required in relation to role identity. These changing roles and responsibilities for the person with dementia and their partners created conflict due to the changing family dynamic. Roach *et al.* (2016) also identified changes to family relationships which were described as the most challenging transition. However, these challenges were related to the family members having to cope with watching the change in the person with dementia, unlike Pesonen *et al.* (2013) where there was tension linked to the changing roles.

Supporting research

Changes in roles and relationships are not unique to YPwD, and have been well documented in dementia research across all age groups. However, it is perhaps the age and stage of the younger person that causes a greater impact. Snyder (2002), in discussing a previous study conducted in 1999, identified how men with younger onset dementia came to accept the change in role and relationships with their spouse and families, commenting on the difficulties they encountered in accepting their changed position in the family structure. Weaks, McLeod and Wilkinson (2006) considered counselling for people with early stage dementia, which highlighted the importance of understanding the changing roles and relationships, this was from the perspectives of all those affected not just the person with dementia.

Social isolation

Developing further on this theme of changes in roles and responsibilities, previous studies identified a loss within their social identities (Clare *et al.* 2008; Clemerson *et al*. 2014; Harris, 2004; Harris and Keady, 2004; Harris and Keady, 2009; Roach *et al.* 2016). Harris (2004) referred to 'extreme social isolation' (p. 29) where there was an attrition of social relationships through friends' failure to maintain contact. Harris and Keady (2009), who were using the same data as Harris (2004) with the addition of the carer's perspective, referred to feelings of abandonment following a decrease in their social circles. These feelings of isolation were further identified where participants experienced isolation or a disconnection from others (Clare, *et al.* 2008; Clemerson *et al.* 2014), a loss of friends, which was attributed to a lack of understanding and inability to cope (Harris 2004). There was surprise at the lack of specialist services and it was felt that this impacted further on their social isolation (Clemerson *et al.* 2014).

Disclosure and reactions from others and stigma

Disclosure about diagnosis was met with fear and anxiety due to perceived stigma and negativity. The perceived negative reactions from others, or actual negative reactions from others, have the potential to impact on feelings of social isolation. Pipon –Young *et al.* (2011) identified a concern around the negative perceptions to the word dementia, and the reaction that this provoked in others when participants shared that they had dementia. This negative reaction was suspected to be linked to fear, other people feeling fear of dementia. Pesonen *et al.* (2013) found that participants limited their disclosure to others as a way to protect social identity for fear of social stigma.

Supporting research disclosure of dementia diagnosis and stigma

In Husband's (1999) case study a younger participant was so fearful of her diagnosis and reactions from others that she did not tell anyone apart from her sister, consequently this led to isolation as she was frightened that she would embarrass herself socially. Fear to disclose illness is not unique to YPwD, but the limited literature available with a direct focus on YPwD required this section to draw from literature relating to older people and literature related to chronic illness. Charmaz (1991) in her study about chronic illness, suggested that fear of disclosure about chronic illness was closely linked to stigma, as is the fear to disclose dementia (Langdon, Eagle and Warner, 2007; Weaks, Wilkinson and McLeod, 2014). However, perhaps there are more real fears associated with the younger person with dementia because of the connotations associated with old age, along with the stigma associated with dementia. Pesonen *et al.'s* (2013) findings about selective sharing of diagnosis are consistent with the finding in the study by Langdon *et al.* (2007) of older people with dementia. Although in Langdon *et al.* there were mixed views about wider disclosure, there was a consensus that people were comfortable in their disclosure to their private inner circle. The reasons cited for this reluctance was the fear of being viewed differently, along with negative connotations attached to the words Alzheimer's and dementia, similar to the findings in Pipon-Young *et al.* (2011). However, there is perhaps a potential risk to social isolation through not sharing with others, as was found in Husband (1999) which was supported by findings in Weaks *et al.* (2014). Conversely, people with dementia have suggested that by not speaking out or talking about dementia, could potentially contribute to the stigma associated with dementia (Weaks *et al.* 2012).

Langdon *et al.* (2007) suggested that the fear of sharing or disclosing illness is linked to one's selfhood and a threat to the person's unique identity. While Langdon *et al.'s* study was around older people with dementia, the issues identified in regard to impact of disclosure on selfhood and identity is equally applicable to YPwD. When a person shares with others that they have dementia the reaction from those people is very important. If a person receives a negative reaction and those same people start to behave differently, then there is affirmation that the dementia has changed them, or they are different in some way, because of the dementia (Langdon *et al.* 2007; Weaks *et al.* 2014). This links to selfhood and identity which are discussed in detail later in this chapter.

2.4.4 Work

Issues around employment and work and YPwD have been cited as one of the main differences between YPwD and people with late onset dementia (Cox and Keady, 1999). This section examines research published which specifically explored the development of dementia while still being in employment, and how this was managed and draws on findings from qualitative studies (Chaplin and Davidson, 2016; Clare *et al.* 2008; Evans, 2016; Harris, 2004; Harris and Keady, 2004; Ohman, Nygard and Borell, 2001; Roach and Drummond, 2014; Roach *et al.* 2016; Robertson and Evans, 2015; Robertson, Evans and Horsnell, 2013), which focused predominantly on the lived experience of individuals with dementia. Finally, the section reviews research that has evaluated work based projects and the impact on YPwD.

Previous research has highlighted the impact of forced retirement as being a traumatic process where YPwD are required to leave work because of the unknown symptoms they are experiencing, and prior to actually receiving a diagnosis (Roach and Drummond, 2014). The more recent studies have shifted their focus to explore YPwD and their experience of the work place and the onset of symptoms with transition to retirement (Chaplin and Davidson, 2016; Evans, 2016; Roach and Drummond, 2014), and have extended the work theme to explore how YPwD can be integrated back into the workplace (Robertson and Evans, 2015; Robertson *et al.* 2013).

Loss of employment through early retirement has the potential to impact on a person’s well-being particularly where this is not planned or foreseen (Roach *et al.* 2016). This was identified as impacting on the person’s identity (Harris and Keady, 2004) and a loss of self (Clare *et al.* 2008), and with the additional complexities of loss of earnings impacting on finance (Harris, 2004; Harris and Keady, 2004). Research has found that while some YPwD are forced to take retirement (Harris and Keady, 2004), other studies did not report any issues in relation to work or financial difficulties (Beattie *et al.* 2004; Pipon-Young *et al.* 2011). Studies that included younger people who were under 65 and had already retired prior to symptoms and diagnosis, found work and finance not to be an issue (Pipon-Young *et al.* 2011). However, studies where participants gave up work following diagnosis, and were not working at the time the research was conducted, commented on the issue of having to give up work through forced retirement (Clemerson *et al.* 2014). This is important because it suggests that where a person is younger, but has already retired before the onset of symptoms they are less likely to experience the same impact, compared to those that were forced to give up work. This indicates that there is a significant difference on the person’s well-being where a person has voluntarily retired or planned their retirement prior to diagnosis. This was supported by Roach and Drummond (2014) who found that an immediate cessation of work was distressing to YPwD, and impacted on their ability to accept that they were no longer working.

Signs and symptoms in the workplace

Previous research suggests that there is a likelihood that the onset of dementia symptoms transpire within the workplace (Evans, 2016), which is important to note since it could lead to the person seeking an early diagnosis (Evans, 2016; Roach and Drummond, 2014). It was clear that those participants who were working found difficulties at work when undertaking routine tasks (Chaplin and Davidson, 2016; Evans, 2016; Harris, 2004; Harris and Keady, 2004; Pesonen *et al.* 2013). Previous research has suggested that although the first signs of cognitive changes are identified in the workplace (Chaplin and Davidson, 2016), these changes are subtle and not always considered to be serious (Chaplin and Davidson, 2016; Evans, 2016; Ohman *et al.* 2001), suggesting an almost insidious nature to the onset of dementia. However, as they progressed they experienced symptoms of severe tiredness and difficulty in coping with stressful situations (Ohman *et al.* 2001).

Strategies to compensate for changes

The research reviewed highlighted that strategies were developed by the individual to enable them to cope with the changes they were experiencing in the work place (Chaplin and Davidson, 2016; Ohman *et al.* 2001). The previous research indicates a high level of insight and self-awareness by the younger person with dementia into the changes to their abilities. Some of these strategies included spending more time to plan and organise work tasks (Chaplin and Davidson, 2016) or going into work earlier (Evans, 2016), but similar to Ohman *et al.* (2001) the strategies were not feasible in the long term. While strategies were employed to compensate for the change in ability to undertake tasks, these clearly did not work since the person experienced feelings of being watched and scrutinised by managers who had also noticed changes in the person’s performance (Chaplin and Davidson, 2016; Ohman *et al.* 2001). These findings suggest that there is a lack of confrontation or discussion about the observed changes; however, no rationale as to why managers did not confront the person was provided.

Reasonable adjustments and retirement

Where a person meets one or more of the protected characteristics, such as disability, under the Equality Act (2010) they should be provided with reasonable adjustment to enable them to perform their duties. The previous research identified feelings of being treated unfairly and that employers did not investigate why the person was experiencing difficulties. The later studies provided evidence of adjustments in the work place to support the younger person experiencing difficulties prior to diagnosis. Despite these adjustments these were not deemed adequate by the younger person with dementia to be ‘reasonable adjustments’ as defined by the Equality Act (2010) (Chaplin and Davidson, 2016). Previous research identified that prior to receiving a diagnosis life changing decisions with regard to work were being made, either by the employer terminating employment due to sick leave, or the younger person with dementia choosing to take early retirement (Chaplin and Davidson, 2016; Evans, 2016; Roach and Drummond, 2014). Where a person did remain at work there was difficulty in receiving support from their peers and other employees (Evans, 2016).

Supporting literature on work and retirement

Retirement is now deemed to be a process rather than a single life event linked to reaching the age of 65 years (Holcomb, 2010). However, it is suggested that society still links retirement to age and that the age 65 is synonymous with old age, Holcomb refers to this as a paradigm. The research reviewed identified YPwD experiencing a sense of loss associated with giving up work, but there is also perhaps a more symbolic meaning in regard to age. Retirement signifies old age or reaching an age where one is deemed to be old. Having to give up work, or retire early perhaps reinforces the ageing process which could be particularly detrimental to a person who is under the age of 65. Indeed retirement can reinforce stereotypical views of age such as being seen to be ‘put out to pasture’ (Holcomb, 2010, p. 135).

While there is a shift with retirement age, with no person having to retire at 65, there is likely to remain a stigma associated with age and retirement.

Retirement is deemed to be a stressful event and requires the person to adapt to the change that retirement will bring (Holcomb, 2010). Research around retirement has been undertaken by Atchley and Barusch (2004) which identified a series of phases related to the transition to retirement. These are not discussed in detail here as these phases relate to normal ageing and planned retirement even if that retirement is pre-retirement. The research identified a lack of awareness within the workplace about younger onset dementia; additionally, there was evidence to support unfair treatment and a lack of recognition that dementia creates disability which is a protected characteristic under UK law (Equality Act, 2010). The research also provided insight into the impact on well-being and how a sudden termination of work was traumatic to the person.

The next section continues with the work theme to explore programmes that have enabled YPwD to return to work and meaningful activity in relation to the person's well-being.

Work and meaningful activity

Meaningful activity was identified in the research that included YPwD (Harris, 2004; Harris and Keady, 2004; Roach and Drummond, 2014; Roach *et al.* 2016) or having a meaningful role in society (Chaplin and Davidson, 2016; Pesonen *et al.* 2013). Roach *et al.* (2016) suggested that the onset of early dementia creates feelings related to a loss of purpose in life. Additionally, there was a connection between loss of role and identity, alongside the structure of a person's day (Roach *et al.* 2016). Evans (2016) identified feelings of frustration and anger where there was a lack of opportunities for YPwD to re-engage in meaningful activities. These findings support the requirement for specialist services for YPwD which was identified in Chaplin and Davidson (2016). Positive outcomes for YPwD were identified where they were provided with access to a service for YPwD which enabled them to access opportunities to become active within their communities (Chaplin and

Davidson, 2016). Roach and Drummond (2014) raised concern about the lack of specialist services in relation to this issue.

The previous research supports the need for people to remain in work and be given easier tasks (Roach and Drummond, 2014). However, there is the potential for work to become a stressor; therefore, education or the development of programmes to integrate YPwD into the workplace may be the approach necessary (Roach, 2017). A good example of such a programme was identified in Robertson *et al.* (2013), where seven YPwD were assisted back into work. Robertson and Evans (2015) evaluated the programme and identified four outcomes, one of which was well-being based with improved self-esteem, self-worth and confidence. Further, their participants were enabled to undertake meaningful activities, and felt that they were contributing to society. The programme had an added benefit of increasing socialisation, thereby providing a solution to the feelings of isolation which were identified above. The findings in Robertson and Evans (2015) support the earlier findings in Kinney, Kart and Reddecliff (2011) where YPwD were supported to engage in meaningful activity through a volunteer programme at a zoo. An example of improved feelings of well-being was also identified in Clare *et al.'s* (2008) study which focused on developing a shared social identity through a support group. Clare *et al.'s* (2008) internet based research identified that the six members who took part in the research felt that they once again became valued and contributing members of society.

Supporting literature on work and meaningful activity

Meaningful activity has been identified as a need for people with dementia, regardless of age (Phinney *et al.* 2007). However, there is a strong argument that suggests YPwD are likely to feel a greater loss due to the age and stage in their life course and the disruption to their lives (Clemerson *et al.* 2014; Harris and Keady, 2009), along with the sudden cessation of work (Roach and Drummond, 2014). Clemerson *et al.* (2014) referred to Erikson's theory of psychosocial development (1963) eight stages of development, with 'generativity vs. stagnation' in adulthood - age and stage 40 to 65.

Generativity refers to areas such as establishing your career, bringing up family and contributing to society. Stagnation refers to the inability of the person to contribute to their community or society. The stagnation would materialise where there is failure in achieving generativity. It is suggested that younger people who develop dementia at this stage in their life cycle are at risk of failing to achieve generativity, which would lead to a sense of loss and unproductivity. By supporting younger people to continue to put back into society at this stage could help them to achieve a sense of generativity. In support of this theory Roach (2017) suggested the need for YPwD to be supported at work to enable them to support a sense of identity and role. The need for supported employment was identified as early as 1999 when Cox and Keady identified the need for employers to support YPwD to remain at work, or alternatively provide different types of work.

A study by Menne, Kinney and Morhardt (2002) focused on meaningful activity with dementia, where two of the six participants were under the age of 65. Utilising Atchley's (1989) continuity theory and Park and Folkman's (1997) framework of meaning, their research focused on the strategies people draw upon to adapt to their changed circumstances. Their predominant finding was that a person needed to maintain their existing lifestyle, and that it was important for the person with dementia to continue to do things that they used to do in some way. In being supported to continue to do things assists the person to cope with and adapt to changes that dementia brings (Menne *et al.* 2002).

The research studies reviewed identified that a lack of meaningful activity impacts on identity and sense of self (Harris and Keady, 2004). Having a sense of purpose and feeling valued is an important aspect in supporting personhood, and where this is supported this could enable YPwD to live meaningful lives (Roach, 2017), which is important to wellbeing, due to their age and stage.

2.4.5 Self and Identity

This section considers the impact on self and identity on YPwD following a diagnosis of dementia and impact on well-being in relation to the literature reviewed (Beattie *et al.* 2004; Clare *et al.* 2008; Clemerson *et al.* 2014; Davies-Quarrell *et al.* 2010; Harris, 2004; Harris and Keady, 2009; Pesonen *et al.* 2013; Pipon-Young *et al.* 2011; Roach and Drummond, 2014; Roach, *et al.* 2016).

A predominant theme in Harris (2004) was the issue with selfhood and self-esteem, and that dementia had impacted on 'multiple parts of people's self-identity' (p.25). Also reported were awareness to changes in self, which identified insight and awareness about what was happening. Issues about selfhood and identity were also identified in Beattie *et al.* (2004) where participants experienced feelings of being 'invisible or uninvolved in decisions surrounding their care' (p.363). Clare *et al.* (2008) identified feelings of loss, impact on the sense of self and self-esteem. Harris and Keady's (2009) study focused on the shift and change to identities, and found that there had been a change in the person's selfhood and identity which commenced from the time of diagnosis, although it was acknowledged that perhaps some changes to self may have occurred prior to diagnosis. Similar to Harris and Keady (2009), Pesonen *et al.* (2013) identified changes to identity through changes to roles (this was discussed above in the section on roles and relationships). Roach and Drummond (2014) and Roach *et al.* (2016) also referred to changed identities in relation to loss of purpose and meaningful activity. Clemerson *et al.* (2014) identified identity as a theme in which they discovered threats to identity where participants felt the need to hold on to the existing self, or to redefine their sense of self completely. They suggested that the threat to self-identity had the potential to impact on a person's acceptance of dementia and how they related to others with dementia. Where participants developed a new sense of self this appeared to assist with acceptance and the impact of dementia on their future self. Clemerson *et al.* (2014) was the only research that identified a changing self, based on dementia and acceptance of dementia. The other studies focused around changes in abilities and social self or loss of self. Although Pipon–

Young *et al.* (2011) identified maintaining a sense of self to be an important aspect of living with dementia; they did not identify any changes to self within their participant group. The study by Clare *et al.* (2008) focused on the impact of a shared social identity through a support group. Based on their findings they proposed that such models can assist with challenges to self. Similarly, Davies-Quarrell *et al.* (2010) identified reaffirmation of a sense of self in their evaluation of specialist services in the form of a club where YPwD were able to take part in activities which were found to improve their well-being.

Supporting literature on self and identity in dementia

Identity and dementia has been well documented and discussed in relation to whether a sense of identity remains with the onset of dementia (Herskovits, 1995; Caddell and Clare, 2011a). This section provides discussion on self and identity in relation to the literature reviewed and supporting literature. Caddell and Clare (2010) carried out a systematic review to examine concepts used to study self in dementia, finding that there were a variety of methodologies used within both qualitative and quantitative studies due to the many different concepts of self and identity. The research reviewed did not provide explicit detail in regard to concepts of self when referring to self, nor did they refer to models of identity theory. The issue in regard to redefining self has been identified in research focused on chronic illness (Charmaz, 1991) and in older people with dementia (MacRae, 2010). Although loss of self was a concern in younger people as identified in Clemerson *et al.* (2014), this was not considered to be an issue for older people in the study by MacRae (2010).

The loss of self in relation to role identity change and social identity perhaps links to personhood as defined by Kitwood (1997), where '…recognition, respect and trust should be preserved' (p.8). While it may not be possible for the younger person with dementia to continue in certain roles because of their dementia, preserving the person's identity through non erosion of personhood could assist with the person to lessen the experience of loss linked to the changes they experience. An example of where there was a loss of personhood was uncovered by Beattie *et al.* (2004) where participants described feelings of invisibility. Examples that enhanced and maintained personhood were identified where YPwD were provided opportunities to re-engage in society (Chaplin and Davidson, 2016; Clare *et al.* 2008; Kinney *et al.* 2011; Robertson and Evans, 2015).

Supporting literature - Developing identity through supportive networks

The literature and research studies reviewed suggest that attending groups or being part of a group enables the development of a new social identity. Being part of a group provides shared feelings of identity. Social identities involve identification with others who belong to the group (Burke and Stets, 2009). The study by Clare *et al.* (2008) identified a shared social identity and a sense of collective strength was developed through working together in a group that had a sense of purpose and function. It is proposed that enabling contact with other people who have dementia, particularly supporting YPwD to meet other YPwD assists with the development of social identities which will improve well-being. Social identity brings ‘uniformity in thought’ (Burke and Stets, 2009, p.118) and enables a person to positively identify themselves as part of that group (Burke and Stets, 2009).

2.4.6 Services for YPwD

This section focuses on services of YPwD and includes research that included both the views of YPwD and research which did not.

There is debate as to whether YPwD require specialist services, from services that provide diagnosis to services that support the person following diagnosis and through their life. There has been a constant call for specialist or age appropriate services (Barber, 1997; Cox, 1999; Cox and Keady, 1999; Ferran *et al.* 1996), which was supported by Alzheimer’s Society as early as 1991 in their charter for younger people with dementia and their carers (Royal College of Psychiatrists and Alzheimer’s Society, (RCPAS) 2006). Despite the identified differing needs for YPwD compared to older people, there is a scarcity of such specialist services. A study by the Scottish

Executive Social Research recognised that YPwD have complex needs and provision, at the time the research was undertaken, was not able to meet these needs (Stalker, *et al.* 2006), including post diagnostic counselling and continued assessment.

Barber’s (1997) survey on services for YPwD retrieved results from 304 Trusts in England (84% response rate), identified that the majority of services were provided through old age psychiatry, and identified twelve specialist services. While there was a lack of specialist provision, there was appetite from 101 of the trusts who responded for the development of specialist services. Although there was a recognised need for specialist services Barber (1997) noted that the provision in 1997 was limited, and an evaluation of specialist services and the potential benefit they could offer should be undertaken. The questionnaire used by Gibson *et al.* (2014) with carers of YPwD identified a lack of specialist service availability to address their specific needs. A more recent review on UK services found services to be variable across the U.K. (Rayment and Kuruvilla, 2015) The review noted that guidance published in 2006 by the National Institute of Clinical Excellence (NICE) recommended specialist services for YPwD, and that the guidance was further adapted in 2013 in regard to commissioning (Rayment and Kuruvilla, 2015).

Willis *et al.* (2009) identified six themes through their qualitative investigation into satisfaction with the Croydon Memory Service Model. For the purposes of this review it was the experiences of the younger people who were included in the study that was of importance. The sixth theme ‘gaps in service’ articulated the views and experiences towards a carer of a younger person with dementia. The carer expressed concern about their relative attending a service aimed at older people. Willis *et al.* (2009) stated that the carer’s preference was that services provided be designed around the needs of the younger person. The reason for the concern was that the activities that were on offer were limited and not necessarily specific to the interests of the younger person with dementia. Willis *et al.* (2009) explored this issue further in their discussion of the findings where they suggested that the need for specialist services was supported by the literature.

Beattie *et al.* (2004) found that YPwD expressed the need for age appropriate services in their study exploring the views of younger people with dementia and the care services. They discovered that those participants who were in receipt of specialist day care spoke very positively about the services. A principal concern for this group was age and that when they, the younger person, were mixed with older people with dementia, the experience was perceived negatively. One finding was that being with other people of the same age, with the same problems provided a positive experience (Beattie *et al.* 2004).

The peer support gained through specialist services was identified in Kinney *et al.* (2011). The attendees of the 'Get out of the House' (GOOTH) programme found they had a shared understanding. Spouses of the attendees were also interviewed and they found the service provided a number of positive benefits, such as normality and social interaction. The wives found that the benefits in attending the program extended beyond the time spent at the programme. Although Pipon-Young *et al.* (2011) identified the need for peer support and 'sharing a social identity' (p.10), their participants did not request the need for specialist services. However, it was suggested that because all participants were in receipt of what would be deemed age appropriate services, services were not an issue for them, which perhaps suggests the need for specialist services.

Although the two studies conducted by Harris and Keady (2004, 2009) do not specifically discuss specialist services, they did identify the absolute isolation that was felt through the loss of contact with friends and colleagues. They concluded that 'services for people with dementia should be cognisant of the special needs of [younger people]' (p.442), yet in the U.K. this provision remained inadequate (Harris and Keady 2009).

An alternative view about the service needs for YPwD was presented by Reed *et al.* (2002) who argued that there is not necessarily a need for specialist services for younger people. Indeed, they identified specific problems with having specialist services. The primary issue Reed *et al.* (2002) identified was that people had to leave the service when they reached the age of 65. Interestingly they were of the view that staff and carers favoured the specialist service because they felt that those services would be better than those offered to older people. Reed *et al.* challenged this as not being an age issue but more about services that were offered and individuals' expectations. They questioned whether the differences in age at the time of diagnosis really had such an impact on the person. They provided an example in regard to retirement stating that all people, no matter what their age, have to come to terms with retirement. While this is in fact true, the issue is that the younger person with dementia is 'off time' (Harris and Keady, 2004) and out with the life course perspective (Gelman and Greer, 2011).

What can be concluded from the number of articles reviewed is that specialist service provision for younger people with dementia, or age specific services, provided a positive experience offering peer support, company and a sense of being active (Beattie *et al.* 2004; Clare *et al.* 2008; Evans, 2016; Kinney *et al.* 2011; Pipon- Young *et al.* 2011; Roach and Drummond, 2014).

2.5 Summary

This section of the chapter has provided an analysis of the research focused on YPwD, spanning two decades. It is clear that there is a paucity of research that focuses on the views of YPwD. While there has been an increase in qualitative studies over the last three years there still remains little research that clearly articulates the experiences of YPwD. The review has identified a number of themes, such as difficulty in prompt diagnosis, impact on identity and self, social isolation and exclusion, lack of meaningful activity further impacting on self and self-esteem. These findings indicate a decrease in well-being and wellness and are suggestive of experiences of ill-being. Linked to well-being were the issues identified about fulfilling the needs of YPwD and the question about whether services provided meet their needs remains unclear. Perhaps the issue about service needs and experiences have not been clearly expressed from YPwD's perspective.

The quality of the literature selected for the review that included YPwD did provide insight into their experiences but they are limited by number. Only 24 included the views of YPwD and six of these used data collected from the same cohort of participants, therefore, the actual number of YPwD included in research is less than appears. The research that included the participation of YPwD provided the rich data and insights in to their experiences, but the numbers are limited. The more research undertaken that includes the views of YPwD will assist policy makers, commissioner and service planners with development and design for YPwD. Additionally, it may go some way to support recognition for this service user group.

There is a clear research gap, and the literature review indicates the need for further studies which hear the voice and provide insights into the lived experiences of YPwD.

2.6 Theoretical Context

As a nurse and a lead commissioner within health and social care, my theoretical perspective is based around promoting choice and autonomy, promoting independence and social inclusion, enabling people to be the director of their care and support, which is linked to the Talking Point Outcomes. I have worked with the Talking Point Outcomes through commissioning, and designing outcome based assessment tools for nine years, this has been embedded into my practice. The Talking Point Outcomes assist with identifying quality of life and well-being through an outcomes approach.

Following the initial analysis this research study utilised Self-determination Theory, Basic Psychological Needs Theory (BPNT), autonomy, competence and relatedness, to consider the lived experiences of YPwD and well-being.

There are many different motivation and well-being tools that I could have chosen to assist me in identifying the experience of well-being with YPwD. Kitwood's model (1997) provides five psychological needs: comfort, identity, occupation, inclusion, attachment, and was considered by Kaufman and Engel (2016) who identified an additional need of agency. Further consideration could be given to the Eden Alternative, with seven domains of well-being – identity, connectedness, security, autonomy, meaning, growth, joy (Powers, 2014). These two models have been developed around older people and people with dementia.

Other motivational and well-being theories provide a greater number of needs such as Ryff's six factors of well-being which include self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, personal growth (Ryff, 1989). However, there have been criticisms in regard to whether there is, and it has been suggested that there is not, enough distinction between the six factors (Springer, Hauser and Freese, 2006). Additionally, Ryff's model has been questioned as recently as 2016 (Henn, Hill and Jorgensen, 2016).

Self-determination Theory (SDT) is a motivational theory which promotes the support of three basic psychological needs (BPN), autonomy, competence and relatedness, to ensure personal motivation and wellbeing

It was my preference, based on the simplicity of the basic psychological needs, autonomy, competence and relatedness, and the fact that I could see clear links to my theoretical underpinnings, to use SDT, BPNT as an approach to identify well-being. It is easy to identify the three basic psychological needs within each of the models described above. The basic psychological needs are easy to understand, they are linked to eudaimonic well-being and easily applied to understand well-being by identifying where the three needs are supported or thwarted.

The basic psychological needs in SDT clearly link to some key points in the literature review. There were links to loss of autonomy through diagnosis and access to services. The need for meaningful activity links to autonomy and competence. The literature reviewed identified an impact on relatedness where participants experienced feelings of social isolation (Harris, 2004) and changes to social identities (Clare *et al.* 2008; Clemerson *et al.* 2014; Harris, 2004; Harris and Keady, 2009; Roach *et al.* 2016), which impacted on the persons' wellbeing. Further, there were indications of increased well-being where participants were engaged with meaningful activity, with improved self-esteem and where they felt they were contributing to society (Clare *et al.* 2008; Kinney *et al.* 2011; Robertson and Evans, 2015). Therefore, the findings in the literature review also supported the use of SDT as a framework to assess wellbeing. In order to assess well-being utilising the concepts of SDT, BPNT, a secondary analysis was undertaken with the superordinate themes that were identified through the primary analysis.

Self and identity are also important concepts in relation to wellbeing, which was identified in the literature reviewed. The Self's framework (Sabat, 2002) was utilised in regard to the self along with social identity theory (Burke and Stets 2009) when referring to self and identity. Self and identity are discussed in detail below.

2.6.1 Theoretical underpinning

2.6.2 Introduction

This first part of this section provides an overview of theories of personhood, self and identity in relation to dementia and well-being. The literature reviewed in this chapter has identified that a diagnosis of dementia can have an adverse impact on an individual's self and identity, which can impact on their well-being (Harris, 2004; Harris and Keady, 2004; Harris and Keady, 2009; Pesonen *et al.* 2013; Roach and Drummond 2014).

The first section discusses personhood through the work by Kitwood and Bredin (1992) and Kitwood (1997), and provides an overview of the Self's framework (Kelly, 2009), which was devised by Sabat (Sabat, 2002; Sabat and Collins, 1999; Sabat and Harre, 1992). These two theories are important for this study as any changes to responses to the person, or how the person feels about themselves, or how others respond to them, can have the potential to impact on their well-being.

The next section moves on to provide an overview of the motivational theory of well-being Self-determination Theory, BPNT and Talking Points Outcomes (TPO). The TPO are referred to in the discussion chapter (Chapter 6) to identify if the outcomes are important to YPwD and aspects of well-being. This current chapter provides the foundations of an understanding of the models.

2.6.3 Well-being and dementia

Health and social care policy has seen a significant move away from traditional models of health care and support, particularly over the last ten years. In Scotland people with dementia are represented through the National Dementia Strategy (2010, 2013). Additionally, the Scottish Government introduced Self-directed Support (SDS) through legislation in the form of the Social Care (Self-directed Support) (Scotland) Act (2013), which came into force on April 1st, 2014. The Act places a duty on the local authority to offer those individuals who require support through social care, a range of choices in the way their social care and support is provided. Further, there is a shift from service-led models of care towards models of care and support that are designed to meet personal outcomes, rather than purely focusing on services to meet general needs. Through SDS individuals should be empowered to make choices and feel in control, which has the potential to lead to fulfilment and a happier and healthier life (Scottish Government, 2016).

To determine personal outcomes it is necessary for health and social care assessments to be outcome-focused. The TPO is an assessment tool for individuals who require support. There is also a version of the outcomes tool which focuses on their Carers. The TPO are discussed in detail in the section following SDT.

Well-being is considered to be an important key measure for people with dementia (Kaufman and Engel, 2016), and is an important aspect for consideration especially around the loss of functioning and decreased independence. Woods (1999) reviewed early research that focused on improving well-being of people with dementia through non-pharmacological interventions. The review suggested that promoting independence and self-care may have the potential for improved well-being. The study of Holst and Edberg (2011) about well-being and people with dementia and their carers, identified that the person with dementia experienced a deterioration in their mental health over time, where they had moderate dementia or a greater need for support; therefore, suggesting that a decrease in a person’s ability to maintain independence has an impact on well-being. A recent study by Wright (2016) focused on engaging people with dementia in undertaking physical activity. Wright (2016) identified that people with dementia are motivated to undertake an activity and that they experienced a sense of pride in being able to perform these activities. Kaufman and Engel’s (2016) study focused on Kitwood’s five psychological needs model, and their participants identified the need for ‘self-determination, freedom of action or independence’ (p. 784). They concluded that Kitwood’s five psychological needs, comfort, inclusion, identity and attachment, required the addition of a sixth domain ‘agency’.

To identify well-being this current study utilised Self-determination Theory (Deci and Ryan, 1985, 2000) to capture experiences and consider how they related to the three basic psychological needs, autonomy, relatedness and competence. While previous studies do not utilise Self-determination Theory, there are clear links to the fulfilment of the basic psychological needs and supports Kaufman and Engel's (2016) study which identified need for self-determination, freedom and action. Self-determination Theory is discussed in detail in the sections below. In terms of well-being, this study focuses on eudaimonic well-being as oppose to hedonic well-being.

2.6.4 Personhood, Self and Identity

The research reviewed earlier in this chapter identified clear links to well-being and maintaining personhood, identity and sense of self. Identity has been identified as an important component of dementia, as previous research has indicated that dementia may be a threat to identity and self (Caddell and Clare, 2011a, 2011b). This section provides an overview of personhood, self and identity.

The terms personhood, selfhood and identity are difficult to define individually, but all have the intention to emphasise the 'socially-constituted personal experience of dementia' (Tolhurst, Bhattacharyya and Kingston, 2014, p.194). In the past psychological literature has portrayed dementia as 'involving the destruction of the very essence of what it is to be human: the self' (Cheston and Bender, 2003, p.169). This paradigm was thought to be a one-way process through neurological damage which results in the loss of self. Tom Kitwood recognised that an external dynamic in the form of social care practices influenced further the loss of self or personhood.

Personhood in relation to dementia was developed first by Kitwood and Bredin (1992) and further by Kitwood (1997). Kitwood's work identified how professionals and significant others, by their actions undermine the personhood or the person with dementia (Kitwood and Bredin, 1992; Kitwood, 1997). The concept developed by Kitwood and Bredin (1992) provided an alternative to the then dominant biomedical models regarding dementia care (Kelly, 2009) with the concept of person-centred care, which provided a view of dementia as a disability (Archibald, 2004; Kitwood, 1997). Kitwood explored personhood further, drawing on the work of Martin Buber and considered personhood as a social phenomenon occurring through interaction with others, human to human (Cheston and Bender, 2003). Kitwood identified that the negative labelling of people with dementia potentially impacted on their sense of personhood, which he defined as:

> ‘A standing or status that is bestowed upon one human being by others, in the context of relationship and social being’ (Kitwood, 1997, p.8).

Socially, personhood is around the relationships we have with each other (Kitwood and Bredin, 1992) and Kitwood’s definition provides for both the social and the ethical aspect of personhood. The view of Kitwood and Bredin, therefore, was that personhood was something that was gained through relationships with others (Higgs and Gilleard, 2015; Kitwood and Bredin, 1992). Additionally, Kitwood’s application of a social psychological focus identified that people with dementia are disempowered by the treatment they receive from others, in that once they received the label of ‘dementia’, their communication and behaviours would be interpreted as being cognitively impaired and in so doing disregarded (Cheston and Bender, 2003). Kitwood (1997) termed this treatment as *malignant social psychology,* which occurs following diagnosis and the subsequent labelling. Kitwood provided examples of how the social world in which people with dementia live, along with the neurological impairment, erodes their personhood. Examples are disempowerment, things are done for them, they are not provided with an opportunity to do things for themselves, an assumption is made that they are not able; being treated as if they have returned to childhood, infantilised and intimidated (Cheston and Bender, 2003; Kitwood, 1997). Kitwood, therefore, argued that the ways in which people with dementia are treated by others can erode their personhood, where the status that is usually bestowed upon a person is disregarded.

Personhood is a complex concept according to Higgs and Gilleard (2015) who undertook an interrogation of personhood and its relationship to dementia. They argued that Kitwood's view of personhood confuses metaphysical philosophy with moral philosophy. Higgs and Gilleard (2015) are critical of the simplicity of Kitwood's application. Higgs and Gilleard stated that in their view many people who are diagnosed with dementia may not still have abilities such as 'self-awareness, reflexivity, second-order volitions and narrative unity' (p.779), all of which constitute metaphysical personhood. Further, they have suggested that Kitwood's approach places the duty on others to maintain personhood of people with dementia, requiring that others sustain their (people with dementia) moral status as a person, but also to '[preserve] their capabilities for personhood (the metaphysical components of personhood)' (p.779). They argued that if one fails in their support of personhood in relation to moral status then it is easy to assume failure in the metaphysical components. Further, they suggested that personhood, due to its complex and ambiguous meaning, is not a helpful term when developing standards of dementia care and that the term should not be used. Rather, the focus of dementia care should be around supporting the people with dementia to maintain their existing capabilities, while minimising the consequence of any incapacities.

Although Higgs and Gilleard (2015) present an argument against using the term personhood, stating that it is ambiguous and that Kitwood's application is too simplistic, this has not prevented professionals, practitioners or unpaid carers from understanding his theory. Kitwood does not delve deeply into all the philosophical underpinnings to the meanings of personhood; rather, he provides a simple explanation which is easily understood and applied. The suggestions made by Higgs and Gilleard about practice and support for people with dementia cannot be argued with since they also provide the basis of person-centred care, as does the historic work of Tom Kitwood. However, these early foundations of personhood and dementia remain relevant today in regard to care for people with dementia (Higgs and Gilleard, 2015) and can be identified in practice as well as policy (Higgs and Gilleard, 2015; National Institute for Health and Care Excellence (NICE), 2006, 2016; Promoting Excellence, 2011).

Kitwood's work on personhood identified how a person's well-being can be impacted upon by the way others treat them. Where personhood is diminished there is the potential for exclusion of that person (Kitwood, 1997), which could create feelings of isolation which was identified in the literature reviewed for this study (Clemerson *et al.* 2014; Harris and Keady, 2009). Further, exclusion and isolation are linked to the innate basic psychological need of relatedness, which is discussed in this chapter in the section Self-determination Theory.

2.6.5 Self, Selfhood and Identity

Although identity, self and personhood are often used interchangeably, they are synonymous rather than being alternatives of the same thing. Harding and Palfrey (1997) provided a distinction between personhood and self and state that the person in personhood is the 'public being and self the subjective private being which has no physical referents' (p.29). Identity is a part of self and viewed from a symbolic interactionist perspective is defined as:

> 'the set of meanings that define who one is when one is an occupant of a particular role in society, a member of a particular group, or claims particular characteristics that identify him or her as a unique person' (Burke and Stets, 2009, p.3).

Therefore, a person will have role identities that are related to the roles that they acquire, such as a role as a mother, daughter, worker, wife, and husband. There are also 'person identities' which refer to the uniqueness of all individuals and how each person is different from others. Person identity is defined as 'the set of meanings that define the person as a unique individual rather than a role holder or a group member' (Burke and Stets Burke, 2009, p.124). As with other identities, such as role identity and social identity, the person identity requires verification and is sustained by the verification process. It is important to receive individual verification of one's person identity as this creates a feeling of self-esteem, through the feeling of increased authenticity. Authenticity is the ability for one to feel true to themselves (Burke and Stets, 2009). Person identity is linked to the core self, the constant of who someone is as a person across all situations, such as relationships and through their life course (Burke and Stets, 2009). This view is consistent with Kitwood's (1997) definition of identity:

> '…to know who one is, in cognition and in feeling. To have a sense of continuity with the past…It also involves creating some kind of consistency across the different roles and contexts of present life' (p.83).

The onset of dementia may threaten the ability to maintain identity through the inability to retrieve autobiographical memories. Autobiographical memory relates to the ability of an individual to draw on their episodic memory, such as personal experiences in relation to people, place and time (Holland and Kesinger, 2010). Addis and Tippet (2004) suggested that autobiographical memory is required to integrate the past and present selves with a view to maintaining continuity of memory. Where there is a decline in autobiographical memory this may impact on identity (Addis and Tippet, 2004).

With a diagnosis of dementia there is also a perceived threat to self, related to the changes in roles and the difficulty in performing in those roles (Tolhurst *et al.* 2014). Social constructionist theories regarding the self are linked to language and social interactions with others (Caddell and Clare, 2010). The Self's framework (Kelly, 2009) was developed through the work undertaken by Sabat and Harre (1992) and Sabat and Collins (1999) which provided the basis for change in relation to the believed loss of self with the onset and progression of dementia. Sabat (2001; 2002) further pioneered the work of the self and dementia determining that people with dementia retain aspects of self, and that their ability to do this is contingent on others' social interaction. In other words, the self is constructed through the use of language and social interaction with others (Caddell and Clare, 2010). Sabat's work in the area around self and dementia considers the self to have two attributes (Fazio and Mitchell, 2009; Sabat and Harre, 1992), and with further studies developed a third category – Self 3 (Sabat and Collins, 1999).

Selfs' framework

Self 1 – Singular self

Self-1 is deemed the singular self, how the person constructs their own personal unique identity and uses the pronouns or identifiers 'I', 'me', 'myself', 'mine' or 'ours'. Sabat (2002) described this aspect of selfhood as 'each of us had one single point of view of the world' (p. 27). In using first person identifiers we provide our own view, tell our own story of ourselves and take responsibility for our own actions (Kelly, 2010, Sabat, 2002). Where a person has lost their memory their Self-1, personal identity, will still be intact, while they may not be able to provide information, such as where they were educated or where they were born, they would still have a singular view of the world, speak in first person and provide narratives through conversational discourse.

Self 2 – the publicly presented self

Self-2 the publicly presented self, includes qualities and past and present beliefs. This self is about our physical and mental attributes our beliefs about ourselves and our past. Some of the Self-2 attributes are historical such as being a graduate, and some are recent such as being a person with dementia (Sabat, 2002).

Self 3 – social personae constructed across social situations

Self-3 provides the different social personae which we construct across social situations in which we find ourselves. For instance, the way we behave and act with friends will be different to the way we behave when we are in a position of authority, say within the workplace. Therefore, the same person will display many patterns of behaviour. It is necessary to have the co-operation of others in order to construct Self-3. There is a need to be recognised within the role in which one is constructing, such as the teacher needs to be recognised and acknowledged as such by their pupils. It is this

Self-3 that is the most vulnerable to people with dementia. In relation to the person with dementia, if people within their social world do not acknowledge them (person with dementia) as being able or capable of a role, were others only see the cognitive impairment and treat them as such, there would be a sense of loss through the lack of co-operation from others rather than from the neuropathology of the disease.

The Self's framework provides a way to work with identity and self, to ensure that people with dementia are enabled to retain a sense of self. In understanding how actions and interactions from others can influence or inhibit a sense of self can assist in improving the way people with dementia are supported as a person, and how their own sense of self can be maintained. It is helpful to provide clarity on which model of self and identity is being referred to when undertaking research, most of the time selfhood, self and identity are referred to but with no clear identification as to which theoretical model they are relating to.

2.6.6 Well-being

Well-being tends to be viewed as an aspect of quality of life or a component of quality of life (Kaufman and Englel, 2016). Haas (1999) and Cook (2008) state that well-being is not clearly defined and that often the term well-being is used interchangeably with quality of life. Additionally, when well-being is spoken about it is predominantly in relation to happiness and pleasure seeking which is referred to as hedonic well-being, or subjective well-being (Ryan and Deci, 2001).

Eckersley (2007) defines well-being as more than seeking happiness and states

> '…it is about being satisfied with life, fulfilling our potential and feeling that our lives are worthwhile and have meaning.' (Eckersley, 2007, p.1)

Eckersley's (2007) definition is consistent with another view of well-being which is known as eudaimonic well-being, where rather than realising fulfilment through pleasure-seeking attainment, fulfilment is reached through a person achieving meaning through self-realisation and being a fully functioning member within society (Ryan and Deci, 2001). While research suggests that a multidimensional concept, which includes both hedonic and eudaimonic well-being (Deci and Ryan, 2008; Shah and Marks, 2004), this study focuses predominantly on eudaimonic well-being through Self-determination Theory, which supports the concept of eudaimonia (Ryan and Deci, 2001; Ryan, 2009).

Well-being is an important concept in health and social care. Identifying well-being and dementia supports the biopsychosocial model of care, and can perhaps assist with improving the models of care and support for people with dementia (Cook, 2008). Further, health and social care are moving to outcome-based approaches which focus on well-being (Cook and Miller, 2012). In addition, research suggests that there are clear links to health and wellbeing. Research has identified that the impact of psychological well-being can be as detrimental to a person's health risks as those identified through obesity, lack of exercise and smoking (Shah and Marks, 2004).

One important theory of well-being is SDT which is discussed in detail in the next section.

2.6.7 Self-determination Theory

Self-determination Theory (SDT) is a well-documented and evidenced theory of motivation and well-being developed by Edward L. Deci and Richard M. Ryan (1985, 2000), and is a macro-theory of motivation consisting of six mini-theories which create the formal framework of SDT:

- Cognitive Evaluation Theory (CET)
- Organismic Integration Theory (OIT)
- Causality Orientations Theory (COT)
- Basic Psychological Needs Theory (BPNT)

- Goal Contents Theory (GCT)
- Relationships Motivation Theory (RMT)

The mini theory that was utilised in this study is Basic Psychological Needs Theory (BPNT).

Self-determination Theory has identified that as active organisms' human beings have an innate need for autonomy, competence and relatedness, these are referred to as the three basic psychological needs (BPN). Self-determination Theory is situated within the social contextual conditions that will support the BPN or inhibit the satisfaction of the needs (Deci and Ryan, 2002). Therefore, the social environment can be influential in enabling or disabling the person in meeting these innate needs and their development of a sense of health and positive psychological well-being and improved motivation (Deci and Ryan, 2002). Self-determination Theory posits that satisfaction of the needs influence feelings of well-being (Deci and Ryan, 2000).

Self-determination Theory proposes two concepts of motivation: intrinsic motivation, behaviours that are performed solely for the satisfaction and enjoyment of the person; and extrinsic motivation, where there is a requirement to perform to ensure attainment or meet specific outcomes. An example of intrinsic motivation is where a person enjoys sport and undertakes this task for themselves and their own fulfilment. An extrinsic motivation example is where a person may undertake a task to please another, say a person or authority, it is a form of regulation. While a person may be motivated to perform because they are regulated or required to do so, the impact on their satisfaction and well-being can be affected by the external social environment. For instance, where the person is provided with encouragement and the environment is one that is autonomy-supportive and enables the person to experience the freedom of expression, it is likely that the person's performance will improve. They will feel more satisfied because they have a feeling of autonomy and one of competence (Vallerand and Ratelle, 2002). A third concept is 'amotivation' where success is considered to be unlikely or impossible, therefore the individual does not pursue the behaviour. The fulfilment of the three basic psychological needs, *autonomy, relatedness* and *competence*, can increase intrinsic motivation:

Autonomy refers to 'the degree to which individuals feel volitional and responsible for the initiation of their behaviour' (Williams, 2002, p.235). Where a person undertakes an action which they experience as an expression of self, they will identify with the action positively even if the action has been influenced by others, such as feeling supported to be autonomous in one's actions (Deci and Ryan, 2002). To be autonomous is to have the choice to engage in an action (Williams, 2002). Being autonomous does not mean that an individual is abandoned; indeed, people need support from others which helps to support feelings of relatedness, which will enable autonomy. Self-determination Theory is contingent on social environments that support the three BPN. Autonomy should not be confused with independence which is inconsistent with SDT, since to act independently is to act without any support from others (Deci and Ryan, 2002; Williams, 2002).

Autonomy is inextricably linked to competence and relatedness since a person may be intrinsically motivated to become competent in a task they enjoy doing, 'feelings of competence will not enhance intrinsic motivation unless accompanied by a sense of autonomy' (Ryan and Deci, 2000, p.70). Similarly, a person will be intrinsically motivated to help their friends and family, to feel connected and related to those around them. While autonomy is considered to be the central need to SDT, it also functions as a result or consequence of actions that support competence or relatedness (Little *et al*. 2002). Ryan and Deci (2011) suggest that autonomy is a necessary component in life in order to be healthy.

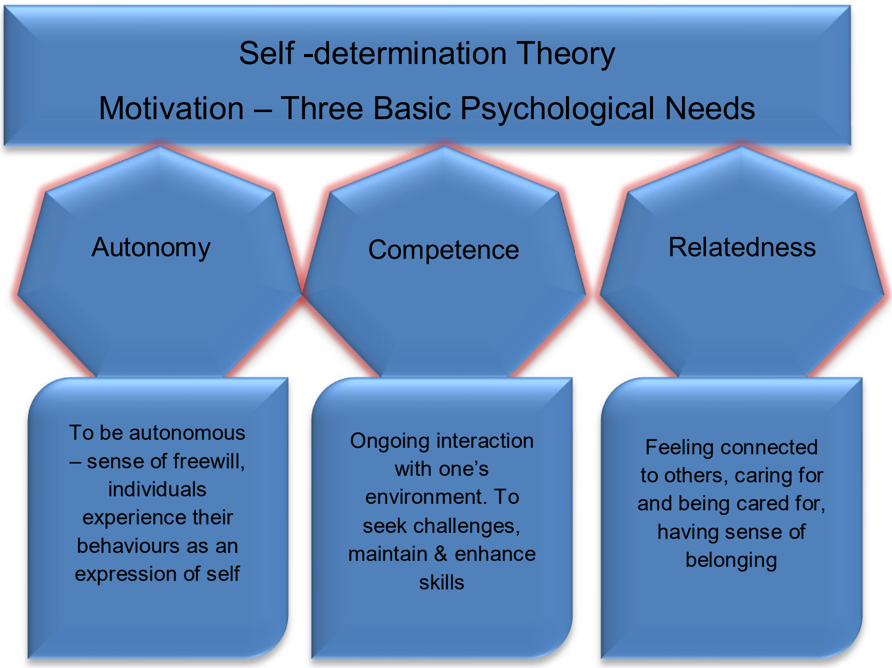
Competence refers to 'feeling effective in one's ongoing interactions with the social environment and experiencing opportunities' (Deci and Ryan, 2002, p.7). Competence is a feeling of confidence in one's own abilities and skills within the environment (Clarke, Wolverson and Moniz-Cook, 2016). According to Deci and Ryan (2002) competence relates to self-confidence and efficacy in relation to an action. They posit that the innate need for competence directs people to identify challenges to enable them to meet their optimum capacity, thereby undertaking activity that will maintain and further develop their skills and capacity. People need to feel challenged, but the problem or challenge needs to be achievable, where the problem is too easy or alternatively too difficult the person will not be stimulated (Deci and Ryan, 2000). Competence is considered to refer to continued ability and challenges to manage activities of daily living and function within society.

Relatedness refers to ‘feeling connected to others, to caring for and being cared for by those others, to have a sense of belongingness both with other individuals and one’s community’ (Deci and Ryan, 2002, p.7), to have unity with another and others through love and caring (Deci and Ryan, 2000). The need for relatedness is linked to the desire to feel connected, and be accepted by others and refers to the psychological need to feel secure and at ease in one’s relationship with others (Deci and Ryan, 2002, p.7). Relatedness also refers to the need people have to assist and support others, so while a person needs to feel supported by others they have an innate need to support others who are close to them (Deci and Ryan, 2014).

2.6.7.1 Basic Psychological Needs Theory (BPNT)

The figure below (Figure 2) presents an overview of the three psychological needs

Figure 2 Self -determination Theory (source Deci and Ryan, 2002)



Basic Psychological Needs Theory is one of the mini theories of SDT, and provides further insight into the concept of the basic needs. The research focused on BPNT has evidenced that where the three needs are satisfied there is a positive increase in health and wellness (Ryan, 2009); therefore, there is increased motivation and mental health. Conversely, SDT suggests a decrease in a person's motivation and well-being where they are not supported to meet these needs. Additionally, the social environment can also impact on a person's ability to meet the three needs. Ryan and Deci (2011) suggested that controlling environments, whether these are related to economic, familial or institutional, will have a detrimental impact on the person's wellbeing and happiness, because these environments impact on a person's autonomy. This issue is important in regard to YPwD where perhaps their surroundings are not suited to their needs, particularly in relation to services that they may access.

Where a person is deemed to be autonomous in their decision making they are considered competent to make decisions about themselves. Where a person is acting autonomously they act with ‘a sense of choice, are more mindful, think flexibly and express their values and interests’ (Ryan and Deci, 2011, p. 60). There is a possibility that people diagnosed with dementia experience a loss of autonomy due to reactions of others, linked to Self-3, as previously discussed. It is perhaps the social context that impacts on the autonomy of younger people who have a diagnosis of dementia. Socially it could be considered that the person with dementia is not able to think flexibly or express their values and interests, which prevents autonomy and impacts on self-determination.

While SDT is interested in well-being, it is also focusses on wellness rather than happiness. Self-determination Theory views wellness to be different to happiness. Ryan and Deci (2011) provide examples of this in relation to wellness and sadness and have suggested that where a person is sad for a specific reason, such as loss of a loved one, then they are said to be authentic since the sadness is related to a specific reason. Therefore, to be authentic is related to wellness even when you are sad, suggesting that you do not need to be happy to be well.

