

**EXPLORING THE EXPERIENCE OF LIVING WITH YOUNG ONSET
DEMENTIA**

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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ABSTRACT

Introduction: Research into the experiences of those with a diagnosis of young onset dementia is extremely limited and the research that does exist tends to be loss orientated. The current study aimed to explore the full spectrum of lived experience of those with young onset dementia, whilst considering the unique impact of diagnosis at a younger age and the possibility of personal growth.

Method: Five individuals took part in semi-structured interviews within which they were invited to bring along anything that helped them to share their experiences. Each participants' transcribed interviews were then analysed using Interpretative Phenomenological Analysis (IPA). A group level analysis was conducted and superordinate and subordinate themes were identified.

Results: Four superordinate themes emerged: 'Fear', 'Anger', 'Sadness', 'Contentment' from which a further thirteen subordinate themes were identified. The findings indicated that participants experienced feelings of fear and vulnerability in response to their diagnosis. Participants felt angry that they did not have a voice, not enough was being done for those with dementia and they were being stereotyped. Participants also spoke of a more depressive state of mind in which they grieved for their past self, experienced isolation and loneliness, and feelings of hopelessness and despair. Finally, participants spoke of a sense of contentment in relation to a preserved self, a sense of living alongside their dementia and an desire to live in the present; making the most of the here and now.

Discussion: The findings of the study were explored in relation to existing literature and psychological theory. This research highlighted the transitory nature of participants experiences as a result of multiple and repeated challenges to one's psychological equanimity. A critical appraisal of the strengths and limitations of this study were explored along with clinical implications. Future areas of research were also considered.

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CHAPTER ONE: INTRODUCTION

Dementia is typically associated with older generations and indeed the statistics suggest that 1 in every 14 of the population aged over sixty-five in the UK is now living with dementia (Dementia UK Update, Alzheimer's Society, 2014). However, a significantly increasing number of individuals are receiving a diagnosis when they are aged sixty-five or under. When dementia occurs in such individuals it is often referred to as early onset dementia, working age onset dementia or, in the case of the current research, young onset dementia (YOD). A diagnosis of YOD poses unique challenges in terms of psychological adaptation to living alongside an existential threat during middle adulthood, a stage of life that is not typically associated with such experiences.

In addition, dementia is also socially constructed as disease of loss and dysfunction, and yet evidence suggests the possibility of personal growth alongside ongoing adversity. More services are calling for acknowledgement of the potential to 'live well with dementia', following the Department of Health's (2009) National Dementia Strategy, as well as for services that engender hope and move away from traditional loss oriented narratives (Pipon-Young, Lee Jones, & Guss, 2011).

Whilst familiarising myself with the literature surrounding the experiences of those with dementia I was shocked at the sparsity of research that explored people with dementias experiences directly. It felt to me that this group of individuals had been silenced, whilst their families and caregivers experiences had been explored in great depth. In addition to this, I had spent most of my life believing that dementia was a diagnosis for those in older age. I became curious to explore what impact a diagnosis at a younger age may have on a person's psychological wellbeing and lived experience. As such, this study combined my curiosity alongside my desire to give voice to a group of individuals who I felt had long been excluded from research.

LITERATURE REVIEW

In the following chapter I will introduce some key demographic information relating to dementia and will also consider the social constructs surrounding such a diagnosis. The concept of YOD will also be introduced, and research surrounding the impact of an 'off-time' diagnosis – one that is more commonly constructed as occurring later in life - will be explored. Several developmental frameworks will then be discussed in an attempt to consider the impact of receiving a dementia diagnosis in middle adulthood. Following this, I will present existing research into the experiences of those living with YOD with a focus on the impact of an 'off-time' diagnosis.

In the second part of this chapter I will discuss the concept of personal growth. The extensive research surrounding the prevalence of this within physical health settings will then be explored. I will then consider the evidence for personal growth in relation to relatives and carers of those with dementia as well as individuals living with dementia themselves. This evidence, albeit limited, will create the rationale for exploring such experiences with individuals who have a diagnosis of dementia; a diagnosis that is so often surrounded by narratives of loss.

1.1 Dementia

Dementia is now categorised as a major Neurocognitive Disorder (NCD) within the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association [APA], 2013) and encompasses of a number of diagnoses including: Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia. In addition, up to five percent of all dementias are accounted for by rarer causes such as Huntington's disease, multiple sclerosis and HIV-associated neurocognitive disorder (Alzheimer's Society, 2014).

Each of these diagnoses carries with it its own set of diagnostic criteria; unique symptoms and experiences for individuals and their families. Perhaps most commonly associated with a diagnosis of dementia is the gradual decline in memory function often experienced by those with a diagnosis of Alzheimer's disease. On the other hand, individuals with a diagnosis of dementia with Lewy bodies may experience fluctuations in levels of alertness and vivid visual hallucinations, whilst those with a vascular dementia

diagnosis can experience sudden, abrupt shifts in cognitive functioning directly attributed to cerebrovascular events (APA, 2013).

Individuals with a diagnosis of frontotemporal dementia (most often seen in those under sixty-five years of age) may be diagnosed with one of three distinctive clinical subtypes. The first of these is considered to be a behavioural variant with which individuals may become disinhibited, apathetic, and display stereotyped and compulsive behaviours. Those with frontotemporal dementia may also be diagnosed with a language variant subtype, for example progressive non-fluent aphasia with which individuals may experience a prominent decline in speech production, word finding and naming or word comprehension. Alternatively, semantic dementia, the third frontotemporal subtype, sees people experiencing difficulty in their vocabulary and may struggle to recognise familiar people or common objects (Alzheimer's Society, 2016).

The number of individuals living with dementia in the UK is estimated at more than 850,000 with projected estimates suggesting that this figure could increase to 1,142,677 by the year 2025 (Alzheimer's Society, 2014). This roughly equates to a forty percent increase in prevalence in the twelve years between 2014 and 2025. This dramatic increase is the direct result of a rapidly ageing population, due in part to advances in medicine and healthcare. Furthermore, as the public awareness of the early symptoms of dementia increases, it should be considered that individuals are more likely to get in contact with their GPs at an earlier stage and receive a diagnosis.

Although dementia is a progressive condition known to impact upon a number of neurocognitive domains including attention, executive function, language, and memory (APA, 2013) it should be considered as much more than just neurological degeneration. Cheston (2012) highlights how dementia should be considered as a process which "both includes a complex network of social and personal factors" and "as one in which death and deterioration are central features" (p.8). Indeed, the common pathways in dementia typically comprise of a gradual decline in function, increasing dependency upon others, threats to one's sense of self (Hawkins, 2004; Cadell & Clare, 2011) and ultimately threats to one's very existence (Cheston, 2012).

Gubrium (as cited in Bender & Cheston, 1997) identifies how "definitions of dementia are social constructions, imposing order upon data in a particular and selective way" (p.514). He argues that such definitions then "act to emphasise particular ways of thinking about dementia and to ignore other viewpoints" (p.514). Typical social constructs of dementia involve dysfunction (Hawkins, 2004) and invoke images of older individuals.

Indeed, a quick search of the term 'person with dementia' on the search engine Google Images produces photographs of much older individuals, many looking confused and in distress.

A study by Ryan, Bannister, and Anas (2009) offers an insight into the impact of such prominent social narratives upon a person with dementia's identity. A number of eloquently written personal memoirs of those diagnosed with dementia are analysed. One theme, 'The changing self', highlights how negative stereotypes can result in apprehension in the presence of different or diseased people and result in perceived incompetence. One quote from Henderson (1998) illustrates this well: "Another really crazy thing about Alzheimer's, nobody really wants to talk to you any longer. They're maybe afraid of us" (p.18). Taylor (2007) illustrates a typical social response experienced by those with dementia: "They switch their eye contact and attention to whomever I am with. It is as if knowledge of the disease immediately cloaks me in invisibility" (p.152).

Furthermore, in Caddell and Clare's (2011) poignantly titled study 'I'm still the same person', Interpretative Phenomenological Analysis (IPA) was utilised to explore people's perceptions of the impact of dementia upon their identity. Their findings suggested that individuals with a diagnosis of dementia typically experience a state of flux between simultaneous continuity and changes in identity. Themes identified, for example, include 'I'm still the same person' versus 'I'm different to what I used to be' and 'I'll always stay the same' versus 'I'm not sure what to expect'.

As well as a threat to identity, dementia poses a further existential threat to the self. As suggested by Yalom (2008, as cited in Cheston, 2012), anxiety surrounding death is often "in the hidden ravine of the mind" (p.9) but when faced with a diagnosis that threatens one's existence, such as dementia, these anxieties may be swiftly projected to the forefront.

1.2 Young Onset Dementia

What impact does a diagnosis of dementia have on someone under the age of sixty-five? More than five percent of all individuals diagnosed with dementia are aged sixty-five or under and have a diagnosis of YOD (Alzheimer's Society, 2014). This accounts for around 42,325 individuals within the UK, with this figure expected to increase by twenty percent over the next thirty-eight years. Although some debate exists surrounding the seemingly arbitrary cut-off age of sixty-five, it can be argued that the lived experience of those who receive a diagnosis of YOD is unique in comparison to older individuals receiving

a diagnosis. For example, it is noted that YOD dementia affects people in the prime of life (Young Dementia UK, 2015) and, although neurocognitive symptoms can be similar, the impact upon individuals' lives can often be substantially more pronounced. For example, when an individual is diagnosed with YOD it is highly likely that they will still be employed, have financial commitments, dependent children and parents, as well as unfulfilled aspirations and dreams (Young Dementia UK, 2015). In addition, the idea that dementia occurs in later life means that those diagnosed in middle adulthood have the added burden of adapting to a diagnosis that is not typically associated with their stage of life.

Although many similarities in the dementia experience may be present for individuals along the lifespan continuum, the current research proposes that young onset dementia should be considered as a unique and separate construct to typical onset dementia. As suggested by Wolverson, Clarke, and Moniz-Cook (2016) "the needs and experiences of people with young onset dementia are likely to be distinct and divergent from those of older people and therefore deserve attention in their own right" (p.678). In addition, the following literature goes some way to further emphasise the distinct experience of receiving a diagnosis that is typically associated with older age.

1.2.1 The impact of an 'off-time' diagnosis

Stone (2005) highlighted the profound impact that social narratives of illness can have upon younger individuals who experience a health condition or illness that is typically constructed as occurring in later life. Stone explored "popular ideas about who is affected by stroke" (p.293), as well as the impact such a diagnosis can have on a psychosocial level, by listening to the stories of twenty-two young women who had experienced a haemorrhagic stroke before the age of fifty. The study included women aged from nineteen to fifty-seven. All of the women in the study were at least three years post-stroke at the time of interview.

One theme that emerged is titled 'But you're so young!' and relates to the significance of participants' age. Interestingly, not only does this theme include reactions of others, but also reactions of the participants themselves in terms of difficulties in coming to terms with a diagnosis at a young age. In addition, participants made reference to the lack of service provision for younger survivors of stroke and the pressure to become a 'typical' stroke survivor with one participant stating, "the only slot for me was that of an old woman

and I should be glad to be in a wheelchair” and “I remember thinking that I knew what it was to be 85 but not 18” (p.297).

A further theme identified in Stone (2005), and one that may share some parallels with individuals with YOD, is titled ‘Must disability always be visible?’ and relates to the significance of appearance. Many participants in the study made reference to the unique challenges of having an invisible disability, such as not being believed and feeling like a fraud. One lady in particular, Maeve, refers to the specific challenges of living with cognitive disabilities, “You know, and people look at you, like my husband for example, take that. He thought there was nothing wrong with me. Why couldn’t I get a job?” (p.301). The findings in this study underwent credibility checks with original participants, suggesting that the findings were valid and a good reflection of a younger females experiences of stroke.

In addition, a study by Allison and Campbell (2009) explored the experiences of young males following myocardial infarction (MI). The study, titled ‘Maybe It Could Be a Heart Attack...But I’m Only 31’, highlighted unique challenges faced by younger adult males experiencing an illness statistically more likely to occur in individuals over the age of sixty. The study utilised thematic analysis in order to explore the experiences of men under sixty years of age. A number of themes were drawn from interview data including ‘Keeping Up Appearances’ which relates to the importance of not showing weakness, and feelings of embarrassment around their experiences.

A further theme ‘Invincibility’ relates to a sense of disbelief around having suffered MI – strikingly similar difficulties in adjusting to a diagnosis as the young female survivors of stroke. It is also worth noting that, once again, participants made reference to a lack of age appropriate service provision. One participant, Mick, spoke of attending a group, looking around at “all these old people” (p.122), comparing ages, and feeling as if he did not belong. These findings again go some way to highlight the unique challenges faced by younger individuals who experience a health condition or illness that is typically constructed as occurring in later life.

1.2.2 Developmental Frameworks

In order to further understand the unique impact that a diagnosis of dementia can have on those under sixty-five, it may be useful to consider a number of developmental frameworks.

1.2.2.1 Erikson's Stages of Psychosocial Development

Erikson's (1959) stages of psychosocial development suggests that individuals pass through eight distinct stages of the self. It is hypothesised that within each stage an individual will experience specific crises involving relevant stage of life issues (Whitbourne, 2008). Erikson's theory would suggest that individuals with a diagnosis of YOD would most likely be designated to the stage of middle adulthood. This stage of middle adulthood identifies with a specific 'crisis' that poses the existential question: can I make my life count? Individuals in this stage are thought to face the challenge of generativity versus stagnation. Generativity, in this sense, relates to a motive to care for the next generation, for example through successful parenting, teaching and training. Stagnation, on the other hand, relates to the introversion of concern and energy (Whitbourne, 2008).

Traditionally, healthy development between such stages is considered to be the outcome of overcoming the challenges that each stage poses. However, atypical transitions between stages are often seen in individuals who receive life-threatening diagnoses, such as HIV, at an earlier life stage. Whitbourne (2008) refers to such experiences as 'critical periods' when specific issues may become more central. For example, research by Merriam, Courtenay, and Reeves (1997) suggests that those in their twenties prematurely enter into later adult stages and must face multiple existential challenges simultaneously. One example comes from Dawn, a twenty-six year old woman who reported how a diagnosis of HIV made her consider "who I was and what I wanted, what kind of contributions I wanted to make and what was important to me" (p.230). This stands in stark contrast to older adults facing an existential threat who may have had more time to engage in retrospection of their lives including fulfilled or unfulfilled hopes and goals.

Is it possible that individuals confronted with the existential threat of YOD may also find themselves driven into later stages of Erikson's model? Following middle adulthood, Erikson proposes a stage of late adulthood. This stage involves a crisis around the existential question: is it okay to have been me? This stage poses the challenge of ego integrity versus ego despair. Ego integrity refers to a sense of reflection and acceptance of both negative and positive attributes of one's life with a sense of acceptance in relation to one's own mortality. In contrast, ego despair relates to feelings of despair and discontentment (Whitbourne, 2008). It should also be considered that although Erikson's theory may initially appear limited in its predestined and apparently chronological fashion it is acknowledged that earlier psychosocial crises can occur in later life. For example, trust versus mistrust from infancy can also be experienced in adulthood if the appropriate

triggers are present. As such it is possible that a diagnosis of YOD poses unique psychological challenges that may trigger crises not typically experienced by many in middle adulthood. This stands in contrast to older adults with dementia who are noted to implement normalising strategies, for example attributing declining memory function to a natural process of ageing (Gillies, 2000).

It should be noted that Erikson's theory of development is just that; a theory, and as with any theory it brings with it a number of criticisms. Many believe that the stages are vague and difficult to distinguish and that they more readily reflect male stages of development. For Example, Gilligan (1982) argued that male and female development do not follow the same pattern, arguing that, for females, "the capacity for intimacy is more likely to precede the establishment of identity than follow it" (Stevens, 2008, p.57). However, Erikson's understanding of psychosocial development offers a useful framework from which to begin to make sense of human experience. This framework offers a way of making sense of the numerous challenges that we face at various life stages.

1.2.2.2 Family Lifecycle

Carter and McGoldrick (1989) offer a systemic developmental framework with their Family Lifecycle. Their model proposes a number of stages that families typically pass through in their development. Each stage in the family lifecycle is accompanied by unique developmental tasks and changes. Typically, members of the family shift through this system in a more or less chronological fashion. Research has implicated the importance of family relationships in the wellbeing of those with a diagnosis of dementia, as well as the reciprocal influences between family relationships and dementia (La Fontaine & Oyeboode, 2014). However, it is necessary to consider how a diagnosis of dementia at a younger age may pose a particular challenge for family systems. Firstly, individuals with YOD are far more likely to have dependent children (Young Dementia UK, 2015). It is also more likely that such individuals will be caring for older generations, developing adult-to-adult relationships with their children and caring for grandchildren. A diagnosis of dementia at a younger age may call for premature changes in family roles, in contrast to older adults with dementia who are likely to already be "accepting shifting generational roles" (Carter & McGoldrick, 2005, p.2).