Self-determination Theory has been utilised as a model to support people to gain better health through the creation of services that are autonomy supportive (Williams, 2002). Aspects of self-determination models have been utilised for a range of health care patients and service providers, such as dental home care (Munster *et al.* 2012); need fulfilment in long-term care for older people (Custers *et al*. 2010); depression and treatment motivation (Sultan, 2013). All these studies followed a quantitative approach utilising questionnaires developed through SDT. Gillard and Roark (2013) presented a qualitative study focused on the basic psychological needs in relation to HIV and disclosure, which has some parity with the issues identified with YPwD. The study by Gillard and Roark (2013) was interesting for this current research as it was the only qualitative study that was identified that considered SDT and BPNT. A number of their findings are perhaps relevant to this current study around the lived experiences of YPwD. They identified issues with autonomy and competence in relation to disclosure, and suggested that their findings identify that BPNT is a useful framework to help support people to maintain well-being.

While this current study utilised SDT, it was used as a framework to undertake a secondary analysis on the identified themes.

Resilience as a response to ill-health can support well-being, the next section discusses how being or building resilience can support well-being linked to SDT.

2.6.8 Resilience

Resilience is an important aspect to consider in relation to Self-determination Theory and well-being. Where a person has improved wellness through the satisfaction of the BPN, there is improved motivation and well-being. Where a person is in a position to feel motivated this may provide them with the ability to cope and be resilient in the face of their diagnosis.

Triveldi, Bosworth and Jackson's (2011) definition was based on Luthar and Cichettie's (2002) definition of resilience and is viewed 'as a process of successfully adapting to maintain or regain emotional well-being in the face of adversity' (p.182). This definition relates to resilience in chronic illness and it describes the person going through a process to overcome distress in order to focus on positive outcomes. Resilience requires an aptitude to create positive experiences from the interruptions created by their illness (Bananno, 2004). Resilience has been linked to personality characteristics. For instance, an optimistic characteristic is seen to be a factor that creates positive outcomes compared to those individuals who are predisposed to negativity (Triveldi *et al.* 2011). Although, Bonnano (2012) argued that personality trait is not a reliable variable explaining that most studies focused on resilience and personality traits are focused post trauma. However, the trauma could have impacted on the person; therefore, there would be no way of knowing whether the trait was present pre-trauma or developed post-trauma. Bonnano does consider personality to be part of the puzzle in regard to resilience, but not the whole. Indeed, studies have suggested that individuals can be supported to be resilient, and researchers have developed models to help build upon a person's resilience (Triveldi *et al.* 2011). Therefore, resilience tools can be utilised as a coping strategy.

There are perhaps personality characteristics that are particularly helpful in regard to health related resilience, such as optimism, conscientiousness and health related hardiness. There is a body of research around these characteristics that are discussed in detail in Triveldi *et al.* (2011). In particular, Health Related Hardiness (HRH) has linked psychosocial adaptation in relation to diabetes, rheumatoid arthritis and hypertension (Pollock, 1986; Triveldi *et al.* 2011). Pollock's work (1990) on HRH identified that persons who have an innate hardiness are able to adapt when confronted with a health stressor, such as chronic illness diagnosis, due to personality characteristics that enable them to adapt through control, commitment and challenge. Brooks (2008) described the person with HRH as having the ability to utilise adverse experiences as an opportunity for self-development and motivation to challenge and manage the health stressor.

There is therefore, a suggestion that some people have characteristics which provide them with the ability to be resilient in the face of health issues (Brooks, 2008; Pollock, 1990). However, there are tools and methods that can be utilised where a person does not possess these traits or characteristics. It is suggested that this is important because these methods could be utilised as tools to enable YPwD to build resilience following the stress of diagnosis, particularly since it has been identified that a person experiences a loss of self-esteem following diagnosis.

2.6.9 Talking Point Outcomes and Well-being

As a commissioner I am familiar with the Talking Point Outcomes which are an outcomes tool used within health and social care. Contracts and assessments within health and social care utilise the TPO to assist people who are requiring support to identify outcomes to support quality of life and well-being. The Talking Point Outcomes are well researched in relation to older people and while they are used across all age groups, there is little research which identifies the outcomes as they relate to younger age groups. This study acknowledges the TPO and considered these as part of the theoretical underpinning.

Outcomes have been introduced into strategy and policy within health and social care in Scotland (Cook and Miller, 2012). Talking Points are a set of outcomes that were further developed by Ailsa Cook and Emma Miller at the University of Glasgow, following research conducted by the Social Policy Research Unit at York University (Miller and Cook, 2011). The aim of the development was to identify how personal outcomes could be incorporated into assessment, support planning and review. The Talking Point Outcomes focus on outcomes for individuals who use services and for unpaid carers (Carers) (Miller and Cook, 2011). The TPO are evidenced based and aim to ensure people remain at the centre of their care and support, therefore, promoting a person-centred approach to care and support (Cook and Miller, 2012).

The table below (Table 5) provides the TPO identifying the quality of life outcomes, process and change outcomes:

Table 5 Talking Point Outcomes (Cook and Miller, 2012)

Quality of Life	**Process**	**Change**
Safety Having things to do Social Contact Staying as well as you can be Living where you want Living life as you want Dealing with stigma	Being listened to Valued and treated with respect Having choice Reliability Responsiveness	Reducing symptoms Improving mobility Restoring skills and confidence

The TPO consist of three areas, quality of life outcomes, process outcomes and change outcomes. For the purpose of this study, these outcomes will be considered in YPwD and aspects of well-being. There are synergies to the TPO and the three basic psychology needs, as identified in BPNT. There are components of autonomy, relatedness and competence in the quality of life outcomes. Similarly, these are identified in the process outcomes, through being listened to – relatedness, choice –autonomy and the change outcomes link to the need for competence.

2.7 Summary

The first part of this chapter provided a comprehensive review of the literature focused around Younger People with Dementia. Findings from studies included in the review identified changes in identity and self, feelings of isolation and the need for meaningful activities which impacted on well-being. Further, there were issues around obtaining a prompt and accurate diagnosis. Previous studies indicated that YPwD may gain benefit from accessing services which allow them to meet with other younger people. However, the need for age-specific or specialist services was primarily informed by the carers of YPwD and providers of services. The literature review identified a gap in substantive research which focused on the subjective experiences of YPwD. The review identified that meaningful and rich data was sourced from the studies which involved YPwD using a qualitative approach.

The second part of this chapter has considered factors that influence well-being following a diagnosis of dementia. The chapter has discussed Kitwood's (1997) theory of personhood and how through the action of others there is the potential for people with dementia to not be acknowledged or recognised as the person that they are. These actions can create feelings of depersonalisation and ultimately impact on a person's well-being. The research reviewed in the first section of this chapter identified loss of identity and impact to self following a diagnosis of dementia, which led to feelings of loss of role, isolation and exclusion, which equally impacts on well-being. This chapter has identified the Self's framework (Kelly, 2009; Sabat, 2001) as a model to identify how the social environment and interaction of others with people with dementia may erode their self and impact on personhood. The Self's framework can assist with supporting people with dementia to retain self and identity. Further, this chapter has discussed how eudaimonic well-being can be achieved through the satisfaction of the basic psychological needs of autonomy, competence and relatedness.

This study considered these basic psychological needs as a reference when discussing the experiences of YPwD to identify how they maintain wellness, and where the social context in which they are situated may influence their ability to achieve well-being. Additionally, the concept of resilience has been briefly discussed as it is considered an important tool that could be utilised where a person feels motivated and able to cope with their diagnosis of illness.

The Talking Point Outcomes are utilised as a tool in health and social care to assist individuals to identify their outcomes and keep them at the centre of their care and support.

2.8 Research gap

A comprehensive literature review identified that research which focused on the subjective view of YPwD is sparse. While there has been an increase in the research which includes YPwD it remains limited. The research reviewed indicated that living with dementia at a younger age affects the person's well-being with a loss of identity and self, through changes in roles, isolation and feelings of exclusion. The review also identified that specialist services were indicated as a need; however, this was the view of the professional or carer rather than the view of YPwD. While younger onset dementia is classed as a rare disease by the WHO, it is acknowledged that there are limited services to meet the needs of YPwD and that there are challenges for most countries because of the small numbers within each area.

2.9 Research aim, and questions

The aim of this study was to explore the human experience of living with dementia at a younger age, to consider interpretations of well-being as defined by the subjective experience of the participants.

The following questions were explored in order to meet the research aim:

1. What are the views of Younger People with Dementia?
2. How do Younger People with Dementia interpret their lives following their diagnosis?
3. What do Younger People with Dementia need to ensure well-being?

3 Chapter 3 Research Design and Methodology

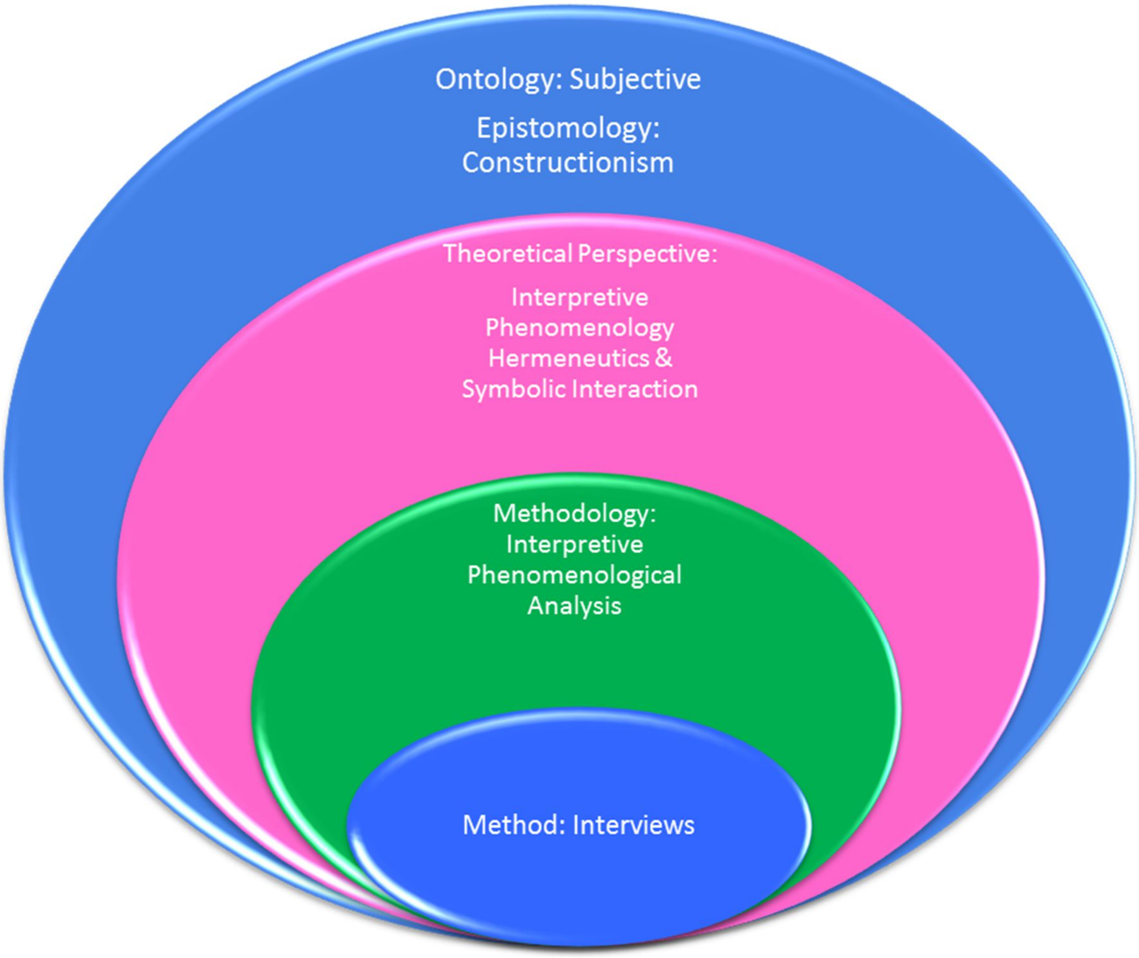
3.1 Introduction

The first part of this chapter provides an overview of the research design chosen to address the research aim and questions, with the second part of this chapter providing the detail of the process that was undertaken to conduct the study. The chapter starts with the theoretical components of ontology, epistemology and theoretical perspective, identifying those that are best aligned to the study and the researcher. The chapter provides detail on the history of the theoretical perspective, phenomenology, before moving on to discuss the theoretical approaches, methodology and methods.

The focus of this research study was to explore the lived experience of living with dementia as a younger person and well-being as defined by the subjective experience from the participants' viewpoints. Research methodology refers to 'the choices we make about cases to study, methods of data gathering, forms of data analysis, in planning and executing a research study. Therefore, methodology defines how we will go about studying any phenomenon' (Silverman, 2005, p.99). This study followed an Interpretive Phenomenological approach which is underpinned by the theoretical perspectives of phenomenology, hermeneutics and symbolic interactionism (Eatough and Smith, 2008). Interpretive Phenomenological Analysis (IPA) is a qualitative methodology that has been utilised to explore the experiences of people with dementia in previous research (Chaplin and Davidson, 2016; Clare *et al.* 2008; Clemerson *et al.* 2014). The theoretical perspective in which this research followed was interpretive phenomenology, utilising the concepts of hermeneutics and linked to symbolic interactionism. The Figure 3 below provides an overview of the research design identifying the ontology and epistemology, the theoretical perspective, methodology and finally the methods.

Figure 3 Research Design

.



3.2 Four Elements of the research process

The four elements of the research process, as described by Crotty (1998) can be utilised as a guide by the researcher in determining the research design. Crotty (1998) suggested that it is necessary to identify the methodologies and methods that are going to be used and how these are justified. Further, he asserted that the justification of the methods and methodologies chosen are integral to the question that the research sets out to explore. However, it is also necessary for the researcher to be aware of the assumptions and knowledge that they bring to the study, and in exposing this and showing this awareness will provide confidence in the research (Crotty, 1998). The researcher will drive the research and will identify the methods in which to undertake the research. However, the researcher will come with a set of views, values, assumptions and influences, which will affect the research design and process (Clough and Nutbrown, 2012).

The four elements described by Crotty (1998) are detailed below:

1. What methods do we propose to use? Procedures used to gather and analyse data.

2. What methodology governs our choice and use of methods? The research design, which links the choice and use of methods to the outcomes.

3. What theoretical perspective lies behind this methodology in question? The philosophical stance which informs the methodology.

4. What epistemology informs this theoretical perspective? The theory of knowledge embedded in the theoretical perspective and therefore in the methodology

Crotty 1998 (pp.2-3)

The next section discusses philosophical underpinning and research assumptions that may influence the research.

3.3 Philosophy

This section will provide clarity on how and why the approach to the study was selected and a rational for the use of qualitative, quantitative or mixed methods (Cresswell, 2009). It is essential to ensure that there is a thread between the methodologies and methods which are congruent with the researcher’s epistemology and ontology, which addresses the research question and suits the subject group (Holloway and Wheeler, 2010).

The terms used to define philosophy within research varies from researcher to researcher, which has potential to cause some confusion. Crotty (1998) defined epistemology as ‘a way of understanding and explaining how we know what we know’ (p.8), and ontology as what is real, ‘ontology is the study of being… what is the nature of existence with the structure of reality’ (p.10). To offer further explanation, how does the researcher view reality, how do they view the world? Researchers, therefore, need to identify how their view of reality (ontology) which can be subjective or objective and how they develop knowledge (epistemology) in relation to their reality, in order for their knowledge claims to be valid (O’Gorman and McIntosh, 2015). These will both inform the theoretical perspective.

I was aligned to subjective assumptions and that how reality is experienced is interpreted in relation to my own values, experience, knowledge and culture. I also recognised that others will interpret their reality as a reflection of their own value base and knowledge. Therefore, the ontological assumptions for this study were subjective.

It is essential to understand personal epistemological views since in tandem with ontology it forms the characteristics of the theoretical perspectives. Further, it is necessary to understand how we obtain knowledge and how we qualify that knowledge. My epistemology is aligned to constructionist rather than objectivist, therefore, a constructionist approach was followed for this study.

The section below provides an overview of constructionism and positivism and why constructionism is preferred over positivism.

3.3.1 Constructionism and Positivism

Constructionism holds the view that there is no such thing as ‘objective truth’ (Crotty, 1998, p.8), that meanings are constructed through the world rather than being discovered (Crotty, 1998), that, ‘truth and meaning do not exist in some objective external world, they are created by the subjects’ interactions with the world’ (Gray, 2009, p.18). Therefore, different meanings can be constructed for the same phenomenon depending on the culture, time and generation (Crotty, 1998; Gray, 2009). Crotty (1998) provided the analogy of a tree to explain the theory of constructionism. A tree has been given meaning by human beings. However, the meaning of a tree will be dependent on the person or the subject which is relating to the tree. To a person, it could be a thing of beauty, but to the animal it could be shelter or food. Therefore, as human beings we construct the meaning of the world by interpreting the environment in relation to our society and culture (Crotty, 1998).

The constructionist paradigm differs from the positivist paradigm. The positivist paradigm holds the belief of existence and order of the natural world, the world exists and is driven by natural causes, the external world is real. This view differs from the constructionist paradigm which posits a more subjective view in that the social world is mentally constructed by individuals (Polit and Beck, 2014). Positivism was deemed the dominant research paradigm from the 1930’s until the 1960’s (Gray, 2009). Positivism is linked to the objectivist epistemology in that ‘only events that can be observed or that only propositions which are testable, have a claim of truth ‘(Ashworth, 2008, p.10). The method of inquiry is scientific, based primarily on what can be observed, dealing with facts and not philosophical assumption and values (Gray, 2009).

A positivist approach would be deductive which would require inquiry to test or disprove the hypothesis. The approach requires the researcher to be as impartial and as objective as possible in their quest to gather empirical evidence. It would be necessary for the researcher to disengage and dissociate from the subject in order to create objectivity. Although a positivist approach suggests searching for the truth, Popper (1968) proposed that one cannot prove a theory to be true it can only be proved to be false. Positivist approaches to research remain popular and are likely to be used for research aimed at clinical and scientific inquiries (Gray, 2009). While positivist approaches are particularly popular in health and medicine, constructionist approaches are no longer dismissed. It is now accepted that some investigations need one approach whereas others will be more suited to the other.

The aim of the current research was to explore the experiences of YPwD, to gain an insight into their world, their subjective view of their perception of living with dementia. Each individual is unique, and each person who lives with dementia will experience and construct their social world differently. Rather than ‘discover’, the aim was to ‘construct’ what it means to live with dementia by exploring the experiences of a small group of YPwD, how they make sense of their experiences and living in the world with dementia. Therefore, the constructionist paradigm is considered to be an appropriate approach for this research study. This approach can be justified further by considering the positivist approach in more detail.

Positivist approaches set out to prove a hypothesis, however, this research was concerned with the lived experience of the participants, therefore, did not set out with a theory to prove. As has been identified through the literature review there is minimal research and as yet, no theories relating to YPwD. This research aim was to generate an insight into the lives of YPwD by exploring their experiences living with dementia; therefore, an inductive approach was deemed appropriate.

Inductive reasoning is the practice whereby the researcher collects data, and through in-depth analysis identifies themes and concepts and patterns of relationship (Grey, 2009). Utilising different methods, such as observation or interview, the researcher will build concepts and themes through the analysis of the data (Moule and Goodman, 2009). Through this process it may be possible to determine relationships or theory regarding the phenomenon studied (Grey, 2009). Deductive reasoning requires the researcher to commence with a general theory, which will be tested through different methods of observation with the aim to, ‘deduce how the theory works, and identify causal relationships through controlled testing or experimentation’ (Moule and Goodman, 2009, p.173). Deductive reasoning is linked to positivism since the aim is to test an existing theory to see if it is correct, is there truth to the theory. The researcher in positivist approaches remains completely separate from the research taking a much more scientific approach. Examples of deductive reasoning would be ‘randomised controlled trials’ (RCT).

To summarise, a constructionist perspective utilising an inductive approach was adopted to generate further knowledge and insight about the experiences of younger people living with and beyond dementia. When this study commenced the literature reviewed suggested that there was minimal research available which specifically presented the experiences of YPwD. Similarly, there was a lack of related theory to be tested. Where research is focused on exploring experiences of individuals it would be difficult to verify a theory since no two people would interpret their experiences identically, since individuals construct their own reality. Adopting a more constructionist approach would identify concepts and themes that may or may not be similar, which would provide an insight into the lives and experiences of the phenomenon, and determine how YPwD make sense of being in the world with dementia. A constructionist paradigm links to the subjective ontology in that reality is interpreted by the individual based on their value base, knowledge and culture.

3.3.2 Theoretical Perspectives

It is important to provide insight into my world view, how I interpret this and the assumptions this brought. Therefore, it is necessary for me to provide clarity on my chosen methodology and underlying assumptions. In identifying my theoretical perspective, I aim to provide insight into personal assumptions (Crotty, 1998). There are a number of philosophical and theoretical perspectives that underpin an interpretive approach to research. These are symbolic interactionism, phenomenology, realism, hermeneutics and naturalistic inquiry (Grey, 2009).

Phenomenology, hermeneutics and symbolic interactionism are discussed in detail below with an overview of the contributors to phenomenology.

3.3.2.1 Phenomenology

Phenomenology is an approach to research that is focused on understanding how individuals make sense of their reality, through their lived experiences and interaction with their environment (Parahoo, 2006). It is a popular choice for research into nursing because of its approach to inquiry and synergy with nursing philosophy (Lopez and Willis, 2004). Sometimes phenomenology refers to the lived experience as the ‘lifeworld’ (Moule and Goodman, 2009). Phenomenology is classed as a theory, and it is also utilised as a method of inquiry (Holloway and Wheeler, 2010).

The philosophy of phenomenology is linked to Edmund Husserl (1857 – 1938), Martin Heidegger (1889 – 1976), Marleau-Ponty (1908-1961) and Jean-Paul Sartre (1905-1980). The result of the input from these philosophers led to the development of three streams of phenomenology: descriptive, hermeneutic and existentialist (Holloway and Wheeler, 2010). Edmund Husserl initiated the theoretical perspective of descriptive phenomenology, sometimes described as transcendental phenomenology. Heidegger, a student of Husserl’s developed hermeneutic phenomenology, at times referred to as interpretive (Polit and Beck, 2006) and existentialist. Heidegger believed in the importance of giving consideration to a person’s background, that all interpretations regarding experiences are related to the person’s history. It was his view that knowledge of a person’s background provided insight into how the person will experience phenomena (Parahoo, 2006).

The theoretical perspective of phenomenology advocates that when researching social reality it is necessary to understand how the person experiences that social reality. The aim, therefore, is to understand how phenomena present themselves and how we (human beings) react to them. It is necessary to ignore previous understandings, where possible, of the phenomena to assess the person's immediate reaction or experience to the phenomena (Crotty, 1998; Gray, 2009). Although this is a predominant feature in Husserl's descriptive approach, where researchers are required to bracket preconceived ideas, it also features, to some extent, in the interpretive approach. By revisiting the initial experience to the phenomena then new meaning may emerge of that phenomena or reinforcement of the former meaning (Crotty, 1998), essentially the aim is 'to take a fresh look at things' (Crotty, 1998, p.80).

The two distinct approaches to phenomenology: descriptive phenomenology (eidetic) developed by Husserl and interpretive phenomenology (hermeneutic) that was first developed by Heidegger, are discussed in more detail below, along with summaries of the phenomenological views of Merleau-Ponty and Jean-Paul Sartre.

Husserl - Descriptive Phenomenology

Husserl, a German mathematician, is considered to be the founder of phenomenology and is predominantly descriptive. Husserl stated that where a person is able to reflect on their individual experiences of the phenomenon, and identify with the essential qualities of that experience, they would transcend the detail of the particular circumstances. Reflecting on the experience would assist in capturing the detail of the experience, which could then be highlighted to others (Smith, Flowers and Larkin, 2009). These insights are referred to as essences (Moule and Goodman, 2009). Husserl believed that these subjective experiences were valuable as they would assist scientists to understand what motivates humans. Husserl argued that humans tend to go about their daily activities without any real conscious thought of the experience, while we are conscious of the activity we are unlikely to reflect on the activity, or consider the values, properties and essential qualities of the activity. For instance, where a person is undertaking a task such as driving down their street they would be conscious of their activities, but would they also focus on the actions, the feel of these, the movement of the car and the environment through which they are driving? To take the time to reflect on the situation, to recall and remember is to be phenomenological, 'the consciousness of the individual' (Smith *et al.* 2009, p.13).

The phenomenological view being that to be conscious is to be conscious of something, to be angry is being angry about something, to remember is to remember about something, to be happy is be happy about something. However, the object (the something) may be real such as a tangible something, or imaginary, or a memory. Husserl used the term 'intentionality' to describe this relationship between the 'process occurring in consciousness, and the object of attention for that process' (Smith *et al.* 2009, p.13). It is through the process of consciousness that humans are able to make sense of, and understand their reality and that this is the only way to gain knowledge (Larkin, Watts and Clifton, 2006).

A concept of Husserl's method of inquiry is 'bracketing' which requires the researcher to eradicate, as far as possible, any preconceptions they may have when they are conducting data collection (Lopez and Willis, 2004). This is undertaken through a process termed 'phenomenological reduction' (Moule and Goodman, 2009). In bracketing off previous knowledge and views of the phenomenon being studied the researcher will enter the field with an open mind. One method researchers utilise to unburden preconceptions is to write these down prior to the commencement of data collection. In undertaking this task, they acknowledge their preconceptions and are cognisant of these to ensure openness to the experience of others (Lopez and Willis, 2004; Moule and Goodman, 2009). When undertaking research following descriptive phenomenological approaches the aim is to identify the essence of the lived experience, searching for commonalities and differences within those experiences from individuals (Moule and Goodman, 2009).

Heidegger Interpretive Phenomenology

Heidegger, a student of Husserl, further developed phenomenology to move away from merely describing the lived experience, to try to understand the experience by interpreting the experience through a process known as hermeneutics (Dreyfus, 1991). Husserl's phenomenology is referred to as transcendental, whereas Heidegger takes a more existential approach through his seminal work 'Being and Time' (1927), where he introduced the concept of Dasein (Dreyfus, 1991; Holloway and Wheeler, 2010). Dasien was his preferred term for existence, 'there-being' (Smith *et al.* 2009). The concept of Dasein is temporal in that it is always looking to the future, but considers the past and the present.

Heidegger believed that humans are socially conditioned by their environments, their culture and social groups. There is a need to belong and feel connected, with a reluctance to deviate from the norm. Heidegger wanted individuals to reflect, to free themselves and to be authentic to themselves, while respecting that in society we need to be cognisant of the norms we can be authentic to ourselves within those norms. For instance, a person will go to work every day and take lunch in the canteen. However, one day they may choose to take their lunch sitting outside on the grass. They would do this within the confines of the rules of that society; they would not sit and sunbathe in their underwear, this would not be acceptable in the workplace, but to just sit and eat their lunch would be acceptable while being authentic.

These actions are what Heidegger refers to when he talks about being authentic; it is this freedom and authenticity that makes a person different, to be themselves, to be an individual. Heidegger's view was that the world is pre-existing, and rather than being separate from the world, we are thrown into it, we are part of the world and being with the world, and with others (Dreyfus1991; Heidegger, 1962/1927 in Smith *et al.* 2009). Utilising Heidegger's phenomenological view requires consideration of the person set in the context of their social environment (Holloway and Wheeler, 2010).

Merleau-Ponty

Merleau-Ponty, through his work ‘Phenomenology and Perception’ (1945/1962), further developed the foundation of phenomenology drawing on Husserl and Heidegger and their allegiance to understanding being in the world (Smith *et al.* 2009). Merleau-Ponty provided a view that rather than being part of the world, humans undertake a process of observing the world and seeing themselves as being different to the world. Merleau-Ponty brought the concept of embodiment and suggested that communication with the world is through the body (Smith *et al.* 2009). He stated ‘the body is the vehicle of being in the world’ Merleau-Ponty, (1962, p.82). Merleau –Ponty suggested that we strive through our body to achieve the best perception of the object in which we are relating to, enabling us to connect with the world and understand it (Finlay, 2006).

Examples are provided in how we relate ourselves to objects to obtain the best view, too close it is hard to understand and too far the detail cannot be perceived. Further, everyone’s perception of any situation or phenomena will always be different (Merleau-Ponty, 1962). Merleau- Ponty added a further dimension to understanding the being and the experience, in that he included the physiological component of the experience, how our bodies react to touch, feel, and situations.

Jean-Paul Sartre

Jean-Paul Sartre developed existential phenomenology through many of his writings but in particular, ‘Being and Nothingness’. Similar to Heidegger he suggested that there is a link between the consciousness and the perception of objects (McWilliam, 2010). However, Sartre’s phenomenological view differs from Heidegger’s in that he believed that humans have the freedom to choose, to determine their own experiences, compared to Heidegger who espoused that humans are bound by history and culture that already exists within the world (McWilliam, 2010).

Sartre also believed in authenticity, where a person is not authentic or true to themselves, he termed this as to be in ‘bad faith’. Sartre suggested that where a person chooses to do something that is not of their true choice then they are in bad faith (Moran, 2000). When a person is presented with a situation, how they choose to respond to the situation would be considered authentic should they do so through freedom of choice. However, should they conform to an expectation of others then this would be inauthentic and bad faith (Moran, 2000). Therefore, Sartre suggested that the self is always developing, through the freedom to choose, in other words that there is the freedom to become rather than just to be (Smith *et al.* 2009).

Sartre proposed that those things that are absent (nothingness) are as important as those which are visible or there. Sartre provided an example of going to meet someone in a café, Pierre, on arrival Pierre is not there, which changed the conscious perception of the person. Sartre proposed that the conscious thought before arriving at the café would be on Pierre, but the absence of Pierre created a different view, where the café then became the focus of the conscious, and the absence notable, the café presented differently to the person. Whereas, if Pierre had been present, then the café would not have been the dominant focus as Pierre would have blended into the surroundings (Sartre, 1956/1943, p.42 cited in Smith *et al.* 2009). What this suggests is that where an event creates a change from something to nothing then the perception or view of the world will be modified.

Sartre accepted that a person is not alone in the world; rather, they form relationships and encounter others which will impact on their perception of the world. Sartre suggested that where we undertake actions that are witnessed by others these can create feelings of shame and anguish, where the action is one that is perhaps not conforming to the culture within which they live. While he is proposing that humans have free-will and choice, this is situated within the complexity of the cultural norm, the social environment and relationships with others (Smith *et al.* 2009).

3.3.2.2 Hermeneutics

Hermeneutics refers to the theory of interpretation, which in the case of interpretive phenomenological research recognises that the researcher will draw on preconceptions, prior experiences and assumptions to understand the situation (Heidegger, 1962/1927, in Smith *et al.* 2009; Willis and Lopez, 2004). So rather than bracket off the preconceptions, it is necessary to acknowledge them to ensure that they do not inhibit, or prevent the person from recognising something new or different in the presentation of the experience.

Heidegger suggested that as part of being in the world we automatically make sense of objects that present themselves, or that there is already an understanding of them through culture and society. Heidegger required that these previous understandings are set aside, to prevent an immediate interpretation of the situation being studied (Crotty, 1998). The hermeneutic approach searches for the meanings attributed to experience rather than a description of the main concepts and essences that are the focus of a more descriptive approach (Lopez and Willis, 2004). Where undertaking a hermeneutic approach the researcher will consider these concepts in relation to the historical, social and political environment (Lopez and Willis, 2004).

Qualitative research suggests a double hermeneutic. As has been discussed through Heidegger's approach, people constantly interpret the world of which they are a part. Therefore, participants taking part in an interview process will interpret their experiences in relation to their world, in which the researcher will then interpret (Ashworth, 2008), this is referred to by Smith and Osborne (2008) as a 'two stage process…the researcher is trying to make sense of the participants trying to make sense of their world '(p.55).

For this study I drew on the interpretive approach, with an understanding that we all perceive the world differently, including experiences which will be interpreted in relation to the social context, time and presence and that this interpretation is subjective. Consequently, I also have my own interpretations of phenomena based on my own views, previous knowledge and background. Therefore, it was necessary to follow an interpretive approach, which required me to be mindful of my own preconceptions, which enabled me to provide a true account and insight into the lived experience of YPwD.

3.3.2.3 Symbolic Interactionism

Favouring the view that humans are influenced by their environment and subjective perceptions, believing that we are not able to separate ourselves from what we know, constructionists reject the objective belief held by positivists (Willis, 2007). There is an assumption that the values held by the researcher cannot be detached from the research process, that there is a link between the researcher and the research. This supports the theory that how we interpret the world and who we are will influence how we interpret and understand others (Cohen and Crabtree, 2006; Holloway and Wheeler, 2010).

Symbolic interactionism is a theoretical perspective in sociology and social psychology and informs a number of methodologies (Crotty, 1998). Crotty (1998) explained that as a theoretical perspective it provides a way of ‘understanding and explaining society and the human world' (p.3). Symbolic Interactionism was born out of the work of George Herbert Mead (1863-1931), pragmatist philosopher and social psychologist, and Herbert Blumer, a student of Mead’s. It was Blumer (1969) who articulated three tenets to the theory of symbolic interactionism (Crotty, 1998; Gray, 2009), which are meaning, language and thought. Benton and Craib (2001), summarised these as ‘people act on the basis of the meaning that objects have for them; these meanings are developed through social interaction and modified through interpretive processes employed in further interaction’ (p.87).

Symbolic interactionism provides insight to ‘self’ and that the emergences of self are based on how others see us. The ‘self’ in interactionism is depicted as a process rather than an entity (Benton and Craib, 2001), and is considered to be a social phenomenon rather than psychological (Holloway and Wheeler, 2010). A person’s social self is developed through a process of modelling through those whom they consider being significant within their social environment. Through this process a person can learn how to behave and act in accordance with the community and behaviour of others.

Eventually, the person is able to play multiple roles within a community and react and respond to other’s behaviour, adapting their behaviour to the situation or to the behaviour of others (Holloway and Wheeler, 2002). This kind of behaviour was identified in Erving Goffman’s study, ‘Presentation of Self in Everyday Life’ (1959). Gray (2009) explained that meanings change depending on the experience of the person and this also relates to ‘self’. Providing the example of a person who is promoted within the company with whom they are already employed, Gray (2009) explained that the person’s perception of the organisation and that of themselves may shift due to the promotion. When a person interacts differently or views themselves or the object around them differently the impact is to create a change in behaviours.

Symbolic interactionism as a theoretical perspective is linked to a number of qualitative methodologies, such as grounded theory and Interpretive Phenomenological Analysis (IPA). Additionally, it is related to subjective ontology and constructionism. Symbolic interactionism views the self as being related to sociology and able to change and adapt rather than rooted in psychology and fixed. I am interested in symbolic interactionism in relation to the self and dementia and I identify with the view that the self can be changeable. Additionally, there is a clear connection to social identity and the Self’s framework, referred to in Chapter two in the section on theoretical underpinnings.

3.4 Summary

Phenomenology is linked to the constructionist epistemology and subjective ontology. Phenomenology also links to the basic psychological needs which are identified in Self-determination Theory discussed in Chapter two. Heidegger’s and Sartre’s phenomenological approach identified the need for human beings to feel connected and related to their environment. Additionally, they have identified with the need to be authentic to self, to live well in life, which could potentially be linked to autonomy. Phenomenology is all about how we experience our reality and how when something happens within our reality we will view the experience differently, we will become cognisant of our surroundings and all that is there or not there.

This research study focused on the lived experiences of YPwD and was aligned with an inductive approach, as the aim was to explore the human experience of living with dementia at a younger age, to consider interpretations of well-being as defined by the subjective experience of the participants. I identify with a subjective ontology and constructionist epistemology which is consistent with an inductive approach. Further, my ontological and epistemological views are linked to the theoretical perspectives of interpretive phenomenology (hermeneutics) and symbolic interactionism.

3.5 Qualitative Approaches/ Quantitative Approaches

Qualitative research has evolved over time and subsequently so has the definition (Cresswell, 2007). Qualitative research provides a holistic approach that centres on the exploration of the human experience. The approach enables the researcher to gain an understanding or awareness into the lives of the person and the phenomena being studied, interpreting the meanings of this experience within the social world (Holloway and Wheeler, 2010)

Considering the research aim helps to inform the methodology, which in turn ensures the most appropriate method; therefore, it is necessary to examine the focus of the research to determine the methodology and method. The purpose of this research study was to explore the human experience of living with dementia at a younger age, to consider interpretations of well- being as defined by the subjective experience, from the participant's subjective viewpoint.

A qualitative approach was deemed the most appropriate and is justified because of the research aim. I will now provide an explanation as to why I came to this decision.

Qualitative research allows for a person-centred and holistic approach, focusing primarily on how the individual sees the world and how they make sense of it (Green and Thorogood, 2009; Holloway and Wheeler, 2010). Qualitative research aims to catch the lived experience of the participant, interpreting this with a focus on the meanings and perceptions attached to that person (Holloway and Wheeler, 2010). The approach enables the researcher to explore the experiences of the individual utilising face to face data collection methods (Moule and Goodman, 2009). There are three different qualitative methodologies: phenomenology, ethnography and grounded theory. The next section discusses two of these methodologies which were considered appropriate to meet the aims of this research study, grounded theory, and Interpretive Phenomenological Analysis (IPA).

3.5.1 Grounded Theory

Grounded theory is predominantly utilised for qualitative studies but can also be used for quantitative study. Grounded theory was developed by, and originates from, sociologists Barney Glaser and Anselm Strauss (1967), and is defined by Glaser and Strauss as ‘the discovery of theory from data systematically obtained from social research’ (p.2). They called this discovery of theory from data, Grounded Theory. Together they published their seminal work, ‘The Discovery of Grounded Theory’ (1967), in which they suggested that ‘systematic qualitative analysis had its own logic and could generate theory’ (Charmaz, 2006, p.5). Grounded theory as an approach does not rely on generating knowledge from existing theory; the approach requires the researcher to look to the data to generate the theory, as the name suggests the theory is grounded in the data collected for the study.

Following its initial inception by Glaser and Strauss in 1967, grounded theory has been further developed. Researchers refer to traditional grounded theory and evolved grounded theory (Birk and Mills, 2011). Strauss, with Juliet M Corbin, adapted the approach (evolved grounded theory), particularly in relation to data analysis, since they felt it necessary to clearly articulate how to undertake data analysis, making the process more technical (Charmaz, 2006; Cooney, 2010). Glaser remains faithful to the origins of the work carried out by him and Strauss, and has been critical of Strauss and Corbin's prescriptive approach, claiming that it 'forces data and analysis into preconceived categories and thus contradicts fundamental tenets of grounded theory' (Charmaz 2006, p.8). It is suggested that Strauss's approach is much more rigid compared to the approach supported by Glaser. Cooney (2010) suggested that to combine the two approaches could be challenging. Charmaz (2003) proposed a new approach termed constructivist grounded theory.

Charmaz (2006) does not see grounded theory as a prescriptive method, rather, she views it as a set of principles. She sees these principles being used by the researcher as a flexible set of guidelines. Charmaz does not view the researcher as an objective observer in the process proposing the researcher is, in fact, part of the study, to quote 'we are part of the world we study and the data we collect' (p.10). Therefore, suggesting that our interpretation of the data is constructed in relation to our values and experiences of past and present, the interaction we have with others and that these cannot be separated (Charmaz, 2006). Essentially, Charmaz is suggesting that the theories generated from the research are constructions of reality, which supports an interpretivist ontology and symbolic interactionism.

Grounded Theory has a number of characteristics, such as theoretical sampling, constant comparative analysis – emergent themes, coding and categorising of data, theoretical memos (Moule and Goodman, 2009). Some of these characteristics are not unique to grounded theory, such as the use of memos, which are also an important component of IPA.

Grounded theory was an approach that was considered appropriate for this study, but it was rejected as the aim of this study was to explore the lived experience of YPwD and well-being, which is aligned to a phenomenological approach. There is a paucity of research focused on the subjective experiences of YPwD and YPwD are a hard to reach group, therefore the ability to recruit enough participants to the study was limited, which would create difficulty in reaching saturation and development of a robust theory through constant comparative analysis.

3.5.2 Interpretive Phenomenological Analysis (IPA)

Jonathon Smith introduced IPA in a seminal paper published in 1996 in Psychology and Health, with the aim to introduce a qualitative research approach that was situated in psychology and focused on the experiential rather than just the experimental (Smith *et al.* 2009). The origins of the theoretical underpinning of IPA are situated in phenomenology and hermeneutics (Eatough and Smith, 2008; Shinebourne, 2011).

The aim of Interpretive Phenomenological Analysis is to consider a person’s reality through a detailed insight into the lived experience of individuals to their reality, and how they perceive and make sense of their experiences with respect to major experiences within their lives (Eatough and Smith, 2008; Smith *et al.* 2009; Smith and Osborne, 2008). It is an approach which embraces the view that the ‘participants are experts in their own experiences’ (Reid, Flowers and Larkin, 2005, p.20).

Undertaking IPA as a methodology proposes three levels of interpretation, suggested by Smith (2004), which researchers should consider when undertaking analysis, such as the social context, the use of metaphors and temporality. The positive aspect of this methodology is that it tries to allow the researcher to experience the life of the participant to obtain an insider perspective (Smith and Osborne, 2008). However, this is complicated by the fact that the participant to the research is interpreting their experience of which the researcher then has to try and interpret. Therefore, it is never completely achieved since the researcher will interpret the situation from their own perspective; this is termed the double hermeneutic (Smith *et al.* 2009).

IPA takes an idiographic approach in that rather than generalise or identify universal themes the aim is to consider a detailed in-depth analysis of the accounts of a case, to give it full appreciation following a thorough and systematic approach. Further, the approach seeks to understand how a person or a group of people perceive and make sense of phenomena situated within a specific context (Pietkiewicz and Smith, 2012; Smith *et al.* 2009).

For this reason, sampling is purposive and small. Large sample sizes would not enable the researcher to undertake the time consuming, detailed analysis required for IPA. While there are no rules governing the sample size, small samples are appropriate in order to achieve the detail required to produce an in-depth examination of the phenomena studied, rather than to generate a theory that could be applied across populations (Pietkiewicz and Smith, 2012; Smith, 2004).

The importance of an IPA study is the richness of the data collected. IPA studies have been undertaken as a single case study, or with a sample four, nine and fifteen. Regarding sample size, the researcher also has to consider a number of factors, such as the richness of the data within each case study, the time the researcher has to undertake the study, access to potential participants, any restrictions that may be in place (Peitiewicz and Smith, 2012). Peitiewicz and Smith (2012) suggest that six to eight participants is an appropriate sample for an IPA study, in reference to Turpin *et al.*'s (1997) recommendation for the British clinical psychology doctoral programmes.

IPA is the preferred choice of methodology to meet the aims of this research study. This study aim was to explore the human experience of living with dementia at a younger age, to consider interpretations of well-being as defined by the subjective experience of the participants. IPA focuses on the significance of a particular experience in relation to a person's life and how they make sense of the experience. Therefore, IPA would enable the researcher to capture how a small group of YPwD reflected on their experiences from diagnosis and how they make sense of their lives following this (Pietkiewicz and Smith, 2012; Smith *et al.* 2009).

An IPA approach to this research study would provide rich data from a small group, with the potential to identify similarities and dissimilarities of their experiences in relation to their experiences of living with dementia at a younger age. In undertaking IPA the detailed in-depth analysis would provide meaningful insight on those experiences of people living with dementia following a diagnosis at a younger age, which could go some way to understand what it is to live with dementia, and what it means to the person with dementia.

IPA underpinnings are interpretive phenomenology, linked to symbolic interactionism, which links to the philosophical approach detailed by the researcher above.

3.5.2.1 Key ideas from Husserl, Heidegger, Merleau-Ponty and Sartre for IPA

Smith *et al.* (2009) draw on each of the phenomenological approaches to identify how they relate to the methodology of IPA. In regard to Husserl, his approach sets the foundations for reflection and the detailed examination of the lived experience. Husserl's model requires bracketing of preconceived knowledge, which is also a key component of IPA but IPA acknowledges the interpretive nature of the researcher, in the double hermeneutic.

The aim of IPA is to illustrate a specific experience as it is experienced by a person or a group of individuals, rather than trying to search for the essence of that experience. Heidegger is important to IPA researchers for his concept that beings are thrown into the world, they are very much part of the world. In being in the world this is temporal, in that every activity is performed with history from the past, includes the present and will have an impact on the future. Further, all experiences of being in the world are relative to the context of the environment, culture and others around the person.

Merleau-Ponty introduces the embodiment and the importance of experience in relation to physicality and perception. How a person physically translates their experiences within the world in relation to objects. Merleau-Ponty's view is an important aspect for consideration when undertaking IPA, to consider how experience impacts on the person physiologically (Flowers *et al.* 2009), and that it is also a component of how a person makes sense of a situation (Finlay, 2006). Sartre proposed that we are always evolving, trying to discover and become ourselves. He suggested that it is necessary to be authentic and that humans have a free will and choice. However, these choices need to fit within the constraints of societal norms.

Interpretive Phenomenological Analysis utilises a hermeneutic approach which is supported by Heidegger, Merleau-Ponty and Sartre, and draws on Husserl’s foundation of experience. The contribution from Heidegger, Merleau-Ponty and Sartre focuses on how the person interprets their world in which they are immersed and all that is constructed within it, such as culture, language, objects and relationships (Smith *et al.* 2009).

3.6 Methods

Qualitative research aims to explore the experiences and understanding of the individual; therefore, it is essential that the technique of collecting data facilitate this process. The most common form of data collection is through interview or observation. Occasionally researchers will utilise different methods to gather data, using a combination of approaches such as focus groups, face to face interviews and observation (Gray, 2009). This study utilised one to one semi-structured interviews with open-ended questioning to facilitate data gathering; this is in accordance with IPA. Additionally, interviews were appropriate for the participant group, since they found it difficult to communicate through other media.

Interviews

Interviews are a common method for collecting qualitative data. This method does not attempt to standardise the data, what it does aim to do is gather the thoughts and expressions of the participant to explore their experiences and feelings, which will enhance the data (Moule and Goodman, 2009).

Semi-structured interviews were utilised for data gathering, through one to one interviews with each participant. The semi-structured interview (sometimes referred to as unstructured) utilises open-ended questions starting with: what, how, who, when. The researcher is advised to limit the use of why since this could suggest to the individual that there is a right answer (Turner, 2010).

Where a researcher has an aim to cover particular points about the research objectives then using a guide will help to ensure the interview remains focused. While the interviewer asks open questions, from which they will hope to elicit the experiences of the person and their meaning and interpretation of events, it is essential that the researcher is able to keep that focus of the participant on the interview

It is important that the researcher remains aware of the potential for ‘power issues’ when utilising interviews as a method for gathering data (Moule and Goodman, 2009). This awareness is essential because a distortion in power balance could impact on the participant thereby affecting the quality of the response. To counteract any limitations, and to ensure rigour to the process, the interviewer needs to employ strategies. Such strategies within qualitative research are reflexivity, and occasionally researchers will ask for external validation of the data. Reflexivity is utilised in qualitative research by the researcher to acknowledge the researcher as part of the research process, which enables the researcher to identify with any preconceptions they may have (Horsburgh, 2002).

The practice of second researchers checking the data is a recognised practice which is sometimes employed to ensure rigour and credibility in the process (Moule and Goodman, 2009). However, it is also argued that this does not add any benefit or merit to the process as people come with their own preconceptions. Additionally, if they have not been involved in the research data collection the study may well end up being more reliant on the person checking the data, rather than the main researcher (Greenhalgh, 2010).

Consent

Before conducting any research it is necessary to obtain informed consent, ‘the universal principle that is applied to the participation in treatment and research’ (Woods & Pratt, 2005, p. 426). Obtaining informed consent can sometimes be problematic when undertaking research which includes people with dementia. In Scotland the Adults with Incapacity (Scotland) Act (AWIA) is used to establish capacity, section 51 subsection 3 covers research. However, not all people with cognitive impairment lack capacity. Obtaining informed consent to participate in research does not necessarily require the need to utilise the AWIA, and where necessary the researcher can access good examples of protocols that have been used to obtain informed consent (Allan, 2001; Hubbard *et al.* 2003). The principles of informed consent are that the person is able to understand the aims and objectives of the research and what their role would be (Woods and Pratt, 2005). These principles promote empowerment ensuring that a reduction in one’s cognitive ability does not automatically exclude them from participating (Sherratt, Soteriou, and Evans, 2007; Wilkinson, 2002). It is good practice for researchers to allow participants the right to withdraw (Reid, Ryan and Enderby, 2001). However, this may need to be time limited since once published the right to withdraw would not be possible (Smith *et al.* 2009).

Safety and risks to participants

It is important that the researcher ensures the safety of the participant at all times. Participants may become anxious, agitated or distressed due to the interview and the researcher must be experienced to note the signs of this. Pratt (2002) recommends the researcher have a question that allows the participant to reflect on how they feel, this allows the researcher to obtain feedback and amend the process should the participant highlight any issues (Pratt, 2002). It is important that the participant is able to withdraw at any time and is made aware of this (Allan, 2001). Reassurances must be made to the participant and relevant others that by opting out of the study will not affect them negatively (Cheston, Bender and Byatt, 2000).

Privacy

The participants' privacy must be maintained, before, during and after the research has been concluded. Participants should be made aware of how the information is to be collated, anonymised and stored and that access will be restricted. The Data Protection Act 1998 (DPA) applies to this type of research (Gray, 2009); therefore, DPA guideline must be followed.

The next section provides the detail of the procedures that were undertaken to conduct the study.

3.7 Procedure

Ethical Approval

Ethical approval was granted by Edinburgh Napier University (ENU) Faculty of Health, Life & Social Sciences Research Ethics and Governance Committee, prior to commencement of recruitment to the study. The application was received positively with no amendments

Further ethical approval was required from Alzheimer Scotland (AS). As the recruitment for the main focus of the research was through the Scottish Dementia Working Group (SDWG), I was asked by AS to complete their research ethics application. The application was agreed and the SDWG were approached.

Ethical approval to seek volunteers from social work was achieved following a presentation of the research to the Director of Social Work and the Senior Management Team, who were responsible for the ethical approval process with their department.

Sample Strategy

A sampling strategy for a qualitative research approach will differ immensely from a strategy applied to a quantitative study. Quantitative studies tend to require the researcher to develop a sampling frame that would be representative of the population as a whole (Gray, 2009). However, such a method of sampling would not be appropriate for qualitative research, particularly because methods of qualitative inquiry are aimed at exploring the experience of certain phenomena. It is, therefore, necessary that the sample of participants recruited include people who have been exposed to the said phenomena (Holloway and Wheeler, 2010).

Sampling

The study used purposeful sampling, which is a form of non-random sampling (Gray, 2009), and which enables the researcher to choose participants for the research due to specific factors in the research (Denscombe, 2007). The sample is selected for the purpose of gaining an understanding into the experiences being explored and is ‘consistent with the qualitative paradigm’ (Smith *et al.* 2009, p.48). This sampling approach is also consistent with IPA (Smith and Osborne, 2008), and other dementia research studies (Katsuno, 2005; Harris and Keady, 2009). Additionally, the sample must be linked to the criterion or criteria set by the researcher (Holloway and Wheeler, 2010). In the case of this research study, there were two criteria, one was the person must have a diagnosis of dementia and the second was that this must have been received before the age of 65.

Purposeful sampling was appropriate for this study since the participant group were required to have a diagnosis of dementia, and be under 65 at the time they received their diagnosis. It was also necessary for participants to have capacity and the ability to articulate their experiences. However, there are weaknesses to this sampling type. Although the participants had a diagnosis of dementia and were under 65 at the time of diagnosis, other demographics were not taken into account such as gender, work history or social class. Although it is recommended to choose a homogenous group (Smith *et al.* 2009), with similar characteristics this may not be possible due to the limitations of working with a minority group of service users, which was the case with this research study sample. It is suggested that factors such as social class, ethnicity and gender can affect the response to diagnosis and its management following diagnosis (Hulko, 2004); therefore, details on the participants’ core demographics were obtained at the time of the interview.

Recruitment

Following ethical approval from ENU, AS and the Local Authority, I progressed with the recruitment process. To recruit participants for the study I made contact with AS to approach them about accessing the SDWG, as mentioned above. The SDWG is an action group which is led by people with dementia for people with dementia, and they will agree to partake in research where they feel the research is meaningful and necessary for people with dementia. Written correspondence to AS requesting a meeting with the SDWG resulted in completing an application to AS ethics committee, where they made suggestions to amend the information sheet, and these were implemented. Once they had approved the study, access to the SDWG was provided.

Following approval, contact was made with the SDWG Coordinator. I was required to provide information about the study and the ethics approval from the ENU and AS before they would agree for attendance to present and ask for volunteers. The SDWG have their own research committee which is supported by an academic advisor, all of the members of the research committee have dementia. This procedure is necessary as the SDWG are inundated with requests from researchers, therefore they will only authorise access to research which they consider to be needed. There was a full majority support for the research from the SDWG, and I was then invited to attend the SDWG meetings to present the aim of the research study and request volunteers for participation.

I was nervous when I presented to the members of the SDWG. This was an unusual feeling for me as I am a confident presenter, but I was attending there as a student and not as a nurse or in my role as a professional. I was presenting to a group of people who were the experts in dementia, and I was not sure how they would react to my study or my request for volunteers. What if I could not answer their questions? What if they were not interested in the study or taking part? All these thoughts and questions were going through my head before I arrived at the centre, but also as I was presenting. I did not need to worry as I was made to feel extremely welcome, the members listened to what I was saying, and they asked questions. They were very supportive of the study and gave positive feedback. Their response helped me to feel confident in my role of student.

I have a lot of experience as a nurse and a commissioner, having worked with people living with dementia, but it was important that volunteers to the study and the members of the SDWG saw me as a student and not see me in my professional capacity. If I had presented as a nurse or a professional my presence may have been received a differently, not only when I presented but also during the interviews.

Two SDWG branch meetings were attended, one in Glasgow and one in Dundee, where I provided information to the group about study aims through a power point presentation, with a question and answer session, and an explanation that volunteers were being sought. Subsequently, I met with individuals who were interested in the study on a one to one basis and they were provided with information sheets **(Appendix 2)**. It was during the one to one sessions that I explained further about what would be involved should they agree to take part in the study. Those members of the SDWG who were interested in participating provided their contact details, some of whom were their significant others. It was important that potential participants were given some time to think about the study and their involvement, plus the need to discuss with their spouse or significant other.

Originally fourteen volunteers from the SDWG noted interest, but full recruitment to the study was met with difficulty when trying to re-establish contact. There were difficulties with following up the volunteers as some of the volunteers did not like the use of the telephone, and some did not use email. Some of the people who volunteered were at ease with using email correspondence, and interview dates were agreed through this method of correspondence. Three volunteers asked their significant others to communicate with me to arrange the interviews, and this was done through email correspondence and telephone calls. Two of the people who noted interest were initially contactable but then failed to respond to follow-up telephone calls. Three of those who noted interest were uncontactable despite various methods of communication. I also spoke with a number of participants' spouses to explain the study further and what would be involved.

Dates, times and venues were agreed via telephone call and email; these were confirmed by letter to the participant's home address or through email where that was the preferred method of confirmation.

Participants

Nine participants were fully recruited to the study, one of whom was not a member of the SDWG. However, the final number of participants who were involved with this study was eight, four male and four female, when one of the potential participants suffered a series of illnesses which prevented her from taking part. While each person recruited to the study had received a diagnosis of dementia at a younger age, they were from different areas of Scotland and they had different backgrounds and education attainment. Therefore, the case studies have a multi-perspectival approach, where the same phenomena is viewed from multi-perspectives, which helps ‘the IPA analyst to develop a more detailed and multifaceted account of that phenomenon’ (Smith *et al.* 2009, p.52). The table below (Table 6) provides information about the participants.

Table 6 Participant Information

Gender	Pseudonym	Age at diagnosis	Dementia Type	Working at time of diagnosis?	Member of SDWG?
Female	Jenny	57	Alzheimer's Disease - Posterior cortical atrophy (PCA) also known as Benson's syndrome	Yes	Yes
Male	Ray	59 (symptoms pre 55)	Small vessel disease, multi-infarct dementia	No	Yes
Male	Paul	59	Vascular dementia, Lewy Body dementia	Yes	Yes
Male	John	57	Vascular dementia	No	Yes
Male	Tom	59	Alzheimer's Disease	Yes	Yes
Male	Peter	57	Alzheimer's Disease	Yes	Yes
Female	Louise	53	Alzheimer's Disease, multi-infarct dementia and vascular dementia	Yes	Yes
Female	Sally	63	Unknown	No	No

Privacy

It was important to alert participants to the fact that although their personal information would be anonymised their words may be published (Smith *et al.* 2009). Since this research involved the participants expressing their personal experiences it was important that all data be anonymised. All participants' names were changed to protect their privacy. In order to ensure compliance with DPA (1998) all transcripts were stored on an encrypted memory stick and a computer that was password protected and only accessible by myself. All participant names were changed for the research in order to preserve anonymity.

Consent

The aim was that where possible all participants would provide informed consent themselves by establishing that they were able to understand the aims and objectives of the research and what their roles would be (Hubbard *et al.* 2003). In this current research, all participants were self- nominating, following a presentation to the group and through the SDWG approval process. The principles of informed consent were followed, and consent was not considered to be a once only act, the researcher observed for continued consent during the interviews.

All eight participants were able to provide their own consent to take part in the research. Prior to the interview commencing consent was agreed and the participant signed the consent form (**Appendix 3**). The participant was provided with information about the research and the interview questions before the interview taking place.

Data collection – Interviews

I utilised a semi–structure to the interview, this was very loose and the preference was towards a conversational approach, allowing the participant to talk about their lives and life with dementia.

Eight participants were interviewed and interviews lasted for approximately 60 minutes to 80 minutes. Four interviews were carried out at the person's own home, with four interviews conducted at resource centres, Alzheimer Scotland owned three of these and one was owned by the Local Authority. Participants were provided with the opportunity to have family or significant others present during the interview process, and two participants decided to have their family present at the time of the interview. One participant requested her support worker be present.

It is important that the interviewer builds a relationship with the interviewee as this can help when speaking about personal and sensitive information (Smith *et al.* 2009; Smith and Osborne, 2008). As I had already met seven of the participants before the interview took place and spoken with them individually I had already developed some rapport, which helped with the interview process. It was important that I gathered insight into the lives of the participants, and this information was provided in full as part of the interview without prompting the participants. Hearing more about the person, their families and their early lives helped to provide insight into their lives and further build the rapport needed.

I had developed an interview guide to aid the interview process and act as a framework. The main questions were around diagnosis, dementia, how they manage their days, keeping well and advice to others, with the aim to explore their experiences. A copy of the interview guide can be found in **Appendix 4.** Although I referred to the guide, rarely did I require use of the prompt questions that I had put into the schedule, as participants talked freely about their diagnosis, symptoms and life following diagnosis. I did occasionally ask additional questions which were generated from the responses to the questions in the guide, which is a form of probing or clarification of what has been said (Gray, 2009; Moule and Goodman, 2009).

I felt extremely privileged to be allowed to undertake the interviews with the participants who volunteered for the study. I was very nervous at the beginning of the first interview but I felt my confidence grow as the interviews progressed. Although I had a guide to assist with the interviews I did not really need it. All participants were so open about their lives and their experiences. They gave information about their private histories and they were expressive when speaking about their experience of living with dementia. I witnessed laughter, sadness, anger, outrage, as they spoke, but also happiness and postiveness. The interviews flowed freely, I felt that the participants wanted to tell their story, to share their experiences and I was humbled to have access to such deep and meaningful information.

After the first interview I felt elated, and this feeling never waned, as each interview gave me another insight and perspective on the experience of the participant's life with dementia. While I have worked with people with dementia as a practitioner and strategist, I learnt more from the participants who were able to find time to share their very deep and meaningful story and experiences of living with dementia.

The interviews were extremely humbling, the participants were very open and provided clear insight into their lives and how they lived with their diagnosis of dementia.

3.7.1 Data analysis

This study was conducted using a case by case approach which is an approach suited to IPA. The number of case studies in the sample was eight, this is deemed to be an appropriate sample for a study utilising IPA, where the aim is to retrieve rich accounts of each case. IPA studies are focused on retrieving rich data and in-depth analysis which would be inhibited by large data sets (Smith *et al.* 2009). The data analyses were consistent with IPA guidelines provided by Smith *et al.* (2009). The interview transcripts were transcribed verbatim as soon as possible following the interview. During this stage of transcription the initial data analysis began in line with best practice, which is to analyse data as it is gathered (Silverman 2005). In this case, the data were transcribed within seven days of the interview being conducted.

Transcribing the interviews from the audio tapes enabled me to become fully immersed in the data and provided further insights and nuances that were not noted during the time of the interview, or had been forgotten. This process also helped to further hear the voice of the participant when the written transcript was read. This process of listening to the audio and then reading the transcripts ensures that the researcher is focused on the participant and that they (the participant) remain central to the analysis (Smith *et al.* 2009).

It is important in an IPA study that each case is analysed individually, with the identification of themes, before moving on to the next case; therefore, I undertook each initial analysis independently. Each transcript was analysed prior to undertaking the next interview. Interviews were conducted over an eight month period and each transcript was analysed prior to the next interview being conducted enabling a case by case approach. The in depth analysis of the first case study provided interesting insights that were explored in the second case study and subsequent case studies.

The data analysis undertook a five step process. The data were analysed manually. The following section provides a detailed account of the analysis through the five stages.

Stage One - The first stage of analysis took place with the transcribing of the interview data. The data were transcribed into a Word document with two columns, one for the data and another for notes. The transcript was then read through quickly and notes were made in the column, but I found that I was not looking deep enough. To help become immersed and familiar with the content of the data, notes were made and words and phrases were underlined (Moule and Goodman, 2009). What I noticed when I was undertaking this exercise was a tendency to focus on the areas that I already knew about, such as the importance of diagnosis and issues regarding work. At this stage I was not looking at the data inquisitively or interpretively, not asking the data any questions, it was just being taken at face value. While this did not allow for the in-depth analysis required for interpreting the meaning of the data, it did enable the identification of what I was already aware of. In identifying what I knew through my insider knowledge I could then go back to the data and regard it inquisitively and with a clear view.

In this first stage I was not looking at the data inquisitively or interpretively, not asking the data any questions, it was just being taken at face value.

Reflecting on this I returned to the data to look deeper into what was being said, this then helped me to move on to initial noting.

Part of the process of IPA is to look for emergent themes, initially within each case (participant data) and subsequently across all cases. Peitkiewicz and Smith (2012) propose that during this stage the researcher work with their own notes; however, I felt it was necessary to work with the participant transcripts and the personal notes combined.

Stage two - the second step in IPA analysis and is the start of the in-depth analysis of the data which is time-consuming. It is during this phase, the researcher looks deeper into exploring the language and meaning of what the participant has said. It was, therefore, necessary to work with the data in a more inquisitive, analytical way. I created another Word document for each participant, with three columns, one for the transcript, for description and interpretation and one for the analytical interpretation. It was during this phase that I felt it necessary to begin questioning what the participant was saying. I reflected that the intensity of reading enabled further interpretation as to what the person was feeling or meaning and questioning the data (Gibbs, 2007).

While this study is an IPA approach, I chose to draw from other qualitative researchers' guidance to assist with delving deeper into the data. Questions such as: 'What is going on? What is the person saying? What do these actions and statements take for granted?' as suggested by Charmaz (2003, pp. 94-5). During this process I interpreted in my own words what the person was saying or meaning, making notes of the context, or why perhaps they were saying what they were saying, making some assumptions. In order to explore the data in more detail, it was necessary to consider language, metaphors, laughter and sadness. For instance, laughter may not always mean that the participants thought what they had experienced was funny or made them happy, it could be an expression of anger, frustration or cynicism.

Freewriting and memos were used to try and capture my thoughts and interpretation of the meaning of the experience. These are a useful tool which enables the researcher to be receptive of what comes to mind and allows the process to surface. This process is recommended as a way for exploratory noting and helps the researcher remain engaged with the data while further exploring to interpretive level (Smith *et al.* 2009). As part of the process it is necessary to remain aware of the impact, such as age, gender and social status, that I as the researcher may have had on the participant and how they, the participant, feels about the interview. This should be considered while reading and exploring the transcripts, being aware that a participant may say something that they think the researcher wants to hear (Pietkiewicz and Smith, 2012).

As I analysed each case line by line I described what I thought the person was saying/ experiencing and I wrote this into one column within the document that I had created; this was my interpretation of their experience. Within the document I also had a column where I wrote my analytical interpretations of what the person was saying. These analytical codes became the initial themes. An example of this is provided with Jenny, when she says:

> *I don't like to say it but inside of me I don't know whether I will be able to do it…you sort of think about it and think can I do that? Of course you can and then you come to do it you go I can' do that'*.

I described this in my own words as 'conflict when experiencing the challenge of being able to do something, Jenny has to talk herself round, and this suggests a loss of confidence'.

Analytically I interpreted this initially as Jenny questioning herself in regard to her own capability, and self-doubt. Reflecting on what this meant I asked the question to myself, 'does a diagnosis bring an expectation of inability?' And I identified an initial theme of loss of confidence in abilities to do things.

I continued with this process throughout the transcript and then looked for emergent themes that matched or contradicted. Comparing and contrasting these, first within the single case transcript, and subsequently across all the transcripts that had been analysed and coded. Although I was looking for patterns and connections, it was equally important to look for instances that contradicted, these are referred to as negative cases (Yardley, 2008)

As the data analysis progressed with each case, a similar process was undertaken with each transcript. I eventually had a word document for each case

Part of the process of IPA is to look for emergent themes, initially within each case (participant data) and subsequently across all cases. Peitkiewicz and Smith (2012) propose that during this stage the researcher work with their own notes; however, I felt it was necessary to work with the participant transcripts and the personal notes combined.

Third stage - When all interviews had been concluded and each case had been analysed and themes identified, the process of searching for connections across cases commenced in detail. Abstraction is the process whereby the researcher clusters those themes that are connected or have similarities in meanings. The researcher then interprets the meaning of the themes and gives it a new name which encapsulates the overarching meaning of the themes (Smith *et al.* 2009); this is then referred to as the superordinate theme. In this study there were initially five superordinate themes but these were reduced to four with further clustering of some of the themes. Smith *et al.* (2009) provide guidance on what to look for when looking for connections with themes, such as, cultural, temporal, narrative and functional components. Further, the researcher considers numeration, the frequency in the occurrence of the theme.

The third stage of analysis was to identify themes and connections within each case and across cases. The first stage in the process of identifying connections between the themes across all the cases was undertaken manually. I took all my analytical interpretations and I printed these off so that I could manually sort them into sub-themes, themes and potential super-ordinate themes, this was a very tangible process. Having the data in hand enabled me to sort through, compare and contrast those that were similar or dissimilar, those that were recurring, and those that were outliers (negative cases). Smith *et al.* (2009) suggest that although the researcher is concerned with identifying connections, they should also be aware of those that signify the opposite, they are still connected as they will be in the same theme, but the experience has been perceived differently by the participant (Smith *et al.* 2009).

Fourth stage - After I had completed the process above I returned to the transcripts and considered the themes that I had identified to check that these were grounded within the data. I then took chunks of data, linked to the themes, from each transcript which were similar or dissimilar, and placed these into a large word document.

The document had the themes in the right hand column with the data from each participant's transcript in the next column, identifying who said what and where it had been said. During this stage some of themes were disregarded, but having them on one sheet enabled accessibility and the ability to move them around and cluster them appropriately, looking for connections and considering how they connect. By clustering the excerpts of transcripts together in the document enabled the connections to be made. Working with the document in this way I was assured that the themes I had identified came from the data.

Once I had identified themes across all cases I then looked again to see if there were connections and links to the themes. By clustering the themes together where I interpreted similarities I created super-ordinate themes.

An example of this can be seen where I was able to cluster themes around, self-awareness. All participants were able to share their experience of living with dementia before receiving a diagnosis. I interpreted this as a period of discombobulation where participants were living in turmoil and chaos, and are together interpreted as the person experiencing life as 'living in a changing world'.

Fifth stage – Once I had identified the superordinate themes and the data to support these, I created a table of themes in an Excel document for each case, with the superordinate theme, themes and sub –themes in one column and the corresponding supporting data in another column, further ensuring that the themes came from the data. I then created a master table of themes where I inserted all the data from each case that supported the super-ordinate themes, themes and subthemes and created a table that identified the recurring themes within each case.

3.7.2 Secondary data analysis

Utilising Self-determination Theory – Basic Psychological Needs Theory, a secondary analysis was undertaken with the super-ordinate themes. This secondary analysis involved utilising the basic psychological needs of autonomy, competence and relatedness as a framework to assess how they related to the super-ordinate themes and sub-themes. I went through the findings and looked at each super-ordinate theme to see how they related to autonomy, competence and relatedness. Using the original findings, within the super-ordinate themes I was able to determine where the basic psychological needs were not being met (thwarted) and where they were supported. The findings of the secondary data analysis are provided in Table 10 at the end of the findings chapter (Chapter Five).

3.7.3 Trustworthiness

There has been much debate regarding qualitative research and how to determine high-quality research. The terms ‘rigour and validity’ are rejected by some qualitative researchers but favoured by others. These terms are deemed to be inappropriate for constructionist research since the term ‘rigour’ suggests that the research can be assessed exactly with precision and objectivity, and would go against the creativity and uniqueness of the interpretive paradigm (Polit and Beck, 2014).

Trustworthiness is considered to be more important than considerations of validity, reliability and rigour (Gray, 2009). There is, however, no standard approach or application quality indicators to assess the quality of qualitative research (Gray, 2009; Polit and Beck, 2014; Rolfe, 2006). However, Lincoln and Guba (1985) developed four criteria to attempt to set the standard to assist with the assessment of rigour and trustworthiness of qualitative research (Gray, 2009; Polit and Beck, 2014). These components are:

‘credibility, dependability, confirmability and transferability’ (Moule and Goodman, 2009, p. 188). Shenton (2004) provided the detail on how the researcher can identify how their study meets the four criteria, which can help to assure the quality of the research. These are based on Guba and Lincoln’s (1985) four criteria. This is helpful as it supports the researcher in identifying how they have ensured that their research meets the four criteria, particularly around credibility. These are now discussed in detail in relation to this research study.

3.7.4 Credibility

It is necessary that data which is presented to be credible in that it is a true representation of the research participants’ views and experiences (Moule and Goodman, 2009). Credibility can be determined by examination of the study design and the methods that were used to identify the findings (Gray, 2009). To promote confidence in the credibility the researcher should follow the process and procedures that have been determined to be appropriate in relation to the research aim and that have been successful in similar research studies (Shenton, 2004). This study followed an IPA approach and the processes devised Smith *et al.* (2009) were referred to. A full account of the process followed has been provided in this chapter in the sections above. Below provides detail on the process that ensured that the data remained credible.

Enabling participants to feel secure in the interview environment in the reassurance that what they say will remain confidential through anonymity allows the participants to speak freely and honestly about their experiences. Providing clear information about the research prior to consent and allowing the participants’ time to consider their involvement ensure that participants are willing to take part. Additionally, utilising the principles of informed consent where participants have the right to withdraw helps to ensure willing participants. In this study all the above were employed in order to ensure that the participant recounts of their experiences were credible.

Another method was debriefing through regular supervision with the supervisory team. These sessions allowed for scrutiny and questioning through a critical friend approach and feedback.

The credibility of the researcher is important and their ability to 'act as the research instrument' (Moule and Goodman, 2009, p.189). Shenton (2004), referring to Patton (1990), suggested the importance of the researcher's skill, competence, qualification and experience which will enable them to undertake the research. Throughout this research study I continued to develop my research skills. While not always able to attend research lectures due to work commitments and the part-time element of study, I explored and utilised other methods to grow and develop knowledge through online lectures, which I followed up with reading.

I have relevant qualifications in the subject of dementia and have worked with people with dementia and younger people with dementia. Further, I maintained a diary throughout the research which was used following the fieldwork to write notes, to record and reflect on supervision sessions, to write ideas and memos and to reflect on the process.

Credibility and negative cases

Including negative or deviant cases within the research adds to the credibility of the study. Including the deviant cases, and comparing these to those which are the norm within the research, helps to identify significant variances within the data, providing a deeper understanding of the phenomenon (Morse, 2015). Further, the presentation of such cases provides reassurance that the researcher has included all the data, not just data that is consistent with the researcher's view (Yardley, 2008).

Deviant cases or outliers were identified during the process of data analysis with each case and across each case. I found this process easier to do manually at stage three and repeated this at stage four as I progressed through data analysis. As I have insider knowledge of dementia it was important that I remained aware of these cases that perhaps did not confirm to the norm or my assumptions. Examples of deviant or negative cases can be identified in the findings chapter.

3.7.5 Dependability

A record of decision making has been maintained. It is necessary for the data to be dependable in order for it to be viewed as credible. Dependability is described as being similar to the process of reliability in quantitative studies (Moule and Goodman, 2009). Dependability means that the study findings are accurate, that readers of the research are able to follow the decision-making processes made by the researcher which will enable the readers to assess the adequacy of the analysis (Holloway and Wheeler, 2010). Dependability requires a clear audit trail which can act as a guide to readers and other researchers. It is accepted that qualitative research cannot be replicated, but where research is conducted using similar procedures and with similar criteria for participants it is possible that the study could be repeated (Holloway and Wheeler 2010).

Throughout the PhD process there has been regular supervision with the supervisory team. Decisions, thoughts and ideas have been discussed at the supervision session and records of the supervision were kept by the Director of Studies, at the start of the process. Formal reviews initially every twelve months and then six monthly, further formalised the decision-making processes and provide a record of the research progress and developments. These records can be used for audit purpose where necessary.

3.7.6 Confirmability

There is a clear audit trail to support this study. It is suggested that an audit on the decision making process, the method and the analysis will help provide some measure in regard to authenticity. This has been criticised since the researcher will influence the data analysis through their own interpretation, values and knowledge (Moule and Goodman, 2009). Holloway and Wheeler (2010) suggest that confirmability is confirmed when readers can trace the origins of the data.

This research has been subject to scrutiny through the formal review process where external supervisors to the supervisory team have provided an overview and direction. Throughout the study I have been required to submit a summary of my work to the review panel. At the review meetings the external member of the review team has read the work to date and then examined this through questioning the data, findings and decision making. I have always had extremely positive feedback from these reviews and always been able to provide a detailed account of the process and decision making verbally. It is suggested that the formal reviews have provided an audit through the research process.

Following the transcribing of the data, the transcripts were read independently by the supervisory team who clarified that they had identified similar potential themes from an initial reading of the transcripts.

3.7.7 Transferability

Transferability is used in qualitative research instead of generalisability, a term used in quantitative studies. It is necessary to show that there is potential for the research findings to be transferred from one situation to another (Moule and Goodman, 2009). In other words can the knowledge acquired in this research be transferred to another area (Holloway and Wheeler, 2010). Holloway and Wheeler (2010) suggest that there is little difference between transferability and generalisability.

To enable this transferability the researcher must provide a detailed description of the research process (Moule and Goodman, 2009). This chapter has provided a detailed description of the processes undertaken.

3.7.8 Reflexivity

Reflexivity was used to promote self-awareness and self-monitoring in relation to the research project (Polit and Beck, 2014). Reflexivity assists with providing some identification of transparency in regard to the decision making through the research process (Engward and Davis, 2015).

When undertaking this research it was helpful to keep a diary to aid reflexivity. The views of YPwD were not clear at the start of the research process, as the research available expressing these was minimal. At the outset I did not identify with YPwD having different needs or experiences to that of older people with dementia. Part of the reflexive process was to consider these views with the issues that were emerging through the data. For instance, I considered how the emergence of YPwD having a difference to that of older people with dementia was something that I had not necessarily thought about previous to this study. However, this was something that became apparent early on in the research process, it was overwhelming, although difficult initially to articulate.

As part of the reflexive process it was necessary to be self-aware, as a researcher it is necessary to understand what you bring to the research. I found it essential to consider this when undertaking the analysis of the data, to be aware of my age, values and knowledge when coding the data. What I identified early on was that I was drawn to the obvious issues relating to YPwD and deemed it necessary to clear my mind, become impartial and immerse myself in the data.

Keeping a reflexive diary was valuable in capturing some of the thoughts, feelings, emotions and self-development throughout the research process. I have reflected that as I developed and I became more confident in undertaking the research I found I was able to critique and enquire more into other literature. For example, when I went back to the literature as part of the discussion chapter, I found that I noticed more about the way the papers were written, the quality of the research and issues around this that perhaps had not been noticed previously. I have found that being reflexive enabled me to question and consider how the process was going, and identify the changes in myself developmentally.

3.8 Summary

This chapter commenced with consideration of the philosophical underpinnings that met my view of the world and reality and also identified with the aims of the research. I identified with the subjective ontology with a constructionist epistemological paradigm. The history of phenomenology was discussed with an overview of the dominant contributors, Husserl, Heidegger, Merleau-Ponty and Sartre. The chapter has identified how aspects of phenomenology link to Self-determination Theory, as discussed in Chapter Two, in relation to the basic psychological needs. The chapter then explored the theoretical underpinnings which are linked to the ontology and epistemology but also meet the aims of the research and the participants to the study.

Interpretive phenomenology was the theoretical perspective, which is rooted in hermeneutics and symbolic interactionism. An inductive qualitative approach was deemed appropriate given the exploratory nature of the research aim, and the minimal research currently in existence exploring the experiences of YPwD. Two qualitative methodologies were considered, grounded theory and IPA. Interpretive Phenomenological Analysis was preferred to grounded theory, because YPwD are a hard to reach group due to numbers, the aim of the research was to consider individual experience, the idiographic nature of IPA would allow for this. Additionally, the primary focus of IPA is to explore experiences, which was the aim of this research study.

The chapter has provided an overview of the research methods utilised to meet the aims of the study. Justification has been provided regarding the methodology of choice, ontology, epistemology and theoretical perspective through which the research was conducted. The method of data collection was interview. An IPA approach was deemed appropriate; analysis of the data was consistent with the IPA guidelines.

The second part of this chapter has provided detail of the research design and the process undertaken, providing a detailed account of the analysis which followed an IPA process. Further, an account of how trustworthiness has been maintained has been provided as an assurance to the credibility and dependability of the research and the findings.

4 Chapter 4 Case Stories

4.1 Introduction

This chapter provides the case stories of the eight participants who took part in this research study. An IPA approach was utilised to analyse the data, with an in-depth case by case analysis undertaken. The case stories present information about each participant and a summary of each of their experiences.

The case stories are presented with an outline of the participants' life and character, then follows an outline of their pre-diagnostic phase experience, the post-diagnostic phase experience and finally to living well-beyond dementia.

All names used are pseudonyms to protect the identity of the participants who took part in the study. The cases are presented in the same order as the interviews were conducted. Table 7 below provides a diagnostic overview of the participants.

Table 7 Participant information

Gender	Pseudonym	Age at diagnosis	Dementia Type	Working at time of diagnosis?	Member of SDWG?
Female	Jenny	57	Alzheimer's Disease - Posterior cortical atrophy (PCA) also known as Benson's syndrome	Yes	Yes
Male	Ray	59 (symptoms pre 55)	Small vessel disease, multi-infarct dementia	No	Yes
Male	Paul	59	Vascular dementia, Lewy Body dementia	Yes	Yes
Male	John	57	Vascular dementia	No	Yes
Male	Tom	59	Alzheimer's Disease	Yes	Yes
Male	Peter	57	Alzheimer's Disease	Yes	Yes
Female	Louise	53	Alzheimer's Disease, multi-infarct dementia and vascular dementia	Yes	Yes
Female	Sally	63	Unknown	No	No

4.2 Jenny's Story

Jenny was diagnosed with dementia at 57 but had developed symptoms sometime before her diagnosis. She has Posterior Cortical Atrophy (PCA), also known as Benson's Syndrome.

Jenny lives in a rural village in Scotland to which she moved following her diagnosis. She and her husband used to own a Bed & Breakfast (B&B) which they ran together. Jenny lives with her husband, who is her primary carer.

She has one son who lives in Scotland but he is not nearby. Her son had recently married and she was expecting her first grandchild within the next few months. She was very excited about the birth and facing up to becoming a granny. She is very dependent on her husband who takes care of everything, and she said that she does not need to worry about anything because she has her husband. They come across as being a close knit family. Jenny enjoys walking and reading and these are activities that they had always done together as a family. At the time of the interview Jenny presented as being comfortable with herself, happy and relaxed, with a good sense of humour. At the time that Jenny developed symptoms she and her husband were still running the B&B, but Jenny did not think that this had been a problem as her husband took care of the business. She was not worried about finances, or the future, and she came across as feeling secure. She enjoys living in a small village where people are friendly.

Pre-diagnosis

Jenny had been aware of her symptoms before her diagnosis was officially made. She did not know that it was dementia and had not been aware that dementia could be a diagnosis for younger people. She was aware of the changes in her abilities and capabilities and found herself in situations that were perhaps dangerous to her, awkward and embarrassing. She knew within herself there was something wrong.

Jenny's family were also aware of the changes which were taking place and while these changes did not impact on her relationships with her family, they remained concerned. However, it was only following a driving incident when Jenny's husband realised that something was not right and they agreed that she should no longer drive.

Jenny struggled to get a diagnosis and had other tests on her eyes, but that test was inconclusive and they found nothing wrong with her. It was not until her son visited with a friend, who was a medical student that they realised that she may have dementia. The friend suggested the name of a Consultant that she should visit and an appointment was arranged.

Post - Diagnosis

Jenny’s experience of diagnosis was a positive one. She was able to clearly recall the day as she talked about the concern they had about getting parked. Jenny was delighted and relieved to find out what was wrong with her, and that she was not in fact ‘going mad’. Although the diagnosis brought a sense of relief it also highlighted the changes and adjustments that were now required. Jenny had experienced a loss of confidence and trust in herself, and her abilities. She no longer felt that she was able to be spontaneous- to just do something. While she wanted to maintain her independence she initially thought that this was not possible because of her dementia diagnosis.

Post diagnosis Jenny experienced other changes in her life, she found herself easily fatigued which impacted on her cognitive abilities. She was offered the opportunity to attend day services with older people, but the idea of this horrified her. Jenny was clear in her perception that she was still young and not ready to be sitting around doing nothing.

Jenny accepted her dementia diagnosis and was aware that the condition would deteriorate, she preferred to view her condition as a ‘terminal illness’ but one that would not prevent her from looking to the future and living her life. She also referred to her illness as ‘this’ or ‘it’, keeping it in the abstract. In accepting this view of dementia Jenny explained that this was a different experience and lifestyle to that of an older person with dementia.

Jenny was able to disclose that she has dementia but explained that she is careful about who she tells, however, mostly people were supportive. She found it easy to explain her condition as she has the same diagnosis as Terry Pratchett, which people understand. She suggested that his openness about his dementia has helped her.

Living with dementia

Jenny looked forward to the future, becoming a granny and going to Australia. She was clear in her view that she still has a life to live, despite her dementia. The support of a family network has enabled Jenny to be as independent as possible and live her life. Although living with dementia is frustrating Jenny remained positive. It was important for Jenny to have things that she can do on her own. Her husband is her primary carer but ‘normalisation’ and doing things independently of her husband, were also important. Planning and organisation are an important aspect to assisting with independence. Jenny explained that she becomes frustrated when she can’t work something out, but that it was important for her to keep doing things, to remain positive. She explained how her part in supporting the Scottish Dementia Working Group (SDWG), enabled her to meet other people her age with dementia. Being part of this helped Jenny to share her experience and to feel supported by others with a similar condition. Jenny expressed the need for people (professionals) to listen to Younger People with Dementia (YPwD), to let them tell their story of what it is like to live with dementia so that services can be adapted to meet their very different needs.

4.3 Ray’s story

Ray was 59 when he finally received his diagnosis, but he had symptoms before the age of 55. His diagnosis is Small Vessel Disease and Multi-Infarct Dementia. Ray is married with two adult children. He worked as a clerk doing accounts and was in full time employment before his diagnosis. He had previously worked in a large psychiatric hospital and had seen people with dementia; this was when he was much younger.

Ray has a great sense of humour and he is a skilled photographer. He had always enjoyed photography, but never had the time to pursue this beforehand as he was busy working. He loves his family and enjoys reading, although he said at times he loses track of where he is. He is great raconteur and his humour always shines through.

Pre - Diagnosis

Ray's experiences before diagnosis were frightening**.** He did not know what was going on, and found himself not able to do simple tasks, such as count money which was his job. He became fearful and mistrustful of others. Because of the changes his family experienced a different Ray, he would swear at them, something that he had not done previously and he was aggressive. His wife and his young children were scared and frightened of this changed man. Ray's world had been turned upside down and his wife finally made the decision to seek advice from the family Doctor.

Post diagnosis

Ray found it difficult to get a true diagnosis and unfortunately he was misdiagnosed. However, eventually Ray was diagnosed with dementia but sadly this information was not shared with him but with his wife. Ray recounted how he experienced a change in his wife's behaviour towards him, but he was not aware why this was happening until he was eventually informed that he had dementia.

Ray was devastated by the diagnosis and he retreated into himself, experiencing a deep depression, he thought he was going to die and he was scared. Ray was ashamed of his diagnosis and did not want to share it with his children, nor would he venture outside for fear of ridicule. He cocooned himself within the four walls of his house. Ray experienced a number of negative feelings over the post diagnostic phase. He had heard of dementia and had seen people with dementia, but they were old people. He was scared that he would age and become like them and was unaware that younger people could get dementia.

Ray had to make changes to his life he had to stop driving and he lost his job. To this day, Ray recounted how devastated he was about losing his licence, and continues to experience a loss of independence and freedom at not being able to just jump in a car and go somewhere. Losing his job was also extremely difficult for Ray to accept, he had a young family and was the main earner. Ray felt that he was treated unfairly and that if there had been more awareness about younger onset dementia then he may have been able to continue to work, albeit in a different role. Eventually through the help of others Ray was coaxed out of the shell that he had built around him. He was taken to the SDWG. Initially he was cynical about attending and did not want to mix with people who had dementia, but from the minute he stepped outside and then into the group he changed. Ray started to accept his dementia, he began to see himself as Ray who lives with dementia, helped by meeting other people who were younger who have dementia.

Living with dementia

Once Ray accepted his diagnosis his life began to take a different course and he became an active member of the SDWG. With the assistance and support of others, including his family, Ray has been enabled and empowered to be independent and develop hobbies. Further, he developed the art of public speaking and has travelled across Europe to assist with widening the knowledge of dementia. He developed the confidence to assist other young people to come to terms with dementia, in telling his story others can relate, additionally he provides lectures to students and university. These are opportunities that he would never have experienced in his previous life. Ray does require the support of others to assist him in his pursuits to raise awareness and he is reliant on his wife and support worker. However, he is still confident to go off on his own around the City, but has developed strategies which enable him to maintain his independence. He is aware that he could get lost but is comfortable to ask for help should he need it.

4.4 Paul's Story

Paul was 59 when he received his diagnosis of Vascular Dementia and Lewy Body Dementia. Paul is a softly spoken, gentle, clever and bright man. Previously, he had worked in social care looking after people with dementia. In his early life he had been in the Forces. He has a daughter and a wife and a child from his previous marriage, and remains sad about his lack of contact with this child. Paul is extremely close to his daughter and his wife who is his primary carer. He has one grandson with whom he spends a lot of time. He recently got a dog, which he loves and finds great company. He had wanted a dementia dog but it was not possible because of the type of dementia that he has. He is keen to learn new skills and is involved in other research projects. He uses his iPhone to assist with navigation and reading. He is confident in himself and comes across as being very open and honest.

Pre-diagnosis

Paul's wife was the first to notice that Paul was experiencing challenges, although when Paul reflected on this he indicated that he had awareness that something was wrong. His wife noticed that he was not able to use the remote control, that he was holding it upside down and putting in the wrong numbers. He destroyed two microwaves by putting tins of soup in them. In time other devices also became difficult such as the computer, which in the past was an area in which he was proficient. Paul created strategies to enable him to find where he had put things, and he had safe places for his jewellery and watches and money, unfortunately he could not remember the safe place. As one of Paul's dementias is Lewy Body, he also started get hallucinations which were frightening. He would see little cats, people, complete strangers, sometimes people he knew; these people would poke fun at him.

Post-diagnosis

Paul's wife instigated the diagnosis process. He explained that he was very frightened by his diagnosis and for a long while he was not able to accept it. Although he had a good relationship with the Consultant he thought the Consultant had 'turned against him' because of the diagnosis. The Consultant told him that it was progressive and that it was terminal. Paul did not like the word 'terminal' and in order to cope with dementia he looks at life being terminal.

Following the diagnosis Paul took a year out, he described this as not knowing where he went. Then one day he looked at his wife and he told her that he had dementia. With his previous experience of working with people with dementia, he had insight into the condition but thought that it just affected older people. Paul had to retire from his job following his stroke and the onset of dementia, this saddened him as he really enjoyed working. Paul accessed services for older people but he became very distressed as the services did not meet his needs. He begged his wife not to send him back there and he then joined the SDWG. He was pleasantly surprised by the people he met there, so much so that when he went in he asked where the people with dementia were.

Paul commented on the loss of independence and freewill. He talked about the times that he used to spend in the attic and how this was important as this is where memories are. Paul eventually came to accept his dementia and he explains to others that he was frightened initially but that he is now content. Paul was keen to stress that he is not dementia, and needs to be seen for who is and what he has done.

Living with dementia

Paul became very involved with the SDWG and research. As part of another research project he was involved in doing a ‘blog’. From doing the blog he was given an honorary season ticket for his football team with ‘VIP’ treatment.

In order for Paul to manage throughout the day he needs to be organised through a process of planning. Without planning he would not know what is happening. He is reliant on others to help him with this. He has a very supportive family and it is important for him that they live a normal life, do normal things. He and his wife do something every day together, even if this just going to the supermarket. Paul talked about not looking like he has dementia and commented on how he has met lots of people with dementia and they look ‘normal’. He likes it when people say that he does not look like he has dementia.

4.5 John's Story

John received his diagnosis when he was 57, and has Vascular Dementia. John is a strong, solid man who is family oriented. He had recently retired from his job before his diagnosis so he said he did not have work issues or money issues. He is happy that his three children are all settled in their own lives. His wife is his primary carer. The family are very close and his children call him throughout the day to make sure that he is ok. He comes across as confident and able to take charge. Once a week he goes to the cinema with his children, this is something that they had done for years. He still enjoys playing bowls and he does this with his son. He has an opinion and he wants to make a difference for people with dementia, particularly younger people.

Pre-diagnosis

It was John's wife that noticed that something was wrong, when he could not remember how to switch on the computer, or he was sitting with the newspaper trying to read it upside down. John is emotional and embarrassed about some of the difficulties he experienced with his dementia, but he is not afraid to talk about this or tell the story how it is, he is very real. John started to get memory problems about three years before he received an actual diagnosis. He recalled his wife telling him to do things and him denying that she ever did. He did go to see his GP but was told that there was nothing wrong with him. When he reflected on this fact he says that he found that quite annoying. As his memory problems progressed his children started to notice too. He became slightly paranoid and thought that his family were making things up. John started to get worried about the memory problems and he was scared that he would go into a shop and walk out without paying for something. This was a significant issue for him because of his previous career.

Post diagnosis

Eventually John attended a specialist clinic where he was put through a memory test. He recalled the experience with agitation, remembering that he felt like he was being interrogated and eventually he refused to answer any more questions. He walked out of the clinic and all he had heard was that he had dementia, and that he only had six months live. He explained that he was given no information and his wife had to scour the internet to find out about dementia. At first John said that he did not know anything about dementia, but later he admitted that he had come across it in his job. Later he commented on the fact that he is young and this only happens to older people.

Following the diagnosis John retreated in to himself wondering what he was to do over the six months following his diagnosis. The literature that had been retrieved from google reaffirmed this death sentence, referring to dementia as being terminal which put him back further. John had already retired by the time he received his diagnosis and he was not concerned having to give up driving. John eventually accepted that he had dementia and although he was scared and fearful of disclosure he did begin to share his diagnosis with others. He found positive support from people that he disclosed to. John talked about not changing, that he is still him. He accepts that he has a problem with his memory but that he is still the same person.

Living with dementia

John was introduced to the SDWG and became an active member. He has learnt new skills, developed the art of public speaking, and helps others by sharing publicly what it is like to live with dementia. Being part of the group keeps him busy and he believes that this keeps his brain functioning. John commented on the fact that he does more now that he has ever done. John continues to keep active with his bowls and finds that he is still accepted by all his friends, who treat him ‘normally’. He knows that he does not have the same skills that he used to, and that he cannot play for as long as he used to be able to, but he continues to be motivated to play.

In order for John to live independently with his dementia he needs supports from others. His family play a key part in maintaining his independence as do his close friends. His family are very important to him and they continue to do things together and maintain a sense of normality. One of the things that

John looks forward to the most are the days when he goes out with his wife for a coffee, the normal things in life being the most important.

4.6 Tom's Story

Tom was 59 when he received his diagnosis, he has Alzheimer's disease. Tom is an amazing character; he is an artist and has a Doctorate in engineering. He is bright, intelligent, worldly and extremely interesting. He lives on his own and has a girlfriend who he sees regularly. He is incredibly independent and has lived with his dementia for eleven years. In his flat he is surrounded by his art work and his books. He is very articulate and easily explains his experiences of having dementia, living with dementia and coping with dementia. He was one of the early members of the action group, the SDWG, and played a very active role in getting dementia on the political agenda. Tom explained that he received a diagnosis following an admission to hospital, that he had been working very hard, he had a responsible position as an engineer and thought he had been stressed. When he was given the diagnosis he really could not make sense of it.

Pre-diagnosis

Tom was working extremely hard before he was diagnosed with dementia he ended up collapsing and being admitted to hospital. He had a high level job and he had put the symptoms that he was experiencing down to stress. Tom thought he was going to have a heart attack, and talked about feeling very tired prior to the admission and thought he had exhaustion or depression. He noticed that he was not able to concentrate on his work and that he was regularly making mistakes. Tom worked hard and thoroughly enjoyed his job, he talked about being fascinated by his work and considered that to be part of the problem.

Post-diagnosis

Tom's experience of diagnosis was extremely traumatic, he was just told he had dementia and at the same time he was also told that he would have to give up his job and stop driving. The Consultant Physician took his driving licence away there and then.

When Tom recalled his experience it was easy to sense the trauma that he had experienced. He became reclusive and withdrew into himself. With the assistance of a Community Psychiatric Nurse (CPN), Tom was able to come back and take an interest in life. Tom explained about the loss of confidence following diagnosis, that he was scared to do anything, the loss of spontaneity. Tom also talked about the fatigue and the tiredness which he had to live his life around. Tom did not go out of the house for around two years, but eventually he was persuaded by his CPN to go to the SDWG and he became an active member. Tom talked about not becoming dementia, not changing. While he accepts that he has dementia, he does not see why he has to change. He referred to dementia as ‘this dementia character’.

Living with dementia

Slowly Tom regained some of his previous confidence and he started to venture out. He created strategies to assist him, should he get stuck. He had a card with his name and address and he also took enough money to get a taxi home if he got lost. His involvement with the SDWG grew and he worked for other groups to raise money for mental health.

Tom has a supportive family and partner. He is keen to continue to be independent and stated that he will not accept services until it is clear that he can no longer be independent. He continues to do the things that he can. Normalisation is important for Tom and he talked about spending his day cooking a nice meal, having a glass of wine or going to an art exhibition. He is an avid painter and although he has experienced a change in his colour spectrum he continues to paint. Tom believes that the person with dementia is the expert, and that people with dementia need to be listened to and heard. Tom is confident in himself and not afraid to challenge those who think that they know better than the person with dementia.

4.7 Peter's Story

Peter was 57 when he received his diagnosis of Alzheimer's disease. Peter is a quiet and gentle man who comes across at times as being nervous and worried, but every now and then there is strength of feeling that comes through. He lives with his wife who is his primary carer. He has one son who also lives at home. Peter is very thankful of his wife and the care that she provides. He is aware that he forgets things and that he can repeat himself, and he knows that this must be extremely frustrating for her. They have a dog which he loves and he takes for walks. Peter was working when he developed symptoms of his dementia. He explained that he was fine until they changed the system and then he could no longer cope. He did not want to stay at work as he found it really stressful, so he took early retirement. Peter enjoys playing golf and he has a group of friends who he goes with once a week. His sense of humour comes through when he talks about his golf and his ability or inability to play. He feels strongly about early diagnosis and expresses the need for people not to be afraid, that to get a diagnosis is the best thing.

Pre-diagnosis

Peter was working before he received a diagnosis and did not really recall any signs and symptoms until there was a significant change at work. He did recall that moving from a paper based system to a computerised system confounded him. He remembered not being able to work the new system. It was at this time they realised that there was something wrong. Peter had also experienced problems with driving.

Peter was allocated a Community Psychiatric Nurse (CPN) and getting a diagnosis seemed to be through her, although Peter could remember seeing something about a memory clinic at the Doctor's surgery. Peter was able to recall that his CPN also organised a scan for him. Peter did not comment on the diagnostic experience, the main issue for him was the impact of the dementia on his ability to do his job.

Post -diagnosis

The biggest impact on Peter's life was the change in his ability to do his work. He reflected on how his employers were extremely supportive and tried to make reasonable adjustments to enable him to continue working. Ironically this caused Peter a lot of stress, he remembered that he felt that he was letting the team down and that he was putting pressure on them. He believed it was not fair on him, or the other staff in the team.

Peter is very reliant on his wife for his care and support needs and conscious of her need for respite from him. He explained that he has stayed in a residential home for short periods. While the home was for older people, he was satisfied with the care and support he received. However, when he talked about this he was more concerned about his wife getting a rest. Peter said that he knew very little about dementia, only that it was older people that had dementia.

Living with dementia

Peter had lost confidence in himself and would not just go and do anything spontaneously, he did go off once on his own and was able to get back, but he is now very cautious when he is doing something and ensures that he plans ahead. Peter joined the SDWG, and found this to be supportive, comforted by meeting other younger people with dementia and sharing experiences

Peter talked about the importance of remaining active and independent. An aid to independence was planning and structure, ensuring he knew what day it was and what he was doing that day. To assist with safety and independence Peter carries a card with identification. He continues to take the dog for walks and play golf. Peter is supported by others who know that he has dementia and they enable him to continue to play golf. Peter is a great advocate for early diagnosis and would urge people to get tested, and following a diagnosis he would urge people to tell others that they have dementia.

4.8 Louise's story

Louise was 53 when she received her diagnosis of Vascular Dementia and Multi-infarct Dementia and Alzheimer's disease. Louise lives alone in a small flat and has a dog and a cat for company. She also has a grown-up daughter who lives nearby, and a sister who cares for her at times. Louise is quite emotional but she comes across as being strong. She wants to keep focused and keep well, but she doubts herself a lot. She had been working before she received her diagnosis and had a responsible job with a staff group to manage. Louise maintains her independence by taking her dog for a walk. Her relationship with her sister and her daughter is very important to her. She is upset that she is not able to take care of her daughter as a mother should. She continues to have a sense of humour and although she gets angry with herself she has the ability to laugh at herself too.

Pre- diagnosis

Louise did not have a lengthy pre-diagnostic phase that she was able to recall. She talked about having a significant event where people thought she was drunk at work. She did not recollect any other symptoms before this event. However, this event was embarrassing and shameful. Louise can recall protesting that she was not drunk, and she sought reassurance from others on that day to confirm that she had not been drinking. She thinks this was when she had her first stroke. Clearly, this was an extremely distressing event and Louise referred to it many times throughout the first stage of the interview. She repeatedly said that people thought she was drunk, she said that she 'cried her eyes out'. Following this event she went to the Doctors and had to undergo a number of tests. Although Louise was not able to recall any real changes before the significant event she did have a faint recollection of forgetting to do important things at work.

Post- diagnosis

There was no lead in to her diagnosis and therefore it came as quite a shock when she was told that she had been having small strokes. There was an assumption from the Consultant Psychiatrist that Louise knew this information, but she was not prepared for the news. Louise had to give up work, because of the type of job that she had. She recalled that she had been forgetting to do things and that her job was stressful. She did not think that she would survive if she were to carry on working. Louise had to make a lot of changes following her diagnosis including moving into rented accommodation and having to sell her house because she could no longer afford the mortgage payments. Louise was quite reflective about this, thinking of the irony how we can’t wait for the time when we can leave work, and have nothing to do. Louise felt safe in her new flat, she knows the area well and people know her, so she was not afraid to go out and about. Louise was very accepting of her condition. She talked about her whole life changing but how she feels that her life has changed for the better; she had changed her whole lifestyle in regard to keeping well and eating well

Louise had some knowledge of dementia and remembered her grandmother having it. However, she referred to her gran’s dementia as ‘late dementia’. She reflected on how her dementia has changed her and that people had commented on how she was now a nicer person, more approachable. She said that because of her dementia she is more at ease with herself. She did not feel stressed in the same way as she used to, although she had other stresses in her life these were manageable. Although Louse is independent she received one to one support from a support worker. While one to one support should be more individualised, in Louise’s case it did not seem to be. Louise did not feel she was able to tell her support worker that she did not want to go out shopping all the time.

Louise talked about feeling tired and that her eyes become affected, her tiredness impacts on her energy and prevents her from doing things. Louise had lost confidence in herself and does not trust herself at times. Although she remains independent she described herself as being cautious, that she is conscious of her dementia. One of the ways that Louise seems to cope with her dementia diagnosis was using a form of rationalisation, reflecting on how she could have something worse. Louise talked about her dementia in the abstract, she referred to dementia as ‘it’ and ‘this’.

Living with dementia

Louise is pragmatic about her dementia accepting that she has dementia and that it will get worse. However, she is keen to live well with her dementia and in order to do this she had made changes to her lifestyle. Louise talked of the struggle of living with dementia having good days and bad days. On the day of the interview she was upset about leaving her key behind when she was out for a walk. She said this was because that is the kind of thing people expect you to do when you have dementia. She has a supportive family who visit her regularly, and feels her relationship with her daughter is much improved since she was diagnosed with dementia.

Louise goes out on her own with her dog, and finds this therapeutic. While she said that she is cautious she also talked about putting herself in danger, qualifying this by saying ‘who doesnae’. She felt safe where she lived, as people know her and they know she has dementia, therefore should she get stuck someone will help her. Louise is a member of the SDWG, and felt that she had made friends there and that is was a place where she was able to share experiences. While Louise said that she would disclose her diagnosis with people, she stated that it would only be to people who she trusted. Louise reports she still loves life and while at times she can feel down she can laugh about things. She said that it is necessary to remain positive and not dwell on things, to make the most of every day.

4.9 Sally’s story

Sally was 63 when she was diagnosed with dementia, although she was not too sure about her exact age at the time of the interview. Sally was not able to say what type of dementia she has. Sally lives in a small country town and has been a housewife all her life. She is a small, dainty, quiet woman, very unassuming. She has cared for her husband and her son, both who have mental health illnesses. Her son went to a top university down south but due to his mental health had to leave and come back home. She has another son who is married, and she has two grandchildren. She does not see as much of her grandchildren as she would like. Sally does not get much support at home as her husband does not understand her illness, and he is ill himself. She comes across as having an inner strength and being brave. She seems to be lonely but gets support from the day centre where she can be with other people who have dementia. She claims she is sad but it is not the dementia that is making her sad, but she could not say why she was sad.

Pre-diagnosis

Sally described her pre-diagnostic phase with a metaphor, saying that 'she fell into a black hole', that she had been out walking one day, near the High School and suddenly she fell into a black hole. She explained that she managed to get out of the black hole but it happened again as she turned the corner to go home. While she was able to recall this incident she also reflected that she most likely had experienced memory problems, and had been getting lost when she went out. Sally mentioned that she thought it was like any other illness and that it would go away, suggesting that she did not share her experiences initially with anyone. Sally was not able to say who initiated her getting a diagnosis

Post diagnosis

Sally was not able to recall whether she had received a diagnosis of dementia. She recounted that she had been to the Doctors and she had been given a lot of tests, and that she been seen by two Doctors. She was not able to recall what the Doctors had said following the tests that she had received, nor how she felt.

Sally was pragmatic about her diagnosis, she talked about having to accept it and make the best of it. Repeatedly Sally talked about 'it could be worse'. When asked what she meant by this she responded saying that she is fit, and can get around. She was aware that dementia is progressive, that it will get worse although she looked for confirmation and reassurance that this was the case. Sally also referred to her diagnosis in the abstract, using terms such as 'it' and 'this'.

There were things that annoyed Sally since developing dementia, mainly associated with her memory and forgetfulness. She had lost confidence to venture out alone for fear of getting lost. On occasion she said she has woken up in the morning and not known where she is.

Sally’s home life was not supportive as there were suggestions that she was subject to ridicule and intolerance of her inability to remember things. However, Sally does enjoy the support she receives from the two carers who visit daily and help her to get washed and dressed. They help her with her makeup and clothes on the day that she is attending the day service.

Living with dementia

It is clear from the way Sally talked that she values the day centre that she regularly attends. She explained that she does not have to watch what she is saying there, and that she will not be ridiculed if she can’t remember a word. While the service she accesses is for older people this does not faze her, the day service is her sanctuary, where she is able to meet other people with dementia, where she is able to feel normal. Sally continues to do all things that were important to her as a housewife. She said that she enjoys washing and ironing and is fastidious about clothes being clean. She worried about not being well presented and there were indications that she was concerned about not noticing if her clothes are not clean, because of her dementia. The process of washing and ironing gives her a sense of structure and order in her day. Sally is keen to remain positive, despite her personal challenges and her home life. She said that it was important to listen to people with dementia, try to understand them and what their situation is like. She was clear that unless you have dementia you really don’t know what it is like.