Another example of the unique challenges faced by younger adults living with an existential threat comes from a qualitative study by Dunn and Steginga (2000). The study identifies how a younger woman's experience of breast cancer may differ greatly to that of

an older woman. For example, younger women may be perceived as being in the early stage of a family lifecycle which in itself includes expectations around the development of marital systems and child rearing. However, disruptions to self-image and sexuality as well as societal pressures to adhere to 'typical' stereotypes of a 'young female' make younger females' experiences of such an illness unique. Furthermore, the aforementioned Stone (2005) study highlights how young female stroke survivors again experience unique stage of life experiences in relation to the family lifecycle. For example, these women are more likely than older stroke survivors to be responsible for or planning to raise young children.

1.2.3 Biographical disruption in young onset dementia

Bender and Cheston (1997) suggest that research has historically gone as far as to exclude people with dementia as an invalid source of information. Whilst research into the full range of experiences of caregivers is extensive, studies into the experience of those with dementia tend to be limited. Thankfully, in recent years, research has begun to shift its focus to the unique experiences of people living with a diagnosis of dementia. However there remains a distinct paucity in the amount of research exploring the experiences of those with YOD. In fact, a recent meta-ethnographic review was able to identify only eight qualitative research studies that directly explored the experiences of those with YOD (Greenwood & Smith, 2016).

This meta-ethnographic review synthesised findings from studies exploring the unique experience of those living with YOD. A number of key concepts were found across the studies including:

- Difficulties surrounding the process of **diagnosis** culminating in experiences such as shock, disbelief, confusion and feeling overwhelmed;
- The importance of continuing to engage in **meaningful activity** as well as the experience of meaningful activity reducing;
- A strong theme of **loss** was found, including loss of memory, independence, competence, employment, friends and family;
- Participants in almost all of the studies made reference to the impact upon **self-identify**, including being treated differently, feeling 'outside themselves', and experiencing reduce self-esteem and self-respect;

- **Relationship** challenges such as being treated differently, experiencing stigma and being avoided;
- **Social isolation**, feeling excluded and disconnected from society as well as spending more time alone;
- **Emotions** such as anger, sadness, frustration, and anxiety;
- **Coping** processes, including the importance of acceptance, hope and willpower.

A further key concept found across a number of the studies analysed in Greenwood and Smith's (2016) review, and one of particular relevance when considering YOD as an 'off-time' diagnosis, was one of **biographical disruption**. Participants in one study spoke about feeling too young for a diagnosis (Clemerson, Walsh, & Isaac, 2014), similarly in another study participants spoke about difficulties in relation to the age in which they received their diagnosis (Pipon-Young, Lee, Jones, & Guss, 2011)

One of the studies included in Greenwood and Smiths (2016) review was conducted by Griffin, Oyebode, and Allen (2015) and explored the lived experience of individuals with a diagnosis of behavioural-variant frontotemporal dementia. Although this type of diagnosis is relatively rare it is noted to be more common in those between forty-five and sixty-five years of age. Indeed, the authors make explicit reference to the possibility of distinct subjective experiences of those with such a diagnosis, on the basis of younger onset. The study included five participants aged between forty-six and sixty-two years of age. As in the aforementioned studies a sense of disbelief was apparent in a number of participants due to discrepancies between viewing the self as younger and simultaneously holding constructs of 'dementia equals old people'. The following transcript taken directly from Griffin, Oyebode, and Allen (2015) goes some way to illustrate such experiences:

Jayne: They could not give a diagnosis at first. And then as the time went on dementia started to be mentioned.

Interviewer: Okay. How did you feel when they first mentioned that?

Jayne: Horrified.

Interviewer: Okay. Can I ask what images came into mind? What did you think?

Jayne: Christ (wells up with tears). That's for old people. (p.1360)

Another of the studies included in Greenwood and Smith's (2016) review comes from Clemerson, Walsh, and Isaac (2014). This study recruited eight participants aged between thirty-five and sixty-three years of age, all with a diagnosis of Alzheimer's disease. The findings in this study are particularly interesting when holding in mind Erikson's (1959) psychosocial stages of development. A number of participants in the study make reference to feeling too young for a diagnosis of dementia, whilst others coped with the diagnosis by creating a new identity of an 'older' person, allowing for normalising: "... everybody gets older and nearer to dementia anyway" (p.457). As a result, some participants referred to being projected to a later life stage that required them to contemplate death. Others made reference to simultaneously entering earlier life stages, as a result of losing adult skills and feeling more child-like.

In addition, it should also be considered that those currently in the middle adulthood stage of life currently fall into the World War II 'baby-boomer' generation. Ideas around ageing for these individuals may be subjectively very different to, for example, their parents' views around what it means to be 'old'. As Martin (2014) suggested that these baby-boomers "seemed to be expecting more of their lives and did not define themselves as ageing: they still feared an old age they envisaged happening in the future" (p.10). This vital contextual information adds another layer to the impact of an 'off-time' diagnosis of dementia and should be held in mind when conducting research with this unique cohort.

1.2.4 Summary

As illustrated by the literature, developmental frameworks typically suggest models that strongly relate to chronological age. However, it is acknowledged that critical periods or psychological challenges can disrupt the natural progression through such frameworks. Indeed, research seems to suggest that major life events such as the receipt of an 'off-time' diagnosis may go some way to cause some degree of disturbance. It is possible then that a diagnosis of dementia at a younger age may result in projection into later life stages, within which reflection and acceptance or denial of one's own mortality are present. The current, albeit limited, research into the experiences of those with YOD seems to suggest that this may be a common, universal experience.

1.3 Personal Growth

As well as prominent social narratives around dementia being an older adult disease strong constructs also exist around dementia and concepts of loss. However, researchers have begun to make links between dementia and the concept of ‘personal growth’.

Post-traumatic growth (PTG) is a phenomenon that can be defined as “positive change arising from the challenge of difficult circumstances” (Tedeschi & Calhoun, 2004, p.2). Literature around this phenomenon incorporates a vast array of often ambiguous and interchangeable terminology including benefit finding, adversarial growth, thriving, resilience, meaning-making, positive change, positive growth, and personal growth. As much research and its subsequent literature utilises such variable terminology, the current document will aim to utilise the terminology adopted by the original authors referenced within the current literature review. However, in relation to the current research, the term ‘personal growth’ will be utilised to encompass the aforementioned experience of “positive change arising from the challenge of difficult circumstances”.

An extensive literature surrounds the term PTG following natural disasters, bereavement and war. Tedeschi and Calhoun (1995) suggest that following a traumatic or adverse event, individuals may experience perceived changes in self, closer family relationships, changed philosophy on life, a better perspective on life, and a strengthened belief system. As this statement illustrates, the concept of ‘personal growth’ can be considered from both an external sense of change, for example closer relationships, and a more intrapsychic or psychological sense of growth such as changed philosophies.

The concept of ‘post-trauma’ itself can be misleading, suggesting that growth is purely dependent upon a positive outcome. Indeed, in much of the literature individuals have ‘overcome’ trauma, illness or adverse events, for example survivors of war (Tsai, Sippel, Mota, Southwick, & Pietrzak, 2015) and cancer survivors (Arpawong, Oland, Milam, Ruccione, & Meeske, 2013). However, PTG can also be conceptualised as a process, a meaning-making coping strategy or form of psychological adjustment (Zoellner & Maercker, 2006). In this sense PTG does not require the presence of a medical model form of ‘recovery’ (i.e. a return to former states of health) but in fact takes a much more psychological view of recovery such as the “establishment of a fulfilling, meaningful life and a positive sense of identity founded on hopefulness and self-determination” (Andresen, Oades, & Caputi, 2003).

In other words, PTG can be a concurrent process alongside ongoing adversity. In fact, recent research has begun to consider the occurrence of PTG in individuals with physical illness, in particular those of a chronic or life-threatening nature. This research includes individuals with newly diagnosed or terminal cancer (Halldórsdóttir & Hamrin, 1996; Tomich & Helgeson, 2012), human immunodeficiency virus (Sawyer, Ayers & Field, 2010), multiple sclerosis (Pakenham, 2007), inflammatory bowel disease (IBD) (Purc-Stephenson, Bowlby, & Qaqish, 2015) and those who have been disabled by traumatic illness or injury (Waft, 2006).