4.10 Summary

The case stories presented provide an insight into the participants’ personalities and their experience of living with dementia, before diagnosis, following diagnosis and beyond diagnosis. While their experiences were unique to them, there were clear links across the stories which have been interpreted in to four super-ordinate themes. The next chapter provides the detail of the super-ordinate themes which fit clearly in to four phases of transition from pre-diagnosis to living well beyond dementia.

5 Chapter 5 Findings

5.1 Introduction

This first part of this chapter provides a detailed account of the findings identified through an IPA approach. The chapter also provides a provides a section detailing of the findings in relation to the super-ordinate themes and Self-determination Theory.

Utilising APA an in-depth analysis was undertaken individually with each case which identified primary themes as laid out in Chapter 4. Each case was then further scrutinised to identify patterns and links across all cases. The analysis drew upon the lived experience from the participants' perspective, identifying experiences that were shared and therefore emergent themes, while also identifying themes that may have been unique and pertinent to one or more participant.

Four super-ordinate themes have been identified:

1. Living in a changing world
2. Anger and Relief
3. The challenge of learning to live with dementia as a younger person
4. Living well beyond dementia

As the analysis was being undertaken it was clear that each super-ordinate theme related to a phase of transition and with an impact on self. The superordinate themes are presented as a transition pathway following four phases:

1. Pre-diagnosis - changing self - discombobulation
2. Diagnosis - fragmented self -consideration
3. Post-diagnosis - evolving self- assimilation
4. Living well beyond dementia - consolidated self - consolidation

5.2 Superordinate Theme and sub- themes

A superordinate theme is:

> 'a construct which usually applies to each participant within a corpus but which can be manifest in different ways within the cases' (Smith *et al.* 2009, p.166)

Table 8 below details which participant's experiences contributed to each theme.

Table 8 Identification of superordinate themes

Identification of recurrent themes									
Super-ordinate themes	Jenny	Ray	Paul	John	Tom	Peter	Louise	Sally	Present in over half the sample
Living in a changing world	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Anger & Relief	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
The challenge of learning to live with dementia as a younger person	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Living well beyond dementia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

.

Table 9 below, presents the detail of the themes within the super-ordinate theme. Where possible the theme is described using a participant's words

Table 9 Group themes with four superordinate themes, themes & sub-themes

Superordinate theme	Themes & Subthemes
Living in a changing world Pre-diagnosis Changing self Discombobulation	• 'What the heck's wrong with me' • 'There's something wrong with you' • 'Thrashing about in the darkness ' • Embarrassment & shame

Anger and relief
Diagnosis
Fragmented self
Process of consideration
	• Diagnostic experience 'astonished and angry, very angry'
	• Reaction to diagnosis 'Very, very frightened & sense of relief'
	• Making sense of dementia as a younger person
	Sub –themes
	  • 'I thought it only happened to elderly people'
	  • 'How would people react?'
	  • 'People accepted me, we even joke about it'

The challenge of Learning to live with dementia as a younger person Post-diagnosis Evolving self Process of assimilation	• 'It's like curtains coming down' (stress & tiredness) • 'Stop work, stop driving, I still get upset going back to it' (loss, changes to independence) • 'I'm, here if you want to know how I am, I'll tell you' (being listened to and acknowledged) • 'Duck out of water' (diversification of needs) • 'Freedom, things that I feel I can't do unless someone helps me' • 'I don't see why I should change and become this dementia character'

Living well beyond dementia
Consolidated self
Process of consolidation
	• 'Eventually I went out and got lost' (risk taking)
	• Meaningful activity
	Sub-themes
	  • 'Changes in confidence, just because we kept on doing it' (rebuilding confidence and autonomy)
	  • 'You need to be allowed to do things to keep yourself okay'
	  • 'Learning new skills, the old skills that I have lost'
	  • Making a difference
	• There is life after dementia, it's a good life
	Sub-themes
	  • Coming to terms with the progressive illness
	  • Rationalisation
	  • Continuing family supports and maintaining relationships
	  • Building support networks and forming meaningful relationships.

The next section presents the detail of each super-ordinate theme and sub-themes drawing on the narrative from the participants.

5.3 Super-ordinate theme - Living in a changing world - Pre-diagnosis, changing self, discombobulation

This super-ordinate theme, living in a changing world, identifies awareness of the changing self, identifies how frightening it was for the participants who had been living with a clear sense of awareness that something was wrong, this is interpreted as discombobulation. The findings identified how they were trying to cope with changes but not able to understand why they were no longer able to undertake simple tasks, such as counting money, or driving the car. While they were aware that something was wrong, so were their relatives, who equally were trying to make sense of the changes. However, no one was talking about this, both parties were trying to cope independently or ignoring what was happening. During this phase the participants experienced feelings of ill-being through the distress and anxiety of not knowing what was wrong with them, these feelings are interpreted as discombobulation.

There are four themes related to this super-ordinate theme:

1. ‘What the heck’s wrong with me?’
2. ‘There’s something wrong with you’
3. ‘Thrashing about in the darkness’
4. Embarrassment and shame

The changes in the participants’ cognitive capacity impacted on their ability to perform simple tasks, thereby resulting in a loss of skill, confidence and resulting in a subjective questioning of themselves, indicating a cyclical pattern. They talked about their thoughts and processes, about how they tried to make sense of the changes, and then reflected on their loss of skill. There is a relationship between the two, the loss of cognitive ability transmits itself in the loss of functioning ability.

5.3.1 Theme- ‘What the heck’s wrong with me?’

This first theme, ‘What the heck’s wrong with me?’, within this superordinate theme, identifies the participants’ confusion and concern that was provoked because of the changes. This was expressed by Jenny who was able to clearly articulate her pre-diagnostic experience, when she recalled this period in her life she was expressive and sounded annoyed, not with herself but with the situation she was in:

> *‘What the heck's wrong with me, what's going on?...I would get in a muddle and before I got any treatment I was quite in a muddle*.. *I am not going mad, as you think, you know …You begin to think you are going mental, I am mad…I did not know if I should tell people, you know am I going mad… I had got to a point by then, I was really worried, what the heck’s wrong with me, what going on.’ (Jenny*)

The excerpt above clearly identifies how Jenny experienced the world before she was able to get a diagnosis. While all participants experienced changes that they could not make sense of, each of these experiences were very different. For example, Sally used a metaphor to describe her experience of not knowing where she was:

> *‘I was walking in the High School and I was walking in the road and I just suddenly fell into this big black hole. So I must have managed to get out of there and then I went further on into the home and just at the back corner I fell into another big black hole.’ (Sally)*

John recounted his awareness of his memory impairment which was a major worry for him, firstly because he could not remember what he had been asked to do, this lead to him becoming mistrustful of his family, secondly, he was concerned about the potential of walking out of a shop and not paying for something:

> *‘Memory problems were getting worse cos then my wife was telling me do something I said you never said it and my son or daughter would say yes mum did say it…Certain things, going to the shops and walking out with nothing I don’t know why I walked out of the shop and I am saying “did I take anything”?' (John)*

The reason this was a concern for John was because of his profession prior to retiring, he did not want to commit a criminal act or be accused of doing such a thing when in the past his role had been to uphold the law.

5.3.2 Theme - 'There's something wrong with you'

This second theme, 'there's something wrong with you', linked to the participants' and their respective family's awareness of change. Five participants commented on how their partners or other family members were aware that there were changes in their abilities. It was clear that in some cases this caused friction in the relationship and one participant , Ray, explained how the changes in his behaviour impacted on his wife and children, so much so that she was about to leave him:

> *'It was a very unpleasant time at home* [because of the way I was changing]*. My wife was going to leave me, in fact she was looking for somewhere else to go, it was only once I got a diagnosis that everything became clear that I was ill ... Being the good wife that she was she stayed and she is still here...my wife was going to leave me, in fact she was looking for somewhere else to go.' (Ray)*

While participants were aware that their partners were noticing the changes there did not appear to have been any discussion around what was going on. In Ray's case his wife was going to leave, because she could not live with his changed behaviour. It is perhaps the age of the participants and the lack of awareness about dementia affecting younger people, which resulted in a failure to alert the person that something was wrong with the person.

Jenny's family were also aware that there were changes in her functioning:

> '*You know, and um my son's friend said…..I know exactly what's wrong with your mum I've had a lecture off Mr Smith in, uh, um….. So that was then and Gerrard said don't drive anymore, we don't, there is something wrong with you…. Family started to notice, family they were worried and they were talking.' (Jenny)*

Jenny's statement about her family being worried and talking suggests that they were talking to each other about their worries, but not necessarily discussing these with her. She herself said that she did not tell others about her thoughts of going mad, although these thoughts remained in her head.

One participant, Sally, was not able to say whether her family had noticed the changes in her, but she assumed that there would have been awareness:

> '*I don't know… I mean folk are bound to notice that something's wrong, I mean if folk are a bit doolally.' (Sally)*

Although Sally said that she did not think that her family were aware, she then contradicted the statement by saying that people would notice if you are acting differently. Sally's family life was very different from the other participants, and the statement by Sally is perhaps indicative of her unsupportive family, due to their own mental health problem. She does however display an awareness of dementia and the fact that it changes cognitive abilities and behaviours.

5.3.3 Theme- 'Thrashing about in the darkness'

This third theme, 'thrashing about in the darkness', provides insight in to the frustration that was experienced by participants in regard to their inability to function. This theme differs from the first theme, 'what the heck's wrong with me', in that here the participants are frustrated because of their loss of skills in regard to tasks and abilities, compared to the cognitive awareness (psychological) that something was wrong. This theme identifies the physical and social impact following the onset of dementia. Although participants had diminished cognitive abilities they were fully aware that they were not able to perform routine tasks. Three participants were able to recall their initial loss of skills, and their experience of this. Simple tasks that they had performed since childhood, such as adding and subtracting, became impossible. These symptoms did not tend to present instantly but almost insidiously, therefore, there was no real tangible or visible illness or condition that they, or their significant others, could identify with and relate changes to.

Ray provided an example of his inability to perform simple tasks, and how this created frustration and anxiety:

> *'I was just thrashing about in the darkness, why can't I do this you know?…The things you have done all your life, now I can't do this. Why can't I count money? Money was the first thing that happened.' (Ray)*

Ray had previously worked in a bank, so he needed to be able to count money; ironically this was the first thing that he noticed he was no longer able to do. Using personification Ray was able to provide a clear insight into his experiences during this period of his life. The way Ray described his experience enabled the researcher to visualise his world, imagining how he felt in a world not knowing what was happening and trying to make sense of it. The use of the word 'thrashing' suggests that he was trying to find a reason, trying to understand but not able to do so. Ray appeared to experience this with agitation and frenzy

Further examples of the loss of skills and the frustration that this brought are provided by John:

> *'That was frustrating for me because it was something I should have been able to do. How do you put the laptop on, how do you get it started, and it just went away from me.' (John)*

Not only does John's example provide insight into the frustration at not being able to perform a simple task, but the abruptness at which he lost this skill. When John says, *'it just went away from me'*, this is interpreted as the inability to perform the task suddenly. So while the nature of the changes were insidious as a whole, there was an abruptness at the loss of function with certain tasks. It is suggested that this and the normal simplicity of the actions required to perform the task caused frustration. The impact of the loss of ability leads to the subjective awareness and questioning, described in the theme above.

5.3.4 Theme- Embarrassment and shame

This fourth and final theme, embarrassment and shame, is about the experiences by the participants when in public situations. It is suggested that this is not necessarily linked to the awareness of loss of cognitive ability but is more the result of exposure to others. Three participants, Jenny, Louise and John, recalled events that were pertinent to them during the period before diagnosis. While it could be that the embarrassment was a result of the reaction of others, it is interpreted as stemming from an awareness or insight on the part of the participants about how they were presenting to others. They were trying to function ‘normally’ in the social world but they were aware of their struggle to do so.

The example presented below is from Jenny from a social situation that she recalled where her memory failed her. In order to hide this Jenny created a strategy:

> *‘I can remember things, like I can remember that Christmas, relative's friends, they came down for drinks and she asked would you like a coffee, would you like..? I was thinking of having a coffee. It was morning but the time she had gone round the list [the last] was a glass of wine, which I didn't want and of course everybody looked at me as if I was a bit off, so quietly I put it behind [the sofa] and thought I don't want it anyway.’ (Jenny)*

In this example Jenny explained that she could not remember the list of drinks, so she asked for the last drink that was offered, a technique that may have worked, if it had not been early in the morning and the last drink had not been alcoholic. Jenny was fully aware that everyone thought her request was strange, and she also understood why this would be viewed as strange. It is suggested that Jenny was embarrassed because she had exposed herself and her memory problem, which she had tried to hide by using the strategy of choosing the last drink on offer. She then felt shame because the drink was alcoholic which was inappropriate due to the time of day. In order for her to take some control and to manage the situation she hid the drink surreptitiously and made the statement that she didn’t want it any way.

It is clear from Jenny’s example that social situations are difficult and that she felt completely exposed because of her memory and her inability to remember a short list. Another example of an embarrassing situation brought on by the unknown symptoms of dementia was provided by Louise:

> *‘I remember being in work and seemingly something was wrong and I was slurring my words, seemingly. I went home and I was crying to my ex-husband cos on my way home I popped in, and he said just go home and go to bed, let me smell your breath and he said you've not been drinking.’ (Louise)*

Louise had presented as, and was accused of, being drunk at work, and because of her alleged drunken behaviour she was sent home. Louise mentioned the situation more than once throughout the interview, suggesting that she continued to be distressed about being accused of being drunk. Later in the interview Louise referred to her old behaviours and habits mentioning that she used to like to take a drink. There are perhaps reasons for Louise’s embarrassment in this situation, one being the accusation of being drunk at work due to her past history, secondly Louise did not know what was going on, or what was wrong with her. She knew that she felt strange but did not know why; people thought she was drunk and she was not able to defend herself against the accusations. In seeking reassurance from her husband, she was perhaps questioning herself as she was not able to make sense of the situation.

5.3.5 Summary

This superordinate theme, living in a changing world, is situated prior to diagnosis where participants were living in their world with a changed sense of reality. They tried to make sense of their changes but were fearful that they were going mad. They identified with the changes in their functioning but tried to manage these through strategies they developed at work and in social situations. This period was extremely stressful and anxiety provoking. These feelings can be described as discombobulation, and impacted on their well-being. Despite their awareness and their families’ awareness of the changes they did not confide in anyone.

5.4 Super-ordinate theme - Anger and relief - Diagnosis, fragmented self, consideration

This super-ordinate theme, anger and relief, identifies how at this phase the diagnosis impacted on the person. The way the diagnosis was delivered is one important aspect and this influenced the way the diagnosis was accepted. The diagnosis shattered the participants, creating feelings of fragmentation and further impacted on well-being. The phase identifies the immediate reaction to diagnosis, and then how the participants transition through a process of consideration where they try and make sense of a diagnosis of dementia as a younger person. There are three themes, and three subthemes linked to the theme making sense of dementia as a younger person. The three themes are:

1. 'Astonished and angry, very angry'
2. 'Very, very frightened' and 'sense of relief'
3. Making sense of dementia as a younger person

5.4.1 Theme - 'Astonished and angry, very angry'

The first theme in the superordinate theme 'astonished and angry, very angry', provides insight into the way the diagnosis was received by the participants, and suggests the time it took to reach acceptance was dependent on the way they experienced the diagnostic delivery. Four of the participants had a bad experience while three accepted their diagnosis with some immediacy. The examples provided below demonstrate how a poor experience can impact detrimentally on the participant's well-being.

Paul described his experience as being negative, resulting in anger and astonishment:

> '*Ummm, I was very frightened when I got the diagnosis…I refused to believe that I had dementia…Stunned absolutely stunned and I had a very good relationship with the consultant then and I thought she had turned against me and I took it very personally. I told her the word dementia was not appropriate... Her only answer to that was it was progressive and she said once you accept that it is terminal you will*

> *come to terms with it. I just did not want to know... I was ummm astonished and angry, very angry.' (Paul)*

Paul knew his physician well prior to being given the diagnosis, therefore he had a relationship with her. Consequently, he was upset with several issues, particularly that he did not like the word dementia. Paul felt that this was an inappropriate term for his illness as he considered himself to be too young. He had an understanding of dementia due to his profession, which is perhaps why he thought it was inappropriate. While he did have knowledge of dementia he was not aware of younger onset dementia. Other terms that upset Paul were 'progressive' and 'terminal'. While dementia is a progressive condition, it is perhaps too much for the person to take in at the time of diagnosis.

John's experience was equally traumatic and the excerpt below provides an example of the sense of the indignation he felt at the time of his diagnosis:

> *' [I] was there for an hour, the person talked to me, asked me about objects adding up…ummm I had to give an answer back to each question she actually gave me. Umm I actually didn't know if I was right or wrong she never said to me, but after umm the hour I just said I'm not going to answer any more of your questions I feel like I am being grilled. That's what it felt like to me and because I had worked in the police I said enough, enough. She said to me, and my wife and daughter were out in the waiting room which is ridiculous because she could have eased me right enough... what the doctor said to me was umm there's no cure for vascular dementia, there's no medication for vascular dementia, come back and see me in 6 months' time... [I] walked out the door, walked past my wife and daughter...I said I've only got 6 months to live.' (John)*

John's example provides insight on the way the tests can impact on the person. He wanted to know whether he was getting the answers right; additionally, there was a lack of communication as he did not seem to know what the doctor was testing him for. He related the questioning as being similar to that of interrogation, perhaps reminiscent of his professional experience. Furthermore, John was alone in the room, despite the fact that his wife and daughter accompanied him to the appointment they were not invited into the room to support him. John was so incensed by the experience that he was not able to focus on what was being said to him and believed that he only had six months to live. It is clear that John's experience of the situation was poor. One way to improve this situation for John would have been to invite his wife into the room to support him. Additionally, taking time to explain the diagnostic process would help the person to understand what was happening and why.

The account recalled by Tom was not dissimilar to John's. In this case there was no precedent into his diagnosis, and no time to prepare. He was in a hospital bed when two physicians arrived at his bedside and took him by surprise:

> '*uhh he was just saying a bit of bad news for you, and I was still thinking oh I am tired I need a bypass [heart operation], something daft, and he says well you've got dementia and all I could [think] was hell what's dementia. He went on to explain it and I said well I don't feel anything. He said well you're going to have to stop work, stop driving; I still get upset going back to it.' (Tom)*

It was clear from Tom's statement that he did not know what dementia was, and the manner in which he was told was harsh. Although Tom was aware that something was wrong him, he was not prepared for a diagnosis of dementia. Tom's statement, that he did not feel ill suggests that he could not take on board the seriousness of the diagnosis; therefore, it was difficult for him to accept what he was being told. There is another element to Tom's diagnostic experience, in the same period of time that he was being told that he had dementia, he was also told that he had to make dramatic changes to his life, such as giving up work and giving up his driving licence. This was not an uncommon finding in the experiences of the participants, where suddenly they had to make life changing decisions about work, home and freedom to travel. It was clear that Tom's experience was very upsetting.

5.4.2 Theme - 'Very, very frightened' and 'sense of relief'

This second theme, 'very, very frightened' and 'sense of relief', considers the impact of diagnosis on the person and demonstrates a connection between the way diagnosis is delivered and the impact this has on health, well-being and recovery. The examples provided in this theme illustrate how participants were affected where they had a positive diagnostic experience and a poor diagnostic experience.

There was an example of a positive diagnostic experience from Jenny, where rather than experiencing feelings of anger and fear, she felt relief and validated as it put everything into perspective. However, Jenny also reported that the Physician spent time with her, which would appear to be an important element:

> '*I was lucky because this consultant… I got to have everything possibly, could be one and three quarter hours whereas she had 2 mins [friend]...He did all these tests, gave me every test. But the first thing he said was that he had never seen anybody as bad as you , that makes you feel, ha ha.' (Jenny)*

When Jenny spoke about her experience she sounded happy and excited. She recalled the day of diagnosis with clarity and remembered that it was the same day as the Tsunami. She realised that her diagnostic experience was very different to others as she had a friend who also had younger onset dementia. Jenny reflected on the time taken to provide her diagnosis. It was also important that she was given a variety of tests. She appeared to be content that her dementia symptoms were classed as severe. This is perhaps because she was very distressed prior to the diagnosis, wondering what was wrong with her, thinking that she was going mad.

The experiences identified here suggest that the person who is responsible for providing the diagnosis needs to be cognisant of the power they have, and how they can influence how this is received and accepted. The examples provided demonstrate the way the person experiences the diagnosis and the potential this has to impact on their well-being and their acceptance of the diagnosis.

It is interesting to note that there was a difference between the genders in the way they talked about their diagnostic experience. While Jenny was the only female to have an exceptional experience, both Louise and Sally appear to have not focused on the event compared to four male participants.

The example of Jenny’s experience post diagnosis is interpreted as being one of relief. Jenny was pleased to find out what was wrong with her:

> ‘*Someone knows there is something wrong with me... He was one of these people who tell you straight ...Sense of relief, I am not going mad, as you think you know, and you do feel I think, yes, knowing your diagnosis. Not knowing was much worse but once I knew [I] even almost felt it wouldn’t have mattered if they said it’s going to be really hard for you for the rest of your life, I have to deal with it.’ (Jenny)*

She accepted the diagnosis without question. Jenny’s fear that she was going mad was diminished as the diagnosis provided clarity of why she had been experiencing difficulties in her daily life. Just knowing enabled Jenny to move on and deal with things and she received the diagnosis positively. There is a stark contrast to how Paul reacted to his diagnosis compared to Jenny:

> *‘Very, very frightened, did not accept diagnosis… I was frightened… I took a year out, I don’t know where I went, I took 12 months to accept.’ (Paul)*

Paul was so alarmed by his diagnosis that he was not able to function and he entered a void of depression. Ray, Tom and Paul experienced similar reactions to their diagnosis, shutting themselves away and hiding from the world for a period of time.

Further, where people had a prior knowledge of dementia this had a different impact on diagnosis. Paul and Ray had previous knowledge of dementia, and the example below from Ray distinguishes how previous knowledge of dementia impacted on his ability to accept his diagnosis:

> ‘*Because my previous experience having seen [people with dementia] I thought I was going to be like that any day now, so I retreated into the house, shut the door and closed the curtains and stayed there for about 6 months.’ (Ray)*

Ray was drawing on his previous experience of dementia where he observed people in the later stages of the condition. He was frightened and scared and thought that within a few months he would be bed ridden, unable to do anything for himself, with no recognition of his family. People will interpret information, based on what they already know, no matter how limited that information is.

Having a diagnosis of dementia was an uneasy experience for the participants. However, regardless of the discomfort experienced at the time, participants confirmed the importance of getting that diagnosis. All the participants were keen to endorse the need for early diagnosis. A diagnosis, despite how this was provided or acknowledged, ultimately brought a sense of relief, which appears a little contradictory given the person is being told they have dementia. Despite this, it provided participants with verification and validation that something was wrong with them and that something had a name. It helped to alleviate the feelings of anxiety and reassured them that they are not going mad. Peter's comments, similar to Jenny's above, emphasise this:

> *'The person who is ill, that old story, when the person gets told, thank god for that, I thought I was going mad…You think you are going mad…' (Peter)*

The quote below is from John who was extremely concerned as he believed there was reluctance from clinicians to diagnose people who were presenting symptoms under the age 65:

> *'I don't care, I've heard the pros and nots [not to diagnose] and I'm one of these, you are better knowing what you have rather than not knowing. That one about not knowing it's kind of strange... I mean I' m saying of course you want to know. I mean that's me I would want to know. At least I had a diagnosis, I didn't know what it was but... Ok it took me long enough to get settled with it, but once you've got [it] in your head I can't sit here and mope I need to do something, I've got to get out and do something. I'm that kind of person...they shouldn't be saying your too young.' (John)*

While John took time to come to terms with his diagnosis, he was clear that it was important to receive a timely diagnosis. Peter was also keen to express the importance of diagnosis:

> *'You've got to encourage people to realise to ask for it. Don't be afraid to ask. It might not be anything at all. None of these things are easy. Definitely important to get a diagnosis, no matter what age. I*

> *think that was very good. I think diagnosis is very important, you get a diagnosis then you know that's it.' (Peter)*

The example provided above reiterates and strengthens the need for an early diagnosis. Peter also touches on this, when he, like Jenny above, made the statement about going mad. Having the diagnosis enabled the participants to deal with and manage the situation, Peter expressed this when he said '*then you know that's it'*. Despite some negative diagnostic experience, participants were all relieved to find out what was wrong with them. All participants were aware that the world was changing for them, that they were finding it difficult to understand their environment and the people in it. Getting a diagnosis enabled the person to start making sense of the changes that were happening.

5.4.3 Theme - making sense of dementia as a younger person

This third and final theme, making sense of dementia as a younger person, provides insight into how the diagnosis was processed and how participants finally accepted their diagnosis through a process of consideration. Participants were clearly shocked by their diagnosis and only related dementia to older people. Participants were scared of telling people that they had dementia and some of them wanted to hide it away; however, when they did tell people about their dementia they found they were accepted as themselves. There are three sub-themes within this theme:

1. 'I thought it only happened to elderly people'
2. 'How would people react?'
3. 'People accepted me, we even joke about it'

5.4.3.1 Sub-theme - 'I thought it only happened to elderly people'

Part of the consideration process was identifying with dementia. Participants either gained knowledge about dementia following their diagnosis, or they had some previous knowledge of dementia. What was apparent was that none had knowledge of the potential to have a diagnosis of dementia at such a young age, this added to their concerns as they were being diagnosed with a condition they perceived was related to an older person. Participants were able to distinguish between older and younger dementia. There were examples in the data of compartmentalisation, where participants were able to talk about dementia, but did not associate themselves with older person's dementia. This was indicated by Jenny who referring to her father-in-law, who has dementia, she made the statement:

> '*But it's just like elderly dementia' (Jenny)*

When Jenny spoke about her father-in-law she seemed quite accepting that he had dementia. She did not really relate his dementia to her own diagnosis. It was as if he had something different to her, it was not as if she was in denial about having dementia, it was almost as if her dementia was a 'special' type of dementia. Her tone, when speaking about her father in law's dementia was almost dismissive. Similarly, John's view of dementia was that it was just older people who got it, and it was predominantly about poor memory, being forgetful and deteriorating physically:

> *'I did know what dementia was… I thought this only happened to elderly people.' (John)*

It was clear that the participants did have knowledge, or experience of dementia, but they saw their experience of dementia as being a very different experience to that of an older person with dementia. It would appear that to them a diagnosis of dementia at an older age is acceptable. The participants were also keen to ensure that in accepting that they have dementia, they did not lose their identity of age. The example below indicates the need to ensure that YPwD are acknowledged as a minority group in regard to dementia and references for YPwD being seen in your own right:

> *'I thought this only happened to elderly people. I said I'm young and I found that when I was looking at booklets and on the picture it was an elderly man or elderly woman that really annoys me because I was 57 at the time and I'm saying these people are in their 70's. I'm saying why I have got it when I am only 57.' (John)*

John expressed his annoyance that the only information available to him at the time of his diagnosis related to older people. There was a sense of unfairness and despair where he questioned why he had developed dementia at the age of 57. It is as if the information booklets were adding further ‘insult to injury’, reinforcing the fact that dementia is predominantly an older person’s disease. Paul was also of the view that dementia in younger people needs to be considered differently, that getting that diagnosis impacts on the person because of their age:

> *‘Please consider when somebody is only 60 they are not naturally what you would call a pensioner because that is 65 and I took very badly to that.’ (Paul)*

These statements provide insight into how John and Paul see themselves as being different to that of an older person. Paul acknowledged that he has dementia, but he was concerned about being considered an older person because of this. He indicated that dementia is synonymous with old age and references that a pensioner is someone who is over 65. His emotional response to being classed as an older person was understandably negative, indicating that coping with dementia is one thing, but suddenly being classed as an older person because of such a diagnosis is another impact on identity.

Both John and Paul talked about the emotion they felt following the diagnosis. In Paul’s case he was annoyed because he was being classed as an older person. Similarly, John’s emotional response is annoyance to the literature depicting older people, therefore reinforcing the fact that it is older people who get dementia.

5.4.3.2 Sub –theme- ‘How would people react?’- Self-stigma

The participants were ashamed to say they had dementia, and one participant, Ray, would not share this with his family. They wanted to hide away from the world because they thought that if they went outside they would be the subject of ridicule laughed or pointed at, because they had dementia. They were resistant to meeting other people because they did not want to be associated with dementia. The stigma associated with dementia was evident with Ray who would not leave the house following his diagnosis:

> ‘*Well, getting out of the house, because I was frightened, first of all the stigma attached to dementia, how would people react? Would kids in the street shout at you? uuhhh … Apart from things like change [using money in shop], uhh not forgetting the names of things in shops. How would people treat you?’ (Ray)*

Following diagnosis Ray was worried about going out and being recognised as a person with dementia. Ray mentioned the stigma associated with dementia, but equally he was concerned about the reactions from others through his behaviour and inability to manage normal tasks. It is interesting that following the diagnosis there is an anxiety once they are in receipt of the knowledge that they have dementia, yet during the pre-diagnostic phase it was the not knowing that created the anxiety and fear. Ray explained further the connotations around the word dementia in this very short statement:

> ‘*It's just the word [dementia].*’ *(Ray)*

Further, Ray did not tell his children that he had dementia for fear of his children being ridiculed:

> ‘*We weren’t open with the diagnosis because I was frightened they would get bullied cos they would say your father’s daft.’ (Ray)*

Ray explained that taking his first steps outside was a major turning point in improving his quality of life because of his fear of ridicule from others:

> *‘Improved by taking that first step outside the house, cos you know you thought everybody would be looking at you and pointing and saying you’ve got dementia.’ (Ray)*

The self-stigmatisation manifested itself in a number of different ways. Some of the participants talked about not looking like dementia, whereas others were quite self-focussed, thinking that either they were the only person with dementia, or that they were unique and nothing like those other people with dementia. Paul and Ray reflected on the time they first attended at the SDWG:

> *‘And I said no I am not going to a meeting with bunch of people with dementia, what do they look like.’ (Ray)*

The participants appeared to have an image of what a person with dementia would look like and they were not keen to be linked with that. The most effective way of dispelling the self-imposed stigma would appear to be meeting other younger people with dementia, but convincing them to attend meetings was difficult because of the perceived stigma. To this extent participants described their fears of going to the meeting and the surprise they felt when they attended:

> *‘I was hit by a cacophony of sound, laughing and joking men. I asked where the persons were with dementia and they said that’s it, you are here (laughs).’ (Paul)*

The examples above provide insight into how the participants processed their diagnosis and what it meant. The self-stigma is part of the process of accepting the diagnosis of dementia, it does not last and is perhaps linked to the loss of confidence that participants identified following their diagnosis.

5.4.3.3 Sub-theme - ‘People accepted me, we even joke about it’

This sub-theme focuses on the participants’ experiences of disclosure, the fear they had of sharing with others about their condition and their perceptions of the reaction from others when they disclosed. There is a link here to the sub-theme above about stigma, and also acceptance of self with dementia, since the ability to share your diagnosis with others will only come when there is an acceptance of the diagnosis of dementia. The sub-theme has been placed in this section because it is the reaction of others towards them that is important for the participants. This finding identified that where participants are accepted, by others, with their dementia, this enabled them to regain confidence in themselves and their identity. However, participants were wary about with whom they shared their diagnosis, some stated that they would only tell people who they trusted. On the whole participants received a positive response from those they disclosed to.

Jenny found that when she disclosed it helped her to explain that she had the same dementia as the author Terry Pratchett:

> '…*don't go up to people and say excuse me I am Jenny and I've got dementia but gradually, fairly quickly I let them know because I feel worse they are thinking I am mad, you know rather than I've got this form of dementia and I often say I don't know if you heard of it but it's the same as Terry Pratchett. A lot of people will say oh yes I know so and so, always someone who knows someone.' (Jenny)*

Jenny explained that she does not boldly go up to people and tell them that she has dementia, but she does tell people who she is with because she worries about what they may be thinking about her. This is possibly associated with her pre-diagnostic experience, when she was aware that others were aware that she was acting strangely or inappropriately. Another aspect for Jenny was the link to Terry Pratchett, which helped to put her dementia into context and enabled others to understand.

Peter stated that he does tell people and that in doing so found most people were helpful

> '*When I say tell people, tell people who are suitable to tell. You will find the majority of people will give you a hand or take a little time with you. You have to be careful who you are maybe speaking to, that would be a judgement matter of that.' (Peter)*

Peter also indicated that there is a judgement to be made in regard to who a person with dementia would disclose to. Louise was also careful about who she disclosed to:

> *'So as few people I can trust, but I would not tell everybody saying you know I've got dementia…You know people I can trust people who have known me since I was young… few people do know that I have my illness, certain people that I think I can trust.' (Louise)*

The concern and the necessary judgement required related to disclosure is perhaps linked to the participants' sense of vulnerability. Disclosing that they have dementia could subject them to abuse, as a person may try to take advantage of them due to their diminished cognitive ability. So while there is a need to disclose, for reasons such as explanation or need for assistance, the participants were also mindful about their situation and how if they were to misjudge this they could put themselves into a vulnerable situation.

John expressed fear of disclosing his dementia to his friends but found them to supportive:

> *'My friends have been good. I've got really good friends and they look after me when I get out. All my fear about telling people uh came to nothing, people accepted me, we even joke about it, you just get on with it.' (John)*

Generally, people were accepting of the changes in his abilities and enabled him to continue to be part of the social scene with which he was familiar. He went on to say:

> '*That's what I've done and they still treat me as myself' (John)*

John found that his friends still saw him as John assisting him to maintain his identity.

Sharing their diagnosis with friends and family was a dilemma for participants for different reasons. There was concern about who they shared their diagnosis with and there was an element of judgement required, which may be difficult for a person with cognitive impairment. All participants were met with positive responses, which could be interpreted as an affirmation of acceptance by others. For the participants coming to terms and accepting dementia required them to be accepted by others, as themselves with dementia.

5.4.4 Summary

This superordinate theme is set within the context of diagnosis and the immediate reactions following this experience, which presented as a dilemma for the participants. Receiving a diagnosis of dementia at a younger age came as shock to the person, but it also brought a sense of relief. There was a sense of fragmentation following diagnosis, which was initiated by the diagnosis and how the diagnosis was delivered. There was an impact on well-being for those participants where their experience of diagnosis was poor. In this diagnostic phase the participants transitioned from feelings of fragmentation moving to consideration of the diagnosis and what this means to them as a younger person. The participants questioned how they could have dementia at their age and felt that their dementia experience was different to that of an older person with dementia. Further, they experienced feelings of self-stigma, which were dissipated through meeting other people with dementia and disclosure of their diagnosis to others. Participants wanted to be accepted, but were apprehensive about reactions from others when they shared their diagnosis of dementia. While they had all received positive reactions, there was still the need for them to be cautious about whom they would tell, which is perhaps linked to a sense of vulnerability, along with fear of ridicule. Meeting other people with dementia helped to dissipate feelings of self-stigma along with the positive reactions from others and it is suggested that this created some improvement to well-being.

5.5 Super-ordinate theme –The challenge of learning to live with dementia as a younger person - Post-diagnosis, evolving self, assimilation,

This superordinate theme, the challenge of learning to live with dementia as a younger person, starts to explore challenges the participants experienced due to psychological and physical change within themselves and their lives. There is a process of assimilation of the losses and the changes that had to be made by the participants in order to manage their lives with dementia, and an evolving sense of self with dementia. Also identified are the physical changes experienced by the participants, which resulted in a loss of some form or another. The themes within the superordinate theme capture the aspects of being younger and how the impact of the changes may be greater on the person, because of the age and stage at the time of diagnosis. The process of assimilation identifies how participants start to live a life with dementia, the challenges they experience and how these impact on their self and well-being. This super-ordinate theme provides insight into their experiences and needs, in regard to the external influences and treatments by others, and the impact on selfhood. In order to move on with their lives it was important for participants to accept their dementia; however, it was important that they were still accepted by others and within their peer group. The themes touch on the participants' view of their identity and the risk of their selves being diminished by others. The participants in this study were keen to be recognised and heard by others.

There are six themes related to this superordinate theme:

1. 'It's like curtains coming down'(stress & tiredness)
2. 'Stop work, stop driving, I still get upset going back to it' (loss and changes to independence)
3. 'I'm here if you want to know how I am, I'll tell you' (being listened to and acknowledged)
4. 'Duck out of water' (diversification of needs)
5. 'Freedom, things that I feel I can't do unless someone helps me' (the consciousness of dementia)
6. 'I don't see why I should change and become this dementia character' (managing dementia)

5.5.1 Theme - 'It's like curtains coming down'

This first theme provides an insight in to the challenges faced by extreme fatigue and the consequences of this. Due to the changes in cognition and other abilities participants found that they had to make dramatic changes to their lifestyle. This created feelings of loss and anger directed towards themselves and their situation. Participants expressed feelings of frustration and loss of aspects of their previous life through a diagnosis of dementia. The frustration related to a number of factors, such as not being able to complete simple tasks, anger at self for not being able to remember how to do tasks, or for making mistakes. Others expressed annoyance about the loss of short term memory and functional ability.

Managing day to day was difficult and often created feelings of stress. Jenny provided an example of this:

> *'Cos, I get frustrated if something has gone wrong, because I can't work out how to get back.' (Jenny)*

Ray provided a similar example of frustration at not being able to do simple, routine tasks:

> *'Things I could have handled with aplomb just a year ago I just cannot and it gets you mad at yourself, why can't I do this? I am a man, I have brought up four children, why can't I do this? Very frustrating.' (Ray)*

There was a sense of shock and upset which is communicated through his choice of words. He was almost incredulous as to how he was not able to undertake simple tasks. The way he expressed this comes through in the excerpt below, the use of the word *'aplomb'*, and the '*why can't I do this'*, which he repeated twice. Ray was aware that if he gets stressed then his ability to cope with situations or to undertake simple tasks deteriorates. Ray talked about how his level of ability fluctuates when he is under stress. This was particularly apparent for him when his mother died. He explained that he was struggling to place relatives getting his daughter mixed up with his sister:

> '*…say for example if I am under stress my level of capability diminished quite rapidly, not just me others as well*.' (*Ray)*

Jenny, Tom and Louise also experienced tiredness which impacted on their abilities. Tom articulated this well when he talked about experiencing this fatigue:

> *'One of the things with dementia is you nose dive and you can't do anything about it, it's like curtains coming down and you can't do anything about it and you have to learn to cope with it.' (Tom)*

Tom uses a metaphor to provide a visual picture of how the tiredness affected him. The way he described this is interpreted that the tiredness is of sudden onset, that the only way to manage it is to rest but also to be aware of it. The person with dementia has to think through everything that they do:

> *'……Get tired because you are not [able to work something out] [requires you to] got to think.' (Jenny)*

This example above from Jenny illuminates how the tiredness she experiences is from thinking through everyday tasks. Similarly linked to this

Tom explained that it is the constant awareness that a person with dementia has to have in order to function daily:

> *'You now get tired of feeling aware, having to think through rather than just think I will go for a walk.' (Tom)*

The tiredness can be prohibitive to a certain degree and can stop the person from doing activities, or at least taking part in activities that they enjoy:

> *'I used to play two games [bowling] in a day and I say, you know, I can't do that. Once I've finished a fifty end game I'm shattered.' (John)*

Participants gave further examples of their frustration and anger at the changes in their abilities, particularly in relation to their memory. Paul explained that for him one of the main problems he had encountered was the loss of his short term memory, describing this as '*a nuisance'*.

5.5.2 Theme - 'Stop work, stop driving' - loss and changes to independence

This second theme identifies how dementia can impact on the person's ability to remain independent. Participants found they were required to make high impact changes to their lives which impacted on their freedom and independence, creating further feelings of loss and disempowerment. This theme provides insight of how those changes affected participants in different ways.

One example of change, which created feelings of loss and disempowerment, was the requirement to relinquish one's driving licence. Tom talked about the impact of having to give up driving and work:

> *'You're going to have to stop work, stop driving; I still get upset going back to it.' (Tom)*

Tom provided a clear example of this, recalling the freedom he got from driving. Tom was made to give up his licence at the time of diagnosis, having to hand it over there and then. He realised later that he was not competent to drive, but this realisation was only apparent to him after he had attempted to ride a motorcycle. He went on to talk about going out on his motorbike and sensing the danger he was in, realising he could no longer handle the bike. Being able to realise this enabled him to come to terms with his loss, and he described this as '*in your time'.* Tom further explained that he had a second licence in the house and he used this to hire a car. After he hired the car he realised that it was dangerous for him to drive so chose to cut up the licence. He expressed the loss of the freedom in being able to just go out for a drive.

It is suggested that had Tom been given time to relinquish his licence, acknowledging the danger that he would be to himself and others, would have enabled him to come to the terms with loss more quickly. This signifies that where there is choice and control about when, or how you give up your licence provides the person with self-empowerment, so while this is a life changing event, the impact on the person is less because they have been able to make this choice themselves. An example of this is where John decided to give up driving, it was a conscious decision by him:

> '*The only thing that has changed is that I have given up driving but my wife was pleased. I think my driving must have been bad, I can get a lift from one of the children or my wife. I thought I would have missed driving, but I thought I've got somebody to drive me.' (John)*

Other participants made the choice to give up driving because of concern they had of causing an accident, or people getting annoyed or being aggressive with them, creating a feeling of vulnerability. It was this that initiated them into giving up driving. When they spoke about this experience they were content with their decision. Peter provided an example of this:

> *'I had an accident driving and this guy was claiming all sorts of things. But we got that sorted and I gave up driving. I mean if something happened and I met the wrong person or people they could take advantage of the situation.' (Peter)*

Both Jenny and Peter recognised the need to give up driving following a number of accidents. Not only were they putting others at risk, they were putting themselves at risk. Because the decision was made in relation to their safety and others there was a clear acceptance and they did not express any sense of loss.

It is proposed that losing your licence is disempowering, and allowing the person with dementia time to deal with this would appear to assist with acceptance. Allowing the person time to come to terms with their limited or diminished ability, may enable acceptance.

Another area of where loss was experienced was for those participants who had to give up work. However, the feelings of loss associated with this high impact change was multifactorial, such as had they retired, did they have income through pension or other means, were they provided with opportunities for transition, or to continue working, was work causing stress, or pressure for the person?

Two of the participants' experiences were very different, Peter was supported to remain at work and came to the decision to give up work himself, whereas Ray was not provided with any opportunities and felt that he was made to leave work, believing that had he been offered a different role he may have been able to continue. Ray explained he had to give up work because of his inability to function in his role, yet it was a further four years before he received a diagnosis of dementia. He lost his income and his pension and he had a young family, he talked about this change impacting severely on his family life and his well-being. Ray continues to promote the importance of enabling people to remain at work:

> '*It can be devastating for some because you might have to stop your job. If you're a brain surgeon … maybe they could be put into a teaching role, teach things but don't actually operate on someone.' (Ray)*

Ray was keen to promote that people should be supported to remain at work, in the quote above he suggests that a person's role could be adapted so that they could continue to work, perhaps in a less demanding role.

It is possible that where a person is given time, or is enabled through transition to give up work, the impact of the loss is decreased, and therefore there is less impact on well-being. Peter provided evidence of this as he was given opportunities to carry on working. He felt he was not coping with the role because he was in a small team and he felt he was a burden. This created anxiety for him and, although in his case his employers were very supportive, the right thing for him was to give up work:

> *‘Giving up was the best thing to do because working with figures put the wrong figure in [laughs], I mean the punters not going to tell you. The employers were fine with me they came across and discussed everything [after diagnosis] so they were uh very good really, treated me alright, kept me going and sorted out everything that needed to be done.’ (Peter)*

Peter’s experience enabled him to continue to go to work through the support of his employers. Although it is suggested giving up work is a major impact on the person some participants expressed, or implied, a sense of relief at giving up work. Peter’s experience is quite unique compared to others who were interviewed.

5.5.3 Theme -‘I’m here if you want to know how I am, I’ll tell you’ - being listened to and acknowledged

This third theme provides insight into the participants’ need to have their voices heard. Their experiences were important to them and only they could understand their needs, and what it was like to live with dementia as a younger person. Participants wanted to be listened to as the experts of their illness and not have others, such as professionals, assume that they know what it is like for them to be living with dementia. Additionally, the theme provides examples of where participants experienced an impact on self, where they were diminished by others through not acknowledging them.

When Peter spoke about living with dementia and recognising that the person with dementia knows best he put it quite simply:

> *‘The person who has got it knows more about.’ (Peter)*

Peter stated this as a fact, which was also supported by Tom, who was a little more expressive when he said:

> *‘The person living alongside their brain has a much clearer image of it…We’re the expert.’ (Tom)*

Tom's statement is strong and powerful, using the imagery to help explain to professionals and others that the person with dementia understands their dementia. This was important to the participants because it was implied, by what the participants were saying, that they do not get asked, or there is an assumption by the professionals that they (the professionals) know best.

Jenny and Sally also commented on the need to listen to the person with dementia. Jenny said that it was important that they were encouraged to express their needs and experiences:

> '*To listen [to] what they say, let them tell you what they want and make it easy for them to feel that they can tell you what, how they feel.' (Jenny)*

Sally further expanded on this when she talked about the need to listen:

> *'Understand people, speak to them and uhh and try and understand you know what their situation is like, cos it's alright saying someone's got dementia but I mean you honestly don't know what it's like until you have it… it's to listen, listen, not to really talk, listen… for somebody to listen to you. You've got to see and right enough if you're wrong be corrected but yes it's the listening thing.' (Sally)*

Sally repeated the word listen and then further emphasised the point by saying that it was important to listen and not talk.

Ray also reiterated the need for listening and being treated with respect but he offered some hope that this is improving:

> '*Treat them as a human being and listen to them…I think people are showing us more respect.' (Ray)*

What this indicates is that they are not listened to in regard to their experiences of living with dementia. In listening to them and their experiences there is a sense that professionals, and others, can improve and develop support services and environments for people with dementia. However, it is suggested that this is not happening and participants in this study did not feel that they were being listened to.

There was identification of further impact on the participants' selfhood because of their diagnosis. Participants struggled with being recognised and acknowledged. This theme identifies different experiences of being accepted as a younger person with dementia, and being respected through recognition and acknowledgement.

Ray provided an account of his experience with a Physician recently and his experiences a number of years ago:

> '…*and saw a top consultant privately and he kept saying to my wife he this and he that and that was only two months ago. So that's a top man, paying £159 just to speak to him. I was too ill at the time, normally I would jump at that but I was ill and did not have the heart for a fight. That attitude now I think back then. Some people never spoke to you, they patted you on the head or they would come up to you shove you aside, cut your sandwich and ask you how do you talk. You have no idea what I went through... treat them as a human being...Don't use negative derogatory words, even in private because to me it shows disrespect.' (Ray)*

Ray's experience was of non-acknowledgement and he interpreted this as a lack of respect to him as a person, it was assumed that he could not participate in his own care and support needs because he had dementia. Ray explained that he could not challenge the situation because he was unwell and did not have the energy. However, it was clear that he was still angry about it and he linked it to the way he was treated when he first was diagnosed a number of years ago. Further, he touched on how he would be described, such as a sufferer of dementia, which he found offensive. This was something that was remarked upon by other participants. The verb suffer used in the context of an illness suggests that the person is severely affected by the illness. It is suggested that when the term suffering is used in regard to dementia it further diminishes the person and their selfhood, along with their life. Others, such as professionals, are interpreting the lived experience of the person with dementia without the knowledge of how that person views their life.

Ray was not alone in experiencing a dismissive approach from others, John also talked about his experiences of people not recognising him as being there or acknowledging that he could comprehend what was being said:

> *'But the worse feeling I ever got were, my wife and I were out and we were walking down to the shop and the person stopped and said [to my wife] and "How's John" and I said "I'm here". I just said, "I'm here if you want to know how I am I'll tell you how I am". That happened two or three times.' (John)*

In John's situation he was able to speak up for himself, but this did not prevent it from happening again. Conversely, Paul had a more positive experience and felt that he was being respected as a person:

> *'The fact that I am being treated as an equal and that people look at me and don't look at the numbers… I have often said seeing me with a walking stick there is something physical. And people, do you know I have dementia, respect me for what I am and I respect them for what they do… Need to respect me for what I am, what I have been and what I want to do.' (Paul)*

While Paul felt that he is being respected and treated as an equal he also commented on the need to be respected as a person first. So while Paul acknowledges he has dementia, he does not want people to just see the dementia. Paul also stated that there is a need to consider the person's past, where they have been, what they know. This is important in regard to selfhood, linking to the Self-2 and the publicly presented self.

This theme provides insight in the personal experience in regard to living with dementia and impact on self and identity. The participants clearly want to be seen as a person first. They are not denying that they have dementia, but they are clear that they are not 'dementia'.

5.5.4 Theme - 'I felt like a duck out of water' - diversification of needs

This fourth theme provides an insight in the inappropriate services that younger people with dementia are provided access to. The fact that people in this study were offered older people services to support their needs, symbolises a lack of acknowledgement of the individuality of their dementia related to their age and stage, the focus being on the dementia rather than the person.

Each participant experienced different services, some of these experiences were extremely negative while others were reported as positive experiences. Age was a factor for the participants as they felt strongly that they required access to age appropriate services. It is suggested, that by not considering the needs of younger people in regard to their support needs, there is a failure to accept the differences in having dementia at a younger age.

Paul provided an emotive account of his experience of services. He described feeling like ‘a duck out of water’ when recounting his experience of accessing day care for older people. Paul thought the day care would help him but he referred to the ‘generation gap’, and although the staff were very good in trying to find things of interest to him, he felt that he was being treated unfairly:

> ‘*Then he referred me to day care. I thought that’s good as it will probably help, but I was referred to older people’s service and it was the psych geriatric day care and I felt like a duck out of water...the nearest to me was 76. I worked with older people with dementia in my working life. I understood a bit of it, what people can do and not do. I wasn’t doing these things and I thought this is not fair. So apparently, I went to [my wife’s] room one night crying at three am in the morning and I said “please don’t send me back there”. And she sat me down and realised that I hated it... [I] know what it was like moving in to older people’s services at 60.’ (Paul)*

Attending the day centre for Paul was extremely stressful and upsetting. There are indications in his account that he believed that he had to go the day centre and required permission from his wife to stop. Paul had good insight into his abilities and his age and stage. The excerpt above clearly identifies what was wrong for Paul, and potentially would be wrong for other younger people with dementia.

Conversely, Sally was positive about her experience of an older person’s day service. Attending the service (the bungalow) was important as it helped to keep her well:

> *‘Coming to the bungalow – don’t know what I would do without the bungalow.’ (Sally)*

However, although Sally provided a positive account of the service she accessed she did not have any other options. So while hers was a positive outcome it is not clear whether this would be further improved if more age appropriate services or individual services were made available to her.

Other participants were in receipt of one to one services, which should support the person’s individual needs. Jenny and Louise provided different experiences of the one to one supports they were in receipt of. Jenny’s experience was positive and person centred:

> *‘Yes, I have, like, a carer comes for a few hours once a week, Judith, she’s really lovely... Having these carers we go out, as I say, some people need them to do all sorts of things whereas we just go off and do what everybody else does, normal... there are groups for lots of people to go to but they are quite a bit older...and I don’t want to join, they all sit round together and I don’t want to be like that yet, I feel I am younger enough... they were all of them quite happy to sit you know the whole room like that.’ (Jenny)*

Jenny reflected on her experience of the service positively, but she made reference to her being younger and acknowledged that the older people services were, at this time, inappropriate for her.

Louise on the other hand found her one to one support intrusive and she felt that the support worker was not listening to her and respecting her needs. She explained that the support worker would take her out to the shops, but this was not something that she wanted to do.

A variety of services were accessed by participants, similarly the services were varied in their ability to meet the person’s outcomes. One to one services should meet the individual needs of a person, however, that will be dependent on the support workers skills. Additionally, where a person accesses older people’s services their experience and acceptance of this may be impacted on by what other options are available to them.