A systematic review of qualitative literature was conducted by Heffernon, Greal, and Mutrie (2009) in which links were explored between PTG and life threatening illness related trauma. A number of the studies included directly investigated PTG, however a number presented the phenomenon as a purely serendipitous finding. The emerging results suggested a number of themes including 're-appraisal of life and priorities'. It is noted that individuals often re-appraised relationships with family and friends resulting in closer and more open relationships. A number of the studies spoke of a 'new appreciation of life', an appreciation for both the past as well as the 'here and now', and a re-evaluation of goals, a desire to change regrets and achieve new things. It was also found that individuals, including men with HIV, possessed a desire to create a legacy and contribute to helping others.

A further theme of 'trauma equals the development of self' illustrated this sense of personal growth that is possible alongside an ongoing existential threat. Individuals reported spiritual, emotional or psychological transformation and the development of a 'better self'. They often identified as a 'stronger self', 'a fighter' and reported increased self-esteem, confidence, empathy, and compassion for humanity. This resulted in a desire to 'give back', be it through educating others, fundraising or participation in research. An additional theme of 'existential re-evaluation' was also found, which included reflections upon mortality, purpose in life, and making meaning from illness. One study (Gotay, Holup & Muraoka, 2002) identified an awareness of 'the shortness of time' with subsequent spiritual changes including a strengthened faith and discovery of a new meaning to participants' lives.

Heffernon, Greal, and Mutrie's (2009) review incorporated studies from over thirty-two years of research, offering a unique insight into the links between PTG and physical illness. It should be noted however, that the studies included in the review tended to

recruit individuals with a diagnosis of cancer and, as such, may not be generalisable to all those diagnosed with a life threatening illness.

Further research investigating older adults within hospice care has also demonstrated the presence of resilience and the ability to “achieve wholeness in life’s final phase” (Nelson-Becker, 2006, p.87). Again this is a demonstration of personal growth occurring simultaneously alongside an existential threat. Utilising a grounded theory method, four main themes were derived from data collected from thirty adults within hospice care.

These themes included:

- Redefinition of self;
- Use of religion/spirituality or openness to uncertainty;
- Maintenance of social investments;
- Guarding independence even as the scope of life contracted.

Nelson-Becker poignantly suggests that “in the shadow of mortality, individuals may discover that their philosophical values stand in sharp relief to the prior decades of habitual and unexamined living” (p.88). It should be noted that methodological limitations in this study meant that only those who were deemed to be ‘coping well’ with death were invited to take part in the study by hospice staff. As such, these findings may not reflect the experiences of those who were more anxious at the prospect of death, and may reflect only one end of the spectrum of experience.

Further studies into the experiences of younger individuals facing an ‘off-time’ existential threat also demonstrated the occurrence of personal growth. For example, a qualitative review of literature highlighted how stroke in young adults caused them to “question who they were before their stroke, who they are now and who they want to be in the future” (Lawrence, 2010, p.246). Furthermore, research into individuals with the neurodegenerative condition MS has demonstrated evidence of a new appreciation of life and new opportunities (Pakenham, 2007). A sense of personal growth is illustrated by direct quotes such as “I have found inner strength”, “I have become more patient” and “I have learned to accept myself as I am” (p.193).

1.3.1 Dementia and Personal Growth

With regards to personal growth in dementia research, a substantial proportion of this has been conducted with caregivers. For example Lloyd, Patterson, and Muers (2014) conducted a systematic review around positive aspects of caregiving (PAC) in family

caregivers of those with dementia. Results identified a number of themes emerging from the qualitative literature including 'role satisfaction', 'emotional rewards', 'personal growth', 'competence and mastery', 'relationship gains', 'sense of duty', and 'reciprocity'. Further research has also demonstrated a sense of personal growth within caregivers, including a sense of peacefulness and an opportunity to discover more about themselves (Peacock et al., 2010).

Consequently, may this also apply to the experiences of those with a diagnosis of dementia? Dementia is considered a threat to psychological equanimity (Cheston, 2012) and indeed much of the research into the experience of those with dementia illustrates the difficulties that individuals face following a diagnosis (Whiting, 2002). However, research has also gone some way to highlight the possibility of personal growth following a diagnosis. For example, Hawkins (2004) highlights that, in living with a sense of threat to self, individuals with YOD can develop resilience and a sense of hope. Furthermore, in a study by Beard and Fox (as cited in Robinson et al., 2011) it is suggested that for some "receiving a diagnosis appears to offer an opportunity to reconsider their priorities and make positive changes, such as spending more time with family, focusing on positive tasks that bring enjoyment" (p.1039). In an extract from one study, a participant speaks about her changed perceptions around relationships: "I now realize how much I love my husband" (Vernooij-Dassen, Derksen, Scheltens & Moniz-Cook, 2006, p.403).

Dementia is typically constructed as a disease of loss and dysfunction, although in order to explore the full spectrum of lived experience, current narratives around loss and dysfunction may need to be challenged. Personal narratives by those living with dementia have painted pictures of hope, growth, and acceptance "contrary to cultural expectations of disease" (O'Brien, 2005). Quotes from the aforementioned autobiographical accounts of living with dementia from a study by Ryan, Bannister, and Anas (2009) go some way to illustrate this. For example McGowin (1993) speaks of a desire to "savour life more openly and ravenously" (p.87), De Baggio (2003) writes "As I grow older with Alzheimer's, I become more open" (p.168). Furthermore, Bryden (2005) writes:

"I choose a new identity as a survivor. I want to learn to dance with dementia. I want to live positively each day, in a vital relationship of trust with my care-partners alongside me" (p.170).

Accounts such as these are noted to stand "in stark contrast to the popular notion that dementia is a state of perpetual decline" (Ryan, Bannister & Anas, 2009, p.155).

1.3.1.1 Personal Accounts

Further autobiographical accounts from those with YOD also suggest the possibility of personal growth. One such example comes from Davis (1989) who, in his autobiographical book titled 'My Journey into Alzheimer's Disease', relayed his experience of positive spiritual growth and his search for meaning following his diagnosis. With the development of social media, blogs, and support websites more people are now sharing their experiences of YOD online. For example, a BBC webpage explores how one gentleman, Mr Oliver, believes dementia has changed the way he feels about and interacts with other people: "It's made me more reflective. Made me a more emotionally-aware person. Made me, I guess, less distant from people" (Eley & Reed, 2015).

Personal stories shared on the website Young Dementia UK offer further experiences of positive change including those of Ken H who states "I like to push things, do things that are scary – it makes me realise how alive I am". Another individual reports on their blog how "this disease [dementia] has given me a renewed and strengthened courage and inner strength" (Swaffer, 2011).

Personal correspondence with Wendy Mitchell, an internet blogger diagnosed with YOD in 2014, has offered further examples of personal growth:

"It has certainly provoked personal growth in me, both from a perspective of seeing the world differently but also from the perspective of embracing technology that I once would have avoided. I used to be a very private person but since I found the amount of awareness sadly lacking I've opened up my personal world to anyone who cares to read about it and speak where I would once have been silent." (11th June 2016)

Within her blog Wendy writes about her "Top 5 opportunities that wouldn't have come my way if I hadn't been diagnosed with Alzheimers..." 'The advantages of having Alzheimers'" in which she makes reference to closer family relationships, opportunities to raise awareness and meet new people (Mitchell, 2015).

Why is it important to consider the possibility of positive change in the shadow of an existential threat? Research suggests that higher levels of PTG have generally been shown to negatively correlate with anxiety and depression, whereas PTG positively correlates with gratitude, positive relationships and contentment (Ruini & Vescovelli, 2013). Positive growth also correlates to increased quality of life (Tomich & Helgeson, 2012), positive mental health, reduced negative mental health and better subjective physical health (Sawyer, Ayers & Feld, 2010). A sense of existential meaning is noted to be extremely important in an individual's ability to cope and adapt to changing life

circumstances (Reker & Chamberlain, 2000). Furthermore, on a pragmatic level personal growth may encourage and enable an increased engagement with life rather than social isolation or withdrawal. In turn, it is possible that this may go some way to promote self-esteem and a sense of identity, consequently slowing down cognitive decline.