5.5.5 Theme - ‘Freedom, things that I feel I can’t do unless someone helps me’- the consciousness of dementia

This fifth theme provides insight into the loss of confidence experienced by participants following their diagnosis, which resulted in a questioning of their ability to do things. The impact of diagnosis had the potential to impact on self-belief and self-determination. All participants expressed changes in their ability to be spontaneous and a lack of confidence. Participants talked about a lack of spontaneity at not being able to just do something. Participants expressed concern about undertaking spontaneous acts, feeling there was a need to think through what they were doing, or when asked about doing something question themselves as to whether they were able. Louise provided an example of how she is careful and cautious:

> ‘*Sometime I seen me mebbe going up the road over to the square end and I am walking round and suddenly I will stop. This might be a trait of the illness, I think I better turn back. I would go further normally I think I better turn back. I am scared I will take a wrong turn. I am conscious of the illness... I mean I don’t think, oh I’ve got dementia, but I am aware. I mean I used walk anywhere cos I knew where I was going, basically without thinking that I might get lost. …Wee daft things hit you, so I’ll go to where I think I can go, but I get to a stage where I know then I think I turn back just in case I take a wrong turn. I am being awful cautious, maybe a wee bit more cautious. It’s a good thing otherwise I may walk here, there and everywhere, which I have done on many occasions. Wee things, I have maybe become more cautious and I think that may come with the dementia.’ (Louise)*

Louise is independent in that she goes out for walks, but she talked about being cautious, that she is conscious that she has dementia. While it is important for someone with dementia to take care and ensure their own safety, Louise’s caution is interpreted as being related to her knowing that she has dementia. Louise’s example suggests that she is now less spontaneous than she was before she knew she had dementia.

Jenny commented on the lack of spontaneity that comes with having something like dementia, almost as if she were not able to trust herself or her ability. She explained how she questioned her ability to do something, continually doubting herself:

> '*Come on, you've got to do it. Come on Mrs, yes you've got to do, come on you got to have some life…Freedom, things that I feel I can't do unless someone helps me, umm, just things [you] do on the spot, you know let's do this, yes I might be able to do, but hang on let me think about it, will it be difficult.' (Jenny*)

Jenny used the word freedom and later in the sentence she talked about not being able to do something 'on the spot'. It is suggested that she was referring to the loss of spontaneity that an adult experiences along with making your own choices. Not being able to make spontaneous decisions can impact on a person's autonomy and their independence, as they are reliant on others to enable them to do the things they want to do.

Similar to this Sally explained that she would not go out on her own because of the fear that she would not know how to get back:

> '*I couldn't go out and away down the street just by myself. I would be too worried in case I didnae get back. That's one thing that really bothers me if I went away on my own, I mean I know where I am going, but if I went away down the town I would probably get lost.' (Sally)*

Sally does not say that she knows she will get lost, but it was clear that she was fearful of getting lost, therefore, would not take the risk of going out on her own. Although this can be viewed as restrictive it also shows a level of insight into her own ability.

The loss of confidence participants experienced potentially impacted on their autonomy. Paul reflected on how dementia brought a loss of spontaneity by not being able to just do something like go up into the attic, thereby impacting on his independence:

> '*I miss some of the independent things I used to do. I used to love going into the attic. A lot of my memories are up there, I can't do that now. I did go up once when she was out but I fell down.' (Paul)*

Paul misses the act of spontaneous thought and action. For Paul it would seem that this was a past-time, to go to the attic and look over old things and reminisce. This is quite symbolic, the image of the attic holding his memories, he has dementia and is losing some of his capacity to remember.

The dementia has prevented him from going into the attic to assist with recall of those lost memories.

While knowing that you have dementia provoked the need to question their ability, creating a loss of trust in themselves, there was also a determination to re-build confidence and self-belief.

5.5.6 Theme - 'I don't see why I should change and become this dementia character, you know' - managing dementia

This sixth and final theme within this superordinate theme provides insight into the management of dementia as being separate from self. Participants appeared to manage and accept their dementia by keeping it in the abstract, and not referring to 'my dementia', preferring to refer to dementia as 'it', 'this' or 'this illness', and stressing that they did not need to become dementia.

An example of this was Louise who when speaking about her dementia she said:

> *'Rather something else but not this…I don't have this…this happening to me.' (Louise)*

Louise also referred to dementia as 'this' when speaking about the condition deteriorating. Jenny and Sally also referred to 'it' when they were speaking about dementia.

It is suggested that in keeping dementia in the abstract, and talking about 'this' and 'it' rather than my, is linked to dementia not changing the person.

Tom was keen to stress that you don't have to become dementia when he said:

> *'I don't see why I should change and become this dementia character, you know.'(Tom)*

When Tom spoke about dementia, he was talking about not becoming someone else because you have dementia. He had accepted his dementia but it was not him. The participants did not refer to 'their dementia' or 'my dementia', when speaking about dementia, which suggests their way of accepting that they have dementia is to keep it in the abstract, they will not be dementia.

5.6 Summary

This super-ordinate theme is situated in the post-diagnostic phase and has identified a process of assimilation and an evolving sense of self with dementia. This theme has identified how the participants' lives have had to change because of the diagnosis of dementia and how those changes have impacted on their self and well-being.

There are challenges to be faced with feelings of loss through fatigue and tiredness, which impacts on how the person lives their life. Additionally, the participants identified with feelings of frustration because of the tiredness and stress, which impacted on their cognitive abilities. It was clear that having dementia required the participants to manage their daily lives differently. It was necessary for them to avoid stressful situations, not take on too much and to be aware of the fatigue that having dementia brings. They had to think through the processes and tasks which caused the tiredness. This impacts on the person's way of life and impacts on their self-determination, in that having dementia prevents them from doing the things they may want to do at their age, or at their time of life.

Further losses were experienced where high impact changes, such as relinquishing one's driving licence, or having to move house and take early retirement. Not being able to drive was linked to loss of autonomy, freedom and independence. These high impact changes were more acceptable to the person when they were given time to make changes and they were enabled to be autonomous in the decision making. They are strong in their conviction about their dementia experience being different and that they are the experts of their illness. Issues were identified in relation to being heard and being listened to. This links to identity and being recognised as a younger person with dementia.

Services were an issue for the participants who accessed a variety of different services. Older people's services were not felt to be appropriate by two participants. It was also noted that where one to one supports were provided, the success in meeting the person's outcomes were dependent on the skill of the support worker. This indicates that their needs are not always recognised, there is still perhaps an assumption that older people's services will suffice.

Participants experienced a loss of confidence, feelings of disempowerment and loss of autonomy, which impacted on their ability to be autonomous and spontaneous. Participants found themselves restricting activities and not undertaking spontaneous acts. They identified with cautiousness, an awareness of dementia, which also acts as a risk management tool and is discussed further in the next section.

Participants identified that they did not want to change and become dementia. As part of accepting dementia but not becoming dementia, participants talked about dementia in the abstract, referring to 'this' and 'it', and not 'my' when referring to their condition.

5.7 Super-ordinate theme - Living well beyond dementia - Living well beyond dementia, consolidated self, consolidation

This super-ordinate theme, living well beyond dementia, was identified by all participants and also identified as the fourth phase. The theme provides insight into how the participants perceived their experiences and life following diagnosis and acceptance of their condition. It was patently clear that participants experienced a good life living with and beyond dementia. This theme presents a consolidating process and a consolidated self. Participants have transitioned through a process of acceptance and they are content with themselves and living beyond dementia.

There are three themes related to this superordinate theme:

1. ‘Eventually I went out and got lost’ (risk taking)
2. Meaningful activities, with four sub-themes:
    a) Changes in confidence
    b) Being allowed to do things
    c) Learning new skills and retaining old skills
    d) Making a difference
3. ‘There is life after dementia, it’s a good life’ with four sub-themes:
    a) Coming to terms with progressive illness
    b) Rationalisation
    c) Family supports
    d) Meaningful relationships

5.7.1 Theme – ‘Eventually I went out and got lost’ - positive risk taking

The first theme within in the superordinate theme is linked to autonomy, while participants were restricted by their diagnosis they eventually started to take risks, which enabled them to regain independence. Participants articulated their experiences of how they managed risks in order to maintain a sense of independent living, enabling them to make their own choices.

Participants developed their own strategies to enable independent living, empowering them to manage their lives and carry out tasks themselves, such as travelling independently.

This was particularly evident with Tom, who following his diagnosis was required to make a lot of changes in his life which impacted on his mental health and well-being:

> *‘ Eventually I went out and got lost , quite regularly, but I used to take enough money to get a meal or a taxi and phone number on a little card, you know a little help card. And sometimes it’s really quite hysterical. An example was I went to Glasgow and I could not find my way out of St Georges Square and it was impossible…But I was just trying to work out a strategy and I said right I’m gonna live my life and that’s it.’ (Tom)*

Getting lost for Tom was part of a process which helped increase his self-confidence leading to a regain of skills, and eventually a return to autonomy. Tom had awareness that he may experience problems with navigation, but he developed a strategy which enabled him to manage and remain safe. What is important about this experience is that it is linked to living and experiencing life.

Similarly, Louise talked about being cautious, but how this was a good thing:

> *‘I am being awful cautious, maybe a wee bit more cautious, it’s a good thing, otherwise I may walk here there and everywhere which I have done on many occasions… I have something in my purse don’t I? Well, I put myself in danger going to strange places but who doesnae?’ (Louise).*

This statement about being cautious was included in the theme above about loss of spontaneity, but here the cautiousness acts as a protector for the person with dementia. The person is alert to the fact that they have changed cognitive abilities, being cautious of their dementia enables them to take risks and lead an independent life. Louise also carried identification, a strategy that most of the participants utilised, which alleviated stress for them and their significant others when they were out on their own. What is interesting is the statement Louise made about going to strange places, it is as if she is being defiant over her dementia, and will continue to live an independent life, like all people do. So, while she is cautious she does on occasion step out and go and walk to places that she is not so familiar with.

5.7.2 Theme - Meaningful activities

This second theme, meaningful activities, is divided into three sub-themes which demonstrate how the participants started to regain self-confidence through undertaking activities, first of all by continuing to do the things that they enjoy, and then moving onto learning new skills. The theme also identifies the need for participants to be supported and empowered to do things. Participants talked about learning new skills, the importance of this, but also retaining old skills even if competence was diminished. Participants were keen to stress the importance of keeping active and having meaningful things to do. Further, the theme identifies how important it was for participants to make a difference and help others.

5.7.2.1 Sub-theme - 'Changes in confidence, just because we kept on doing it' - increased autonomy, confidence and independence

This sub-theme demonstrates how the participants moved from a position of negativity, feeling disempowered and experiencing loss of independence, to one where they experienced an increased self-confidence and self-belief. Participants felt strongly about being independent and exercising autonomy. Following their diagnosis the participants felt a loss of confidence which impacted on their autonomy and self-determination, and as a result they experienced a loss of independence. This was identified in the super-ordinate themes above, the challenge of learning to live with dementia as a younger person. However, there appeared to be a period of regain where participants were able to gain confidence in themselves and self-belief.

Regaining confidence and self-belief was demonstrated by participants as they accepted that they had dementia and started to understand their abilities and disabilities. It has been identified that participants experienced loss of confidence in themselves and questioned their ability to understand situations or manage tasks. While participants did not fully recover from the feelings of being restricted, they were able to re-establish a sense of autonomy, improved self-confidence and a sense of belief.

Commenting on this Jenny stated that she now felt more confident:

> *'…took a long time, I am much better at it now, I am quite happy now when you go to public places and you go to the toilet and things and if I can't, I get muddled cos you go in one door and then another, and um now I just say to someone excuse me is that the [toilet] door, is this you know? Change in confidence just because we kept doing it.' (Jenny)*

For Jenny regaining her confidence and self-belief took time. Jenny talked about continuing to undertake certain tasks, suggesting that in doing this she regained her confidence. Jenny also appears to be saying that she had worked out a strategy for managing difficult situations, such as getting to the toilet. She now has the confidence to ask for assistance. On another note, Jenny touched on the difficulties experienced in negotiating the environment and how complex this can be for someone with dementia.

Another participant, Tom, commented about how his confidence had plummeted following his diagnosis and how he built it up again:

> '*Basically that's it and I think there are things that I have always liked doing but my confidence had been trashed... I used to like baking and cooking. I used to have people up for meals, and I like to have people up for meals and seeing them eating and I just started to get back into it... Umm I know I think what you got to be careful of, is people don't consciously, intentionally instil fear into. I mean you go to the kitchen and use a knife and you think you should not be using...I mean I knew I had to eat, but I was not motivated to cook or wash up and my CPN said come on you've got eat properly. So she said you like cooking so why don't you cook…So I spent time going through cook books and think that looks crap, crap, oh that looks good, so I would tear the page out or put a marker on the page or photocopy.' (Tom)*

Tom talked about what he used to enjoy and how he thought about reengaging with these activities. He made an interesting comment about how other people can influence a person's confidence. Tom related this to using knives in the kitchen, he was cautious about this, and perhaps a well-meaning person had told him to be careful because he had dementia. In doing this Tom avoided using kitchen utensils, and therefore stopped cooking for himself and others. Tom was also demotivated, and it is suggested that there may be a link to the demotivation he experienced and the fact that he had been told not to undertake certain tasks.

The comment below from Louise further demonstrates how participants regained their confidence and their self-belief:

> '*I am confident going about now whatever... I still feel confident in myself I can still do things for myself and as long as that happens I'll be doing it.' (Louise)*

Louise's use of 'now', in the first sentence in relation to her going out and about, suggests that at one stage she was not confident to do these things.

5.7.2.2 Sub-theme - 'You need to be allowed to do things to keep yourself okay' - keeping busy, having things to do-

This sub-theme provides insight into the participants' lives beyond dementia. Being busy and leading a meaningful life following diagnosis was important, it is suggested that this is particularly pertinent to the participants in this study, because of their age and stage. Participants shared how they kept busy, and stressed the importance to continue to do the things that you can, even if you are not able to do as well as you once could. Having things to do provided structure to the participants' day, enabling them to be independent. Peter stressed the importance of keeping active and told how he still plays golf with a group of friends:

> '*You need to be allowed to do things to keep yourself ok, keep active. I play golf I have a friend and we go and play golf with the group. They know I have a problem so I don't get to mark the scores [laughs], they help, but I have to hit the shots, terrible, they won't do that for me [laughs]. It gives you a structure, Tuesdays such and such, Thursday I do that.' (Peter)*

Peter used the word 'allowed', perhaps because there is a tendency for people (families/professionals) to be over-protective of people with dementia.

Although he knows that he cannot play golf the way that he used to, he is supported by the group who assist him with keeping scores. From the way he tells this experience it was clear that he feels supported by the group and he enjoys the time he spends on the golf course. Peter actually stated that it gives him a structure to his week.

Participants' activities were varied and really depended on what they liked doing before they had dementia. Tom explained that his evenings and days are interesting and varied:

> '*Some nights we just put on a DVD and open a bottle of wine. I was away last week at the Glasgow gallery looking at the Jack Vetriano exhibition and last year the Glasgow Boys exhibition.' (Tom)*

This is important as it supports the theory that a 'normal' life can be lived with dementia, living beyond the diagnosis.

Although all participants expressed the need to keep busy and be active, they were also aware that they may not be able to do tasks that well. However, the fact that they were cognitively impaired did not faze them in their pursuit to be active. Jenny enjoyed going to a class:

> '*So I go to a keep fit class and they are great and they know what I have got, and they don't worry if I go the wrong way.' (Jenny)*

Jenny was completely at ease with the fact that she was making mistakes; she was accepted by other members of the class who understood that she has a disability.

In keeping active it was also important for participants to be enabled to undertake activities that were 'normal' and independent of others:

> *'Having these carers we go out, as I say …we just go off and do what everybody else does, normal…. we go off and have a coffee and just a chat and it's another thing, it's like, you know you often see people in a coffee shop, two women having a chat…' (Jenny)*

For Jenny it was important that the activity was something that she would have done prior to dementia, a 'normal' life.

5.7.2.3 Sub-theme- 'Learning new skills, the old skills that I have lost'- learning and relearning new skills

This sub-theme is important as it demonstrates how the participants were able to develop themselves, despite their dementia. Many participants had developed skills because they were given opportunities through having a diagnosis of dementia. Participants talked about doing things that they had never dreamed of doing in their life before dementia. Once Ray had accepted that he had dementia he became active within the SDWG. His support worker enabled him to develop the art of public speaking. Ray talked about how he was supported to do this:

> '*I tried it once [public speaking]) and it was a disaster but Claire [support worker] working on me, never takes no for an answer. Keep working on it and practise and practise, She would sit close to me and then move and move further, and now I can do talks without her being there.' (Ray)*

Ray is now a confident public speaker; he later talked about how he lectured at universities and met with Members of Parliament. Ray also talked about how his network of friends and acquaintances grown:

> '*But my socialising has increased leaps and bounds, that's a positive thing. I meet so many lovely people. I have got lots of acquaintances… when I think about my life before it and have quite a circle of acquaintances. I have the places I go, speak with Scottish Government ministers face to face …Alex Salmond wrote to me. Went to Holyrood… I go to universities and talk to students and ehh, think they enjoy it. I think the lecturers like it because I have been asked back for ten years.' (Ray)*

While having dementia is a life changing event and participants experienced anger, frustration and loss, there are also positive experiences. Ray's examples provide an insight into how his life has grown following his diagnosis. For instance, Ray stated that he would never have gone into public speaking in his previous life. This is not to say that he prefers his life with dementia, but it qualifies the statements about having a new life, a different life, which is a good life (identified in the next theme). This is important as it highlights how a younger person with dementia can remain an active citizen within society.

Further, Paul provided insight into his life with dementia, in regard to learning new skills:

> *'Learning new skills, the old skills that I have lost. I have related better to my family since I have been able to do that. I can now keep in contact... Over the next few weeks I am going to be very busy. Yes that's what makes life go round for me, Alzheimer Scotland and the SDWG.' (Paul)*

Paul was gaining independence through learning how to use an iPhone, and learning to manage reading again with a Kindle. Paul was also keen to share how busy he was, through the SDWG, being involved in research and public speaking.

5.7.2.4 Sub-theme - Making a difference

While participants were keen to remain independent and keep active, they were also altruistic. Participants were aware of the struggles that they had before their diagnosis and afterwards, the fear they experienced of being propelled into old age, losing their memory and the general unfairness of getting dementia at a younger age. However, regardless of the adversity they faced, they wanted to help others who were faced with the same situation. Tom talked about being challenged, how making a difference helped him:

> *'I like a challenge, I like to feel like I'm actually doing something, making a difference rather than just moping, staring out of the window thinking oh poor me, poor me. I could do that for about two days.' (Tom)*

Tom's recovery from the impact of the diagnosis was slow, but he found that by helping in some way, and making a difference, he had a sense of purpose.

Similarly, Ray talked about how he has helped people:

> '*I feel quite happy because I feel I have helped people. People come up and thank me and I feel like I have helped people understand, for carers and [it] gives professionals something to think about...' (Ray)*

Ray also mentioned helping people without dementia, and his comment about professionals is linked to the need for people with dementia to be recognised as the experts of dementia. Essentially, in helping others participants help themselves, but they also promote themselves as the experts which is important.

5.7.3 Theme - 'There is life after dementia, it's a good life'

This third and final theme, 'there is life after dementia, it's a good life', provides insight into how the participants think about their life now- living with dementia. The theme is constructed of four sub-themes.

While participants clearly accept that they have dementia, it is not dominating their life. There is a sense of determination to carry on and live the life they have to the full, they are evolving into their new life, living this new life.

John spoke about his life after dementia, adamant that there is life after receiving a diagnosis:

> '*There is life after diagnosis. I would say it's a full life. I think if you want to scare monger somebody nothing will help, but they are getting things in place now. Ok you've got to adjust to certain things but that's part of life anyway. It's just like a new chapter, that's how I look at it...I'm positive, uhh you've got to try and you've got to have your wits about you, you learn all the time.'(John)*

John talked about having a full life after diagnosis, but he was concerned about the way dementia is portrayed. John's life has changed because of his condition but he does not view this as the end, rather it is a different chapter. He talked of being positive and continuing to learn. John reflected that he was able to get through the experience of having a diagnosis, he was now positive with his views and the way he addresses his life. It is possible that this positive outlook on life helps a person to cope with dementia.

John was not alone with this view of life after diagnosis. Ray talked about enjoying his life with dementia, about being able to contribute to society and just getting on with it:

> ‘*Don’t write people off because they have got dementia, treat them as a human being. More often or not I was contributing something... We are going out into the community and showing there are things that we can’t do, but there are things that we can do...it’s an illness but just get on with it...Your life has not come to an end, it’s just taken a different turn ... I shock people when I say I enjoy my life with dementia.’ (Ray)*

Ray’s comment about ‘writing people off’ further indicates a negative view from others of people with dementia. Similarly, he also talked about his life taking a different turn. It is clear that Ray has accepted that he has dementia, but this has not stopped him living his life, it is just different and he still enjoys it. There is a definite distinction between the life before and after dementia. Participants talked about closing one chapter and moving on to the next, that life does not come to an end it is just a different turn.

Jenny also commented on her life with dementia in a positive sense:

> ‘*There [are] things beyond it, it’s not the end, I have not come to a wall that I can’t get through.’ (Jenny)*

In this statement by Jenny she acknowledged that her dementia will get worse but she is not there yet, and having a diagnosis is one thing, but it is not the end of her life.

Other participants commented on the importance of remaining positive, (Louise). Sally simply said:

> *‘Well, you just have to make the most of your life, do what you can, when you can.’ (Sally)*

Sally’s comment is pragmatic and suggests that she has accepted that she has dementia, but she is still going to make the most of her life.

While participants were able to accept that their condition would deteriorate they talked about the future. Participants lived their lives beyond dementia, accepting that they will experience changes in their abilities, but that they have to just get on with it. Participants continued to project a ‘joie de vivre’ when speaking about the future.

Jenny talked about being excited, looking forward to her first grandchild:

> '*And I am very excited at the moment because I am going to be a Granny, in November [laughs]. Yes so we have got lots of things going on because that's coming, and then in, we are going in, thinking it's February, to Australia...Grandchild coming, exciting...You do feel be positive all the time.' (Jenny)*

When Jenny spoke about these future events the excitement was detected in the way she spoke with a sense of happiness in her voice. She used the word excited to describe her feelings about her new grandchild and becoming a granny. She laughed about this with happiness, speaking quickly stating 'that they have lots going on'. Further, she mentioned about feeling positive. Participants talked about still being able to do things, taking a day at a time, and loving their lives and living their lives. There was a need for participants to remain positive and not dwell on their situation, this was identified by Sally:

> *'But I'm not going to sit down and cry about it. I'm going to carry on as far as I can. As well as I can I should say. As otherwise you might as well not be living if you are going to just sit down.' (Sally)*

This statement by Sally evidences a sense of determination to not just focus on having dementia, to carry on living her life. This was echoed by Tom, who following a period of reclusiveness realised that he still had a life to live:

> '*… but you can't go on with your life doing nothing, and or being a recluse … so eventually I went out and got lost, quite regularly ... But I was just trying to work out a strategy and I said right I'm gonna live my life and that's it... If you don't step out and live your life you're just throwing it away. And if you value things what you've got to remember they are just things.' (Tom)*

There was a sense of determination by Tom to live his life, step out, and get on with it. Tom emphasised further when he talked about being in the present and acknowledging what you have:

> '*One of the things about dementia is that it disinhibits you so much as you think what else have you got to lose because you know you are terminally ill... I mean I enjoy life I have a great time... I would say get up in the morning, get yourself dressed, nice shirt/ blouse, get your*

> *hair done, stand in front of the mirror and say I'm gonna enjoy myself today. Or even get up and look in the mirror and say hi. You've got to like yourself, I don't mean be fascinated by yourself. As much as possible kick negativity into the bin and don't over analyse the whys and wherefores... Whatever you are doing today this isn't practice, this is your life, I mean this isn't going to happen again. Basically, love your life, be fascinated by it. I don't see it as being anything heavier than that. Occasionally once a year walk out in bare feet in the rain and remember what it feels to be like this.' (Tom)*

Tom talked about remaining positive, taking stock and being conscious of life. Tom talked about loving life itself; this was something that was reiterated by other participants:

> '*Well, I still love life.' (Louise)*

As Tom talked about getting on with life, so did Ray, the comment below illustrates this:

> *'There's nothing shameful about it [dementia] - it's just like catching bronchitis or asthma or diabetes. You have developed an illness and you don't give into it and you learn to live with. There is going to be limitations in your life so you've got to accept limitation, but there [are] many opportunities for you, so go for that. Don't stay in the house, keep going out into the community and just laugh at things. What I've found out is people who can laugh at things seem to last longer with the dementia, people with a sense of humour if they do something stupid they won't berate, as I did, themselves they just laugh. It's an illness, but just get on with life.' (Ray)*

Ray's view of dementia is that it is an illness, like any other illness, but whatever, it is important to move beyond the illness, to get on with life and enjoy the time that you have.

Participants were keen to promote a good image about their lives following a diagnosis. They talked about how they lived their lives accepting what they were able to do, maintaining the ability to do the things they want to do and to remain independent. They spoke about living a good and meaningful life with dementia, not dwelling on the condition. The predominant message being that there is a life beyond diagnosis and that can be a good life.

5.7.3.1 Sub-theme - Coming to terms with the progressive illness

As part of living with dementia participants make sense of the progressive nature of their illness, how they are accepting that their abilities will deteriorate, that dementia is terminal and they will deteriorate. There was a general acceptance that ‘it’, their life, their dementia, will get worse. Although there was a sense of pragmatism about this, it was an abstract concept.

Jenny spoke openly with resignation when she talked about the progressiveness of dementia:

> ‘*It will eventually get worse, but I feel that that’s for me quite a long way away.’ (Jenny)*

While she accepted she was living with a progressive disease, this was not something she was going to focus her thoughts on at the moment, she considered this to be away into the future.

John and Tom were pragmatic:

> ‘*I would have to accept that I've got it, I can't do much about it.’ (John)*
>
> *‘So just have to get on with it.’ (Tom)*

The statements are uncomplicated and provide an insight into the acceptance of dementia and that really there is nothing they can do, so why dwell on it. Similarly, Louise accepted that her abilities will change, and used the word deteriorate to describe this:

> ‘*I know it’s going to deteriorate, I know it’s going to deteriorate, but I’m going to ward it off because I am going to be a fighter. I am going to do everything by the book I am not going to put myself into danger.’ (Louise)*

Louise repeated the word ‘deteriorate’ twice, but there is a determination to prevent her deterioration and delay any progression.

While Sally talked about the progression she also required affirmation that it is a progressive condition. In Sally's case this was probably due to her ability to comprehend due to her cognitive changes:

> '*You know I realise now that that's not the case it doesn't really improve... But never mind I say now if I keep as well as I am at the moment I will be ok. I will be quite happy at that really. Because I know it is a progressive illness, isn't it? Bound to get worse ...but I think, because I mean dementia will be a progressive illness, is it? So what I mean what would happen. I mean it is, it will get worse, will it? (Sally)*

The participants did not use the term 'I' when they talked about deterioration, rather they used the term 'it'. This suggests further that they see the dementia as separate from themselves, almost abstract. They did not talk about 'they, themselves getting worse'; they referred to the dementia as getting worse. Although the participants talked about having a progressive disease, accepting that it will get worse, they cope with this by distancing themselves from it.

5.7.3.2 Sub-theme - Rationalisation

Participants appeared to cope with having dementia by comparing their situation to other people with different conditions. It is suggested that this is a coping mechanism which enabled them to come to terms with the diagnosis, which while there is a stage of acceptance, there is continuity to accepting that you have dementia, reaffirming on a regular basis. The participants appeared to be benchmarking themselves by comparison to other conditions that they thought would be worse to have.

Statements such as '*it could be worse'* or '*there are worse illnesses'* were used to reassure themselves, that having dementia was not that bad. For example, when asked to expand on what could be worse Sally says that she is reasonably well, she can get around and about:

> *'But then again I keep saying well I could be a lot worse....I've got to laugh at it, I've got to laugh about it because if I didnae I would be really demented... However, it could be worse. Oh dear, well I would*

> *think…. Well I'm reasonably well I'm not fit but I can get around… I keep saying, never thought I would be like this in my life, but well there you go, it's a good job we don't know what's in from of us...Gosh I never thought I would be like this, but never mind, could be worse.'(Sally)*

Sally acknowledged that she was not in the greatest physical health, but she felt that she was better off than most people. Her statement about 'being really demented', is interesting, and suggests that she did not focus on her dementia or give it too much thought, because if she did it would impact on her ability to carry on with her life. While she says that she could be worse, she also seemed to disbelieve her situation.

Similarly, Louise also appears to use rationalisation as a coping mechanism to enable her to accept dementia:

> *'… there are worse illnesses. There are people out there with cancer people out there in pain, they live in a wheelchair… I would rather not have it, put it that way, but the thing is when you've got it you've got it. It's not the end of the world in many ways, but it's your family, the person they have known is changing. But there are worse things than this…' (Louise)*

Louise seemed to be suggesting that if she had to have an illness she would rather have dementia than cancer, for instance. She then, like Sally, reasoned with herself, taking a pragmatic view with the statement '*when you've got it you've got it'*, in other words there is not a lot you can do about it, and you need to accept it.

5.7.3.3 Sub-theme - Continuing family supports, maintaining family relationships

Family supports featured strongly with the participants, some of whom were very reliant of their spouses or siblings to help and support them live their life with dementia. It is important that this is recognised.

Jenny was aware that she was lucky to have her spouse who was dedicated to supporting her:

> '*…and because [my husband], I've got [my husband] all the time, because my friend, who had got, it has no one, so she needs help with finances and things like that. But [my husband] will be there that's why I am so lucky, he is very caring and thinking.' (Jenny)*

Jenny compared her situation to that of her friends who also has dementia, and who did not have any family support.

Ray described his wife as being a 'tower of strength', and Paul described his wife as:

> '*My soul mate….she is my rock.' (Paul)*

John was aware that he was reliant on his wife:

> '*My family treat me the same, but I rely on the likes of my wife and she remembers to do things.' (Paul)*

Doing things with their families was also important for participants, and provided a sense of normality, which links to the theme above 'keeping busy'. Paul talked about doing something each day with his wife:

> *'…and we do something every day together even if is just going to Tesco's. We make sure we do something we can share together each day, go for coffee or visit place, just simple things that obviously was important to me in the previous life.' (Paul)*

This statement from Paul provides insight into the importance of maintaining a sense of normality, sharing a life together, to do things that they used to do.

This was echoed by John who similarly wanted to continue to do things with his family and was supported to do so:

> '*The thing, might sound silly, what I look forward to when my wife is off we go out for a coffee, we go out for coffee go for the papers. We enjoy that you know. I get taken to the pictures with my son, you wouldn't believe it the four of us still go to the pictures, and we've done that for years. We just make a date, a film we want to see. We try and make sure we don't pick my sons, he's into these fantasy films*

> *like Star Wars, and I don't like and I don't think my girls like either, so we normally pick the film.' (John)*

John's statement also provides insight into the importance of continuing family relationships, doing things together. The things that they are doing are 'normal', they are not letting dementia interfere with their relationships, for them their experience is one of normality. Additionally, this provides insight into the importance of continuing relationships perhaps more pertinent because of the age and stage of the participants.

5.7.3.4 Sub-theme - Building support networks and forming meaningful relationships

In order for participants to cope with their lives living beyond dementia, they identified the need for strong support networks. It was important for them to build new relationships with other YPwD, while maintaining old friendships.

Participants experienced in being with other younger people with dementia as kindred spirits. All participants talked about the importance of meeting other people with dementia, and how being part of the SDWG or a day service, where they could relate to people, provided them with a sense of community and developing identity. Meeting other people initially helped participants in accepting their dementia, ongoing interaction and the forming of relationships assisted them to continue to cope and live their lives beyond dementia.

John particularly stressed the importance of meeting other people who were the same age as him with dementia:

> *'Knowing that somebody is roughly the same age as me is very good. If I was the only person of that age group then I would be worried, I would be even more worried… you know we are all roughly the same age. We talk, we laugh, we enjoy each other's company and I think that's a good thing. It keeps you, keeps your wits about you as well.' (John)*

John admitted that he was worried about having dementia at a younger age, but took comfort from meeting other people who were in the same position.

John then reflected on what he got out of the group, the importance of the social experience, being able to talk and laugh with others provided John with support through a community that was united through their commonality.

Similarly, Peter expressed the importance of meeting people with similar issues, how by hearing their experiences helped him to cope:

> '*Went to that [SDWG], and I was meeting other people, of about the same age group, who had the same sort of things happening to them. You met other people who had this, and experiences that they had and what they had done to get over this...That was a good thing as well…you get to meet other people who have had a diagnosis and went to groups with others and hear their stories, it becomes a lot easier. Getting to know other people who have it, I mean initially you think, oh goodness gracious.' (Peter)*

Peter used the term 'goodness gracious', as a way to emphasise the stress and anxiety of living with a diagnosis of dementia at a younger age. The SDWG helped Peter through the sharing of stories and experiences.

While Sally was not a member of the SDWG she sought solace from the specialist day service she attended:

> *'…I feel normal here, I do, it makes you feel. I think it's because everybody's like the same you know…Because if I hadn't come here goodness knows where I would have been, or what I would have been like today.' (Sally)*

Sally's comfort and support came from just being around other people with dementia. This gives emphasis to the need to ensure people with dementia are provided with access to meeting other people with dementia.

5.7.4 Summary

This super-ordinate theme presents how the participants started to manage their lives beyond dementia. Participants moved from feelings of loss of confidence and autonomy, to taking risks and acting under their own volition. These changes indicate improved well-being. The participants provided insight into how they managed risk taking, using their awareness of dementia to keep them safe by being cautious. This did not prevent them from doing things. Participants were keen to continue to undertake previous activities and were supported and enabled to do this. Further, they were able and enabled to learn new skills which helped them to undertake meaningful activities and contribute to society.

Part of the consolidation process was to accept that dementia is a progressive condition. Participants were aware of this, but this did not prevent them from making plans and looking to the future. Participants shared that they were experiencing a good life living beyond dementia, that they had experienced things that they would not have, had they not developed dementia. They accepted that they were now in a new chapter of their life.

To assist the participants to live beyond dementia it was important to build friendships and networks, which was achieved through the SDWG and meeting other people with dementia. Further supports came from family networks and continuing to undertake normal activities.

Coping with dementia was managed through helping others and making a difference, also they showed that they had the ability to retain and learn skills. Participants were able to reassemble their lives with support from other YPwD, and importantly their family networks. In doing so, participants were able to regain confidence and self-determination, ensuring that they were once again living autonomously.

5.8 Self-determination Theory and Well-being

This study aim was to explore the human experience of living with dementia at a younger age, to consider interpretations of well-being as defined by the subjective experience of the participants. Self-determination Theory, BPNT has been discussed in detail in the second half of Chapter 2, where it was discussed that SDT, BPNT, autonomy, competence and relatedness, would be used to determine well-being. A secondary analysis was undertaken where the findings and the super-ordinate themes, theme and sub-themes were mapped across the basic psychological needs to consider where autonomy, competence and relatedness were being thwarted, or where they were being supported.

The findings from the secondary analysis were put into a table to assist with identifying where the needs were fulfilled and where they were thwarted, and what the outcomes of this were on the participants and their well-being. The table (Table 10) is presented below and identifies where the basic psychological needs were fulfilled and where they were being thwarted within the super-ordinate themes, themes and sub-themes. There are four columns which identify the context where the basic psychological needs may have been fulfilled or thwarted, there are the four phases: pre-diagnosis, diagnosis, post-diagnosis and life beyond dementia. The table is divided into three sections:

1. The first section, identified in yellow, considers the need of autonomy, identifying where this need was fulfilled suggesting feelings of motivation and well-being, and where they were being thwarted, where there is the potential to create feelings of ill-being.
2. The second section, identified in green considers the need of competence and where this need was fulfilled or thwarted.
3. The third section, identified in blue considers the need of relatedness and where this need was fulfilled or thwarted.

Table 10 Findings from secondary analysis using SDT, BPNT

Basic Psychological need	Autonomy to act autonomously under own volition, to have choice

Autonomy	Context: Pre-diagnosis	Context: Diagnosis	Context: Post-diagnosis	Context: Living well beyond dementia
Need Fulfilled Identified	Acted under own volition -to manage social and work situation. Participants displayed autonomous behaviour – acting under their own volition and freewill.	Example of participant seeking diagnosis. Diagnostic environment was autonomy supportive where participant was given time and full explanations provided. Choosing when to disclose their diagnosis to others.	Choosing to face the challenges and accept changes in self. Choosing to not become dementia.	Choosing to take risk. Managing risks. Utilising cautiousness of dementia positively. Choosing to live life beyond dementia. Autonomy supportive environments: supporting initiation of old skill & learning new skills, doing their own thing and doing things on their own
Need Thwarted Identified	While participants acted autonomously during this period the need was potentially thwarted by their inability to fulfil their other needs. Feelings of loss of control were experienced during this period.	Diagnosis was sought by others rather than the person. The diagnosis – there is no control over the illness. Poor diagnostic experience, feeling of loss of control during & following diagnosis. Loss of control over information provided or not provided.	Loss of self-determination & freewill. Loss of spontaneity. Forced to make lifestyle changes due to dementia. Loss of choice: Driving, retirement. Stress & fatigue. Access to non-appropriate services. Not being recognised for age & stage.	Risk- averse behaviour from others.
Outcome	Need partially met as acting under own volition at times but compromised due non-fulfilment of other 2 needs.	In the early stage of this phase most participants felt a loss of autonomy due to the diagnosis, the diagnostic process. Following a period of consideration participants could make choices around disclosure.	Feelings of anger, frustration & loss due to changes in choice & freedom Accepting dementia, not becoming dementia	Improved confidence & Self-efficacy. Increased independence. Positive about their life with dementia, a good life beyond dementia.

Basic Psychological need	Competence : ongoing interaction, to seek challenge, to maintain & enhance skills

Competence	Context: Pre-diagnosis	Context: Diagnosis	Context: Post-diagnosis	Context: Living well beyond dementia
Need Fulfilled Identified	No	Disclosing their diagnosis successfully with positive reactions.	Learning to live with the challenges.	Challenged their cautiousness. Developed new skills – art of public speaking. Supporting others & raising awareness. Recommenced past hobbies. Acceptance of abilities. Confident in their skills to raise awareness about dementia. Normalised activities Supported through SDWG.
Need Thwarted Identified	Identified difficulty in undertaking simple tasks at work; numeracy problems; loss of competence in driving. A further loss of competence was identified where participants tried and failed to manage situations socially & in the workplace. The reactions from others were not competence supporting, negative responses to actions were received from others.	During and immediately following diagnosis. Loss of self-confidence Self-stigma; Diminished self-belief.	Continued loss of confidence. Developed sense of cautiousness because of dementia. Loss of licence Changes in cognitive and functional abilities.	
Outcome	Loss of confidence and self-efficacy.	Loss of competence, loss in self-confidence and self-efficacy.	Feelings of frustration due to decrease in cognitive and functional abilities. Learning to challenge changes, managing lifestyle.	Feelings of living life, contributing to society & helping others. Feeling supported Improved confidence & self-belief.

Basic Psychological need	Relatedness: to feel connected to others, being cared for, having a sense of belonging

Relatedness	Context: Pre-diagnosis	Context: Diagnosis	Context: Post-diagnosis	Context: Living well beyond dementia
Need Fulfilled Identified	No	Meeting younger people with dementia. Joining the SDWG Supportive relationships families & others. Positive reactions from friends	Having a voice. Being listened to Not becoming dementia.	Continued development of relationships & networks. Supporting other people with dementia. Relating to others with dementia. Strong & supportive family relationships.
Need Thwarted Identified	This need was not met during this phase: Loss of connectedness with work & colleagues. Communication diminished between family & significant other. Feelings of being unsupported in work & socially. Relationship problems due to changes in relationship.	Loss of connections with others immediately following diagnosis. Withdrawn and reclusive behaviours. Self-stigma. Self-isolation.	Not being listened to. Services not meeting needs of YPwD. Not recognised for their age & stage.	
Outcome	Feelings of isolation & exclusion, feelings of disconnection with others, misplaced	Initial feelings of isolation, fear & anger; loss of self-confidence, self-exclusion due to self-stigma. Improved feelings of connectedness when introduced to other people with dementia Improved family relationships Need to hold on to self & age identity	Potential to be distressed & unfulfilled due to inappropriate service provision. Further development of relationships. Being listened to, holding on to age & stage	Feeling connected to society, contributing through meaningful activities. Development of strong social identity.

5.8.1 Findings from secondary analysis

The secondary analysis was carried out in order to identify and confirm areas where the Basic Psychological Needs were being supported or thwarted, and identified periods of well-being and motivation, and periods where participants experienced ill-being. The following sections provide a written overview of the findings in table 10.

5.8.1.1 Autonomy

By mapping the three needs across the findings it was identified that in the pre-diagnostic phase the needs of competence and relatedness were affected. The table identifies that particularly in the pre-diagnostic and diagnostic phase the BPN were thwarted.

Autonomy was fulfilled at the pre-diagnostic phase as participants were acting autonomously as they tried to manage their changed situations. The outcome of the analysis identified that during this diagnostic phase, superordinate theme, living in a changing world, participants’ needs were only partially met as they were able to act under their own volition, but were compromised due to the need for competency and relatedness being thwarted.

In the diagnostic phase the need was fulfilled where there was a positive diagnostic experience, suggesting that the environment was one which was autonomy supportive, created by the physician. Conversely, the negative experiences identified the BPN as being thwarted where participants experienced a loss of control during and following the diagnosis. Further losses were experienced over the information and support they accessed or failed to access following diagnosis. The outcome in the early stage of the diagnostic phase was a loss of autonomy; however, following the period of consideration the findings identified how participants had feelings of autonomy, particularly with whom they shared their diagnosis.

In the post-diagnostic phase there was a shift towards more autonomy being exercised, with participants going through a process of assimilation. The superordinate theme, the challenge of learning to live with dementia, identified participants choosing not to become dementia. However, the needs were thwarted where they experienced a loss of self-determination through a loss of confidence and experiencing a loss of spontaneity to act under freewill. Further loss of autonomy was identified when accessing services, not being given a choice in regard to the services. Participants were able to feel autonomous where they were given the choice, or time to make high impact change, whereas those participants who were forced to relinquish their driving licence or retire from work, experienced ill-being and an extreme sense of loss. The outcomes in this phase were that participants experiences feelings of anger, frustration and loss due to changes in choice and freedom. However, there were positive experiences of choosing not to become dementia.

In the final phase, living well beyond dementia, the need for autonomy was fulfilled where it was identified that participants were choosing to take risks, utilising the cautiousness of dementia to do this. Participants made a positive choice to live well with and beyond dementia, not seeing it as the end, but a different turning. Autonomy supportive environments enabled them to live their lives in this way by being enabled to learn new skills and continue with old skills. There was only one area in this phase where autonomy may have been thwarted and that came from others, such as professionals and family networks that could potentially be risk averse, and transfer their concern to participants. The outcome of this phase with autonomy supported environments, was improved self-confidence, self-efficacy, increased independence. Participants were positive about living a good life with dementia.

5.8.1.2 Competence

It was identified that in the pre-diagnostic phase that the need for competence was completely thwarted. Participants experienced difficulty in undertaking simple tasks at work, such as numeracy problems. Further losses of competence were identified with driving skills. Participants also experienced diminished ability to manage social situations. Reactions from others reinforced their loss, as they did not feel supported by others where there were negative reactions, because of their (the participants) inability to undertake a task or manage a situation. The loss of competence in this phase led to a loss of confidence and self-efficacy (Bandura, 1994).

Situating competence in the diagnostic phase participants experienced competence when disclosing their diagnosis to others. This was evident through the reactions of acceptance by others. It was identified that the need was thwarted during and immediately after diagnosis where the diagnostic experience was not autonomy supportive. The reaction to diagnosis created feelings of loss of competence leading to loss of self-confidence, self-stigma and a diminished self-belief. The outcome in this phase was loss of competence, self-confidence and self-efficacy.

In the post-diagnostic phase the need for competence was fulfilled as participants started to learn to live with the challenges of living with dementia. The analysis identified that competence was thwarted with a loss of confidence, and the development of a sense of cautiousness because of the diagnosis of dementia, leaving participants feeling that they were unable to do something because they had dementia. Further, the need for competence was thwarted where participants were forced to relinquish their driving licence or retire from work without the time to come to terms with these high impact changes. The outcome in this phase was one where participants experienced feelings of frustration, mixed with the positive experiences of learning to challenge changes and managing their lifestyles.

The final phase, living well beyond dementia, identified a complete shift with competence being supported where participants challenged their cautiousness, daring to do things, using the cautiousness positively to risk manage. In this phase they developed new skills and recommenced old skills, further supporting the need for competence. The findings did not identify any thwarting of the need in this superordinate theme during this phase. The outcome in this phase was that participants experienced living life, contributing to society. They felt supported and experienced improved confidence and self-belief.

5.8.1.3 Relatedness

In the pre-diagnostic phase it was identified that participants experienced this need as being thwarted completely. Participants experienced a loss of connectedness at work and at home. There was diminished communication between their family and significant others. The need was further thwarted where they experienced feelings of being unsupported in work and socially where they experienced relationship problems. The outcome in this phase was that participants experienced feelings of isolation, exclusion, disconnection with others and feeling misplaced.

During the diagnostic phase participants experienced a fulfilment of this need when they met other younger people with dementia. They also felt accepted by others where they shared and disclosed their dementia diagnosis. However, it was identified that the need was thwarted where they experienced a loss of connections immediately following diagnosis, where they felt isolated and alone. Those participants who had a poor diagnostic experience became reclusive. The analysis identified participants experienced feelings of self-stigma and self-isolation, which impacted on the need for relatedness and the ability for this to be supported. The outcome in the diagnostic phase was that participants initially experienced feelings of isolation, fear and anger, which led to self-exclusion linked to the self-stigma. However, as they moved through a process of consideration the need for relatedness became supported where they were introduced to other YPwD, and the relationship with their family and significant others improved. It was identified that there was a need to hold on to their age identity.

Following the post-diagnostic phase participants experienced the need for relatedness being supported and at times being thwarted. The need was thwarted where they experienced difficulties with their voice being heard, not being listened to. There was a disconnection for some participants with the services that they were offered, they could not relate to services where they were accommodating older people. Further, they felt that they did not relate to older people and dementia and desired a need to hold on to their age and stage. The need for relatedness was supported where they were able to have a voice, where they related to their dementia experience as being different and not becoming dementia. The outcome in this phase was that where the need was thwarted there was the potential for participants to feel distressed, particularly around access to services. Where the need was supported participants were able to develop relationships through being listened to, holding on to their age and stage where people related to them rather than dementia.

During the final phase, living well beyond dementia, participants experienced a fulfilment of the need for relatedness. They continued to develop relationships with others, developing their social networks and their relationships with their family continued to be supportive. They related to other younger people with dementia and they supported others following a diagnosis. The outcome, therefore, was positive, participants felt connected to others and society, contributing through meaningful activities and developing a strong sense of social identity.

5.8.2 Summary

The secondary analysis has clearly identified where the three basic psychological needs have been supported or thwarted. There is a clear link to feelings of well-being where the needs are met fully; conversely, the findings suggest that the participants experienced ill-being where the needs were thwarted. The secondary analysis also identified how the three needs are connected, and how in order to experience well-being all three BPN must be met. This was indicated in the pre-diagnostic phase where although participants remained autonomous, the BPN of competence and relatedness were diminished and it was clear that they experienced feelings of ill-being during this phase. However, in the final phase, living well beyond dementia, it was identified that all three BPN were supported and participants felt positive, suggesting that they experienced feelings of well-being.

5.8.3 Conclusion

This chapter has presented the themes identified through the data analysis in detail. Four superordinate themes were identified which followed a transition pathway from the pre-diagnostic phase through to living well beyond dementia. The four phases are linked to a three stage process, participants moved from feelings of discombobulation, through a process of consideration, assimilation and finally consolidation.

The themes identified that participants experienced feelings of anxiety and distress in the first two phases, suggesting ill-being. The diagnosis brought feelings of anger and relief, and their reaction to the diagnosis was perhaps a natural reaction given the diagnosis, their age and the way in which it was delivered. There were indications that the way diagnosis is delivered impacts on the person's reaction. Further, feelings of frustration and loss were experienced in the third phase, post –diagnostic phase, but through the process of assimilation they were able to move to full acceptance, which appeared to create improved feelings of wellness.

Participants identified with feelings of loss of autonomy and self-determination following diagnosis, which indicates a loss of motivation and well-being. However, following assimilation of the diagnosis participants underwent a process of learning to live with the challenges of life with dementia at a younger age. In this phase participants identified how they overcame their loss of confidence and started to take risks and manage their lives in a more independent way. They utilised the cautiousness of dementia to keep them safe, turning the loss of spontaneity into a positive. They were supported by building networks and relationships with other people with dementia and through their families. The participants provided a positive account of how they now experience their life beyond dementia.

The secondary analysis, utilising SDT, BPNT, identified that where the three BPN, autonomy, competence and relatedness are thwarted, the participants experienced ill-being. However, where the three needs were supported, as in the final phase, living well beyond dementia, participants experienced feelings of well-being.

6 Chapter 6 Discussion

6.1 Introduction

The previous chapter presented the findings following analysis of the data using an interpretative phenomenological approach, and the secondary analysis utilising SDT, BPNT. This chapter discusses the findings and how they relate to previous research in relation to YPwD, and drawing on literature related to the experience of chronic disease at a younger age. The discussion also draws on relevant practice and theories such as the Self's framework (Sabat, 2002) personhood (Kitwood, 1997).

The aim of this research study was to explore the human experience of living with dementia at a younger age, to consider interpretations of well-being as defined by the subjective experience of the participants. In relation to well-being the research is discussed through the lens of Self-determination Theory, using the three basic psychological needs as a framework.

Self-determination Theory (SDT) is a well-documented and evidenced theory of motivation and wellbeing developed by Edward L. Deci and Richard M. Ryan (1985, 2000). SDT has identified that as active organisms human beings have an innate need for autonomy, competence and relatedness, which are referred to as the three basic psychological needs (BPN).

Self-determination Theory suggests the need for a 'unified self' (Deci and Ryan, 2002). This current study has identified that the self is impacted on and changes through different phases, from the pre-diagnosis phase through to living well and beyond dementia, through a process of consideration, assimilation and consolidation. This current study draws on the Self's-framework, discussed in chapter two, to try and understand how the participants' sense of self was impacted upon and provides some explanation as to why.

The discussion chapter has placed the super-ordinate themes into four phases of transition, along with the processes that were identified through the findings in Chapter five: 1. Pre-diagnostic phase - living in a changing world –changing self, discombobulation; 2. Diagnostic phase – anger and relief, fragmented self, consideration; 3. Post-diagnostic phase – the challenge of learning to live with dementia as a younger person, evolving self, assimilation; and 4. Living well beyond dementia – consolidated self, consolidation. This chapter explores each of the superordinate themes situated within each phase, drawing on the previous literature focused around YPwD and other supporting literature.

The findings identified that participants were able to live well beyond their dementia, and that through the transition there was improved well-being, motivation, resilience and an increase in independence. It is suggested that age is an important factor in their ability to cope with moving on to live a new life while living with dementia, in that they need to be seen within their age and stage. Participants were of the view that their experience of dementia is different to that of late onset dementia. One of the coping strategies to manage acceptance was to keep dementia separate from themselves.

6.2 Super-ordinate theme - living in a changing world - Pre-diagnostic phase, discombobulation

6.2.1 Introduction

This super-ordinate theme, living in a changing world, uniquely identifies the lived experience of the time before diagnosis and the psychosocial changes that were being experienced, and is situated within the pre-diagnostic phase. While previous studies have identified an awareness of memory problems prior to diagnosis (Pesonen *et al.* 2013), this current study provides a detailed insight into a small group of YPwD and their lives before their diagnosis that goes beyond previous accounts.

This study found participants were able recall their time before diagnosis with clarity, providing a clear insight into this period of their life. The theme, living in a changing world, provides an in-depth view of the participants' experiences of dementia prior to diagnosis. During this phase participants continued to experience their world and create meaning of it in relation to changes in their reality, as they developed dementia they tried to make sense of the world around them. All participants experienced an awareness of change within their world and spoke about ‘going mad’, ‘being bewildered’ and using metaphors, such as ‘falling into a black hole’ to interpret their experiences.

During this phase participants could not understand what was happening within their social environment; therefore, their basic psychological needs of autonomy, competence and relatedness were thwarted. The findings provide insight of the participants’ struggle to cope within an environment that no longer makes sense to them (Ryan and Deci, 2002). Participants described how the environment became strange, they viewed it differently and found themselves having to live day to day within the changing world, which evoked within them feelings of confusion and incomprehension.

It is suggested that there were issues with social isolation at this phase, because of the challenges they were trying to cope with, this links to the basic psychological need for relatedness (Deci and Ryan, 2002). Social isolation was a theme identified in previous studies (Harris, 2004; Harris and Keady, 2009), but this was in relation to the experiences following diagnosis. In relation to the BPN, there was a decrease in their abilities which resulted in participants experiencing a diminished competence in social situations, leading to a further impact on relatedness (Clarke, *et al.* 2016; Deci and Ryan, 2002). They experienced difficulty in making sense of social events, which created feelings of anxiety and fear about their ability to interact in those situations. There were feelings of isolation in regard to their relationships with family, as they had become paranoid and mistrustful. Similar to previous studies (Chaplin and Davidson, 2016; Evans, 2016; Ohman *et al.* 2001) coping strategies were developed to manage the challenge of living in ‘this strange world’, particularly for those participants who were working, indicating that there is a high level of insight and self-awareness by the younger person.

What this super-ordinate theme highlights is a need for early diagnosis (Bakker *et al.*2010; Draper *et al*. 2016; Draper and Withall, 2016; Knapp *et al.* 2007; Luscombe *et al.* 1998; Sperlinger and Furst, 1994), as participants found themselves left to cope with the onset of dementia through a lack of awareness about dementia in younger people. However, as this current study is able to provide a clear insight into life before diagnosis, which was extremely distressing, it perhaps provides support to the argument of early diagnosis to add to those already presented in previous research, such as seeking treatment and future planning (Sampson *et al.* 2004; Weaks *et al.* 2012). Raising awareness of dementia in younger people is required particularly since diagnosis can be more complicated in younger people (Rosser *et al.* 2010) and that presentation of symptoms can be subtly different (McLennon, 1999).

6.2.2 Theme - 'What the heck's wrong with me?'

This theme, 'what the heck's wrong with me?' provides insight into the dynamic process of change experienced and expressed by the participants, and how they tried to navigate their lives through these changes during this phase.

This current study identified that during this phase there was an impact on participants' own beliefs in their self and identity (Self-1, and Self-2) (Sabat, 2002). Everything they believed about themselves, their world and their abilities as based on their attributes and learning, had been distorted by the onset of dementia, which they themselves questioned. Further, this relates to the three basic psychological needs and how the onset of symptoms impacted on these.

This study found that participants were acutely aware of their changing self and changing environment; therefore, this period was fraught with anxiety and distress, causing a disruption to their lives and creating feelings of ill-being (Bury, 1982). One suggestion for this greater distress at this phase is the age and stage of the participants' life, because their life is more complicated and challenging to that of an older person (Roach and Drummond, 2014). Participants did not associate their symptoms with dementia which is similar to Personen *et al.* (2013), and is perhaps due to the fact that participants in both studies were younger and would not have had an awareness of dementia affecting younger people. These findings imply that having absolutely no insights into why the world feels different is more distressing and anxiety provoking than having some knowledge that you may have dementia.

Consistent with previous research, participants experienced difficulties with getting a prompt diagnosis (Beattie *et al.* 2004; Clare *et al.* 2008; Harris, 2004; Harris and Keady, 2004). Similarly, the participants could recall a long wait to accurate diagnosis, which has been well documented in previous qualitative studies (Harris, 2004; Harris and Keady, 2004), and a theme that was supported by the quantitative studies reviewed (Armari *et al.* 2012; Luscombe *et al.* 1998; Novek *et al.* 2015; Sperlinger and Durst, 1994).

This finding identifies an ongoing need to raise awareness of the realities of dementia in younger people. The length of time to diagnosis, the reported misdiagnosis and the very clear insight into changes to self, clearly indicates an impact on well-being. Campbell *et al.* (2016) described the process from pre-diagnosis to diagnosis as 'living with uncertainty' (p.40), whereas this current study would describe this phase as 'living in turmoil and chaos' with feelings of discombobulation.

Although participants perceived their environment to be changing, it was themselves that were changing in regard to their perception of their environment. Self-determination Theory posits that the social environment can impact on the basic psychological needs of autonomy, competence and relatedness, since there is a continual interaction between the person and their social context (Deci and Ryan, 2002). The delay in prompt diagnosis, and the lack of awareness about dementia in younger people, provides an environment that is not supportive of need fulfilment.

Previous research relating to YPwD and awareness of changes to self, have been identified mainly as the person progresses with dementia and following diagnosis (Beattie, 2004; Harris 2004; Harris and Keady, 2009; Pesonen *et al.* 2013). These previous studies provided limited accounts of awareness to changes to self on the stage prior to diagnosis for YPwD. A recent study focused on older people, identifying transition from pre-diagnosis to diagnosis, acknowledged some self-awareness that something was wrong prior to diagnosis (Campbell *et al.* 2016). Keady and Gilliard (2002) identified feelings of fear due to changes in memory and a validation that something was wrong, creating feelings of relief. Leung *et al.* (2009) identified changes in functional abilities. Both those studies focused on late onset dementia.

While those studies provided detail in regard to symptoms experienced in the pre-diagnostic phase for older people, the experiences articulated by participants in this current study were alarming in the disruption that they caused, and the feelings of anxiety and fear that they created. It is suggested that the experiences of the changes due to dementia prior to diagnosis were greater for the participants in this study, due to their age and stage and complex nature of their lives during that time, compared to the lives of older people.

It is suggested that a disruption in the life course commences at this phase with a full of 'biographical disruption', as described by Bury (1982), occurring fully in the diagnostic phase. Although participants had not received a diagnosis, their lives were being disrupted by the onset of symptoms of dementia, thus they were forced to make dramatic changes to their life course, such as taking early retirement without knowing why or what was wrong with them.

Although previous studies identified a disruption within the person's life with a diagnosis of dementia (Clemerson *et al.* 2014; Harris and Keady, 2004; Pesonen *et al.* 2013), this was not associated at the pre-diagnostic phase. An early diagnosis would have avoided the stress and anxiety created by not knowing what was going on.

6.2.3 Theme - 'There's something wrong with you'

The theme, 'there's something wrong with you', identified participants' families and significant others were aware of the changes in the person. Participants' spoke about their families and significant others being aware of the difficulties and changes they (the participants) were experiencing.

Despite these changes the findings identified that there was a lack of communication about the concerns that each party were experiencing. While previous studies also identified awareness of change by family members, conversely, they also identified that not all party members were aware of the changes being experienced (Pesonen *et al.* 2013).

The reason why there was avoidance of discussion by both parties and the changes experienced was not provided, but could perhaps be linked to denial that there is anything wrong or as Husband (1999) posited, that it is a mechanism to protect the spouse. Having no one to confide their fears and anxieties with suggests that the participants were trapped and alone in their changing world, trying to make sense of what was happening around them. This inability to discuss the issues that were being experienced by each party impacted on their relationships and the BPN need for relatedness. This has the potential to create feelings of social isolation for all parties involved with the younger person who has dementia. SDT asserts that relationships are crucial in supporting well-being and supporting the need for relatedness. Additionally, to support the need of relatedness there is a need to feel supported by the partner to assist with meeting the needs of autonomy and competence (Deci and Ryan, 2014).

Clearly within the situation created by the onset of dementia, and the failure to receive a prompt and accurate diagnosis, there was difficulty with sustaining relationships which thwarted the three basic psychological needs. This was identified where participants spoke about their failing relationships and the near breakdown of these.

6.2.4 Theme - ‘Thrashing about in the darkness’

The theme, ‘thrashing about in the darkness’, provides insight into the frustration that was experienced by participants in regard to their inability and function. Cheston and Bender (2003) suggest that neurological changes are experienced by all people prior to diagnosis, along with psychosocial changes, such as a loss of competence in previously mastered skills. For those participants in this current study who were still working, the predominant changes in skill competence were experienced at work with an inability to undertake simple tasks and issues with numeracy. This finding supports the findings in previous studies (Chaplin and Davidson, 2016; Evans, 2016; Harris, 2004; Harris and Keady, 2004; Pesonen *et al.* 2013), and indicates that changes are more likely to be noticed within the workplace. Further, Roach and Drummond (2014) identified that issues and changes at work tend to be overlooked and remain unquestioned. It is unlikely that workplaces would link changes to competence in performing tasks to dementia where the employee is younger (Roach and Drummond, 2014). This lack of awareness could result in unsupportive environments and lead to unnecessary retirement which was identified in this current study. This finding highlights a need for raising awareness about younger onset dementia in the workplace.

From the perspective of SDT, competency is one of the needs that if not supported can create feelings of ill-being and decreased motivation (Clarke *et al.* 2016; Deci and Ryan, 2002). Feelings of frustration and anxiety were experienced by participants in the early stages due changes in their abilities and their difficulty to master simple routine task, which caused confusion and a questioning of self.

Strategies were developed by the participants to cover up their difficulties in the workplace, such as staying late or taking work home in order to keep up with the work load. The implementation of strategies to hide difficulties in coping at work supports the findings in Chaplin and Davidson (2016) and Evans (2016). Similarly, these current findings, as with those two previous studies, identified that the strategies failed. Managing at work with the onset of dementia was further exacerbated where changes were introduced, no matter how small the changes were. This supports the findings in Ohman *et al.* (2001) and Chaplin and Davidson (2016) where it was identified that YPwD experienced feelings of constant anxiety and worry in the workplace, and how seemingly small changes in work routines impacted on the person’s ability to work effectively.

This need to develop strategies to manage at work is related to competence and autonomy. SDT suggests that as active organisms there is a need for challenge and to feel masterful in the tasks that are undertaken (Clarke *et al*. 2016), but where the challenge is too great this can have a detrimental impact on feelings of well-being (Deci and Ryan, 2000). In this first phase, where participants experienced noticeable changes in their abilities, they responded to the challenge in order regain competence in the task but they were unable to master this, therefore, they experienced feelings of ill-being due to their inability to do this.

6.2.5 Theme - Embarrassment and shame

The theme, embarrassment and shame, is about the experiences by the participants when in public situations. During the pre-diagnostic phase there were indications of an erosion of Self-3, which is considered to be the self that is most vulnerable since there is a reliance on others to help maintain this (Sabat, 2002). This was identified where participants' social personae had to be reconstructed within the different social situations in which they found themselves. Participants developed strategies in order to manage socially, but they were exposed when the strategies failed, creating feelings of exposure. This suggests a diminished sense of competence when interacting in social situations. They were met with intolerance from others when in these situations, and it was in these situations that embarrassment and shame was felt. Further, it is suggested that these reactions from others created feelings of isolation and impacted on their need for relatedness through relationships with others (Deci and Ryan, 2000, 2002, 2014), suggesting that this basic psychological need was being thwarted.

The feelings of embarrassment were perhaps experienced because participants knew they were acting in a way that was incongruent with their world. This is important as it identifies a complete awareness of their changing self and their environment, and further identifies a loss of the need of competence and one of choice and control (autonomy). Further, it indicates participants' complete understanding and awareness of their changing self and their situation; they even had awareness and insight of their failure with their coping strategies. So, despite the neurological changes and psychosocial changes, their ability to be aware was unchanged. This insight is important as it could be utilised to help raise awareness in the younger communities.

6.2.6 Summary

This super-ordinate theme has identified the first phase, pre-diagnosis, where participants have a clear insight into the changes to self and ability. The participants were required to manage day to day situations that would ordinarily have been easy, but had become extremely complex during this phase. This was a result of the beginnings of cognitive impairment leading to diminished functioning, along with not knowing what was wrong but knowing that they were not right. Trying to make sense of their reality led them to think that they were going mad, but also led to mistrust of others. Participants tried to manage complex situations and changes to self through the development of strategies, however, when these failed them they felt exposed, leading to a sense of vulnerability to self. The findings identify a need for early and accurate diagnosis, along with raising awareness of dementia in younger age groups.

6.3 Superordinate theme - anger and relief - Diagnostic phase, consideration

6.3.1 Introduction

This diagnostic phase identified the experience of diagnosis and the impact this had on the participants. This study identified that participants' responses to diagnoses were strongly influenced by the diagnostic process itself. Where this was positive there were feelings of relief and some elation was detected; however, this contrasted strongly with participants who felt that their diagnostic process was an extremely poor experience, particularly in relation to communication, information provided and the time it took to receive this information. It is suggested that the impact of the diagnosis can create feelings of a fragmented self (Kondo, 1990). The impact of diagnosis has been identified in previous research as one of devastation (Clemerson *et al.* 2014) and of having a profound psychological impact on the person (Pipon-Young *et al.* 2011). These are discussed in detail in the themes below.

Four participants (male) provided traumatic accounts of their diagnostic experience and the impact thereafter, one participant (female) provided a positive account of her diagnostic process and her experience following this. Although the three female participants commented on diagnosis they did not experience the same trauma as was identified with the four males; therefore, suggesting a gender split in the reaction to diagnosis. Previous studies have noted that men are more likely to display their anger and frustration compared to women in regard to difficulties (Caddell and Clare, 2011a), and this current research suggests that females react differently to males in their response to the diagnosis. Delivering a diagnosis is in the control of the physician, and SDT provides evidence that environments that support the BPN such as autonomy can be created by others (Williams, 2002).

6.3.2 Theme - 'Astonished and angry, very angry'

This study found the recalling of the actual diagnostic process to be interesting and informative to the research. Four participants spoke about being very angry about their experience of diagnosis; however, one participant viewed the process positively. While previous research refers to diagnosis (Beattie *et al.* 2004; Pesonen *et al.* 2013), there is limited detail around the actual subjective experience of the diagnosis. This current research differs as it identifies clearly the subjective experience of the diagnosis and how the way diagnosis is delivered is dependent on how it is accepted.

This study identified that participants were able to communicate their experiences of the diagnosis, articulating how they felt at the time they received their diagnosis. Four participants recalled a particularly negative experience about how and when they were told they had dementia. They were angry and astonished with visible signs of emotional distress, which were displayed during the interview as they recalled their experiences.

Previous research has identified challenges around the diagnostic process and experience. The findings in this current research shares similarities with Beattie *et al.* (2004) where their participants referred to their experience as being ‘baffling and brutal’ (p.363) due to the number of tests that they were subjected to. However, this study differs to Beattie *et al.* (2004) as the participants in this current study talked at length about their experiences when receiving their diagnosis with detail and clarity, whereas the previous research provided limited narrative around the actual experience of diagnosis. Pesonen *et al.*’s (2013) primary focus was on diagnosis although they did not identify, nor did they go into the detail of the experiences of the person receiving the diagnosis.

The positive diagnostic process identified was linked to the time given, the information that was provided at the time of diagnosis and the clear explanations communicated by the physician during the diagnostic process. Previous research also indicated that YPwD can have positive diagnostic experiences (Beattie *et al.* (2004) related to a specialist diagnostic service. Relating this experience to SDT it is suggested that in the case of the participant in this current study, she experienced a social context that was autonomy supportive, one which considered the participant’s perspective, one that provided her with a sense of control and choice over the situation (Williams, 2002).

Conversely, a negative diagnostic experience was perhaps due to feelings of lack of control over the situation, and possibly the environment was one in which participants found themselves without an opportunity to be autonomous, consequently this generated feeling of being controlled (Williams, 2002). Certainly, there were feelings of relief following the diagnosis where that diagnosis was a positive experience, which was not experienced by those participants who interpreted their experiences negatively.

In accordance with SDT it is suggested that a positive diagnostic process would be one that is autonomy supportive which enables the person to feel in control of their situation. Where the person is given time, where the physician is not rushed, having explanations that are clear and precise, having support from others at the time of the diagnosis, would be considered to be autonomy supportive. Additionally, the person who is responsible for providing the diagnosis needs to be cognisant of the power they have and how they can influence how the diagnosis is received and accepted. They require an understanding of how they provide the diagnosis could have a major impact on the person.

This study's findings suggest that preparation and information to support the diagnostic process would perhaps help prepare the person undergoing tests. Receiving a diagnosis has the potential to be devastating to the person, and the impact of diagnosis is dependent on the delivery (Innes *et al.* 2014). The findings in this study indicate that it was the delivery of the diagnosis and the manner in which it was given that affected the participants greatly, and supports findings in Innes *et al.* (2014).

The emotions following diagnosis can vary depending on the individual and in the way the diagnosis was provided. These findings suggest the need for counselling and information prior to actual diagnosis. Where a person is prepared for the diagnosis their reaction and ability to cope with the diagnosis should be improved. While post diagnostic support is now recommended for all people who receive a diagnosis of dementia (Innes *et al.* 2014), it is suggested that those younger people undergoing investigations for dementia are provided with opportunities for pre-diagnostic counselling.

This current study indicates that poor diagnosis, with no follow up, contributes to a period of withdrawal and feelings of depression. The study by Pesonen *et al.* (2013) found that YPwD are less prepared for the diagnosis, and this current study has found that those participants who had a poor diagnostic process found difficulty with adjustments and acceptance. Therefore, further supporting pre-diagnostic counselling which may help prepare them for the diagnosis and improve their ability to accept their diagnosis.

6.3.3 Theme - 'Very, very frightened' and 'sense of relief'

This theme identifies the impact of the diagnosis on the person and it is suggested that the way the diagnosis is provided can impact on recovery time, and on the time it takes for the person to accept and adjust to their diagnosis of dementia. There are clear indications of different reactions to diagnosis, which appeared to be dependent on the diagnostic process. Participants talked about experiencing deep depression, negative thoughts and becoming introverted and reclusive. This is interpreted as a fragmentation of the self (Kondo, 1990), with a diffusion of the self or identity, causing a collapse of the self within the known world.

Comparison of the finding with other studies confirms that diagnosis has a profound psychological impact on the person (Pipon-Young *et al.* 2011); similarly, Clemerson *et al.* (2014) identified feelings of complete devastation. Pipon-Young *et al.* (2011) and Clemerson *et al.* (2014) interpreted the reaction of diagnosis to dementia being a condition that affects older people.

A similar interpretation was also supported by Pesonen *et al.* (2013), who suggested that the impact of diagnosis on younger people is greater because it is predominantly a condition that affects older people. This current study also supports this interpretation, although considers the reaction to the diagnosis not just related to the fact that it is a condition that is dominant in the elderly population, but also as a response to the actual diagnostic process.

During this phase there were indications that participants experienced a 'biographical disruption' as described by Bury (1982). There is similarity to Bury's participants as they struggled with the diagnosis of rheumatoid arthritis, a condition primarily linked to older people, where the thoughts and feelings identified in that study have parity with the experiences felt by the participants in this current study at the time of diagnosis. Bury describes this as ‘a marked biographical shift from a perceived normal trajectory through relatively predictable chronological steps…the relationship of internal and external reality was upset’ (Bury, 1982, p.171).

Pesonen *et al.* (2013) described diagnosis as being a point of change where participants felt a disruption to their life course, and experienced fear and sorrow in response to the diagnosis. Although they do not refer to this as a biographical disruption, it is suggested that the emotions and feelings equate to this. Interestingly, Pesonen *et al.* (2013) found that those participants in their study who were older (over the age of 65) were less psychologically impacted upon by the diagnosis of dementia, which provides further indication that an impact of diagnosis on a younger person is greater to that of a person with late onset dementia. It is important to note that in this current study no such disruption was experienced by the participant who recounted a positive diagnostic process and experience, suggesting that the way the diagnosis is provided influences the impact on the person and self.

The experiences of depression fear and anger following diagnosis are interpreted as a ‘biographical abruption’, as defined by Locock *,* Ziebland and Dumelow (2000) study of people with motor neurone disease (MND). They use the term ‘biographical abruption’ where an individual is provided with a diagnosis of a terminal disease, causing the person to feel that their life is going to end suddenly, which encapsulates the commonly reported feeling that the diagnosis was a ‘death sentence’ (p.1047). Abruption refers to ‘life simply not happening at all – the story is already over’ (p.1048). This current study also identified the distinct feeling of abruption with some of the participants following their diagnosis.

Locock *et al.* (2000) described how their participants hid themselves away and wished they were already dead. Participants in this current study talked about hiding away and thinking their life was over. It is acknowledged that some forms of MND have a fast progression, however, there are similarities with this current study due to the age group and that both conditions are terminal. It is proposed that those participants who went through a negative diagnostic experience felt a ‘biographical abruption’. Following abruption the participants moved on to biographical disruption. Locock *et al.* (2009) describes disruption as ‘disturbance and unwelcome change’ (p.1047) suggesting that a biographical disruption is manageable, as was identified in this current study, where participants displayed that they were able to readjust their lives following a process of consideration and assimilation.

It is recognised that while participants struggled with the knowledge of their diagnosis they were unified in their support for early diagnosis, and the importance in getting a diagnosis. It was a dilemma for participants in that they did not want to hear that they had dementia and reacted to the diagnosis negatively, on the other hand diagnosis brought them a sense of relief, even to those participants who were most impacted upon by the diagnosis. Similar to this research Pesonen *et al.* (2013) found that diagnosis brought a sense of relief in knowing the reason for their symptoms. Participants in this current study were provided with verification and validation that something was wrong with them, alleviating those feelings of anxiety and fear, reassuring them that they are not going mad.

Previous research supports the need for early diagnosis regardless of age (Harvey, 1998; Knapp *et al.* 2007; Sampson, 2004; Weaks *et al.* 2012; Werner *et al.* 2009). Having an early diagnosis enables the person to plan their future and access appropriate treatment (Sampson, 2004). While that is an important factor for all people, this research identifies the distress and anxiety of not knowing what is happening to you in the pre-diagnostic phase.

The pre-diagnostic phase provides a clear insight into the disruption caused through living with dementia without knowing you have dementia, not only for the person living with it, but for those living with it vicariously. This is the primary reason that an early diagnosis is required. In 2012/2013 the Scottish Government introduced the HEAT standard promoting the right for a person to have a diagnosis; additionally, with the first Scottish National Dementia Strategy (2010) the right for a person to have a diagnosis was an objective. This study provides further support for early, prompt and accurate diagnosis.

6.3.4 Theme - Making sense of dementia as a younger person

The study found during the diagnostic phase there was a process of consideration. The findings have interpreted the pre-diagnostic phase as an experience of discombobulation, in entering the diagnostic phase participants experienced a shattering of their world, leading to fragmentation of their known selves. There were also mixed feelings, those of relief and those of fear. Following their diagnosis participants reflected on what this meant and tried to make sense of it in relation their age and stage. There was a need to comprehend a diagnosis of dementia in relation to their age, moving through feelings of self-stigma and fear of telling others that they have dementia. This theme is comprised of three sub-themes which are discussed below in relation to the literature. The three sub-themes suggest a process of consideration, the challenges the participants faced in the aftermath of the diagnosis.

6.3.4.1 Sub-theme - 'I thought it only happened to elderly people'

Dementia is viewed by society as a condition that affects older people, a view which is supported in previous research focused on YPwD and their view that it is only older people who get dementia (Clemerson *et al.* 2014; Pipon-Young *et al.* 2011). This current study identified that participants tried to make sense of their dementia compared to late onset dementia. There were early indications that participants held a view that their dementia, younger onset dementia experience, was different to late onset dementia.

The study identified that the participants did not want, nor did they, associate with late onset dementia, and that it was important that they were given title to their age and stage. Although it was difficult to articulate or tangibly identify why their dementia is different, it was implied in the statements made by most of the participants that they would not accept being classed in the service group of older people with dementia. While participants had varied knowledge of dementia prior to diagnosis, they were clear in their view that their experience of dementia, younger dementia is different to that of older dementia (late onset dementia). This is important since currently dementia is seen as dementia, regardless of age.

It is suggested that the age of the participants is a factor, that their outlook on life at their age and stage is different to that of an older person. Logan, Ward and Spitze (1992) note that within a chronological age reference it is likely that people will vary in their view of the category in which to place themselves. Being given a diagnosis at a younger age would force a consciousness on age and identity, perhaps being middle aged becomes the reference point, with a need to hold onto that age range. It is interesting that participants did not consider themselves to be old or ageing, rather they were keen to keep their age identity of young or middle aged, which differs to the results in Logan *et al.* (1992). Further, participants in this current study did not identify any positive aspects of ageing compared to Clemerson *et al.* (2014) where participants in that study felt that is was more acceptable to be forgetful when they were of a certain age.

Information available about dementia at the time participants were diagnosed exacerbated the irritation and frustration they felt in regard to age, as it related to older people with photographs of older people. However, in 2014, Alzheimer Scotland launched the NHS Scotland information booklet for YPwD (NHS Health, Scotland, 2013); additionally, there is now a website that is dedicated to support YPwD hosted via Alzheimer's Society.

The feeling that dementia is a condition that affects older people supports previous studies (Clemerson *et al.* 2014; Pesonen *et al.* 2013; Pipon-Young *et al.* 2011). However, this current study found that participants also focused on their age and stage and not being classed as an older person. Part of the consideration process was accepting that they were still at midlife at the time of diagnosis and that they had not aged just because they have dementia. This suggests a desire to hold onto their mid-life identity.

The issue about being seen as old is multifaceted, relating to identity and also stigma associated with ageing. As stated by Rozario and DeRienzis (2009) 'old is infused with negative connotations and demeaning stereotypes' (p.540), so it is not surprising that participants would want to hold on to their mid-life identity. Logan *et al.*'s (1992) study on ageing identified negativity when transitioning to old age, whereas the transition to mid-life was viewed positively, with this period being one that gained the most respect and influence. Furthermore, they found that people who identified themselves as old were more likely to experience feelings of distress.

There still remains a stereotypical view that being old equates to being ill, or that in fact being old is an illness, which provides a negative view of ageing (Stewart *et al.* 2012). It is suggested that some of the feelings experienced by the participants were linked to a fear of ageing and the stigma associated with ageing. These emotions are not exclusive to younger people who receive a diagnosis of dementia as they have also been identified in studies of chronic disease where individuals have been diagnosed with debilitating conditions, such as arthritis or rheumatism, which are equally viewed as age related (Bury 1982). Bury states that a 'reaction of disbelief, mixed with anxiety is thus common among those with an emerging illness of this kind' (Bury, 1982, p.171).

6.3.4.2 Sub-theme - Self-stigma

This study identified feelings of 'self-stigma', also referred to as perceived stigma (Corrigan, Watson and Barr, 2006; Link and Phelan, 2001). While stigma related to dementia is well documented (Prince *et al.* 2015), it is suggested that there is a greater stigma attached to having dementia at a younger age.

Within this study self-stigma is considered to be an important finding, with previous studies which focused on YPwD referring only to stigma in their conclusion and, with the exception of Husband (1999) whose study included one person with dementia under the age of 65, no previous studies reviewed made reference to self-stigma. Burgener *et al.* (2015) identified a lack of research focused on self-stigma and dementia. It is suggested that self-stigma is more likely to be identified within YPwD since late onset dementia is more accepted by society (Burgener *et al.* 2015).

I would suggest that there is a greater awareness about dementia within the general public, but the awareness about dementia under the age of 65 is negligible. There are now strategies in place, such as the National Dementia Strategy for Scotland, which should help to raise awareness about dementia and assist with combating dementia related stigma; however, it is unlikely that young onset dementia awareness will be raised by these strategies.

The feelings of perceived stigma has the potential to impact on the participants' well-being, which can have a detrimental impact on perceived competence and a reduction in self-esteem (Corrigan *et al.* 2006). This suggests that these feelings of perceived stigma experienced by participants could impact on their motivation. SDT provides the need for social conditions to be supportive to enable satisfaction of the basic psychological needs, where a person has diminished self-esteem associated to perceived stigma this could impact on the needs of competence and autonomy (Ryan and Deci, 2002).

6.3.4.3 Sub-theme - 'How would they react? People accepted me, we even joke about it'

Linked to stigma was the fear around telling people about the diagnosis. The fear about sharing a dementia diagnosis has been well-documented and is not a unique feature to YPwD, having been identified in chronic illness (Charmaz, 1991), and older people with dementia (Langdon *et al.* 2007; Weaks *et al.* 2014). The concern about disclosure supports previous studies focused around YPwD (Pipon-Young *et al.* 2011) and limiting disclosure was found in Pesonen *et al.* (2013), which was similar to this study where participants considered who they would tell.

Sharing their diagnosis and the initial trepidation about disclosure appeared to be linked to the fear of not being accepted, or being seen as changed in some way, therefore being treated differently because of this. This suggests anxieties related to selfhood and identity which were also established in Langdon *et al.'s* (2007) study with older people. When a person shares with others that they have dementia the reaction from those people is very important. If a person were to receive a negative reaction and those same people start to behave differently towards them, then there is affirmation that the dementia has changed them, or that they are different in some way because of the dementia (Langdon *et al.* 2007; Weaks *et al.* 2014).

The environment and the way other people respond to a person is linked to the Self-3 in the Self's framework, which is reliant on the co-operation of others (Sabat, 2001, 2002). If others were to concentrate only on the younger person's dementia and their changed ability, they could potentially reinforce a loss of the Self- 3 personae. Additionally, there is a risk that the person could be placed in a negative position through positioning by others, or their decreased ability to position themselves (Cheston and Bender, 2003). However, despite the fear of telling others, especially friends and acquaintances, participants found they were received positively and felt they were still accepted. While they were prepared to share their diagnosis, they were cautious about to whom they spoke, similar to Pesonen *et al.* (2013) and Langdon *et al.* (2007).

Despite this initial caution participants felt able to share and disclose to members of the public. Certainly, one participant was clear that she would rather tell people than let them think that there was something wrong with her. Similarly, another participant said that you tell people and they would help, although he said it was a matter of judgement but should not be restricted to friends and family. It is suggested that the more that people disclose about their dementia increases awareness and destigmatises dementia (Weaks *et al.* 2012).

Self-determination Theory states that there is an innate need to feel connected to others through relatedness, a psychological need to feel cared for as well as caring for others, a need for relationships (Deci and Ryan, 2000; Deci and Ryan, 2002). Gillard and Roark (2013), in their study about disclosure and HIV status, identified that autonomy was supported where their participants had choice and control over who they told. Additionally, they found that disclosure was linked to relatedness and relationships, in regard to trust and friendships surviving following disclosure. Having a diagnosis of dementia was a traumatic experience that participants had to come to terms with; however, not being able to share this with friends and others has the potential to thwart the need of relatedness, which perhaps impacted further on their feelings of well-being.

6.3.5 Summary

The outcome of this study suggests that in the first part of the diagnostic phase the participants' lives were 'blown apart', they become fragmented and distorted. While there was relief with the diagnosis there was fear, anxiety, seclusion and isolation. In the second part of the diagnostic phase there was reflection, consideration and the beginning of the assimilation process.

In this phase participants considered what it meant to have dementia at a younger age, and the study suggests that they want to protect their identity of age and stage. They contemplate what dementia means and how this fits with them. Similarly, they subject themselves to stigma, which only creates further seclusion. Linked to stigma and impact on the selves, is the fear of telling people, even close family and children, and a fear of going out because they think everyone will know they have dementia.

6.4 Superordinate theme - The challenge of learning to live with dementia - Post- diagnostic phase, the evolving self, assimilation

This super-ordinate theme, the challenge of learning to live with dementia, is situated in the post-diagnostic phase. This super-ordinate theme discusses the experiences identified by the participants and how they managed the biopsychosocial changes that impacted on their lives to enable them to commence living their life with dementia. The biopsychosocial and physical changes are identified in the form of loss of independence, having to make changes to where they lived and how they live, to the fatigue experienced because of the impact of changes to their brain and thought processes. Psychologically and socially participants identified challenges, particularly in relation to access to the right services and being acknowledged for their age and stage.

There was evidence of forms of ‘positioning’ where they were placed in a lesser position or a negative position (Cheston and Bender, 2003; Harre, 2012) because of misinterpretation of what dementia means. It was clear diagnosis impacted on their confidence and the participants also identified with the ‘consciousness of dementia’, which prevented spontaneity and loss of autonomy.

This study found that following the impact of diagnosis participants moved from a phase of consideration into a phase of assimilation, where they started to adapt to the changes and challenges that they were presented with. This study identified that participants were adapting to and adjusting to living life with dementia, evolving a new sense of self as part of the acceptance process. Clemerson *et al.* (2014) found that developing a new sense of self enabled the person to accept their future self with dementia. Additionally, they identified a split in the management of identity in self where some of their participants attempted to hold on to their previous self, with others attempting to completely redefine their identity. This current study however, found no indication that the participants denied their previous selves, nor did they try to hold on to previous self, apart from holding on to their identity of age, preferring to move through a process of acceptance and evolving self with dementia.

6.4.1 Theme- ‘It’s like curtains coming down’

This theme identified the feeling of fatigue identified by all participants and described as debilitating, which was expressed by a participant as ‘curtains coming down’. Fatigue was identified in Ohman *et al.* (2001), in regard to increasing tiredness and difficulty in coping with stressful situations within the workplace. This has been identified as a consequence of the illness (Weaks *et al.* 2012). While the experience of fatigue is not unique to YPwD it does perhaps cause a greater impact on their life because of their age and stage, their lives being more complex and challenging than that of an older person (Roach and Drummond, 2014). Similar to Ohman *et al.* (2001) this current study identified that the tiredness and fatigue was further impacted upon by stress. When participants were under stress they were no longer able to undertake simple tasks, resulting in a reduction in the level of functioning and competence which they found frustrating.

The tiredness exacerbated by stress also impacted on their cognitive ability creating memory impairment. In order to manage the tiredness participants learnt to accept it as part of their daily living, giving into it and resting. Stress is known to affect cognition and memory in different ways (Calvo and Gutierrez-Garcia, 2015; Music and Rosell, 2015), so although stress can impact on cognitive ability it is not unique to younger people; however, it is an important insight given their age and stage.

Although participants discussed the debilitating effects of dementia, they also spoke about being aware of it and managing it. This provides insight into how participants were motivated to self-manage the impact of their condition on their lives. From a SDT perspective it is suggested that their knowledge of their condition, and the impact this has on their functioning and ability, enables them to act autonomously to manage their symptoms. It is important for YPwD to be informed about the challenge this tiredness brings, and how stress can impact further on their ability to function.

Knowing that there is a period within the day of extreme fatigue can help with the planning of routines, and can support the person to do things that they enjoy at times when they are less tired. If YPwD are to have any semblance of a life that is in some way parallel to a life that would be lived at their age and stage, they need to be aware of the factors that impact on their cognitive ability and well-being. Being informed that stress can cause a reduction in cognitive ability can assist with the avoidance of stressful situations, and prevent unnecessary decline in ability and competence. This finding provides an insight in to the life style changes that participants had to make to enable them to continue to function independently day to day.

6.4.2 Theme - ‘Stop work, stop driving, I still get upset going back to it’ - loss and changes to independence

This study found participants were challenged by the sense of loss and how changes impacted on their independence and loss of choice associated with living with dementia, creating feelings of disempowerment. Feelings of loss are consistent with previous research in relation loss of role and identity (Harris and Keady, 2009). This study specifically relates the loss to independence and feelings of disempowerment (autonomy). Rather than focus on the loss of self this theme focuses on the evolving self, so while these losses may have a potential impact on self and identity, participants related these changes as one of the challenges of learning to live with dementia.

Two participants in this current study experienced an immense sense of loss following the requirement to relinquish their driving licence. Conversely, those participants who had experienced small accidents when driving, due to their decline in cognitive and functional ability prior diagnosis, realised that they, and those around them, were vulnerable on the roads, and easily accepted the need to give up their licences. This is interpreted as a loss of freedom and choice, and a loss of independence (Charmaz, 1983) where participants were not given choice or could not see that they had a choice. Self-determination Theory separates independence from autonomy, so while there is a loss of independence in that the person is not able to drive themselves from A to B, there is perhaps also a loss of autonomy as their freedom to choose to drive and when to drive has been removed (Snyder, 2002).

It was notable that the two participants who had to relinquish their licences had no preparation time for transition and they struggled with the impact, compared to those participants who were able to understand the reasons and chose to give up their licences. This suggests that support and counselling around this area would be beneficial to people who receive a diagnosis of dementia, particularly those who are younger because of the impact of the loss due to their age.

Further losses were experienced for those participants who had to retire from work. There were conflicting views on the impact of giving up work where a participant felt that he had not been given opportunities to remain at work; he strongly believed that if he had he would have been able to remain in meaningful employment. However, another participant who was supported to remain at work by his employers, experienced feelings of stress and a burden to others, which resulted in him choosing to retire. While previous studies support the view, where appropriate, that people should remain at work by providing amendments to their workload (Roach and Drummond, 2014), the findings in this current study suggest that peer support would be beneficial.

This current study acknowledges the need for time for transition to support the person’s wellbeing (Roach and Drummond, 2014), particularly in relation to work and driving. Further, this current study supports that immediacy of change in these areas impacts on the person’s ability to accept changes in lifestyle, with the potential to cause distress (Roach and Drummond, 2014). This study has identified that where a person is given the time to adjust to these high impact changes, the sense of loss is decreased with an increased acceptance of changes in self with dementia.

Each participant spoke about the challenges they faced living with dementia. The frustration and anger that participants spoke about was around the inability to work something out which ordinarily would have been so simple. Clemerson *et al.* (2014) identified feelings of loss related to adult competency, particularly in relation to functional abilities, whereas this current study considers the cognitive abilities and the emotional feelings associated with their inability. It is suggested that these feelings are linked to the innate need for competence.

Deci and Ryan (2002) proposed that people identify challenges to enable them to meet their optimum capacity, thereby undertaking activity that will maintain and further develop their skills and capacity. People need to feel challenged, but the problem or challenge needs to be achievable, where the problem is too difficult or alternatively too easy the person will not be stimulated (Deci and Ryan, 2002). For participants in this study they experienced a loss of ability in simple tasks, these had become a challenge that they were unable to overcome. Relating this to SDT, it is suggested that to support the person would be to either enable them to overcome these challenges through assisting them, or developing a programme of rehabilitation so that they are able to undertake the task. Alternatively, assist the person to accept that they cannot do the task, but encourage them to do the things that they can.

6.4.3 Theme - 'I'm here if you want to know how I am, I'll tell you' - being listened to and acknowledged

This theme identifies the importance of hearing the voice and listening to the person with dementia. There were two parts identified, one was the need for others such as professionals, to listen to the person with dementia and accept that YPwD are the experts on their condition, and secondly 'positioning' was identified where the person was not acknowledged or was ignored because of their dementia.

While previous research did not identify this as a unique theme, being listened to has been identified as an outcome for older people, which supports wellbeing and is identified in Talking Points as a process outcome (Cook and Miller, 2012). While these outcomes were focused around older people, this current research suggests that this outcome is also important to younger people.

Being listened to and being heard was a strong theme identified by all participants, and indicates that participants in this study did not feel that they were being listened to, or treated as experts of their own condition or illness. This is perhaps linked to their need to be recognised as a younger person with dementia rather than a person who has dementia; therefore, the need to be heard and be listened to is perhaps associated with their need to be seen within their age peer group.

The second issue was the concern expressed by participants that they were diminished by others by not being acknowledged. It is suggested that this is a form of positioning and links to personhood and Kitwood's malignant social psychology (Kitwood, 1997). These experiences are not significant to YPwD and have been well documented in previous literature focused on dementia (Kitwood and Bredin, 1992; Kitwood, 1997). However, it is considered important for this study as there is the potential for the person's age identity to be lost or not recognised through positioning. Additionally, there is a risk of diminishing self, through the continued non-recognition of dementia in younger people as a service user group.

This finding identifies a challenge for YPwD to evolve a cohesive sense of self with dementia where they are not acknowledged for having dementia at their age and stage. Previous research accepts that there is an impact on self and identity for the YPwD (Beattie *et al.* 2004; Clemerson *et al.* 2014; Harris, 2004; Harris and Keady, 2009; Pesonen *et al.* 2013). It is suggested therefore, that there is a need to support the person in developing a new sense of self, by acknowledging that dementia in younger people is a different experience to that of older people.

6.4.4 Theme- 'I felt like a duck out of water'- diversification of needs

Participants accessed a diverse range of services from day services, respite care in the form of residential care and one to one supports. The study found that participants struggled to access age appropriate services and highlighted distress, experienced when services did not meet needs due to age and stage. However, the findings indicate that where a participant accessed services to meet a specific aim, this was presented as satisfactory. Although one to one support should meet a person's outcomes by the nature of the service, it was identified that where one to one support was accessed this did not always provide satisfactory outcomes for one participant. It was clear that where a more planned and individualist approach was provided, one to one support was entirely satisfactory.

There were issues around the person being provided with opportunities to input into their needs and service requirements. This is further identification of ‘positioning’ where the person is not consulted with, therefore has the potential to impact on their sense of self. This is similar to the findings in Beattie *et al.* (2004) where feelings of invisibility at not being involved in the decision about care and support needs were identified. Self-Directed Support (SDS), through the Social Care (Self-directed Support) (Scotland) Act 2013, provides that a person must have involvement in relation to their health and social care assessment and the support or services they require. Through SDS the person can choose how their care is provided or commissioned, therefore, they have a right to be provided with opportunities to express any views about the options available to them and to make an informed choice.

During this post diagnostic phase the person is learning to accept and live with dementia developing a new sense of self. However, where services are required, but are considered to be ‘undesirable’ by the person this can create feelings of being ‘discounted and devalued when the care [reflects] a new and undesirable identity’ (Charmaz, 1983, p.186). This related to the experiences of the participants in this study, where participants felt there was need to hold onto their identity of age and stage, yet services did not support them to do this.

This study identified the need for specialist or age appropriate services, which was indicated by the experiences of the participants. Referring to previous research the need for specialist services has been well documented, but not all these studies included the voice of the person with dementia (Barber, 1997; Beattie *et al*. 2004; Cox, 1999; Cox and Keady, 1999; Ferran, 1996; Kinney *et al*. 2011; RCPAS, 2006; Willis *et al*. 2009). Only two of those previous studies actually involved YPwD (Beattie *et al*. 2004; Kinney *et al*. 2011), which has provoked questions about whether there is a need for services that are aimed at meeting the age and stage of the person (Reed *et al.* 2002). This current study provides the subjective experience of YPwD and how they perceive their needs; therefore, this study’s findings provide the necessary insight into the needs and service requirements of YPwD.

Self-determination Theory specifies that the three innate needs of autonomy, competence and relatedness are dependent on the social environment being one that supports the satisfaction of these needs. It is suggested that these findings identify that the support services accessed by participants in this study did not provide environments that would achieve need fulfilment, particularly given their age and stage. This is confirmed in Custers *et al.* (2010) where need fulfilment in service provision could be thwarted or supported dependent on relationships and the environment.

6.4.5 Theme - 'Freedom, things that I feel I can't do unless someone helps me'- the consciousness of dementia

This theme identified the loss of freedom related to a loss of spontaneity, self-determination and a consciousness (conscious continual awareness) of dementia. Interestingly prior to diagnosis participants continued to try and undertake activities even though they experienced diminished competence. However, while they were questioning themselves they did not experience the feelings of restriction that having a diagnosis of dementia brought.

This study identified that participants experienced a form of restriction of themselves in their spontaneity, suggesting a loss of self-determination. Further, they experienced a loss of confidence and fear to just do something, resulting in feelings of disempowerment, with one participant describing this as experiencing a loss of freedom. This finding would appear to be unique to this research and links to SDT. What is noticeable is that while this loss of spontaneity remained, over time the participants were able to use this to enable them to do things rather than disable them.

The need for self-determination, freedom and independence was identified in Kaufman and Engel's (2016) study where they identified a need for agency based around 'self-determination, freedom of action or independence' (p. 784), in relation to well-being. Although they do not refer to SDT, rather they focus on Kitwood's model of psychological needs, which they extend from a five to a six-domain model to include agency.

Autonomy is the central need where a person undertakes an action which is an expression of self, an action which they undertake under their own volition or with support from others to be autonomous (Deci and Ryan, 2002). Self-determination Theory asserts that to be autonomous is to have a choice to engage in an action (Williams, 2002).

While participants spoke about lack of spontaneity, not doing something under their own volition (autonomy), there are also links to other basic psychological needs, such as competence. It is perhaps the term dementia which created the loss of confidence and feelings of incompetence, and that their autonomy was diminished because of the loss of self-confidence. Although participants continued to be cautious about doing something spontaneously, over time as they began to recover from the impact of the diagnosis and what this meant, they were engaged and enabled to be autonomous in a way that ensured they remained safe. This is discussed below in the section on Living well beyond dementia.

As the social environment has an influence on the basic psychological needs, the feelings identified by participants could be decreased, or perhaps prevented through robust support following diagnosis. Therefore, this study's findings provide further support to the body of research and policy for post diagnostic support (Innes *et al.* 2014), particularly a programme that is geared towards the complex needs of YPwD.

6.4.6 Theme - 'I don't see why I should change and become this dementia character you know' - managing dementia

This section focuses on the management of dementia as being separate to self. It is suggested that part of the management of dementia is through seeing the self as unchanged by dementia. This current study has identified that participants did not feel that they had changed because of their dementia, which differs to findings in Clemerson *et al.* (2014). Previous studies have considered this theme of change and self, predominantly with older people (Caddell and Clare, 2011a; MacRae, 2010).

This current study found similarities to Caddell and Clare (2011a) and MacRae (2010), where participants felt that they had not changed because of dementia, certainly participants in this current study agreed that they had not become dementia. Caddell and Clare (2011a) found that there was continued tension between continuity of self and change, which was not identified in this current study.

All participants appeared to manage their dementia by referring to dementia in the abstract, avoiding use of the term ‘my dementia’, preferring to talk about ‘it’, ‘that’, ‘this’. It is suggested that this is linked to their identity and self, and suggests that in managing and accepting dementia they did so by keeping their dementia separate from themselves. Therefore, this prevented them from being defined by their dementia, alternatively they developed a new social identity with dementia, and while that was part of their self it was not the total self. This reluctance to change supports the theory that people will reject being defined by their illness, as was identified in Adams, Pill and Jones’s (1997) study with younger people and asthma.

A similar view was found in Tilden’s (2005) study with a younger person with diabetes, who suggested that where a person is only seen as being their illness then there is a loss of self-identity. There were clear indications in this current study that participants reached a point of acceptance and an ability to live well with dementia while keeping their dementia separate from self; therefore, this form of separateness was not considered to be a rejection of their condition. Where there had been a rejection, or failure to accept their condition, there would likely to have been potential consequences to their well-being, identity and management of their condition (Tilden, 2005). In referring to dementia in the abstract participants were able to keep their condition in perspective not allowing dementia to dominate self.

Additionally, considering self in relation to the social constructionist approach and the Self’s framework, it is suggested that it is necessary for the person with dementia to maintain this view, to ensure that others in society do not see the dementia rather than the person. This is particularly relevant with dementia due to the lack of awareness and understanding, knowledge of YPwD and media interpretation of dementia.

6.4.7 Summary

This study has identified a process of assimilation and evolving sense of self as a part of the transition in the post-diagnostic phase. Participants were faced with challenges which required them to adapt and change their life styles. The changes were physical in the form of fatigue and tiredness which was exacerbated by stress. Social changes were required where they had to retire from work or relinquish their licence. Psychologically acceptance of these changes were easier where the person was given time to adjust, supporting the view that autonomy supportive environments improve well-being. There were indications that participants lost a sense of freedom through a loss of confidence and spontaneity, indicating an impact on self-determination and the basic-psychological needs, as a reaction to the knowledge that they have dementia. Participants were keen to have their voice heard, and want others (professionals) to listen to them as they (YPwD) know best about living with dementia at a younger age. There were indications that participants could be at risk of positioning and erosion of personhood. Further, an impact on the BPN was indicated where participants were accessing services, in that services were not always appropriate to meet their needs. Participants managed and accepted dementia separate to self, referring to it in the abstract, and not to become dementia. This phase indicates a shift from feelings of ill-being towards feelings of well-being, where participants perhaps felt, through a process of assimilation, that they were able to control their lives, such as managing their day and accepting the fatigue and not becoming dementia.

6.5 Superordinate theme - Living well beyond dementia - Living well beyond dementia phase, consolidation, consolidated self

This phase, living well beyond dementia, is also the super-ordinate theme and focuses on the final transition where participants experienced a good life beyond dementia, how they coped with living with dementia and what supports assisted them to do this. Living well beyond dementia was identified by all participants, who found their way to accept that they have dementia, that they are not dementia and that they still have a life to be lived, a life beyond dementia. This phase is the final transition in the process where they have consolidated self and fully accepted that they have dementia, enabling them to move on to living a good life. Consolidation suggests merger or fusion, and while the participants appeared to keep their dementia in the abstract, they were able to do this by accepting they have dementia, but they are not dementia. It is during this phase that participants gain confidence and through autonomy supportive environments, that support the basic psychological needs, they experience improved well-being (Ryan, 2009; Williams, 2002)

This superordinate theme provides an indication that participants displayed resilience, which requires an aptitude to create positive experiences from the interruptions created by their illness (Bonanno, 2004), and the findings in this study suggest that the participants displayed this aptitude. As discussed in Chapter Two, resilience tools have been developed and are utilised as coping strategies (Triveldi *et al*. 2011). These tools could be utilised to enable YPwD to build resilience following the stress of diagnosis, particularly since it has been identified in this current study that there is a loss of self-esteem following diagnosis.

6.5.1 Theme – ‘Eventually I went out and got lost’ - positive risk taking

This theme, ‘eventually I went out and got lost’, identified that participants were able to take some control and manage risks, which led to an increase in independence. The study identified that all participants experienced a loss of self-confidence at the pre-diagnostic phase and following diagnosis, which led to a questioning of self and ability, a decrease in autonomy and competence, and feelings of disempowerment. There was an inability to be spontaneous due to the consciousness of dementia, which at first had inhibited the participants. However, through the transition process participants utilised their consciousness of dementia to assist them to manage risks positively. Relating this finding to SDT it is suggested that there is a shift within the social environment through others, such as supportive family networks, and being part of a support /action group like the SDWG. These factors enabled participants to be motivated to take risks, and to become autonomous, suggesting the environment was one that was autonomy supportive (Deci and Ryan, 2000).

In order for participants to continue to live a life commensurate to their age and stage it was necessary for them to embrace risk taking. It is suggested that this desire to regain independence and to be autonomous is linked to the age and stage of the participant group. Maintaining independence or being enabled to maintain independence is recognised to improve wellbeing (Holst and Edberg, 2011; Woods, 1999). It is interesting to note that while participants experienced a lack of spontaneity and felt they were more cautious, they were able to be independent.

Independent living and management of risk changes with age, research suggests that as individuals get older risk taking is modified, or adapted to accommodate changes due to ageing (Rush, Murphy and Kozak, 2012). Additionally, there is a stereotypical view that as a person gets older they are less likely to take risks (Mather *et al.* 2012). However, it is important not to generalise as there are many variables in relation to risk and ageing that contribute to risk taking decisions, such as cognitive ability, and an actual willingness to take risk, social risk and financial risk (Dror, Katona and Mungur*,* 1998), and gender (Rolison *et al.*2013). It is proposed that people within the mid age group, as were the participants in this study at the time of diagnosis, are more likely to take risks, based on Rolison *et al.* (2013) who confirmed a change in relation to ageing and risk.

Previous studies focused on YPwD did not identify positive risk taking; however, Beattie *et al.* (2004) did find that there was reluctance, particularly from the statutory services, to allow YPwD to take risks such as travelling alone. Their study indicated that YPwD who were service users were not enabled to manage risks or maintain independence, whereas this current study found participants either managed their own risks or were assisted to do so by utilising assistive technology or by other people. The knowledge that participants were able to learn to live independent lives, take risks and manage those risks is another important finding. This finding suggests that there is hope for people who are diagnosed at a younger age, and that they should be supported to maintain a way to live their lives that supports their age and stage. Where a person requires assistance with their risk management the approach should be one that is person/relationship centred (Clarke *et al.* 2010), this type of approach would be autonomy supportive.

6.5.2 Theme - Meaningful activity

This study identified that participants were motivated to take risks, following a process of assimilation. The positive risk taking further motivated them to recommence activities that they had previously enjoyed undertaking, which impacted on their life positively. Participants transitioned from experiencing feelings of total loss of self- confidence, resulting in a loss of autonomy and competence, to experiencing increased self-belief and self-confidence resulting in improved well-being. Due to the fulfilment of the needs autonomy and competence, it is suggested that participants were able to improve their independent living. The strategy employed by participants to gain self-confidence was to continue doing things, even if they could not do them as well as they once could, which also impacted on their sense of independence.

Participants were motivated to continue to undertake tasks and activities regardless of how well they could undertake these, which could perhaps be viewed as motivation to continue with their lives. Menne *et al.'s* (2002) study, which included two YPwD, based around Atchley's (1989) continuity theory and Park and Folkman's (1997) framework of meaning making, suggested that where a person is enabled to do the things that they used to do, it can help them to cope with and adapt to changes that dementia brings. There is a suggestion that participants in this current study were not initially enabled to take risk, as implied in the comment 'to be allowed' which suggests risk aversion by others, which is similar to findings in Beattie *et al.* (2004). It is understandable that others, such as carers of people with dementia and practitioners, will be concerned about the person living with dementia and their safety, which ultimately results with the person ceasing certain activities. This can be managed more effectively through an individualised approach to risk assessment, where risk assessment is required, as discussed above in the section on positive risk taking (Clarke *et al.* 2010).