In addition, an action research study into the experiences of younger people with dementia not only highlighted the unique struggles faced by such individuals, but also called for the provision of information that fosters a sense of hope and resilience (Pipon-Young, Lee, Jones, & Guss, 2011). The study called for a reframing of the way YOD is considered, with a shift of focus to “services that engender hope” and “encourage the establishment of positive self-identities” (p.612). Similarly, Hawkins (2004) identifies how a dementia is typically determined by failure or dysfunction, whilst McGowin (1994) suggests the need to shift the focus of research to strengths and abilities of those with diagnosis, as opposed to solely losses and limitations.

1.3.2 Summary

Emerging anecdotal information and serendipitous findings suggest that personal growth, of both an external and psychological nature, is a process that is possible for individuals diagnosed with YOD who are meaning making, re-appraising values and priorities, and pursuing a fulfilling life. As such, it feels important for the current narratives around YOD to be challenged further and accounts shared of how living with YOD may provoke personal growth. As the late Terry Pratchett once stated, “It is possible to live well with dementia and write best-sellers ‘like wot I do’” (Duell, Gillman, & Willgress, 2015).

1.4 Conclusions and Research Aims

As has been discussed in this chapter, several developmental theories suggest a typically chronological trajectory in which a sense of reflection and life review occurs in older age. However, research has also suggested the possibility of premature projection into later life stages in the presence of a threat to one’s mortality, specifically when receiving an apparently ‘off-time’ diagnosis. Furthermore, research around PTG has gone some way to suggest the possibility of personal growth in the presence of adversity through the process of adaptation and the establishment of meaning. It is hypothesised that individuals with a diagnosis of YOD face both such experiences: a sense of living with an existential threat at a younger age and facing ‘adversity’ in the form of a diagnostic label that is typically associated with loss and dysfunction.

Although previous research has offered some insight into these experiences, there is a lack of research directly exploring the lived experience of those with a diagnosis of YOD. Of the research that does exist findings appear to be loss orientated and may not reflect the full spectrum of experience; including the possibility of personal growth that is shared by many through personal accounts of living with YOD. As such, the current research proposed to give voice to a group of individuals who have long been silenced in research as well as opening up conversation to encompass discussion of all experiences. It was hoped that this research would go some way to offer a unique insight into the lived experience of those with a diagnosis of YOD. The aims of the current study were as follows:

- What is it like to live with young onset dementia?
- What is it like to receive an 'off-time' diagnosis?
- Is there possibility for personal growth amongst people with a diagnosis of young-onset dementia?

CHAPTER TWO: METHODOLOGY

In the following chapter I will introduce the qualitative methodological approach that was chosen for this study, that of Interpretative Phenomenological Analysis (IPA). I will then consider the various methods of data collection that can be harnessed within an IPA study. In addition, I will discuss creative means of making qualitative research more accessible to those with a diagnosis of dementia. Finally, I will present the concept of reflexivity and its role within IPA.

3.1. Methodological Approach

The methodological approach for the present study was one of a qualitative nature. It was felt that a qualitative methodology was more appropriate due to its ability to explore individuals' experiences, as opposed to a quantitative method which would be best suited to hypothesis testing (Elliot, 1995).

Consideration was given to a number of qualitative methods including discourse analysis and grounded theory. Discourse analysis is primarily concerned with the study of language and how this is used to construct meanings of reality. On the other hand, grounded theory is concerned with developing explanatory theories of basic social process (Starks & Trinidad, 2007). There is no doubt that both of these qualitative methodological approaches would have produced rich and valuable results, offering an insight into the world of those with a diagnosis of dementia. However it was felt that as the present study aimed to explore lived experience the most appropriate methodological approach was that of IPA.

3.1.1 Interpretative Phenomenological Analysis

IPA itself is a methodological approach that is underpinned by three distinct philosophical concepts: phenomenology, hermeneutics, and idiography.

3.1.1.1 Phenomenology

The first major philosophical approach that informs IPA is that of phenomenology; the study of experience. Husserl (1927, as cited in Smith et al., 2009), one of the major phenomenological philosophers, highlighted the need step for us to away from what he termed the 'natural attitude' in which we hastily attempt to understand experience in

terms of our preconceptions, or pre-existing categorisation systems (Smith et al., 2009). Husserl argued that we need to adopt a 'phenomenological attitude' in which we shift our perception from our taken-for-granted experience of the world to a more reflective and introspective position.

A phenomenological approach to qualitative research "provides us with a rich source of ideas about how to examine and comprehend lived experience" (Smith et al., 2009, p.11). As an approach that aims ultimately to understand the human experience, it felt appropriate to employ within the present study that aimed to capture an insight into the lived experience of a particular sample.

3.1.1.2 Hermeneutics

The second major philosophical approach that informs IPA is that of hermeneutics; the theory of interpretation. Heidegger (1962, as cited in Smith et al., 2009), emphasised the subjectivity of human experience, based on an individual's given context. Hermeneutics proposes that it is this subjectivity of experience that influences how individuals make sense of their experiences and in turn how they relay them to others, in this case to the researcher. As Smith et al. (2009) highlight, hermeneutics is concerned with the "dynamic relationship between the part and the whole" (p.28) and emphasises the need to consider each individual's attempts at sense-making in the larger context of their experiences.

In addition, a double hermeneutic is present in any IPA research; the researchers themselves bring their own subjectivity and experience to the interpretative process. Often referred to as the hermeneutic circle, the resulting interpretations made within any IPA study are considered to be not only a reflection of the participant's sense making, but of the researcher's attempts to make sense of this sense-making.

3.1.1.3 Idiography

Finally, the third major philosophical approach that informs IPA is that of idiography; the experience of the individual. Smith et al. (2009) highlight how this is a concept that is in contrast to most psychological approaches that often focus on making more generalisable claims about larger populations. Within IPA the exploration of the individual experience is paramount, and value is placed on each individual participant's experience through thorough in-depth individual analysis.

3.1.1.4 Summary

As suggested by Smith and Osborn (2008) “IPA is a suitable approach when one is trying to find out how individuals are perceiving the particular situations they are facing, how they are making sense of their personal and social world” (p.55). IPA also allows for the “exploration of meaning and sense-making links” (Smith & Osborn, 2008, p.54) and is particularly interested in the individual experience in context, aiming to “capture the meaning and common features, or essences, of an experience or event” (Starks & Trinidad, 2007, p.1374). As such, it was felt that IPA was an appropriate methodological approach through which to explore the individual lived experience of a very specific population (those with a diagnosis of YOD) as well as how such individuals are making sense of those experiences. It was felt that the key features of IPA, with its focus on personal meaning and sense-making (Smith, Flowers, & Larkin, 2009) within particular contexts, was an appropriate methodology for the current research question.

3.2 Data Collection: Semi Structured Interview

Although it was possible to collect data through the use of a variety of methods, including focus groups, web based data collection or structured interviews, each of these methods posed their own unique challenges and limitations. For example, the use of focus groups within IPA research faces criticism by some as it is felt such an approach is a step away from the traditionally idiographic stance of IPA. Furthermore, focus groups are felt to reflect more complex group dynamics and highlight more ‘in-the-moment’ sense making through social discourse (Tomkins & Eatough, 2010).

Web-based data collection poses challenges in terms of the richness of data collected and the opportunity for more in depth exploration. Similarly, the use of a structured interview may have reduced the capacity for appropriate exploration and reduced opportunities for participants to guide the interview into areas of discussion that were most relevant to their experience.

Smith et al. (2009) highlight the benefits of semi-structured interviews within IPA research. They suggest that the use of open ended questions allows for more in-depth exploration, reflection and opportunity for participants to tell their own stories, resulting in a more genuinely participant led medium of data collection. In addition, a semi-structured interview permits the interviewer much more flexibility during the interview to adapt questions in response to what the individual participant is presenting. This, in turn, results in a much more genuinely idiographic means of data collection that allows for more in-

depth exploration of areas that may not have been considered pre-interview. They suggest that this method of data collection facilitates a conversation that allows participants to tell “their own stories, in their own words” (Smith et al., 2009, p.57).

The use of focus groups, web-based data collection, and structured interviews are perfectly acceptable approaches to data collection within IPA research. However, I felt that, within the current study, a data collection method that allowed participants to provide a “rich, detailed, first-person account of their experiences” (Smith et al., 2009, p.55) would be most suitable, specifically: semi-structured interviews.

3.2.1 Interview Guide

The use of an interview guide offers numerous benefits to both the interviewer and the participant as highlighted by Smith et al. (2009). The use of an interview guide within the present study provided benefits in a number of areas:

- As is typically the case with IPA, the interview guide (Appendix 1) was developed from the literature surrounding YOD and personal growth, as opposed to being theory-driven (Smith et al., 2009) in that the questions developed did not aim to prove a particular theory, but instead aimed to gather data in relation to participants’ experiences. As such, the development of a guide prior to interview gave me the opportunity to carefully consider areas that may be important to explore during interviews. This encouraged me to fully immerse myself in literature relevant to my research aims.
- The development of an interview guide allowed me to carefully consider areas that may be sensitive or distressing topics and prepare for these by forewarning participants and considering referral pathways in the event of distress.
- An interview guide also provided me with a tangible framework to draw upon if the interview became difficult, thus containing both my own and the participants anxieties. This was felt to be particularly relevant with a novice interviewer, as in the case of the present study.
- The development of an interview guide allowed me to consider how best to ‘ease’ the participant into the interview. As a result, the interview guide began with a question that encouraged the participant to “recount a fairly descriptive episode or experience” (Smith et al., 2009, p.59) in an attempt to make the participant feel comfortable and confident. In this case “Could you tell me about when you first started noticing [memory] changes?”. It was expected that participants may have

relayed information relating to these experiences before (e.g. at clinic appointments or during memory assessments) and so would be in a better position to offer a more 'scripted' response and thus feel eased into the interview. Later questions, including prompts, use a more analytical, deeper level of exploration.

3.3 Qualitative Research and PWD

A review paper conducted by Murphy, Jordan, Hunter, Cooney, and Casey (2014) aimed to explore key strategies for "meaningful inclusion of persons with dementia within qualitative research studies" (p.800). With an acknowledgement that those with a diagnosis of dementia have long been excluded from qualitative research, the authors set out to explore what, if any, strategies were being utilised in those qualitative research studies that achieved meaningful inclusion. Several papers that explicitly highlighted strategies for maximising meaningful inclusion were explored and a list of 'strategies' was extracted. Results suggested that four main areas should be considered: gaining **CO**nsent, maximizing **R**esponses, **T**elling the story, and **E**nding on a high (CORTE).

The four areas highlighted by Murphy et al. (2014) were considered throughout the planning and implementation of the present study. For example, a number of studies in Murphy et al.'s (2014) review highlighted the importance of taking the time to build a trusting relationship with participants (e.g. Hubbard, Downs, & Tester, 2003; Hellström, Nolan, Nordenfelt, & Lundh, 2007). It was felt that such an investment early on in the research process, prior to interview, would help the participant to feel more comfortable, thus resulting in more honest, reflective conversations. In the present study each participant was offered a more informal meeting prior to interview, with the aim of easing participant anxieties. However, one area highlighted by Murphy et al. (2014) felt particularly pertinent in the context of an IPA study: telling the story.

3.3.2 Telling the story

Many of the studies included in Murphy et al. (2014) utilised strategies that aimed to support participants in 'telling the story'. These included interviewing with prompts, and gathering data from a number of sources including photos, diaries and recorded audio accounts (e.g. Bartlett, 2012). In addition, Smith et al. (2009) highlight how researchers can combine semi-structured interviews with further creative means of data collection and how strategies that aid the reflective efforts of participants are deemed to be worthy ones:

There is great room for imaginative work in collecting data for IPA. This is an approach which benefits from detailed engagement with a small sample, for

accessing the chosen phenomenon from more than one perspective, or at more than one time point, and from the creative and reflective efforts of participants. Any overall design or particular data-collection strategy which capitalizes on these features is likely to be an effective one. (Smith et al., 2009, pp. 56-57).

Photo elicitation is a method of data collection that incorporates photographs into the semi-structured research interview with the rationale that “images evoke deeper elements of human consciousness than do words” (Harper, 2010, p.13). Often this involves providing participants with cameras to capture new photographs that help to illustrate their current experiences. Examples of photo elicitation used within clinical psychology demonstrate the richness of data obtained through such methods (see Silver & Farrants, 2015). It is thought that semi-structured interviews that incorporate the use of newly obtained or older photographs as a complimentary interviewing technique can help to gain further insight into an individuals’ experience. It is felt that the use of additional media can aid to facilitate richer conversations; indeed experienced IPA researchers have been noted to highlight the opportunities available within a conventional IPA interview to use images as a point of reference (P. Flowers, personal communication, Feb 10, 2017).

This complementary method of data collection was thought to be particularly useful when working with PWD who may encounter memory retrieval or word finding difficulties. Bell (2010) highlights how visual methods in particular work to bring ideas to the forefront that may not be easily verbalised. Indeed, in one study by Griffin, Oyebode, and Allen (2015) such an approach was utilised with individuals with a diagnosis of behavioural-variant frontotemporal dementia. The rationale in this study for the use of such an approach was to overcome any potential communication difficulties and allow for the promotion of expression. One participant, for example, brought along a medal he received from work which was then used as the basis of a conversation around the impact of leaving work. Another participant presented the researcher with photographs of his group of friends which directed conversation into the exploration of changing social roles.

Additional research using more visual methods with client groups for whom purely verbal approaches may not be appropriate, for example those with acquired brain injury (ABI), has demonstrated good outcomes in terms of accessing such individual’s lived experiences. Lorenz (2010), for example, utilised visual methods with individuals with an ABI in order to give a voice to her participants and allow communication of the lived experience of an invisible injury (see Figure 1). Participants in this study utilised “visual

metaphors that foster a multifaceted view of brain injury with room for negative as well as positive aspects of their experience” (p.210)



Figure 1. “Inside my head is scrambled: ‘The shell of my life became broken. Inside my head is scrambled with strands of my life no longer blended.’” (Lorenz, 2010, p.214).

Furthermore, it was hoped that opening up the interview to incorporate the use of additional media would aid to assist in shifting the power differential between participants and interviewer. In a study by Rich, Lamola, Gordon, and Chalfen (2000) visual methods were used with adolescents with chronic health conditions. They write in depth about the patient-clinician relationship and how, typically, this is built on the idea that clinicians (or researchers) have “valuable knowledge and skills to impart to the patient” (p.163). However, the use of visual methodology “shifts this power differential, providing a mechanism for patients to teach clinicians about their illness experience” (p.164). The concept of power differential felt particularly relevant when working with PWD whose experiences, until the 1990s, have been “largely ignored within dementia research” (Murphy, Jordan, Hunter, Cooney, & Casey, 2014, p.801). It was hoped that the the use of additional media could go some way to to give voice to those who have long been silenced.

The literature around the use of visual media in illness research is fast expanding. In one study by Berland (2007), titled ‘Rolling’, individuals in wheelchairs were given video recording equipment to record their everyday lived experiences. The data collected by participants was deemed invaluable and it was felt that insight into such nuances would not have been obtained through the use of a conventional interview technique. With regards to YOD, in her blog Wendy Mitchell has utilised images to express her experience of living with dementia. These images portray unique challenges and experiences in her

everyday life (see Figure 2) that she beautifully illustrates with metaphors. Bell (2010) explains how the use of such creativity can make otherwise isolated experiences more public, changing discourses and challenging stigma.



Figure 2. A selection of photographs from Wendy Mitchell's online blog: (A) "A bad day is a foggy day when nothing is clear" (B) "A good day is a nice walk with clear direction" (C) "A tangled necklace depicts the patience needed to unravel the reality of the day" (D) "The simplest things in life bring so much pleasure" (used with permission).

Within the present study I proposed an expansion of this concept to include anything that helped the participant to tell their story or had particular meaning to them and their experiences. Participants were invited to bring along newly taken or older photographs, objects of importance, drawings, songs, literature, images and articles from popular media (i.e. magazines, newspapers, websites); anything that helped them to talk about their experiences of living with young-onset dementia.

3.4 Reflexivity

“The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world.” (Smith & Osborn 2008, p.53)

The concept of reflexivity is considered integral to experiential qualitative research in psychology (Shaw, 2010). When conducting qualitative research, in this case IPA, the impact of the ‘double-hermeneutic’ means that the fore-structures of the researcher (their prior values, assumptions, expectations, and experiences) naturally play a significant part throughout the research process.