Participants also expressed the need for normalised activity, which is consistent with Beattie *et al.* (2004), regarding activities provided by services and a need to be treated as 'normal'. This need for normal activities also relates to the quality of life outcome 'having things to do', one of the Talking Points Outcomes referred to in Chapter two. This finding is significant since Talking Points have been researched around older people, and are currently used within social care across all age groups, therefore provides further support for the outcomes being suitable for younger people.

Learning new skills and relearning old skills is another important finding of this study, and indicates that people with dementia can retain skills and re-learn. Learning and accomplishing provides a sense of wellbeing through meeting the basic psychological need of competence. This has been demonstrated in previous studies where YPwD have mastered the art of using assistive technology, which when used appropriately with the person can improve wellbeing by generating feelings of control (autonomy) and safety (Arntzen, Holthe and Jentoft, 2016).

The Participants in this study, who were members of the SDWG, were able to access opportunities to develop themselves in ways that they would not have experienced had they not been diagnosed with dementia. Participants felt satisfaction from making a difference, where their activities involved them supporting other younger people with dementia. Despite the adversity they faced, they were keen to become active participants to help others and raise awareness through education and promotion about dementia and dementia in younger people. Helping others and functioning in society supports eudaimonic wellbeing.

The salient point identified here is the need for meaningful activity, the need to be active and feel useful. While all people need to feel active and have a sense of purpose (Cook and Miller, 2012; Phinney *et al.* 2007), it is proposed that there is a greater feeling of loss in YPwD, because of the cessation of work, and their age and stage (Clemerson *et al.* 2014; Harris and Keady, 2009). This finding is consistent with previous studies focused on YPwD (Harris, 2004; Harris and Keady, 2004; Roach and Drummond, 2014; Roach *et al.* 2016).

The specific need of having a sense of purpose and keeping active is consistent with Harris and Keady (2004), Ohman *et al.* (2001) and Pipon-Young *et al.* (2011). Additionally, there are indications in this current research for a meaningful role in society, which is consistent with Pesonen *et al.* (2013), and Chaplin and Davidson's (2016) study which focused on work and YPwD. While this is a constant in all research focused on YPwD, this study differs as participants were able to provide positive accounts of their meaningful activities and their experiences of this, which is similar to those in Clare *et al.* (2008).

Participants spoke positively rather than speaking in the negative or experiencing feelings of frustration, which was the case in Evans (2016), where feelings of frustration were identified, linked to the lack of services to provide meaningful activity for YPwD. Further, this supports Roach and Drummond's (2014) concern about the lack of specialist services for YPwD, specifically about enabling YPwD to take part in meaningful activities and have a place and role in society. When specialist services have been discussed in previous studies there is a natural tendency to think about traditional services, those at the critical end of the spectrum, such as care at home and care homes; however, this study has identified that services need to be diverse.

This study indicated that where participants were provided with opportunities to remain active, then there is a positive impact on their well-being and sense of self (Clare *et al.* 2008; Kinney *et al.* 2011; Roach *et al.* 2016; Robertson and Evans, 2015). The need to be productive and live meaningful lives is linked to eudaimonic well-being and SDT (Clarke *et al.* 2016).

Psychological models of development, such as Erikson's theory of psychosocial development, eight stages of development with generativity v stagnation in adults situated between ages 40-65 (1963), have been referred to in previous studies (Clemerson *et al.* 2014). This current study also supports the view that to support identity and sense of self there is a need to fulfil specific age-related goals. This study is in agreement with previous studies and suggests that the loss of meaningful activity has an impact on the sense of self (Harris and Keady, 2004; Roach and Drummond, 2014).

During this phase it is clear that there was a shift in the social context which enables fulfilment of the basic psychological needs, notably participants began to feel more autonomous and competent in their abilities and feeling connected to their social world. Their environment became more autonomy supportive, and they were provided with access to not only continue with their activities, but also to relearn old skills and learn new skills. In being enabled to access opportunities that provided meaning to them impacted on their well-being. This study identified that participants, in regaining their self-confidence and being enabled to recommence their role in society, there was a consolidation of self with dementia.

6.5.3 Theme - 'There is life beyond dementia, it is a good life'

This study established that participants were unified in their view that they have a good a life beyond dementia and that the life they lead is a good life. This finding was unexpected as it had not been identified in any of the research reviewed that focused on YPwD, apart from Clare *et al.* (2008), which identified a life after dementia as a consequence of being able to contribute to society. This study differs from Clare *et al.* (2008) as it provides a positive view on all aspects of the person's life, identifying a number of contributing factors involved in developing a sense of positivity to living with dementia, one of which is contributing to society. One aspect of this finding was the ability to look to the future and get on with life. It is suggested that the ability to continue to look to the future contributes to a good life with dementia. While participants talked about living a day at a time they also spoke about the future, and there was evidence that they were planning for future events.

Living with dementia as a younger person is mostly depicted in the negative regarding younger people (Beattie *et al.* 2004; Harris and Keady 2004; Harris and Keady, 2009; Ohman *et al.* 2001; Pipon–Young *et al.* 2011). For instance, Harris and Keady (2004) use words such as 'despair', 'victim', 'loss' and 'struggle'. That is not to say that the participants in this current study did not identify with any of those feelings or experiences, but it was not the main thrust of their outlook or experience.

Thus, this present study has identified how the participants were able to reframe their life in the context of living with dementia. Participants were keen to share their positivity promoting a good image of their lives following the diagnosis. They were anxious to stress that they were living lives that were meaningful to them. Expressions such as 'living a day at a time' and 'enjoying the mystery of life' were used to describe their lives, which perhaps assists them to manage their lives with dementia. This has been identified as a strategy employed by people to gain control over their lives, particularly in relation to illness (Charmaz, 1991), and was also identified in the study by Pesonen *et al.* (2013) where participants commented on living for today.

Participants in this current study were aware that their positive experience of life with dementia is unusual, and not something that is ordinarily portrayed through media. It is suggested that participants in this study were motivated to challenge dementia to ensure that they were able to live a good life following a dementia diagnosis. Linked to SDT, motivation is contingent on the environment supporting the fulfilment of the basic psychological needs. This study has identified where the environment has enabled fulfilment, and equally identified situations that thwart fulfilment of those needs.

While positive experiences of dementia are difficult to find in research focused on YPwD, there are a small number of documented studies around living with dementia that provides some insight into positive experiences (Cahill *et al.* 2004; Katsuno, 2005; Wolverson, Clarke and Moniz-Cook, 2010). Harris and Durkin (2002) identified a sense of determination to challenge dementia with comments such as 'I'll take the challenge' and 'I'm not going to give up' (p.172) regarding positive attitude and self-acceptance. These experiences of positivity are also reflected in the essay by Sterin (2002) 'A Lived Experience of Alzheimer's Disease'. Sterin speaks positively about dementia in her statements such as 'you can cope with the disease' (p.9), and she suggests that having dementia should be seen as 'a challenge, as a project instead of a disease' (p.10).

6.5.3.1 Sub-theme - coming to terms with a progressive illness and rationalisation

Coping mechanisms were identified in the form of coming to terms with the progressive nature of dementia, but there was also a sense of rationalisation. The findings identified that participants compared their situation with others or other illnesses which they considered to be worse, as a form of coping. This process of rationalisation is not unique to YPwD and has been identified in studies focused on late onset dementia (Wolverson *et al.* 2010).

Nochi's (2000) study focused on traumatic brain injury (TBI) also identified rationalisation as a coping strategy by persons with TBI, which they categorised as 'the self better than others' (p.1797). This current study, similar to Nochi, identified this as a mechanism of coping where participants would compare dementia to other illnesses which they perceived to be worse. Utilising a psychological approach to defining rationalisation, it is deemed to be a defence mechanism and is a way to cope with unpleasant emotions (Whitbourne, 2011).

6.5.3.2 Sub-theme - Continuing family supports and maintaining family relationships

Maintaining family relationships was an important aspect of the participants' life with dementia, to continue to do the 'normal' activities with their spouse or partner, this links to the need for relatedness and connectivity. This suggests the participants had a need for life to continue, to not let dementia influence their life. This study identified that having a loyal and supportive family and significant others was as an aspect of living well with dementia. Participants considered themselves to be 'lucky' where they had these supports.

Previous studies commented on family relationships in relation to changes to roles and relationships following diagnosis (Harris, 2004; Harris and Keady, 2009; Pesonen *et al.* 2013; Roach *et al.* 2016). This was not something that was experienced by participants in this study, apart from one participant who felt her role as a mother had changed, although this had not changed her relationship with her daughter. The focus on family relationships in this study was identified as a continuation of normality, continuing to do the things that they had always done. The participants in this study found their family networks to be a source of support, which enabled them to continue to live a good life with dementia following diagnosis.

Self-determination Theory, basic psychological need of relatedness is supported through the improved family relationships that were identified in this study following diagnosis. The study has identified how the need of relatedness was thwarted in the pre-diagnostic phase, and how participants felt isolated. In this phase, living well beyond dementia, participants have rekindled their relationships with their families and significant others, feeling happy and contented because of this (Deci and Ryan, 2002).

6.5.3.3 Sub-theme - Building support networks and forming meaningful relationships

One of the contributing factors to enabling the participants to live a good life beyond dementia was the ability to create new support networks and develop meaningful relationships. New and meaningful relationships were developed through groups, such as the SDWG, that enabled them to meet other younger people with dementia, supporting the need fulfilment of relatedness. Additionally, these groups, particularly the SDWG, offered opportunities for meaningful activity where a group is an action group, along with combating social isolation (Snyder, 2002), and fulfilling the need of autonomy and competence. While not all participants were members of the SDWG, the majority had been involved at some point following their diagnosis.

The SDWG provides participants with a sense of community which enabled them to develop their sense of self with dementia. Weaks *et al.* (2012) detailed the experiences of members of the SDWG and identified how members spoke positively about these experiences. Weaks *et al.*'s (2012) participants commented on how they were proud to be part of a group that enabled them to be proactive in campaigning to raise awareness, and to develop policies to ensure lives for people with dementia are improved. Additionally, they confirmed that the group offered support and friendship.

This study's findings illustrate that being with other people with dementia and those of a similar age offers the most support to YPwD, enabling them to face challenges together, and fulfil their need to feel connected to society and their social environment, suggesting that these environments are autonomy supportive (Deci and Ryan, 2000), and supports wellbeing (Ryan and Deci, 2001). Groups such as the SDWG, offer a supportive environment for YPwD, where they can share the challenges they face and further build on their resilience. To want to be with people with whom a person has something in common, with similar feelings and beliefs are not unusual.

Support groups, such as the SDWG, enable people to share their experiences and provide a sense of comfort in the knowledge that they are not the only one feeling or experiencing the issues in relation to, in this case, dementia (Snyder, 2002). Learning that others are experiencing similar problems provides the person with a sense of relief.

Resilience has been mentioned in chapter two, and there is evidence to suggest support groups assist in strengthening resilience through supportive social networks (Clare *et al.* 2011; Triveldi *et al.* 2011). Being part of a peer group, whether this is a working group, such as the SDWG or attending a day service, which offers the opportunity to meet other people with dementia, impacts positively on the individual's self-esteem and confidence building. Clare *et al.* (2011) conducted a randomised controlled trial to test resilience in older persons who were in the early stages of dementia. They found a positive improvement in the quality of life and improved mental health where older people attended a structured support group seminar programme. While their results were positive they do acknowledge that their findings may not be generalisable for YPwD as they have different problems.

Developing a social identity through meeting other people with dementia, in particular people of the same age, was an important aspect of living well with dementia for the participants in this current study. The consequence of the support group enabled participants to develop their social identity which supports the findings in Clare *et al.* (2008). Social identities 'involve identification with others who belong to the group' (Burke and Stets, 2009, p.118), a set of shared values and views which enable a person to positively identify themselves as part of that group.

Participants felt that it was important for them to meet other YPwD because of the social networking that this initiates, which confirms the findings in Beattie *et al.* (2004), suggesting that participants identified with a shared social identity with YPwD rather than dementia. It is proposed that enabling contact with other people who have dementia, particularly YPwD to meet other YPwD, helps with the development of a new social identity which will improve well-being.

6.5.4 Summary

The final superordinate theme and phase has identified how participants move on to living a good life with dementia. As participants grew more confident they began to take more risks, which further increased their independence and reengagement with activities. This superordinate theme has demonstrated the need for meaningful activities and how this can improve well-being. Further support for well-being was identified where participants were able to continue to contribute to society and help others. Families and significant others became an important aspect of their lives in supporting them to live well. Participants developed a new sense of social identity and meaning through specialist support groups, such as the SDWG, where they were able to meet other YPwD.

6.6 Conclusion

This study has identified a four-phase transition process for YPwD through which the participants were able to grow and develop, identifying increased motivation as they progressed through the four phases.

The findings have identified how the psychological and social situations in the participant's life at the pre-diagnostic phase and the transition to living well with dementia, show a fluctuation in the fulfilment of the three basic psychological needs, autonomy, competence and relatedness. Participants struggled to function within their environment before diagnosis, conscious of changes to self. The changes they experienced led to the loss of relatedness with significant others, family and their peers. Although they remained autonomous, trying to find ways to manage situations, they found themselves and their abilities decreased, creating feelings of diminished competence.

While previous research has noted awareness of changes to self before diagnosis, this study provides a clear insight into the lived experience at this stage. Therefore, provides further support for early and prompt diagnosis, along with the need to raise awareness about dementia in younger people.

The second phase in the process is diagnosis and consideration which is divided into two parts. The first part is the actual diagnostic process which participants found extremely difficult, and the impact of this; with the second part focused on how the participants considered what having a diagnosis of dementia at their age and stage means. At the time of diagnosis, the participants are described as being fragmented such was the impact of the diagnosis.

There were indications of a biographical disruption (Bury, 1982), with some participants experiencing a biographical abruption (Locock *et al.* 2009). There was clear support for diagnostic processes that are autonomy supporting, those which enable the person to have some control of the situation, and where this was identified the outcome following diagnosis was positive. Further, the study identifies the need for post-diagnostic support tailored to the complex needs of YPwD, but also indicates the need for pre-diagnostic counselling. The second part of this phase identified a process of consideration where participants tried to make sense of their diagnosis and what this meant at a younger age. This process was a form of reflection, and it was clear that they saw their experience of dementia as different to that of late-onset dementia.

The study identified perceived stigma, which has the potential to impact on well-being and self-esteem and can influence self-competence. Further, this self-stigma can lead to isolation which can impact on relationships and feelings of connectedness; therefore, there is the potential impact on their need for relatedness. Linked to stigma was the concern about disclosing their diagnosis. Participants were anxious about sharing, but were pleasantly surprised to be accepted and received as unchanged by others.

The third phase is post-diagnosis where participants start to learn to live with the challenges of having dementia, a process of assimilation and evolving self was identified. Participants identified that they experienced feelings of fatigue throughout the day, and how this and stressful situations impacted on their cognitive and functional abilities, which could add to feelings of loss and frustration. Being aware and managing this enabled them to live their life around this challenge and to take care to avoid stressful situations. It was clear that services played a part in their well-being, and that the social environments in which some participants found themselves were not conducive to supporting the fulfilment of their basic psychological needs. Further challenges and frustrations were experienced as loss, such as relinquishing their licence or having to take early retirement.

The study suggests that time should be given to adjusting to changes and enable the person to make the decision, rather than forcing the change to happen without giving the person choice and control. This links to need fulfilment and promotes autonomy supportive environments. With diagnosis, participants experienced a loss of autonomy due to a consciousness of dementia; this affected their confidence and their ability to believe that they were competent to undertake tasks. While this was initially a hindrance and created feelings of restrictions to self, they were able to utilise this to assist with positive risk taking.

The study's findings present a need for services that meet the needs of the younger person. Further, the issue around older people's services being utilised for younger people impacts on their age identity. Participants accepted that they had dementia, but they would not be defined by their illness, keeping their dementia condition separate from themselves, so while it is part of them, it is not the total of who they are as a person. They did not feel they had changed, nor did they feel that should change because of their dementia.

The final phase is living well beyond dementia, consolidation, and is identified as the consolidated self. All participants accepted that their lives had changed, but they were in agreement that they had a good life. In this phase, they started to take positive risks which enabled them to learn to live their life again. The study identifies the importance of meaningful activity and how this links to well-being. The participants found they were able to undertake tasks that they had done previously, and learn new skills and relearn old skills. Their relationships with others remained important and they established new relationships with other younger people with dementia. The findings suggest that groups, such as the SDWG, supported the fulfilment of all three basic psychological needs and through this they could develop and grow.

6.6.1 Well-being and the lived experience

The research has identified through the application of Self-determination Theory, BPNT, that participants' basic psychological needs were mainly thwarted in the pre-diagnostic phase and diagnostic phase. This has been discussed in the discussion section above, and the detail of the findings in relation to SDT can be found in Table 10, at the end of Chapter Five. Improved fulfilment of the basic psychological needs was identified in the post-diagnostic phase, although it was also identified a thwarting of the needs during this phase. In the final phase, living well with dementia, their basic psychological needs were fulfilled with only one area identified that was at risk at not being met. The findings have identified that there are contributing factors supporting the fulfilment of the basic psychological needs which are consistent with SDT. The contributory factors that are specific to this research study in relation to well-being and YPwD utilising SDT, are provided in diagrammatic form in Figure 4 below.

This research study focused on eudaimonic well-being, where rather than realising fulfilment through pleasure-seeking attainment, fulfilment is reached through a person achieving meaning through self-realisation and being a functioning member within society (Ryan and Deci, 2011).The findings in this study regarding living well can be identified with eudaimonic well-being, as participants felt that they had meaning to their lives, that they were contributing to their life and supporting others with dementia, therefore they continued to be an active citizen within society.

The Figure 4 provides the contributory factors that enabled participants to live well beyond their dementia. These factors create environments that are autonomy supportive and meet the basic psychological needs and well-being. Working clockwise from left to right, the first box, coloured purple, identifies that family and friends can influence well-being, where these environments are supportive and encouraging this helps to restore and support the basic psychological needs. Moving on to the next box, coloured dark purple, other networks, such as the SDWG, were identified as being important to support the basic psychological needs, particularly where they provide an opportunity for YPwD to meet other YPwD. Moving down to the box below, coloured light blue, it identifies the importance of the environment in supporting well-being and the basic psychological needs, through recognising the age and stage of a person when they are younger with dementia. Where the environments do not recognise a person’s age, such as care and support services, this can have an impact on the person’s identity and sense of self. Moving on round in a clockwise direction, the fourth and final square, coloured dark blue, identifies how the basic psychological needs were supported through positive risk taking, opportunities to learn new skills, relearn old skills, the need to maintain meaningful activities and remain an active citizen in society.

Figure 4 Study's findings in relation to SDT, BPNT contributors to supporting well-being

Family & friends support

Supportive networks & relationships with other younger people with dementia, such as the

SDWG

Environments that are autonomy supportive:

enabling positive risk taking

opportunities to learn new skills

maintenance of old skills

opportunities to contribute to society

meaningful activities

meaningful citizenship

Environments of care & support that maintain the age & identity of the younger person

6.6.2 The transition pathway

Based on the findings of this study it is proposed that participants underwent a process of transition from pre-diagnosis to living life beyond dementia is a four phase process.

Pre-diagnostic phase – Discombobulation

Discombobulation - the person is aware of their changing self, their world and their sense of reality is changing around them and they try and make sense of this but fail.

Diagnostic phase – Consideration

Consideration - the person's life is fractured and they become fragmented, receiving the diagnosis brings an array of emotions, they feel anger, fear and relief, self – stigma and a need to hold on to their age and stage category of identity. There is a process of consideration where they consider what dementia means to them at their age and stage.

The post-diagnostic phase – Assimilation

Assimilation - the person transitions and evolves themselves to adapt to living with dementia, making life style changes to accommodate themselves. Management of their dementia is to keep it outside of themselves, they are not dementia and they do not become dementia.

Living well beyond dementia – Consolidation

Consolidation - is the final transition where the person has consolidated and fully accepts that they have dementia, and moves on to living well with life beyond dementia. Further, we see them move from loss of autonomy, competence, relatedness to fulfilment of these three basic psychological needs which improves well-being.

Figure 5 below depicts the transition pathway. There are three components that form the transition pathway, these are situated in the boxes on the far left of the diagram and are: phase, impact and process. The top row identifies the four phases, pre-diagnosis, diagnosis, post-diagnosis and finally living well beyond dementia. The middle row identifies the impact each phase has on the participant, where they move from changing self, to a fragmented self, evolving self and finally a consolidated sense of self. The bottom row, identified on the far left as process, identifies the process that the person underwent within each phase of transition, these are interpreted as discombobulation, consideration, assimilation and consolidation. The arrow, underneath the pathway, is positioned to show how at the beginning of the transition the basic psychological needs are thwarted, depicted as low and thin moving upward to the needs being supported, the arrow rises and is larger than at the beginning of the pathway. Thus, the arrow identifies how the basic psychological needs, autonomy, competence and relatedness were diminished (thwarted) at the beginning of the transition pathway and moving through the pathway these are supported.

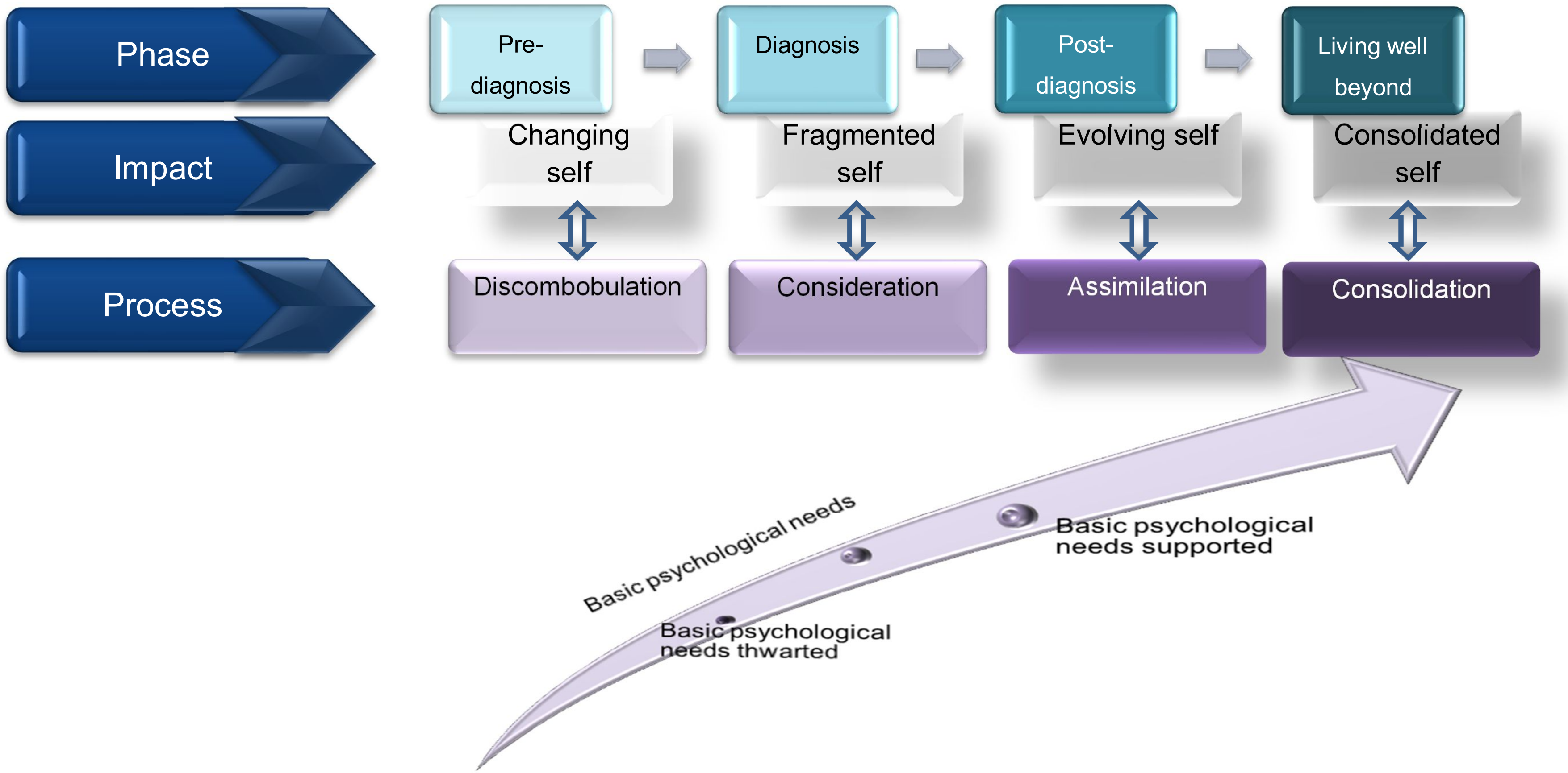


Figure 5 Transition Pathway

6.6.3 Reflective account

I came to this study with practice experience of working with YPwD and OPwD. I also had a theoretical knowledge of dementia following completion of my MSc in Dementia Studies. As a lead commissioner of services for people with dementia I had a view that perhaps the services that we were providing may not meet the needs of YPwD. As part of my MSc I had read research around YPwD and accepted that there would be an impact on the person in relation to work, loss of income and impact of role. However, I was concerned that the issues that were being raised by professionals and colleagues were perhaps an ageist view, in that we could imagine what it would be like to have a dementia diagnosis at a younger age, as we are under 65, but we cannot know how we will feel when we are classed as a senior citizen or older person. Our viewpoint was very much as a younger person. I was keen to understand what YPwD thought themselves. After the first two interviews, I began to see how the younger person saw their experience of dementia as different, following further interviews this was reinforced. I refer to the one of the memos I wrote:

> Memo 16
>
> It is difficult to determine why it is different, but it is. When I first started to think about YPwD and how this was different I could not pinpoint why. In fact, I am not sure that I really thought there was a difference. I am loath to be ageist or suggest that having a diagnosis of dementia would have a lesser impact no matter the age. However, clearly there is a difference. I don’t know what the difference is yet! I cannot say, it is not tangible. It is not just about services, I think it is where you are in your life; is it your life course…maybe?

I was extremely humbled by the participants and their frankness. There was a need within them to tell their story, it was important that their voice was heard. I felt privileged that they had let me into their lives and shared their personal experiences with me.

I feel that in undertaking this research I have gained an insight into the lives of people with dementia, in a way that I could not have gained through just supporting them through my role as a nurse or practitioner.

Over the last six years I have undergone a process of self-development, not only academically, but personally and professionally. I have a better understanding of myself, but also of others.

I have implemented some of this learning and self-development into aspects of my life. As an example I have implemented the principles of SDT into my leadership and management, and also in the way that we support service users. The principles of SDT as a leadership model are easy to understand, and when discussed with teams they can easily grasp the understanding of the basic psychological needs theory and how these should be supported.

7 Chapter Seven Conclusions and Recommendations

7.1 Introduction

The aim of this research was to explore the views of living with dementia from the perspective of younger people with this diagnosis. Participants reported in their experiences that they lived well, a good life beyond dementia; however, there was a process of transition identified, which has been discussed above in the Chapter Six, section 6.6 and called the transition pathway, Figure 5.

The questions that were employed to meet the research aim have been addressed; using the transition pathway we are able to understand the participants' views of living with dementia, before and after diagnosis. Through SDT, BPNT as a framework the study has identified how the participants in this study were able to maintain well-being, and also identified where there was ill-being. The following questions were explored in order to meet the research aim:

- What are the views of Younger People with Dementia?
- How do Younger People with Dementia interpret their lives following their diagnosis?
- What do Younger People with Dementia need to ensure well-being?

This study followed a qualitative interpretative phenomenological approach, and used in-depth interviews to elicit the lived experiences and well-being of eight younger people with dementia. The study initially used an interpretative phenomenological analysis (IPA) followed by a second analysis process utilising Self-determination Theory, Basic Psychological Needs Theory frameworks, to develop the findings and to determine areas that support motivation and well-being. The research has identified that the participants in this study experienced living well beyond their dementia; however, the degree of living well was contingent on fulfilment of the basic psychological needs. To conclude the study the transition pathway is now discussed in relation to the research questions before moving on to limitations, recommendations, contribution to research and suggestions for future research.

7.2 Conclusion

Pre-diagnostic phase - discombobulation - The findings from the study suggested that participants struggled to make sense of their world following the onset of dementia at a younger age prior to their diagnosis. The findings highlighted feelings of isolation and exclusion, and a loss of competence, creating feelings of discombobulation. The view of the participants was that life before diagnosis was difficult and anxiety provoking. Sadly, these people were living with dementia for a number of years within this world before receiving a diagnosis. The first indications that the person was experiencing problems cognitively and functionally were within the work place.

Consequently, five participants retired from work before a confirmed diagnosis, and one participant retired following diagnosis. Utilising SDT, BPNT the study identified how the needs, autonomy, competence and relatedness were thwarted, creating feelings of ill-being. Feelings of social isolation were identified through the loss of relationships with significant others. At this phase the participants experienced feelings of ill-being.

Diagnostic phase - consideration - Receiving an accurate diagnosis was difficult and not timely, in fact, for some participants the diagnostic process was extremely challenging. It was identified that where the diagnostic process was one that was not autonomy supportive the experience was traumatic. Where the diagnostic experience was perceived to be positive would appear to be one which was autonomy supportive. There was a link to diagnostic process and the impact on the recovery time following diagnosis. There were clear indications that participants were not prepared for a diagnosis of dementia. Following the diagnosis participants were left to cope with no support, which caused feelings of biographical abruption and disruption.

While there was a fragmentation of self following diagnosis, participants slowly underwent a process of consideration, where they considered what it meant to have dementia at a younger age, trying to make sense of the diagnosis and then experiencing challenges around this. It is in this phase where age and stage are first identified as being important. Participants thought dementia only affected older people but accepted that they had dementia; however, as part of this acceptance they perceive their dementia, younger dementia, to be a different experience to that of older dementia. It is suggested that there is a need to hold on to age and stage linked to age identity. As dementia is synonymous with being old and ageing, the need to retain one’s age identity becomes more important. There is a consciousness around age and in referring to their dementia experience as being different provides some demarcation between the two dementias, which helps to preserve the age and stage. It is suggested that there is a need to recognise this through acknowledging YPwD as a service user group within their own right, in doing so this helps to support personhood and a sense of self.

The study identified a shift from ill-being following diagnosis towards feelings of well-being as participants considered their diagnosis. Fear was experienced in the form of self-stigma, which can impact on well-being and the basic psychological need of competence and reduced self-esteem. Linked to self-stigma was the fear of disclosure, however, where participants shared their diagnosis with others they were supported. Sharing the diagnosis was important as well as the reaction to this, and links to the basic psychological need of relatedness. In sharing with others that they have dementia and being accepted by others, helped participants feel connected with others, feel cared for and supported. In supporting the basic psychological need of relatedness there is an improvement in well-being.

Post-diagnostic phase - assimilation - The participants in this study shared their experiences of coping with the challenges of living with dementia at a younger age, and described how they underwent a process of assimilation during the post-diagnostic phase. Loss came in different forms, such as physical loss, psychological and social. Physically participants experienced changes in their stamina and experienced debilitating fatigue, which was exacerbated by stress, and further impacted on their ability to function effectively. While this change created feelings of frustration they learnt to adapt their lives to compensate for this. While the tiredness experienced is perhaps not unique to YPwD, there is potentially more of an impact on their life style because of their age and stage.

Social and psychological changes during this phase were experienced where participants had to make life changing decisions. Some of the decisions were out of their control, thereby impacting on their autonomy and affecting well-being. This was noted where participants were supported and were given time to make life changing transition, they did not experience such feelings of loss compared to those participants who felt forced into making changes. Participants who were provided with time to make the changes were more accepting and less frustrated by their sense of loss. Socially further challenges were identified by participants in regard to services that were not suitable for their age range. Loss of spontaneity and freedom were reported, and a need to be listened to as a younger person with dementia was extremely important. Psychologically this study identified that participants kept their dementia separate to self, enabling them to keep a sense of self and not become or be seen as dementia.

There is a need to recognise the person, to hear their voice and listen to their experiences; this was expressed by all participants and is interpreted as a need to be recognised as a younger person with dementia, rather than a person with dementia. Further, this need to be heard and allowed to have voice came from their view that they knew what was best for YPwD, and that their experiences need to be sought, understood and actioned.

Living well beyond dementia - consolidation - The participants presented a positive life following a process of adjustment and transition, presenting a consolidated sense of self. This data were interpreted as individuals being able to take risk and being autonomous. It was important to participants to be enabled to continue with past skills and have opportunities to learn new skills, which is linked to the three basic psychological needs. Taking part in meaningful activities and contributing to society helped to improve well-being. This was further enhanced by developing networks and relationships which created a new sense of social identity with dementia, through the SDWG. Creating environments and engaging people to support the three basic psychological needs would appear to assist in supporting needs and well-being. This study has identified the importance of groups, such as the SDWG, in supporting the three basic psychological needs and well-being, by creating environments that are autonomy supportive.

7.2.1 Limitations

This study was primarily focused on exploring the lived experiences of YPwD. Although eight participants is a recommended number for research that is following an IPA approach, the findings could be considered to be limited because of the sample size. However, qualitative studies are not about proving or disproving a theory, they are about exploring the person's experiences.

Further limitations to this study are evident in the recruitment process. The total number of younger people with dementia in Scotland is small comparative to older people with dementia. If this is added into the limitations placed on the recruitment criteria, such as participants needed to have capacity and be able to articulate their story, this further limits the sample size available. However, this study purposefully chose a small sample size, and given the problems with recruitment an adequate number of participants were recruited who met the inclusion criteria.

Further difficulties with recruitment were experienced due to difficulties with communicating with people who initially volunteered, and problems with illness with potential participants. Previous researchers have also expressed difficulties in the recruitment process when researching YPwD (Clemerson *et al*. 2014). Clemerson *et al*. (2014) struggled to recruit females to their study and explained that people were reluctant to take part because of the emotional impact of the diagnosis.

The findings in this study were positive with participants clearly identifying that they lived well beyond their dementia. However, seven of the eight participants in this study were either members of the SDWG or had previous involvement with the group. There is a possibility that the SDWG has an impact on the way the participants feel about their lives. However, it has been noted in the study the impact of the SDWG, such as providing a place to meet other younger people with dementia, helping to create a new social identity and provide opportunities for development. The participants who took part were able, articulate and confident individuals with support networks. Only one participant was not a member of the group and she had very poor support networks as her family had their own mental health problems. She found solace in attending a day service for older people with dementia. While she was not a member of the SDWG there was still a sense of positivity in her experiences. However, she was maybe less confident than the other participants. It would be interesting to explore experiences of YPwD where they were not accessing any support in regard to services.

Despite the small cohort of participants, rich data was gathered through in depth interviews which provide clear insights into the lived experiences of younger people with dementia. The aim of an IPA approach is to gather rich and meaningful data which undergoes an in depth analysis. Large cohorts of participants would not enable the process of an IPA approach.

The aim of study was to explore the lived experience of YPwD and their well-being, utilising IPA has provided an insight in to their experiences through rich data which has identified that YPwD can be enabled to live well beyond dementia.

I did expect participants to talk more about the services that they required, but while they shared their experiences of services that they accessed or were accessing, they did not speak about future services and what they would want. Only one participant mentioned that he did not want to go into long term care because of poor experiences with his father. I also expected there to be more negativity and perhaps frustration.

Methodological considerations

I believe that in using IPA as the methodology to provide insight into the experiences of YPwD, has provided clear case by case accounts of the participants' experiences who took part in this study. These experiences are a valuable contribution to a small body of research, particularly since it is the voice of YPwD which is being heard. Due to the idiographic nature of IPA I have captured the case by case experiences of each participant, and further been able to find links and connections across each of the cases, which provide rich and informative data.

This study could have been improved perhaps by expanding the pool of participants. The majority of the participants were recruited via the SDWG; future research should consider widening the participants' catchment. Additionally, this study was confined to Scotland, future research would provide greater insights if it were to include YPwD across the UK and perhaps Europe.

Self-determination Theory

This study undertook a secondary analysis using the Basic Psychological Needs Theory of SDT, in order to determine where the BPN were being supported or thwarted, and whether this was linked to participants' well-being. This research provided findings that identified that the BPN were increasingly supported through the transition process.

SDT focuses on three basic psychological needs – autonomy, competence and relatedness, whereas other motivational and well-being theories provide a greater number of domains, such as Ryff's six factors of psychological well-being (Ryff, 1989). However, I was drawn to use SDT, BPNT for two reasons, one my theoretical underpinnings are based around my nursing and health and social care background, where autonomy, independence and social inclusion are promoted, and secondly when undertaking the fieldwork I identified issues with autonomy and self-determination. Further, SDT, BPNT, with three needs is easy to understand and translate.

In regard to using SDT, BPNT in this research, I utilised it in a different way as it was applied qualitatively. There are limited studies that I could source (two) that used SDT in a qualitative approach. However, I do believe that it should be utilised further in qualitative research.

7.2.2 Contribution to research

The findings of this study have identified a potential transition pathway for YPwD (Figure 5), starting with pre-diagnosis through to living well with and beyond dementia. The study findings have recognised that a process which supports the basic psychological needs, autonomy, competence and relatedness of YPwD, indicates there is potential for them to live well with dementia. This study adds to the understanding of the lived experience of YPwD supporting a small, but growing body of research exploring the experiences of younger people with dementia, which were reviewed in Chapter 2.

This study has provided an account of the voices and experiences of YPwD, which included how they saw themselves and their experience of dementia as being different to that of late onset dementia. Age appeared to be an important factor in their ability to cope with moving on and to live a new life with the knowledge that they have dementia. Holding on to age identity perhaps helps with acceptance. Therefore, it is suggested here that there is a need to recognise the differences in presentation and age of this group. This is linked to the need to consider how the current services might be adapted to address some of the key areas of need uncovered in this study, or if indeed a separate specialist service is required. Further, and linked to this finding, is the need for services that are supportive of the unique needs of YPwD. If they are not recognised for their age and stage then they will continue to struggle in a system that sees ‘dementia’, rather than the unique and complex needs of this service user group. Previous studies have identified the need for specialist services for YPwD; however, those studies reviewed for this research identified a lack of voice from YPwD. This research provides the views of YPwD and support for services that are age appropriate, which meet the needs of the person's age and stage. This finding comes from the voice and experience of YPwD.

The outcomes of this research suggest that post-diagnostic support be re-designed and tailored to meet the complex needs of YPwD, recognising the age and life stage of the person at the time of diagnosis. Further, this research supports the need for meaningful activity and suggests that where possible YPwD should be supported to remain at work. People within this age group have a role and a need to contribute to society. In supporting people of this age group to remain active will contribute to supporting their continued wellbeing.

7.2.2.1 The unique contribution consists of five key findings

Firstly, this study has provided a snapshot transition pathway (Figure 5) from pre-diagnosis through to living well beyond dementia, and has identified how YPwD can live well with and beyond dementia. The study has identified how the individual experiences of the group were similar, how their basic psychological needs were thwarted creating feelings of ill-being, and where they were supported resulting in feelings of well-being (Figure 4).

This study has identified that the time prior to diagnosis is one of turmoil and distress, of which the participants were able to clearly recall and articulate. This is perhaps the first study exploring experiences of YPwD that has captured the experiences prior to diagnosis in such detail. Further, that diagnosis, while welcome, needs to be provided in an autonomy supportive environment to avoid issues post-diagnostically.

Secondly, this study identified that while the participants are accepting of their diagnosis they refuse to acknowledge it for what it is, in keeping dementia in the abstract the person does not become dementia. The approach to the management and acceptance of dementia was through seeing dementia as separate to self. In developing a consolidated sense of self the participants underwent a process of assimilation, consideration and consolidation following the pre-diagnostic phase, which is referred to as discombobulation.

Thirdly, this study has identified that there is a loss of independence and spontaneity due to the consciousness of dementia. However, over time this consciousness of dementia is used positively as a form of risk management to aid independence and autonomy, when the person is exposed to environments that are autonomy supportive. The study has identified that autonomy supportive environments create motivation and resilience to carry on with living life, a good life.

A key area of support is the strong networks of family and friends which enabled the younger person with dementia to carry on doing the things that they enjoyed. Further supportive environments came though social groups, such as the SDWG that helped to create a new sense of social identity. Opportunities were created through these groups to do things and learn new skills, because of their dementia. The environments supported them to take on roles and responsibilities and enabled them to continue to live their lives. While they recognised that things will get worse they would live their lives regardless. Therefore, this study has identified that where environments are supportive of the person's basic psychological needs, then a person (YPwD, in this study) is able to live well beyond their dementia, improving motivation and well-being.

Fourthly, YPwD are at risk of self-stigmatisation as a post-diagnostic issue, which impacts on their level of well-being through diminished feelings in competence and motivation. The findings indicate that there is a greater risk of self-stigmatisation in younger people, which could be prevented through bespoke post-diagnostic support programmes.

Finally, this study has recognised that there is a need to support the age and stage of YPwD, through recognition that their experience of dementia is different to that of late onset dementia. In failing to recognise the unique experience of dementia in younger people with dementia there is a failure to recognise the identity of the person. Further, this failure to accept that YPwD have very complex and differing needs those of older people with dementia, will have an impact on service development, which will impact further on YPwD and their well-being.

7.2.3 Recommendations for practice

This study has identified a clear transition pathway (Figure 5), which has recognised that during the pre and post diagnostic phase are times of ill-being. The data identified the need for change in practice and demonstrated how painful the process was during the pre and post-diagnostic phase. The study has also shown how well-being can be supported and that living well beyond dementia is possible. There are contributory components that are required to support living well beyond dementia which have been identified in Figure 4 and Figure 5

The transition pathway (Figure 5) has the potential to be implemented and evaluated as a model for future practice in order to determine whether it would be a suitable care pathway for YPwD, or other service user groups.

By exploring the transition pathway following diagnosis utilising SDT and BPNT, this research will contribute to practice to support motivation and well-being with this service user group.

Health and Social Care, Primary Care, Diagnostic Services - In order to support and prepare a younger person who is undergoing tests and is suspected of having dementia, it is recommended that a programme of pre-diagnostic counselling is developed to help prepare and support the person. In addition, YPwD would benefit from the development of bespoke post-diagnostic support programmes for YPwD should be developed.

Health and Social Care commissioning - This study has clearly identified that the Talking Point Outcomes are also important outcomes for YPwD. Therefore, it is recommended that the Talking Point Outcomes are a suitable outcomes tool for YPwD, and should be used with YPwD when determining outcomes to support their needs.

The findings identify that there is a need to raise awareness for all employers about dementia in the workplace, since it is likely that the first signs and symptoms will be noticed either by the person or their colleagues at work. Linked to this, the research suggests that younger people with dementia respond positively to environments that enable them to take part in meaningful activity and contribute as an active citizen, where possible or able a person should be supported within the workplace.

Health and Social Care -The study has identified the importance of groups, such as SDWG, to help YPwD develop a new sense of social identity and self. YPwD should be provided opportunities to access groups, such as the SDWG, to facilitate this.

Health and Social Care, Policy Makers, and Commissioners - The study suggests that YPwD are identifiable as a defined user group with complex and unique needs due to their age and stage, that they have very different needs from older people, and that they experience dementia differently to that of older people. This needs to be recognised by policy makers and commissioners in health and social care. That in recognising YPwD as a defined user group, they should also recognise that there is a need to tailor services to the person’s age and stage in the knowledge that YPwD are not comfortable, nor are their outcomes met, when accessing services designed to meet the needs of older people with dementia.

These recommendations for practice are beneficial to health and social care: Social Work, assessment and care management, commissioners, service developers and policy makers, primary care, General Practitioners, Consultant Geriatricians and employers.

7.2.4 Recommendations for Policy

The research findings in this study have confirmed that YPwD are a specific user group who need to be recognised. In giving recognition to YPwD by defining their experience of dementia as being different will help to support their lifestyle, ensuring that they remain active participants in society for as long as they are able. Further, in recognising that they are a specialist service user group, there will be a need for policy makers and service developers to design models of care and support to meet the complex needs and outcomes for YPwD. There is a need for a defined budget for YPwD, which will help to ensure that services are there to meet their needs, from specialist diagnostic programmes through to age appropriate services when required.

7.3 Suggestions for future research

This research has identified a transitional pathway from pre-diagnosis through to living well beyond dementia. Future research suggestions are as follows:

1. It is suggested that a longitudinal study, three to four years, is undertaken which plots the journey of younger people with dementia, identifying their time before diagnosis and following. This could be undertaken retrospectively in regard to the pre-diagnostic phase and then actively during and following diagnosis at six monthly intervals. This would help to further develop the transition pathway with a wider geographic area.
2. The transition pathway did not examine the care pathway for YPwD; further studies could be undertaken that enables the transition pathway to be developed into care pathway.
3. Further work with a much larger sample, to include people from England, Wales and perhaps Europe, focusing predominantly on the post-diagnostic phase and how YPwD are enabled to continue to function within society. This type of study would help to gather data to enable service development or programmes of support for YPwD.
4. Finally, it is suggested that a further research study with a larger sample is undertaken utilising Self-determination Theory, BPNT, autonomy, competence and relatedness, as a qualitative approach to explore motivation and well-being with YPwD.

References

Adams, S., Pill, R. and Jones, A. (1997) Medication, chronic illness and identity: The perspective of people with asthma. *Social Science & Medicine*, 45(2), pp.189 - 201

Addis, D. and Tippett, L. (2004) ‘Memory of myself: Autobiographical memory and identity in Alzheimer’s disease’, *Memory*, 12(1), pp.56 - 74

Adults with Incapacity (Scotland) Act 2000. Edinburgh: Stationary Office. Available from: http://www.legislation.gov.uk/asp/2000/4/contents [accessed March 2013]

Allan, K. (2001) Communication and consultation: Exploring ways for staff to involve people with dementia in developing service. The Policy Press and the Joseph Rowntree Foundation. Available at: https://www.jrf.org.uk/report/exploring-ways-staff-consult-people-dementia-about-services [accessed January 2014]

Alzheimer’s Society (2011) *What is Alzheimer’s Disease*. Available at: http://www.alzheimers.or.uk/site/scripts/document_pdf.php?documentID=100 [Accessed: 4 June 2013].

Alzheimer’s Society (2012) *Prevalence and Incidence*. Available at: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documents [Accessed: 2013]

Alzheimer’s Society (2014) *Dementia UK*: Update 2nd Edition ISBN 978-1-906647-31-5

Alzheimer Scotland (2017) Statistics: Estimated number of people with dementia in Scotland. Available at: http://www.alzscot.org/campaigning/statistics

Archibald, C. (2004) ‘Sexuality and Dementia: Beyond the Pale?’ in Innes, A., Archibald, C., and Murphy, C. (*eds.*) *Dementia & Social Inclusion*. London: Jessica Kingsley Publishers. pp.96 - 109

Armari, E., Jarmolowicz, A. and Panegyres, P. (2012) The Needs of Patients with Early Onset Dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 28(1), pp.42 - 46

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

Ashworrth, P. (2008) Conceptual foundations of qualitative psychology. In Smith, J.A. (*ed.*) *Qualitative psychology: A practical guide to research methods* 2nd ed. Los Angeles, CA: Sage Publications Ltd. pp. 4 - 25

Atchley, R.C. (1989) A continuity theory of normal aging. *Gerontologist*, 29, pp.183 - 190

Atchley, R., and Barusch, A. (2004) *Social forces and aging*. Belmont: Wadsworth.

Bakker, C., de Vugt, M.E., Vernooij-Dassen, M., van Vliet, D., Verhey, F.R.J. and Koopmans, R.T.C.M. (2010) ‘Needs in early onset dementia: A qualitative case from the NeedYD study’. *American Journal of Alzheimer’s Disease and Other Dementias*, 25(8), pp.634 - 640

Bandura, A. (1994) Self-efficacy. In V. S. Ramachaudran (*ed*.), Encyclopedia of human behavior (Vol. 4, pp.71- 81). New York: Academic Press. (Reprinted in H. Friedman [*ed*.], Encyclopedia of mental health. San Diego: Academic Press, 1998)

Barber, R. (1997) ‘A survey of services for younger people with dementia’. *International Journal of Geriatric Psychiatry*, 12(9), pp.951 - 954

Beattie, A., Daker-White, G., Gilliard, J. and Means, R. (2002) Younger people in dementia care: A review of service needs, service provision and models of good practice. *Aging & Mental Health*, 6(3), pp.205 - 212

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

Benton, T. and Craib, I. (ed.) (2001) *Philosophy of Science, the philosophical foundations of social thought*. Hampshire, New York: Palgrave.

Birk, M. and Mills, J (2011) *Grounded Theory, A Practical Guide.* London: SAGE Publications Ltd.

Blumer,H. (1969) *Symbolic Interactionism: Perspective and Method*. Los Angeles, London: University of California Press.

Bonanno, G.A. (2004) ‘Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely Aversive events?’. *American Psychologist*, 59(1), pp.20 - 28

Bonanno, G.A. (2012) ‘Uses and abuses of the resilience construct: Loss, trauma, and health-related adversities’. *Social Science & Medicine*, 74(5), pp.753 - 756

Brooks, M. (2008) Health-Related Hardiness in Individuals with Chronic Illnesses. *Clinical Nursing Research*, 17(2), pp.98 - 117

Burke, P. and Stets, J. (2009 *Identity theory*. New York, NY: Oxford: University Press.

Burgener, S., Buckwalter, K., Perkhounkova, Y., Liu, M., Riley, R., Einhorn, C., Fitzsimmons, S. and Hahn-Swanson, C. (2015) Perceived stigma in persons with early-stage dementia: Longitudinal findings: Part 1. *Dementia*, 14(5), pp.589 - 608

Bury, M. (1982) 'Chronic illness as biographical disruption'. *Sociology of Health and Illness*, 4(2), pp.167 - 182

Caddell, L.S. and Clare, L. (2010) 'The impact of dementia on self and identity: A systematic review'. *Clinical Psychology Review*, 30(1), pp.113 - 126

Caddell, L. and Clare, L. (2011a) I'm still the same person: The impact of early-stage dementia on identity. *Dementia*, 10(3), pp.379 - 398

Caddell, L. and Clare, L. (2011b) Studying the self in people with dementia: How might we proceed? *Dementia*, 12(2), pp.192 - 209

Cahill, S. (2004) 'I Know Where this is Going and I Know it won't Go Back': Hearing the Individual's Voice in Dementia Quality of Life Assessments. *Dementia*, 3(3), pp.313 - 330

Calvo., M.G and Gutierrez-Garcia, A. (2016) Cognition and Stress. In Fink G (*ed.*) *Stress: Concepts, Cognition, Emotion, and Behavior. Handbook of Stress Series Volume 1*. London, San Diego, Cambridge: Oxford Elsevier. pp.139-144

Campbell, S., Manthorpe, J., Samsi, K., Abley, C., Robinson, L., Watts, S., Bond, J. and Keady, J. (2016) Living with uncertainty: Mapping the transition from pre-diagnosis to a diagnosis of dementia. *Journal of Aging Studies*, 37, pp.40 - 47

Chaplin, R. and Davidson, I. (2016) What are the experiences of people with dementia in employment? *Dementia*, 15(2), pp.147-161

Charmaz, K. (1983) 'Loss of self: A fundamental form of suffering in the chronically ill'. *Sociology of Health and Illness*, 5(2), pp.168 - 195

Charmaz, K.C. (1991) *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.

Charmaz, K. (1995) 'Grounded Theory', in Smith, J. A., Harrean, R., and Langenhove, L. *(eds.) Rethinking methods in psychology*. London: SAGE. pp.27- 49

Charmaz, K. (2003) 'Grounded Theory: Objectivist and constructivist methods', in Denzin, N.K. and Lincoln, Y.S. (*eds.*) *Strategies of qualitative inquiry*. 2nd ed. Thousand Oaks, CA: SAGE Publications. pp 248 - 291

Charmaz, K.C. (2006) *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage Publications.

Cheston, R. and Bender, M. (2003) *Understanding Dementia, the Man with the Worried Eyes.* London and Philadelphia: Jessica Kingsley Publishers.

Cheston, R., Bender, M and Byatt, S. (2000) ‘Involving people who have dementia in the evaluation of services: A review’. *Journal of Mental Health*, 9(5), pp.471 - 479

Clare, L., Kinsella, G.J., Logsdon, R., Whitlatch, C. and Zarit, S.H (2011) Building Resilience in Mild Cognitive Impairment and Early-Stage Dementia: Innovative Approaches to Intervention and Outcome Evaluation. In: Resnick B., Roberto, K.A. and Gwyther, L.P *(eds.) Resilience in Aging, Concepts Research and Outcomes,* New York, Dordrecht, Heidelberg, London: Springer. pp.245-261

Clare, L., Rowlands, J.M. and Quin, R. (2008) ‘Collective strength: The impact of developing a shared social identity in early-stage dementia’. *Dementia*, 7(1), pp 9 - 30

Clarke, C., Keady, J., Wilkinson, H., Gibb, C., Luce, A., Cook, A. and Williams, L. (2010) Dementia and risk: contested territories of everyday life. *Journal of Nursing and Healthcare of Chronic Illness*, 2(2), pp.102 - 112

Clarke, C., Wolverson, E. and Moniz-Cook, C. (2016) A positive approach to dementia. In: Clarke, C. and Wolverson, E. (*eds.*) *Positive Psychology Approaches to Dementia.* London and Philadelphia: Jessica Kingsley Publishers. pp.41-66

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

Clough, P. and Nutbrown, C. (2012) *A Students Guide to Methodology*. 3rd ed. London, California: Sage.