When conducting an IPA study it is therefore essential for the researcher to be aware of their own fore-structures, and to adopt a reflexive attitude throughout the research process. Throughout the current study I attempted maintain a reflexive attitude by adopting a number of strategies. Firstly, conversations with supervisors throughout the research process ensured I remained curious as to my assumptions, asking myself where such ideas had come from, and what impact this would have on the research. In addition, a reflexive journal was kept throughout the research process, from the design stages up to recruitment, interviews, analysis and write up. This allowed me to continually and consciously revisit my pre-existing values and assumptions. Throughout the current document a number of ‘Reflexive Boxes’ will be presented to the reader in an attempt to provide an insight into my fore-structures, times when these were brought into my consciousness and how I managed these. The first of these (see below) will aim to provide an overview of my values and assumptions in relation to dementia in the early stages of the research process.

Reflexive Box 1: Values and assumptions.

At the beginning of the research process I spent some time considering my understanding of 'dementia' and what this diagnosis meant to me. The first thing that came to mind was a memory from some years previously. I had spent some time as a support worker, and later as an assistant psychologist, on a young-onset dementia ward in a private care-home. I remember clearly being asked to complete some 1:1 work with a gentleman who could have been no older than forty. I remember feeling confused at the time, surely they had made a mistake, wasn't dementia something that older people had? It made me think about why I had come to hold this belief, was this a result of social narratives? As I went to explore the literature surrounding YOD I came to realise that it wasn't just me who held this idea; that this was something many people believed, including those who had received a diagnosis, none-the-less it was an assumption I needed to hold in mind throughout the research process.

Before embarking on the current study I had no knowledge of any family or friends who had received a diagnosis; I later came to learn that a great-uncle was diagnosed with YOD but he had passed away before I was born. Throughout the research process I heard stories about this great-uncle, about how he went a bit 'funny' and had to be put into a home. As time went on I found that I felt some sadness about this story, the fact that nobody had ever mentioned this in any detail to me before, the way that it was almost kept quiet within the family; shame, perhaps, or quite possibly confusion around diagnosis.

Aside from these more significant experiences that influenced my values, beliefs and assumptions, I found that smaller, everyday experiences also came to play their part. A number of times I noted stories relating to YOD were presented on television, in TV shows, and in films. I saw stories about living with dementia on my social media and well as advertisements for memory walks "against" a life with dementia.

I came to see all of these interactions as influential in their own way. I recognised the importance of remaining conscious to these influences and the need to maintain a reflexive attitude. By being aware of these fore-structures I hoped to prevent my own values and assumptions from dominating the research.

CHAPTER THREE: METHOD

The current study aimed to explore what it is like to live with young onset dementia. It aimed to achieve this through the use of semi-structured interviews that invited participants to bring along photographs, objects or any other media that helped them to talk about their experiences. In the following chapter I will present the design for the current study including ethical considerations and service user involvement. I will then present the research procedure, including recruitment pathways for participants and stages of data analysis.

3.1 Ethical Issues

3.1.1 Ethical Approval

As recruitment for the research was being conducted through an NHS setting, ethical approval was required from an NHS Research Ethics Committee (REC) and the Health Research Authority (HRA). An Integrated Research Application System (IRAS) application was submitted to a REC on the 19th August 2016. The REC reviewed the application on the 29th September 2016 with the Chief Investigator present. Following this meeting, a provisional opinion was received on 6th October 2016, with further information and clarification required in a number of areas. Following several amendments, a Favourable Opinion was confirmed on the 26th October 2016 (Appendix 2). HRA Approval soon followed on the 14th November 2016.

Due to difficulties in recruiting solely through the NHS a substantial amendment was submitted to the REC on the 27th January 2017 requesting approval to recruit through the Young Dementia UK website. A supporting letter (Appendix 3) was provided by Tessa Gutteridge, director of YDUK. This was reviewed by the REC on the 21st February 2017 and a subsequent Favourable Opinion was reached on the 28th February 2017 (Appendix 4). HRA approval was then granted on the 10th March 2017 following assessment against the HRA criteria and standards.

A further substantial amendment was made on 5th April 2017 to gain approval for (a) the change of first contact to include telephone contact and (b) interviews to be conducted over the phone when requested by the participant. This amendment was submitted as a direct result of some participants stating a preference for one face-to-face

contact (the interview itself) and preferring to have their first contact with the researcher via telephone. In addition, some participants who were recruited through the Young Dementia UK website lived a considerable distance away and so the use of telephone interviews ensured their inclusion in the study. The amendment was reviewed by the committee on the 20th April 2017 and, following several clarifying questions, a Favourable Opinion was confirmed on the 03rd May 2017 (Appendix 5). HRA approval was then granted on 10th May 2017.

3.1.2 Informed Consent

Black et al. (2008; as cited in Cacchione, 2011) defines informed consent as “the provision of voluntary authorisation given by an individual who has the capacity to understand the research protocol and decide whether to participate in the research” (p.223). When conducting research with participants the issue of informed consent is a fundamental one. When research includes individuals with a diagnosis of dementia the issue of consent becomes even more pertinent and potentially more complex. As aforementioned, the issue of capacity to consent has historically excluded those with a diagnosis of dementia from taking part in research (Bender & Cheston, 1997). Subsequently I sought to be as inclusive as possible within the context of current NHS ethical approval procedures.

Inclusion criteria for the current research specified that individuals with capacity to consent to taking part in the study, as stipulated by the Mental Capacity Act (Department of Health, 2005), could take part. As such it was necessary for all participants to have:

1. A general understanding that they were being invited to take part in a research study;
2. A general understanding of the likely consequences of deciding to take part or not;
3. The ability to understand, retain, use and weigh up the information about what taking part would involve;
4. The ability to verbally communicate their decision.

Unfortunately, these criteria excluded those deemed not to have capacity to consent, however the inclusion criteria did aim to acknowledge the complex and fluctuating nature of capacity. Inclusion criteria aimed to ensure that participants were deemed to have capacity to consent specifically to taking part in a research interview and that this needed to be in place only prior to and for the duration of the interview.

3.1.2.1 Information Sheets and Consent Forms

Cacchione (2011) highlights a number of 'key elements' required in any informed consent process including verbal and written descriptions of the expectations of participants, the purpose, risk and benefits of the study, the voluntary nature of participation and the participants right to withdraw. These 'key elements' were incorporated into Participant Information Sheets (PIS) (Appendix 6; Appendix 7) that aimed to provide potential participants with the answer to questions including:

- Who is doing the research?
- What is the purpose of this study?
- Why have I been invited?
- Do I have to take part?
- What will happen if I choose to take part?
- What will happen to the results?
- Will my answers be kept confidential?
- Who else will be able to see my interview?
- What are the possible disadvantages of taking part?
- What are the possible benefits of taking part?
- What happens if I have concerns about this study?
- What happens next?
- What if I have more questions?

The PIS also encouraged the potential participant to speak to others about the research and ask any questions. It was also possible that some participants, due to the nature of their dementia, may have experienced difficulties in the processing of written information. As such, I developed an adapted PIS (an example of which can be seen in Appendix 8) utilising visual cues from the NHS developed image bank 'easy on the i' (Your Health Matters, 2017). Adapted information sheets were offered to every participant at the point of first contact.

Furthermore, each participant was provided with a Consent Form (Appendix 9; Appendix 10) that highlighted fifteen statements that the participant was required to consent to prior to participation. These statements included those relating to confidentiality and anonymity, rights to withdraw, and what would happen should participants lose capacity to consent. In addition, the consent form invited participants to

consider whether they wanted to be interviewed alone or whether they wanted to have another person present for support during the interview. Each of these documents ensured that participants were fully informed prior to making a decision about whether they would like to participate in the research or not.

3.1.1.2 Assessment of Capacity

An initial stage of capacity assessment for NHS participants came directly from members of the YPWD team involved in their care. A clear Staff Script (Appendix 11) stipulated that only those who were deemed to have capacity, in line with the Mental Health Act (2005), should be approached to take part in the study. This initial screening was not possible for those who were recruited through the YDUK website; however capacity was assessed during first contact with prospective participants through an initial telephone conversation.

A minimum of one week after the receipt of a PIS, contact was made with prospective participants either in person or over the phone. It was felt that this would allow participants the time to fully consider the implications of taking part in the study, weighing up the benefits and risks thus ensuring when consent was provided that this was fully informed. Capacity was assessed during this contact through in depth discussions with participants about their understanding of the study.