Cohen, D. and Crabtree, B. (2006) *Qualitative Research Guidelines Project*. Available from: http://qualres.org/Home.Inte-3516html [Accessed: June 2013]

Cook, A. (2008) *Dementia and Well-being: Possibilities and Challenges*. Scotland: Dunedin Academic Press Ltd.

Cook, A. and Miller, E. (2012) *Talking Points: Personal outcomes approach*. Available at: http://www.jitscotland.org.uk [Accessed: 2013]

Cooney, A. (2010) ‘Choosing between Glaser and Strauss: An example’. *Nurse Researcher*, 17(4), pp.18 - 28

Corbin, J.M. and Strauss, A.L. (2008) *Basics of qualitative research: Techniques and procedures for developing grounded theory*. 4th ed. Thousand Oaks: Sage Publications.

Cordery, R., Harvey, R., Frost, C. and Rossor, M. (2002) National survey to assess current practices in the diagnosis and management of young people with dementia. *International Journal of Geriatric Psychiatry*, [online] 17(2), pp.124 - 127

Corrigan, P.W., Watson, A.C. and Barr, L. (2006) ‘The Self–Stigma of mental illness: Implications for Self–Esteem and Self–Efficacy’. *Journal of Social and Clinical Psychology*, 25(8), pp.875 - 884

Cox, S. and Keady, J. (eds.) (1999) *Younger people with dementia*: Planning, Practice and Development. 1st ed. London: Jessica Kingsley Publishers

Cox, S. (1999) Opportunities and Threats. In: S. Cox and Keady, J. *(eds.) Younger People with Dementia: Planning, Practice and Development*, 1st ed. London: Jessica Kingsley Publishers Ltd. pp.69 - 88

Cox, S. and Keady, J. (1999) ‘changing the mind-set: developing the agenda for change’, in: S. Cox and J. Keady (*eds.*) *Younger People with Dementia: Planning, Practice, and Development*, London: Jessica Kingsley Publishers Ltd. pp.292 - 304

Cresswell, J.W. (2007) *Qualitative inquiry and research design: Choosing among five traditions*. 2nd ed. Thousand Oaks, CA: Sage Publications.

Cresswell, J.W. (2009) *Research Design: Qualitative, Quantitative and Mixed Methods Approached*. 3rd ed. USA: SAGE.

Crotty, M.J. (1998) *The foundations of social research: Meaning and perspective in the research process*. Los Angeles, CA: Sage Publications.

Custers, A., Westerhof, G., Kuin, Y. and Riksen-Walraven, M. (2010) Need fulfilment in caring relationships: Its relation with well-being of residents in somatic nursing homes. *Aging & Mental Health*, 14(6), pp.731 - 739

Data Protection Act 1998, Chapter 29 Available from http://www.legislation.gov.uk/ukpga/1998/29 [accessed 2013]

Davies-Quarrell, V., Higgins, A., Higgins, J., Quinn, P., Quinn, M., Jones, G., Jones, L., Foy, A., Foy, V., Marland, R., Marland, P., Powell, A. and Keady, J. (2010) The ACE approach: promoting well-being and peer support for younger people with dementia. *The Journal of Mental Health Training, Education and Practice*, [online] 5(3), pp.41-50. Available at: http://dx.doi.org/10.5042/jmhtep.2010.0503 [Accessed 8 Apr. 2012].

Deci, E. and Ryan, R. (1985) *intrinsic motivation and self-determination in human behavior*. New York: Plenum

Deci, E. and Ryan, R. (2000) The "What" and "Why" of Goal Pursuits: Human Needs and the Self-Determination of Behavior. *Psychological Inquiry*, 11(4), pp.227 - 268

Deci, E. and Ryan, R. (2002) *Handbook of self-determination research*. Rochester, NY: University of Rochester Press.

Deci, E. and Ryan, R. (2002) Overview of Self-determination Theory: An Organismic Dialectical Perspective. In Deci, E. and Ryan, R (*eds.*) *Handbook of self-determination research*. NY: University of Rochester Press. pp.3 - 36

Deci, E. and Ryan, R. (2008) Hedonia, eudaimonia, and well-being: an introduction. *Journal of Happiness Studies*, 9(1), pp.1 - 11

Deci, E.L and Ryan, R. M. (2014) Autonomy and Need Satisfaction in Close Relationships: Relationships Motivation Theory. In Weinstein, N. (*ed.*) *Human Motivation and Interpersonal Relationships: Theory, Research and Applications*. Dordrecht, Heidelberg, New York, London: Springer. pp.53 - 77

Denscombe, M. (2007) *The good research guide: For small-scale social research projects*. 3rd ed. Maidenhead: Open University Press.

Downs, M. (1997) The Emergence of the Person in Dementia Research. *Ageing and Society*, 17(5), pp.597 607

Draper, B., Cations, M., White, F., Troller, J., Loy, C., Brodaty, H., Sachdev, P., onski, P., Demirkol, A., Cumming, R.G. and Withall, A. (2016) Time to diagnosis in young-onset dementia and its determinants: the INSPIRED study. *International Journal of Geriatric Psychiatry*, 31, pp.1212 - 1224

Draper, B. and Withall, A. (2016) Young onset dementia. *Internal Medicine Journal*, [online] 46(7), pp.77 9- 786.

Dreyfus H.L. (1991) *Being in the World, a commentary on Heideggar's Being and Time*. Cambridge, Massachusetts, London England: The MIT Press.

Dror, I.E., Katona, M. and Mungur, K. (1998) 'Age differences in decision making: To take a risk or not?'. *Gerontology*, 44(2), pp.67 - 71

Eatough, V. and Smith, J.A. (2008) Interpretative Phenomenological Analysis. In Willig,C., Stainton-Rogers, W. (*eds.*) T*he SAGE Handbook of Qualitative Research in Psychology*. London: Sage Publications Ltd. p.179 - 194

Eckersley, R. (2007) The Politics of Happiness. *Living Now*, Issue 93, pp.6-7 Available from http://www.richardeckersley.com.au/attachments/Living_now_happiness.pdf [accessed September 2016)

Economic and Social Research Council (2004) *Research Ethics Framework*. Swindon: ESRC

Eden Alternative (2012) *The Eden Alternative Domains of Well-Being*. Available from http://edenalt.orgwordpress/wp-content/uploads/2014/02/EdenAltWellBeingWhitePaperv5.pdf

Engward, H. and Davis, G. (2015) Being reflexive in qualitative grounded theory: discussion and application of a model of reflexivity. *Journal of Advanced Nursing* 71(7), pp. 1530 - 1538 Erikson, E. (1963) *Childhood and society* 2nd ed. New York, NY: Norton.

Equality Act 2010. UK: The Stationary Office. Available from: http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf [accessed December 2016]

Evans, D. (2016) An exploration of the impact of younger-onset dementia on employment. *Dementia*, 0(0) pp.1 - 20

Fazio, S. and Mitchell, D. (2009) Persistence of self in individuals with Alzheimer's disease. *Dementia*, 8 (1), pp.39 - 59

Ferran, J., Wilson, K., Doran, M., Ghadiall, E., Johnson, F., Cooper, P. and Mccracken, C. (1996) The early onset dementias: a study of clinical characteristics and service use. *International Journal of Geriatric Psychiatry*, 11(10), pp.863 - 869

Finlay, L. (2006) ‘The body’s disclosure in phenomenological research’. *Qualitative Research in Psychology*, 3(1), pp.19 - 30

Gelman, C. and Greer, C. (2011) ‘Young children in early-onset Alzheimer’s disease families: Research gaps and emerging service needs’. *American Journal of Alzheimer’s Disease and Other Dementias*, 26(1), pp.29 - 35

Gibbs,G. (2007) *Analyzing Qualitative Data*. London: SAGE Publications Ltd.

Gibson, A., Anderson, K. and Acocks, S. (2014) Exploring the Service and Support Needs of Families with Early-Onset Alzheimer’s Disease. *American Journal of Alzheimer's Disease & Other Dementias*, 29(7), pp.596 - 600

Gillard, A. and Roark, M. (2013) Support for basic psychological needs in the context of HIV disclosure for older youth. *Children and Youth Services Review*, 35(1), pp.102 - 111

Glaser, B.G. and Strauss, A.L. (1967) *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine de Gruyter.

Goffman, E. (1959) *The Presentation of Self in Everyday Life*. England: Penguin Books, 1990.

Gray, D.E. (2009) *Doing research in the real world*. 2nd edn. Los Angeles: SAGE Publications.

Green, J. and Thorogood, N. (2009) *Qualitative Methods for Health Research*. London: SAGE.

Greenhalgh, T. (2010) *How to read a paper: The basics of evidence-based medicine*. 4th ed. London, United Kingdom: Wiley-Blackwell (an imprint of John Wiley & Sons Ltd).

Haas, B. (1999) A Multidisciplinary Concept Analysis of Quality of Life. *Western Journal of Nursing Research*, 21(6), pp.728 - 742

Harding, N. and Palfrey, C. (1997) *The social construction of dementia*. London: Jessica Kingsley Publishers

Harre, R. (2012) Positioning theory: moral dimensions of social-cultural psychology. In J. Valisner (*ed.*) *The Oxford Handbook of Culture and Psychology,* New York: Oxford University. pp.191 - 206

Harris, P. (2004) The Perspective of Younger People with Dementia. *Social Work in Mental Health*, 2(4), pp.17 - 36

Harris, P.B. and Durkin, C. (2002) 'Building Resilience through Coping and Adapting', in Harris, P.B. (*ed.*) *The Person with Alzheimer's Disease*. Baltimore: Hopkins University Press. pp.165 - 18.

Harris, P.B. and Keady, J. (2004) 'Living with Early Onset Dementia: Exploring the Experience and Developing Evidenced -based Guidelines for Practice'. *Alzheimer's Care Quarterly*, 5(2), pp.111 - 122

Harris, P.B. and Keady, J. (2009) 'Selfhood in younger onset dementia: Transitions and testimonies'. *Aging & Mental Health*, 13(3), pp.437 - 444

Harvey, R. (1998) *Young onset dementia: epidemiology, clinical symptoms, family burden, support and outcome*. Imperial College London

Henn, C.M., Hill, C., and Jorgensen, L.I. (2016) An investigation into the factor structure of the Ryff Scales of Psychological Well-Being. *S.A. Journal of Industrial Psychology,* 42(1), pp1-12. Available from: http://www.sajip.co.za/index.php/SAJIP/article/view/1275 [accessed January 2017]

Herskovits, E. (1995). Struggling over Subjectivity: Debates about the "Self" and Alzheimer's Disease. *Medical Anthropology Quarterly*, 9(2), pp.146 - 164

Higgs, P. and Gilleard, C. (2015) Interrogating personhood and dementia. *Aging & Mental Health*, 20(8), pp.773 - 780

Holcombe, T.F (2010) 'Transitioning into Retirement as a Stressful Life Event', in Miller T. (*ed.*) *Handbook of Stressful Transitions Across the Lifespan*. New York: Springer. pp.133 - 148

Holland, A. and Kensinger, E. (2010) Emotion and autobiographical memory. *Physics of Life Reviews*, 7(1), pp.88 - 13.

Holloway, I. and Wheeler, S. (2002) *Qualitative Research in Nursing*. 2nd ed. Oxford: Blackwell Publishing.

Holloway, I. and Wheeler, S. (2010) *Qualitative research in nursing and healthcare*. 3rd ed. Chichester, West Sussex, U.K: Wiley-Blackwell.

Holst, G. and Edberg, A. (2011) Wellbeing among people with dementia and their next of kin over a period of 3 years. *Scandinavian Journal of Caring Sciences*, 25(3), pp.549 - 557

Horsburgh, D. (2003) 'Evaluation of qualitative research'. *Journal of Clinical Nursing*, 12 (2), pp.307 - 312

Hubbard, G., Downs, M.G. and Tester, S. (2003) 'Including older people with dementia in research: Challenges and strategies'. *Aging & Mental Health*, 7(5), pp.351 - 36.

Hulko, W. (2004) 'Social Science Perspectives on Dementia Research', in Innes, A., Archibald, C., and Murphy, C. (*eds.*) *Dementia and social inclusion: Marginalised groups and Marginalised areas of dementia research, care and practice*. London: Jessica Kingsley Publishers. pp.237 - 254

Husband, H. (1999) The psychological consequences of learning a diagnosis of dementia: Three case examples. *Aging & Mental Health*, 3(2), pp.179 - 183

Hutchison, E.D. (2007) *Dimensions of human behavior: The changing life course (series in social work)*. 3rd ed. Los Angeles, CA: Sage Publications.

Iliffe, S., Walters, K. and Rait, G. (2000) 'Shortcomings in the diagnosis and management of dementia in primary care: Towards an educational strategy'. *Aging & Mental Health*, 4(4), pp.286 - 291

Innes, A. (2009) *Dementia studies: A social science perspective*. London: SAGE Publications.

Innes, A. and Sherlock, K. (2004) 'Rural Communities', in Innes, A., Archibald, C., and Murphy, C. (*eds.*) *Dementia and social inclusion: Marginalised groups and marginalised areas of dementia research, care and practice*. London: Kingsley, Jessica Publishers. pp.32 - 49

Innes, A., Szymczynska, P. and Stark, C. (2014) Dementia diagnosis and post-diagnostic support in Scottish rural communities: Experiences of people with dementia and their families. *Dementia*, 13 (2) pp.233 - 247

Katsuno, T. (2005) 'Dementia from the inside: How people with early-stage dementia evaluate their quality of life'. *Ageing and Society*, 25(2), pp.197 - 214

Kaufmann, E. and Engel, S. (2016) Dementia and well-being: A conceptual framework based on Tom Kitwood's model of needs. *Dementia*, 15(4), pp.774 - 788

Keady, J. and Nolan, M. (1994) ‘Younger onset dementia: Developing a longitudinal model as the basis for a research agenda and as a guide to interventions with sufferers and carers’. *Journal of Advanced Nursing*, 19(4), pp.659 - 669

Keady, J. and Gilliard, J. (2002) The experience of neuropsychological assessment for people with suspected Alzheimer's disease. In P. Harris (Ed.) *The person with Alzheimer's disease: Pathways to understanding the experience* London and Baltimore: The Johns Hopkins University Press. pp. 1- 28

Kelly, F. (2009) Recognising and supporting self in dementia: a new way to facilitate a person-centred approach to dementia care. *Ageing and Society*, 30(01), pp.103 -124

Kinney, J.M., Kart, C.S. and Reddecliff, L. (2011) ‘“That’s me, the Goother”: Evaluation of a program for individuals with early-onset dementia’. *Dementia*, 10(3), pp.361 - 377

Kitwood, T.M. (1997) *Dementia reconsidered: The person comes first*. Philadelphia: Open University Press.

Kitwood, T. and Bredin, K. (1992) Towards a Theory of Dementia Care: Personhood and Well-being. *Ageing and Society*, 12(03), pp.269 - 287

Knapp, M., Comas-Herrera, A., Somani, A. and Bannerjee, S. (2007) *Dementia: international comparisons. Summary report for the National Audit Office*. Personal Social Services Research Unit, London School of Economics and Political Science and the Institute of Psychiatry, King’s College London. http://www.pssru.ac.uk/pdf/dp2418.pdf [accessed December 2016]

Kondo, D.K. (1990) Crafting Selves: Power, Genders and Discourses of Identity in a Japanese Workplace. Chicago, London: The University of Chicago Press Ltd.

Langdon, S.A., Eagle, A. and Warner, J. (2007) ‘Making sense of dementia in the social world: A qualitative study’. *Social Science & Medicine*, 64(4), pp. 989 - 1000.

Larkin, M., Watts, S. and Clifton, E. (2006) Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2), pp.102 - 120

Leung, K., Finlay, J., Silvius, J., Koehn, S., McCleary, L., Cohen, C., Hum, S., Garcia, L., Dalziel, W., Emerson, V., Pimlott, N., Persaud, M., Kozak, J. and Drummond, N. (2011). Pathways to diagnosis: exploring the experiences of problem recognition and obtaining a dementia diagnosis among Anglo-Canadians. *Health & Social Care in the Community*, 19(4), pp.372 - 381

Lincoln, Y. and Guba, Y. (1985) *Naturalistic Inquiry*. Newbury Park, CA: SAGE Publications Ltd.

Link, B. and Phelan, J. (2001) Conceptualizing Stigma. *Annual Review of Sociology*, 27(1), pp.363 - 385

Little., T.D., Hawley, P.H., Heinrich, C.C. & Marsland, K.W. (2002) Three Views of the Agentic Self: A Developmental Synthesis. In Deci, E. and Ryan, R (*eds.*) *Handbook of self-determination research*. Rochester, NY: University of Rochester Press. pp.389 - 404

Locock, L., Ziebland, S. and Dumelow, C. (2009) 'Biographical disruption, abruption and repair in the context of motor Neurone disease'. *Sociology of Health & Illness*, 31(7), pp.1043 - 1058

Logan, J.R., Ward, R. and Spitze, G. (1992) 'As old as you feel: Age identity in middle and later life'. *Social Forces*, 71(2), pp.451 - 467

Lopez, K. and Willis, D. (2004) Descriptive Versus Interpretive Phenomenology: Their Contributions to Nursing Knowledge. *Qualitative Health Research*, 14(5), pp.726 - 735

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

Luthar, S.S. and Cicchetti, D. (2000) 'The construct of resilience: Implications for interventions and social policies'. *Development and Psychopathology*, 12(4), pp.857–885

MacRae, H. (2010) Managing Identity While Living with Alzheimer's Disease. *Qualitative Health Research*, 20(3), pp.293 - 305

Mather, M., Mazar, N., Gorlick, M.A., Lighthall, N.R., Burgeno, J., Schoeke, A. and Ariely, D. (2012) 'Risk preferences and aging: The "certainty effect" in older adults' decision making'. *Psychology and Aging*, 27(4), pp.801 - 816

Manthorpe, J., Iliffe, S., Clough, R., Cornes, M., Bright, L. and Moriarty, J. (2008) 'Elderly people's perspectives on health and well-being in rural communities in England: Findings from the evaluation of the national service framework for older people'. *Health & Social Care in the Community*, 16(5), pp.460 - 468

McLennan, J. (1999) 'Assessment and Service Responses for Younger People with Dementia: A Medical Overview'. In: S. Cox and J. Keady (*eds.*).*Younger People with Dementia: Planning, Practice, and Development*, 1st ed. London: Jessica Kingsley Publishers Ltd, London: Jessica Kingsley Publishers. pp.17 - 36.

McWilliam. C.L. (2010) Phenomenology. In Bourgeault,I., Dingwall, R. & De Vries,R. (*eds.*) *The SAGE Handbook of Qualitative Methods in Health Research* London: Sage Publications Ltd, London. pp. 229-248 Available from : http://dx.doi.org/10.4135/9781446268247.n13 [accessed December 2016]

Mendez, M. (2006) The Accurate Diagnosis of Early-Onset Dementia. *The International Journal of Psychiatry in Medicine*, pp.401 - 412

Menne, H., Kinney, J. and Morhardt, D. (2002) 'Trying to Continue to Do as Much as They Can Do'. *Dementia*, 1(3), pp.367 - 382

Merleau-Ponty, M. (1962) *Phenomenology of perception.* London: Routledge.

Miller, E. and Cook, A. (2011) *Key Messages Talking Points: Personal Outcomes Approach*. Joint Improvement Team. Available from: http://www.jitscotland.org.uk/action-areas/user-and-carer-involvement/ [accessed March 2013]

Milne, A.J., Woolford, H.H., Mason, J. and Hatzidimitriadou, E. (2000) 'Early diagnosis of dementia by GPs: An exploratory study of attitudes'. *Aging & Mental Health*, 4(4), pp.292 - 300

Mills, J., Bonner, A. and Francis, K. (2006) 'The Development of Constructivist Grounded Theory'. *International Journal of Qualitative Methods,* 5(1), pp.1 - 10

Moran, D. (2000). Introduction to phenomenology. London: Routledge.

Morgan, D.G., Semchuk, K.M., Stewart, N.J. and D'Arcy, C. (2002) 'Rural families caring for a relative with dementia: Barriers to use of formal services'. *Social Science & Medicine*, 55(7), pp.1129 - 1142

Morse, J.M. (2015) Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry*. Qualitative Health Research*, Vol. 25 (9), pp 1212 - 1222

Moule, P. and Goodman, M. (2009) *Nursing research: An introduction*. Los Angeles: SAGE Publications.

Münster, A., Halvari, H., Bjørnebekk, G. and Deci, E. (2012) Self-determined motivational predictors of increases in dental behaviors, decreases in dental plaque, and improvement in oral health: A randomized clinical trial. *Health Psychology*, 31(6), pp.777 - 788

Music, S. and Rossell, S.L. (2016) Stress, Memory and Memory Impairment. In Fink G (*ed.*) *Stress: Concepts, Cognition, Emotion, and Behavior. Handbook of Stress Series Volume 1*. Elsevier, London, San Diego, Cambridge: Oxford. pp.145 - 152

National Institute for Health and Care Excellence, (2006) Dementia: supporting people with dementia and their carers in health and social care. NICE [NICE Guideline CG42] updated 2016. Available from https://www.nice.org.uk/guidance/cg42/chapter/Personcentred-care#ftn.footnote_2 [accessed July 2016]

NHS Health Scotland (2013) Younger People with Dementia: Living well with your diagnosis. Available from: https://www.youngdementiauk.org/sites/default/files/Younger%20people%20with%20dementia%2C%20NHS%20Health%20Scotland.pdf [accessed June 2015]

Nochi, M. (2000) ‘Reconstructing self-narratives in coping with traumatic brain injury’. *Social Science & Medicine*, 51(12), pp.1795 - 1804.

Novek, S., Shooshtari, S. and Menec, V. (2015) Comparing the Overall Health, Stress, and Characteristics of Canadians with Early-Onset and Late-Onset Dementia. *Journal of Aging and Health*, 28(6), pp.1016 - 1037

O'Gorman, K. and MacIntosh, R. (2015) Mapping Research Methods. In: O’Gorman, K., MacIntosh, R. *The Global Management Series: Research Methods for Business & Management*. 2nd ed. Oxford: Goodfellow Publishers Ltd. pp.50 - 74

Ohman, A., Nygard, L. and Borell, L. (2001) ‘The vocational situation in cases of memory deficits or younger-onset dementia’. *Scandinavian Journal of Caring Sciences*, 15(1), pp.34 - 43

Panegyres, P. and Frencham, K. (2007) Course and Causes of Suspected Dementia in Young Adults: A Longitudinal Study. *American Journal of Alzheimer's Disease and Other Dementias*22(1), pp.48 - 56

Parahoo, K. (2006) *Nursing research: Principles, process, and issues*. Basingstoke: Palgrave Macmillan.

Park, C.L., and Folkman, S. (1997) Meaning in the context of stress and coping. *Review of General Psychology*, 1(2), pp.115 - 144.

Patton, M.Q, (1990) Qualitative evaluation and research methods, 2nd ed. Newbury Park: SAGE. Cited in: Shenton, A.K. (2004) Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, p.68. Available from: 75https://pdfs.semanticscholar.org/452e/3393e3ecc34f913e8c49d8faf19b9f89b75d.pdf [accessed April 2015]

Pesonen, H.M., Remes, A.M. and Isola, A. (2013) ‘Diagnosis of dementia as a turning point among Finnish families: A qualitative study’. *Nursing & Health Sciences*, 15(4), pp.489 - 496

Phinney, A. (2002) Living with the Symptoms of Alzheimer's Disease. In: P. Harris (*ed.) The Person with Alzheimer's Disease: Pathways to Understanding the Experience*. Baltimore & London: The Johns Hopkins University Press. pp.49 - 74

Phinney, A., Chaudhury, H. and O'Connor, D. (2007) Doing as much as I can do: The meaning of activity for people with dementia. *Aging & Mental Health*, 11(4), pp.384 - 393.

Pietkiewicz, I and Smith, J. (2012) A practical guide to using Interpretive Phenomenological Analysis in qualitative research psychology. *Czasopismo Psychologiczne (Pysychological Journal)*, 18(2), pp.361 - 369

Pipon-Young, F.E., Lee, K.M., Jones, F. and Guss, R. (2011) 'I'm not all gone, I can still speak: The experiences of younger people with dementia. An action research study'. *Dementia*, 11(5), pp.597 - 616

Polit, D.F. and Beck, C.T. (2006) *Essentials of nursing research: Methods, appraisal, and utilization*. 6th ed. Philadelphia: Lippincott Williams and Wilkins.

Polit, D.F. and Beck, C.T. (2014) *Essentials of Nursing Research: Appraising Evidence for Nursing Practice.* 8^{th} ed, International Edition. Philadelphia: Wolters Kluwer Health/ Lippincott Williams and Wilkins.

Pollock, S.E. (1986) 'Human responses to chronic illness'. *Nursing Research*, 36 (2), pp.90 - 95.

Pollock, S.E. (1990) 'Response to "Learned self-help response to chronic illness experience: A test of three alternative learning theories". *Scholarly Inquiry for Nursing Practice: An International Journal,* 4(1), pp.43 - 45

Popper, K.R.R. (1968) *Logic of scientific discovery*. 2nd ed. London: Hutchinson.

Powers, A.G. (2014) Dementia Beyond Disease, Enhancing Well-being. Baltimore, London, Sydney: Health Professions Press.

Pratt, R. (2002) '"Nobody's ever asked how I felt"', in Wilkinson, H. (*ed.*) *The perspectives of people with dementia: Research methods and motivations*. London: Jessica Kingsley Publishers, pp.165 - 182

Prince, M., Wimo, A., Guerchet, M., Ali, G.C., Wu, Y.T., Prina, M., Alzheimer's Disease International (2015) *World Alzheimer Report: The Global Impact of Dementia, an Analysis of Prevalence, Incidence, Cost and Trends.* Alzhiemer's Disease International. Available from: https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf [accessed April 2016]

Rayment, D. and Kuruvilla, T. (2015). Service provision for young-onset dementia in the UK. *Progress in Neurology and Psychiatry*, 19(4), pp.28 - 30

Reed, J., Cantley, C., Clarke, C.L. and Stanley, D. (2002) 'Services for younger people with dementia: Problems with differentiating needs on the basis of age'. *Dementia*, 1(1), pp. 95 - 112.

Reid, K., Flowers, P. and Larkin, M. (2005) 'Exploring lived experience'. *The Psychologist*, 18(1), pp.20 - 23

Reid, D., Ryan, T. and Enderby, P. (2001) 'What does it mean to listen to people with dementia?'. *Disability & Society*, 16(3), pp.377 - 392

Roach, P. (2017) Young onset dementia: Negotiating future workplace roles and identities. *Dementia*,16 (1), pp.5 - 8. (First published 2016)

Roach, P. and Drummond, N. (2014) '"It's nice to have something to do": Early-onset dementia and maintaining purposeful activity'. *Journal of Psychiatric and Mental Health Nursing*, 21(10), pp.889 - 895

Roach, P., Drummond, N. and Keady, J. (2016) 'Nobody would say that it is Alzheimer's or dementia at this age': Family adjustment following a diagnosis of early-onset dementia. *Journal of Aging Studies*, 36, pp.26 - 32.

Roach, P., Keady, J., Bee, P. and Williams, S. (2014) 'We can't keep going like this': identifying family storylines in young onset dementia, *Ageing and Society*, 334, pp.1397 - 1426

Robertson, J. and Evans, D. (2015) Evaluation of a workplace engagement project for people with younger onset dementia. *Journal of Clinical Nursing*, 24(15-16), pp.2331 - 2339

Robertson, J., Evans, D. and Horsnell, T. (2013) Side by Side: A workplace engagement program for people with younger onset dementia. *Dementia*, 12 (5), pp.666 - 674

Rolfe, G. (2006) Validity, trustworthiness and rigour: quality and the idea of qualitative research. Journal of Advanced Nursing, 53 (3), pp.304 - 310

Rolison, J.J., Hanoch, Y., Wood, S. and Liu, P. (2013) 'Risk-taking differences across the adult life span: A question of age and domain'. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 69(6), pp.870 - 880

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

Royal College of Psychiatrists and Alzheimer's Society (2006) *Services for younger people with Alzheimer's disease and other dementias*. Council Report CR135 . Available from: http://www.rcpsych.ac.uk/files/pdfversion/cr135.pdf [accessed March 2012

Rozario, P. and Derienzis, D. (2009) ‘So, forget how old I am!’ Examining age identities in the face of chronic conditions. *Sociology of Health & Illness*, 31(4), pp.540 - 553.

Rush, K.L., Murphy, M.A. and Kozak, J.F. (2012) ‘A photovoice study of older adults’ conceptualizations of risk’. *Journal of Aging Studies*, 26(4), pp.448 - 458.

Ryan, R.M. (2009) Self-determination Theory and Wellbeing. Wellbeing in Developing Countries, Wed Research Review 1. Available from: http://www.welldev.org.uk/wed-new/network/research-review-page.html [accessed September 2016]

Ryan, R.M. and Deci, E.L. (2000) ‘Self-determination Theory and the facilitation of intrinsic motivation, social development, and well-being’. *American Psychologist*, 55(1), pp.68 - 78.

Ryan, R.M. and Deci, E.L. (2001) ‘On happiness and human potentials: A review of research on hedonic and eudaimonic well-being’, in S. Fiske *(ed.) Annual Review of Psychology (Annual Reviews Inc., Palo Alto, CA*), Vol.52, pp.141 - 166.

Ryan, R.M. and Deci, E.L. (2006) ‘Self-regulation and the problem of human autonomy: Does psychology need choice, self-determination, and will?’. *Journal of Personality*, 74(6), pp.1557 - 1586.

Ryan R.M. and Deci E.L. (2011) A Self-determination Theory Perspective on Social, Institutional, Cultural, and Economic Supports for Autonomy and Their Importance for Well-being. In Chirkov V.I., Ryan, R. M., Sheldon, K.M. (*eds.*). *Human Autonomy in Cross-Cultural Context: Perspectives of Agency, Freedom and Well-being.* London, New York: Springer, pp.45 - 64

Ryff, C.D. (1989) Happiness is everything, or is it? explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology,* 57(6), pp.1069 - 1081

Sabat, S. (2001) *The Experience of Alzheimer’s Disease: Life Through a Tangled Veil.* Oxford: Blackwell.

Sabat, S. (2002) Surviving Manifestations of Selfhood in Alzheimer's Disease: A case study. *Dementia*, 1(1), pp.25 - 36

Sabat, S.R. and Collins, M. (1999) ‘Intact social, cognitive ability, and selfhood: A case study of Alzheimer’ s disease’. *American Journal of Alzheimer’s Disease and Other Dementias*, 14(1), pp.11 - 19

Sabat, S.R. and Harré, R (1992) ‘The construction and Deconstruction of self in Alzheimer’s disease’. *Ageing and Society*, 12(04), pp.443 - 461

Sampson, E.L. (2004) ‘Young onset dementia’. *Postgraduate Medical Journal*, 80(941), pp.125 - 139

Scottish Government (2010) *Scotland's National Dementia Strategy*. Available at: http://www.gov.scot/Publications/2010/09/10151751/0 [accessed 2012]

Scottish Government (2011) *Promoting Excellence: a framework for all health and social services staff working with people with dementia and their families and carers* Scottish Government, available from http://www.gov.scot/Publications/2011/05/31085332/12 [accessed July 2016]

Scottish Government (2011) *Standards of Care for Dementia in Scotland*. Scottish Government. Available from: http://www.gov.scot/Publications/2011/05/31085414/0 [accessed 2012]

Scottish Government (2012) *HEAT 2012-2013*. Available from: http://www.scotland.gov.uk/About/Performs/partnerstories/NHSScoltandperformance [accessed: March 2013]

Scottish Government (2016) *Self Directed Support: my support, my choice: your guide to social care.* Scottish Government. Available from http://www.selfdirectedsupportscotland.org.uk [accessed 2016]

Shah, H, and Marks N. (2004) *A well-being manifesto for a flourishing society*. New Economics Foundation [NEF] Available from :http://b.3cdn.net/nefoundation/813660812dc0c82af5_vkm6vve98.pdf [accessed April 2016]

Shenton, A.K. (2004) Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, pp.63 - 75. Available from: 75https://pdfs.semanticscholar.org/452e/3393e3ecc34f913e8c49d8faf19b9f89b75d.pdf [accessed April 2015]

Shinebourne, P. (2011) The Theoretical Underpinnings of Interpretative Phenomenological Analysis (IPA). *Existential Analysis: Journal of the Society for Existential Analysis,* 22(1) pp.16 - 31

Shlosberg, E. (2003) Support for Patients. In: R. Baldwin and M. Murray, (*eds.*) *Younger People with Dementia a Multidisciplinary Approach*, London: Martin Dunitz, an imprint of the Taylor & Francis Group plc, pp.l27-139.

Shlosberg, E., Browne, C. and Knight, A. (2003) Views of users and carers. In: R. Baldwin and M. Murray (*eds.*) *Younger People with Dementia a Multidisciplinary Approach*, London: Martin Dunitz, an imprint of the Taylor & Francis Group plc, pp.179 -192

Sherratt, C., Soteriou, T. and Evans, S. (2007) 'Ethical issues in social research involving people with dementia'. *Dementia*, 6(4), pp 463 - 479

Silverman, D. (2005) Doing Qualitative Research. 2nd ed. London: SAGE Publications Ltd.

Smith, J. (2004) Reflecting on the development of interpretive phenomenological analysis and its contribution to qualitative research. *Qualitative Research in Psychology*, 1(1), pp.39 - 54

Smith, J.A., Flowers, P. and Larkin, M. (2009) *Interpretative phenomenological analysis: Theory, method and research*. London: SAGE Publications

Smith, J. and Osborne, M. (2008) ‘Interpretive Phenomenological Analysis’, in Smith, J.A. (*ed.*) *Qualitative psychology: A practical guide to research methods*. 2nd ed. United Kingdom, Los Angeles, CA: Sage Publications Ltd. pp.53 - 75

Snyder, L. (2002) ‘Social and Family Relationships: Establishing and Maintaining Connections’, in Harris P. B. (*ed.*) *The Person with Alzheimer’s Disease.* Baltimore*:* The John Hopkins University Press*.* pp.112 - 133

Social Care (Self-directed Support) (Scotland) Act 2013.Edinburgh : Stationary Office. Available from: http://www.legislation.gov.uk/asp/2013/1/contents/enacted [accessed April 2015]

Sperlinger, D. and Furst, M. (1994) The service experiences of people with presenile dementia: A study of carers in one London Borough. *International Journal of Geriatric Psychiatry*, 9(1), pp.47 - 50

Springer, K., Hauser, R. and Freese, J. (2006) Bad news indeed for Ryff’s six-factor model of well-being. *Social Science Research*, 35(4), pp.1120 - 1131

Stalker, K., Davidson, J., MacDonald, C. and Innes, A. (2006) *A Scoping Study on the Needs of, and Services to, Younger Disabled People including those with Early Onset Dementia in Scotland*. Scottish Executive Social Research, Scottish Government. Available from: http://www.gov.scot/Resource/Doc/93483/0022475.pdf [Accessed February 2012]

Sterin, G. (2002) Essay on a Word: A lived experience of Alzheimer's disease. *Dementia*, 1(1), pp.7 - 10

Stewart, T., Chipperfield, J., Perry, R. and Weiner, B. (2012) Attributing illness to ‘old age’: Consequences of a self-directed stereotype for health and mortality. *Psychology & Health*, 27(8), pp.881 - 89

Sultan, S. (2013) Patient’s Perceived Autonomy Support Affecting their Levels of Depression and Treatment Motivation. *Pakistan Journal of Social and Clinical Psychology*, 11(2), pp.63 - 68 Available from: http://www.gcu.edu.pk/FullTextJour/PJSCS/2013b/11.finalsarwatsutanrevisedwithdiscussion.pdf [accessed December 2016]

Tilden, B. (2005) Identity and Adherence in a Diabetes Patient: Transformations in Psychotherapy. *Qualitative Health Research*, 15(3), pp.312 - 324

Tolhurst, E., Bhattacharyya, S. and Kingston, P. (2014) Young onset dementia: The impact of emergent age-based factors upon personhood. *Dementia*, 13 (2), pp.193 - 206

Triveldi, R.B., Bosworth, H.B. and Jackson, G.L. (2011) 'Resilience in Chronic Illness', in Resnick, B., Gwyther, L.P., and Roberto, K.A. (*eds.*) *Resilience in aging: Concepts, research, and outcomes*. New York: Springer-Verlag. pp.181 - 198

Turner, D.W. (2010) 'Qualitative Interview Design: A Practical Guide for Novice Investigator'. *The Qualitative Report*, 15(3), pp.754 - 760

Turpin, G., Baley, V., Beail, N., Scaife, J., Slade, P., Smith, J.A., Walsh, S. (1997) Standards for research projects and thesis involving qualitative methods: suggested guidelines for trainees and courses. *Clinical Psychology Forum*, 108, pp.3 - 7

Vallerand, R. and Ratelle, C.F. (2002) Intrinsic and Extrinsic Motivation: A Hierarchical Model. In Deci, E. and Ryan, R (*eds.*) *Handbook of self-determination research.* NY: University of Rochester Press. pp.34 - 64

Weaks, D., McLeod, J. and Wilkinson, H (2006) Dementia. *Therapy Today*, 17(3), pp.8 - 11 Available form:http://eb.a.ebscohost.com.ezproxy.napier.ac.uk/ehost/detail/detail?sid [accessed September 2016]

Weaks, D., Wilkinson, H., Houston, A., and McKillop, J. (2012) *Perspectives on ageing with dementia.* Joseph Rowntree Foundation. ISBN 978 1859358-498 www.jrf.org.uk

Weaks, D., Wilkinson, H. and McLeod, J. (2014) Daring to tell: the importance of telling others about a diagnosis of dementia. *Ageing and Society*, 35(04), pp.765 - 784

Werner, P., Stein-Shvachman, I. and Korczyn, A.D. (2009) 'Early onset dementia: Clinical and social aspects', *International Psychogeriatrics*, 21(04), pp.631 - 636

Whitbourne, S.K. (2011) The Essential Guide to Defense Mechanisms. *Pyschology Today*. Available from: https://www.psychologytoday.com/blog/fulfillment-any-age/201110/the-essential-guide-defense-mechanisms [accessed, April 2014]

Wilkinson, H. (2002) 'Including people with dementia in research: methods and motivations', in Wilkinson, H. (*ed.*) *The Perspectives of People with*

Dementia Research Methods and Motivations. London: Jessica Kingsley Publishers. pp.9 - 24

Williams, G.C. (2002) Improving Patients' Health Through Supporting the Autonomy of Patients and Providers. In Deci, E. and Ryan, R (*eds.*) *Handbook of self-determination research*. NY: University of Rochester Press, Rochester. pp.233 - 254

Williams, T., Cameron, I. and Dearden,T. (2001) From pillar to post - a study of younger people with dementia. *Psychiatric Bulletin*, 25(10), pp.384 - 387

Willis, J.W. (2007) *Foundations of qualitative research: Interpretive and critical approaches*. United States: Sage Publications.

Willis, R., Chan, J., Murray, J., Matthews, D. and Banerjee, S. (2009) 'People with dementia and their family carers' satisfaction with a memory service: A qualitative evaluation generating quality indicators for dementia care'. *Journal of Mental Health*, 18 (1), pp.26 - 37

Wolverson (Radbourne), E., Clarke, C. and Moniz-Cook, E. (2010) Remaining hopeful in early-stage dementia: A qualitative study. *Aging & Mental Health*, 14(4), pp.450 - 460

Woodburn, K. (1999) Epidemiological Issues and Younger People with Dementia. In: S. Cox and Keady,J. (*ed.*), *Younger People with Dementia: Planning, Practice and Development*. 1st ed. London: Jessica Kingsley Publishers Ltd. pp.37 - 51

Woods, B. (1999) Promoting well-being and independence for people with dementia. *International Journal of Geriatric Psychiatry*, 14(2), pp.97 - 105

Woods, B. and Pratt, R. (2005) 'Awareness in dementia: Ethical and legal issues in relation to people with dementia'. *Aging & Mental Health*, 9(5), pp. 423 - 429

World Health Organisation. (1992) *International classification of diseases and related health problems. 10th Revision. In Dementia a Public Health Priority,* 2012, Geneva, Switzerland, pp.5 - 9 http://www.who.int/mental_health/publications/dementia_report_2012/en/

World Health Organisation (2012) *Dementia A Public Health Priority*, Geneva Switzerland http://www.who.int/mental_health/publications/dementia_report_2012/en/

Wright, A. (2016) Exploring the relationship between community-based physical activity and wellbeing in people with dementia: a qualitative study. *Ageing and Society*, pp.1 - 21

Yardley, L. (2008) Demonstrating Validity in Qualitative Psychology. In: Smith, J.A. (*ed.*) *Qualitative psychology: A practical guide to research methods*. 2nd ed. United Kingdom, Los Angeles, CA: Sage Publications Ltd. pp. 235 - 252

Young Dementia UK (2017) https://www.youngdementiauk.org/types-dementia-younger-people-0 [accessed January 2017]

Appendices

Appendix 1 Table of Literature YPwD

Authors	Date	Title	Country	Methodology	Methods	N= YPwD
Armari, E., Jarmolowic, A. & Panegyres, P.K.	2012	The Needs of Patients with Early Onset Dementia	Australia	Statistical analysis	Questionnaire	18
Arntzen C.,Holthe,T., Jentfoft, R.	2016	Tracing the successful incorporation of assistive technology into everyday life for younger people with dementia and family care givers	Norway	Phenomenology	Interviews and observation	12
Beattie, A., Daker-White, G.,Gilliard, J. & Means, R.	2004	How can they tell?' A qualitative study of the views of younger people about their dementia and dementia care services	UK	Grounded Theory	Interviews and observation	14
Chaplin, R. & Davidson, I.	2016	What are the experiences of people with dementia in employment?	UK	IPA	Interviews	5
Clare, L., Rowland, J.M. & Quinn, R.	2008	Collective strength: The impact of developing a shared social identity in early stage dementia	UK	IPA	Semi-structured interviews through email	7
Clemerson, G., Walsh, S. & Isaac, C.	2014	Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed.	UK	IPA	Semi-structured interviews	8
Draper, B., Cations, M., White, F., Trollor, J., Loy, C., Brodaty, H., Sachdev, P., Gonski, P., Demirkol, A., Cumming, R.G. & Withall, A.	2016	Time to diagnosis in young-onset dementia and its determinants: the INSPIRED study	Australia	Statistical analysis	Survey questionnaire	88
Evans, D.	2016	An exploration of the impact of younger-onset dementia on employment	Australia	Life course paradigm	Semi-structure interviews & life grids	10

Harris, P.B.	2004	The Perspective of Younger People with Dementia	USA	Grounded Theory	Focus groups, face-face interviews & online interviews	23
Harris, P.B. & Keady, J.	2004	Living with Early Onset Dementia: Exploring the Experience and Developing Evidence-based Guidelines for Practice	USA/UK	Grounded Theory	In depth interviews using focus groups, face-to-face & online interviews	23
Harris, P.B & Keady J.	2009	Selfhood in younger onset dementia: Transitions and testimonies	USA/UK	Grounded Theory	In depth interviews using focus groups, face-to-face & online interviews	23
Kinney, J.M., Kart, C.S., Reddecliff, L.	2011	That's me, the Goother: Evaluation of a program for individuals with early-onset dementia	USA	Thematic analysis	Face-to-face interviews	6
Novek, S., Shooshtari, S. & Menec, V.H.	2016	Comparing the Overall Health, Stress and Characteristics of Canadians with Early - Onset and Late-Onset Dementia	Canada	Statistical analysis	Survey	420
Ohman, A., Nygard, L. & Borell, L.	2001	The vocational situation in cases of memory deficits or younger-onset dementia	Sweden	Constant comparative approach	Interviews	9
Pesonen, H.M., Remes, A.M. & Isola, A.	2013	Diagnosis of dementia as a turning point among Finnish families: A qualitative study	Finland	Grounded Theory	Low structured interviews	8
Pipon-Young, F.E., Lee, K.M., Jones, F. & Guss, R.	2011	I'm not all gone, I can still speak: The experiences of younger people with dementia. An action research study	UK	Thematic analysis	Interviews	8

Quarrell-Davies,V., Higgins, A., Higgins, J., Quinn, P., Quinn, M., Jones, G., Jones, L., Foy, A., Foy, V., Marland, R., Marland, P., Powell, A., Keady, J.	2010	The ACE approach: promoting well-being and peer support for younger people with dementia	UK	Evaluation	Relationship centred approach expressed through the Senses Framework	Unknown
Reed, J., Cantley, C., Clarke, C.L., Stanley, D.	2002	Services for younger people with dementia. Problems differentiating needs on the basis of age	UK	Qualitative research methodology	Interviews	23
Roach, P. & Drummond, N.	2014	It's nice to have something to do': early-onset dementia and maintaining purposeful activity	Canada	Framework analysis	Semi-structured interviews	9
Roach, P., Drummond, N., Keady, J.	2015	Nobody would say that it is Alzheimer's or dementia at this stage'. Family adjustment following a diagnosis of early-onset dementia	Canada	Qualitative research methodology	Interviews	9
Roach, P., Keady, J., Bee, P. & Williams, S.	2014	We can't keep going on like this': identifying family storyline in young onset dementia	UK	Ongoing narrative analysis	Co-construction of family biography & semi-structured interviews	5
Robertson, J. & Evans, D.	2015	Evaluation of a workplace engagement project for people with younger onset dementia	Australia	Qualitative exploratory response	Observation	9
Robertson, J., Evans, D., Horsnell	2013	Side by Side: A workplace engagement program for people with younger onset dementia	Australia	Evaluation	? Interviews and outcomes	7
Williams, T., Cameron, I. & Dearden, T.	2001	From pillar to post- a study of younger people with dementia	UK	unknown	Semi-structured interviews	unknown

Appendix 2 Information Sheet

Information Sheet

Research Title:

A qualitative study researching the experiences and well-being of Younger People with Dementia

Introduction

My name is Jane Douglas and I am a PhD research student from the Faculty of Health, Life and Social Sciences at Edinburgh Napier University.

I am exploring the experiences of a younger person with dementia living in Scotland. I want to compare their experiences and their well-being.

The findings of the study will be useful because they will provide insight into the lives of younger people with dementia and how they access services and support. This information will be useful to people who receive a diagnosis of dementia, their carers and also to those who are involved in providing and developing services.

This research is being funded by Alzheimer Scotland and Scottish Borders Council.

Volunteers

I am looking for volunteers to participate in the study who have a diagnosis of dementia and were under 65 at the time of receiving the diagnosis.

What does taking part in the study involve?

If you agree to take part in the study, you will be asked to meet with me in a location of your choice. Your expenses will be paid by me if you have to travel to these meetings. The interview will take up to one hour and can take place in your home or in a place of your own choice where you feel comfortable.

Confidentiality

All the information you provide will be anonymised and your name will not be used. It will not be possible for you to be identified in any reporting of the information gathered. All information collected will be kept in a secure place. The information provided at the interview will be typed up but will be kept secure on a password protected computer which only I will have access to. All the files will be kept until successful completion of my study and then they will be destroyed. The results of the study may be published in a journal or presented at a conference.

You will be free to withdraw from the study at any stage, you would not have to give a reason, and it will not affect your future access to services.

If you have any further questions that you would like to ask before agreeing to volunteer for the study or if you are satisfied that you have enough information please contact me on the number below or email

Contact Details

Researcher:	**Jane Douglas**
Email:	**10022563@live.napier.ac.uk**
Telephone:	[redacted]

Director of Studies

Dr Dorothy Horsburgh
Faculty of Health and Social Science
Edinburgh Napier University
Room 4B.40 Sighthill Campus
Sighthill Court
EdinburghEH11 4BN
Tel: [redacted]

d.horsburgh@napier.ac.uk
Telephone: [redacted]

Appendix 3 Consent Form

Consent Form

Research Title:
A qualitative study researching the experiences and well-being of Younger People with Dementia living in rural and urban areas

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I agree to my interview being recorded using be recorded using a small computer. I understand that the information recorded will be typed word for word, following the interviews. ☐

Tick box where appropriate

I do not agree to the interview being recorded and would prefer the researcher to take notes of what is being said. ☐

I understand that I have the right to withdraw from this study at any stage without giving any reason and it will not affect my future access to any health or social care services.

I agree to participate in this study.

Name of participant: ______________________________________

Signature of participant: ______________________________________

Signature of researcher: ______________________________________

Date: __________________

Contact details of the researcher

Name of researcher:	Jane E Douglas
Email / Telephone :	10022563@napier.ac.uk / [redacted]

Appendix 4 Interview Guide Interview Guide

INTERVIEW GUIDE

Hello and thank you for volunteering to take part in my study.

Do you have any questions that you would like to ask before we get started?

I mentioned that I would be recording the interview and I can reassure you that anything you tell me will be treated sensitively and confidentially. If there is anything that you say that you do not want recorded, please let me know and I will stop the recorder.

Please feel free to stop the interview at any point if you feel you do not want to go on.

Interview Guide

I am interested in hearing about your experiences in relation to having dementia.

- Living with dementia at a younger age
    - Diagnosis
        - Can you tell me how you came to receive a diagnosis?

            - When did experience or notice any changes?
            - Could you describe the events that led up to receiving a diagnosis?
            - What was going on in your life then?
            - How would you describe the way felt

- Dementia – your views

        - What, if anything, did you know about dementia before you received your diagnosis?
        - Tell me how you felt when you were told about your diagnosis
        - What positive changes have occurred in your life since receiving a diagnosis?
        - What negative changes have occurred, if any?

- Your day
    - Could you describe a typical day for you?
        - What about a day when you are well/ unwell – probe for different times/ experiences
    - What helps you manage?
        - What problems might you encounter? Tell me what you think causes these problems

- Keeping well

    - What is important to you now?
        - How do you make sure this happens/ continues

    - Who or what has been the most helpful to you during this time.
        - How have they/he/she been helpful
    - What services do you receive to help you
        - Has any organisation been helpful?
        - How have they been helpful?

- Advice to others
    - What advice would you give to give to a person who has just received a diagnosis?
    - What advice would you give to professionals about people diagnosed with dementia at a younger age?

- Is there anything else you would like to tell me or think I should understand?

Appendix 5 Briefing Sheet

Briefing sheet sent to participants prior to interview date

Briefing for Participants

Dear

Thank you for agreeing to take part in my study.
We have agreed to meet on 16th August at around 11.30am. The interview/discussion should last for about one hour.

The aim of the interview/discussion is to explore your experiences of living with dementia. Here are some of the areas that I would like to explore with you.

- Living with dementia at a younger age and your experiences in relation to receiving your diagnosis
- Dementia – what did you know about dementia before this?
- What you do in a typical day
- What you do to keep well
- Any advice you have for people who go on to receive a diagnosis of dementia at a younger age or their carers/ support workers
- Anything else you would like to tell me

Regards

Jane Douglas

Appendix 6 Agenda Scottish Dementia Working Group Agenda

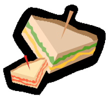
Agenda SDWG

SDWG Meeting in Dundee

Tuesday 16 July 2013

11.00 for 11.30

Time	Topic
11.30 am	**1. Welcome and introductions** **2. Minutes of last meeting on 14 May 2013**
11.35 am	**3. Business** • Dementia Strategy for Scotland • Review of Work Priorities • Section 10 Funding • Transport Sub Group

12 Noon	**Welfare Reform** Andy Paul, Welfare Rights Advisor with Alzheimer Scotland, will talk about how Welfare Reform will affect people's benefits
12.30 pm	 **LUNCH**  - ***Don't forget medication. Claim travel expenses from Martin. We usually give a donation of around £1 for lunch.***
1.30pm	**5. Open Session** Christopher Homfray from the Wisdom in Practice project will discuss developing user-led services
1.45 pm	**6. Research** Jane Douglas from Edinburgh Napier University will talk about her research into the experiences of younger people with dementia living in rural and urban areas in Scotland. Jane is looking for volunteers to participate in the research.
2.00 pm	**7. Forthcoming Events** **8. Any Other Business**

	9. Date of next meeting • Tuesday 17 September 2013
2.20pm	**End of meeting**