Capacity to consent was continually assessed at each subsequent contact between myself and each participant, with an acknowledgement that capacity for any individual could fluctuate on a day by day and hour by hour basis. In the event that a participant was deemed to not have capacity to consent the interview was to be appropriately terminated and participants would not progress to the next stage of the research process. In the event that an individual was deemed to lack capacity following participation in an interview, only those interviews in which the participant was deemed to have capacity were to be included.

Formal written consent was required from all participants at the point of the first interview. Each participant's consent form was re-visited at each subsequent interview.

3.1.2 Anonymity

Participants were invited to select their own pseudonyms to ensure that anonymity was maintained. Although pseudonyms are often allocated by a researcher, I strived to shift power-differentials where possible through the research process. Allowing participants to select their own pseudonym gave participants some degree of ownership over how their

experiences were presented. I also considered how to remove any potentially identifying features including the combination of incidental details (e.g. occupation, age, ethnicity) that may have led to the identification of a participant. Furthermore, all quotations were anonymised and no quotations were used that may have exposed the identity of a participant. Supervisors and other members of the research team were only permitted access to anonymised transcripts and did not have access to any personal information. Discussions around the use of images and additional media and how anonymous these were took place on a case by case basis. In all cases, images that included people were excluded from the final document and attempts were made to censor any other identifying information.

3.1.3 Confidentiality

All participants were fully informed as to procedures relating to confidentiality within the PIS and Consent Form and through discussion with the researcher. In addition, participants were fully informed of situations in which it would be necessary to breach confidentiality, including if it was felt that they were at risk of harm or if a third party was at risk of harm. The researcher adhered to protocols stipulated by the University of Leeds in relation to data management and confidentiality. All patient identifiable information was obtained, held and processed in line with the six Caldicott Principles (The Caldicott Committee, 1997):

1. Justify the purpose.
2. Only use identifiable information when absolutely necessary.
3. Use the minimum information necessary.
4. Access should be on a strict need-to-know basis.
5. Everyone must understand their responsibilities.
6. Understand and comply with the law.

The transcriber involved in the research was required to sign a Confidentiality Statement (Appendix 12) in accordance with the British Psychological Society's Code of Ethics and Conduct (2009).

3.1.4 Data Protection and Storage

All audio recordings of interviews were transferred from a dictaphone to the researcher's personal university drive ('m' drive) on the day they were made, where they were then stored. All recordings were then irrevocably erased from the dictaphone using secure deletion utility software. When it was necessary to access data away from

University of Leeds, this was done through the use of Citrix. Citrix is software that allows remote desktop access through a secure server. When data was transferred, for example when being passed on to transcribers, this was delivered in person on an encrypted and password protected pen drive. As such, NHS IT standards were fully complied with throughout the research process.

Physical security arrangements ensured that personal data (audio recordings, physical copies of transcripts, personal addresses, postcodes, faxes, emails or telephone numbers) were not accessible to any unauthorised personnel. All paper based data (e.g. consent forms) were stored in a locked filing cabinet in the office of the Leeds Doctorate in Clinical Psychology programme research coordinator. At the end of three years all data will be destroyed securely.

3.1.5 Consideration of Risk Issues

3.1.5.1 Participants

The current research included discussion of sensitive topics, as such participant wellbeing was considered throughout the research process. Participants were fully informed of general areas of discussion prior to being interviewed. Participants were reminded of their right to withdraw from interviews at any point as well as their right to not talk about any issues that they did not wish to discuss or did not feel comfortable discussing. In addition, I was aware of the possibility of terminating any interview in which it was felt that the participant had become unduly distressed. A full individualised debrief was offered to each participant following interviews to ensure that each participant felt contented to end the interview and to offer a space to reflect on any issues that had arisen.

In addition, I sign-posted each participant to the services listed on the back of the PIS should they require further support. Pathways were in place to allow for the referral of participants for more intensive professional support if necessary. For NHS participants, this pathway included a referral back to their care co-ordinator, whilst for YDUK participants this included contacting their GP. Each pathway required discussion and permission from the participant before such a referral was made, unless it was felt that the participant or somebody else was at risk.

3.1.5.2 *Researcher*

A number of risk issues were also considered in relation to both the physical and emotional wellbeing and safety of me as the researcher. As aforementioned, interviews included the discussion of highly sensitive and, at times, distressing topics. I managed this through the use of a reflexive journal to consider, prior to interview, any topics that may trigger uncomfortable responses for me. Post interview I attempted to capture any uncomfortable discussions that arose and to explore my responses to these. Should I have become unduly distressed following an interview I would have sought support from a research supervisor.

In addition, as many of the interviews were conducted in participants' homes, a complete University Risk Assessment was completed to ensure the interviewer's safety at all times. Prior to the commencement of each interview a lone-working protocol was also adhered to including the use of a 'buddy' system. This ensured that, prior to each interview, a member of staff at Leeds University was aware of my location, the time the interview would be completed and the my contact details. Following each interview, I contacted an allocated 'buddy' to check in. A protocol was in place should I not be in touch within a pre-agreed timeframe that ensured my safety.

3.2 Service User Involvement and Consultation

In line with guidelines developed by the national advisory group Involve (National Institute for Health Research, 2015), as well as the values of myself and the University of Leeds, service user involvement was prioritised where possible. Early in the research process Wendy Mitchell, diagnosed with early onset Alzheimer's in 2014, offered consultation in relation to the development of PIS, consent forms and interview schedules, as well as overall research aims. Wendy reviewed all documentation with the needs and wellbeing of potential participants in mind, offering many useful comments. I had the pleasure of meeting with Wendy in person on 23rd September 2016 where we were able to have an in-depth discussion about potential barriers that may be in place for individuals who might want to get involved as well as ways to overcome these. Some of the reflections and suggests Wendy brought to light include:

- She highlighted the value of the research aims, highlighting how the area is under-researched and how concepts relating to 'positive growth' are often overlooked.
- She highlighted the importance of ensuring that any documents that are e-mailed out to participants do not become distorted as a result of software issues.

- Wendy validated items on the PIS, stating: “really like how you warn, under disadvantages, that they may become upset or distressed. Researchers often forget this so lovely to see”.
- Wendy highlighted the importance of being approachable and ‘human’ during interviews with participants who may be feeling anxious in the presence of a ‘researcher’ and in the context of a ‘research interview’.
- Wendy wondered whether she would be able to share my study with her followers on social media in order to extend the opportunity to a wider group of people.

Later in the research process the Leeds and York Partnership Foundation Trust Service User Research Panel offered additional consultation. The group reviewed all participant documentation (including PIS, consent forms, invitation sheets) as well as the research aims and procedures. The panel offered a number of helpful reflections and suggestions such as:

- Panel members highlighted the importance of including a statement about what will happen to interview data should a participant lose capacity or choose to withdraw; in response a statement was added into the PIS.
- It was suggested that an interview duration of 1 hour may make participants feel daunted or pressured. As a result, this duration was reduced and made flexible to meet the participants’ needs and a statement in the PIS was added to reflect this change.
- The research panel suggested the inclusion of signposting information on the PIS including The Samaritans and more dementia specific organisations. Subsequently information and contact details of a number of organisations were added to the PIS, including: (1) The Dementia Engagement & Empowerment Project (DEEP) (2) Young Dementia UK (3) Alzheimer’s Society National Dementia Helpline and (4) The Samaritans.

3.3 Recruitment

3.3.1 Inclusion and exclusion criteria

Inclusion and exclusion criteria were generated following in-depth discussions with the research team. It was felt that the following criteria would allow for the identification of a homogenous sample of those diagnosed with young onset dementia but for whom taking part in the research would not cause undue distress.

Inclusion criteria:

- **Individuals with a formal diagnosis of dementia.** As aforementioned, a number of diagnoses may be given to individuals with dementia, including Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, and posterior cortical atrophy. Indeed, each diagnosis carries with it a unique set of symptoms and consequently unique experiences. However, the aims of the current research are to explore the unique experiences of individuals under the age of sixty-five and, as such, this was the only homogenous variable that was controlled for.
- Individuals who were **under the age of sixty-five at the time of diagnosis** (not necessarily at the time of interview).
- Individuals who were at least **12 weeks post-diagnosis**. Processing of a significant diagnosis is likely to take time (Tomich & Helgeson, 2012). Guidance on the experience of diagnosis over time comes from Vernooij-Dassen, Derksen, Scheltens, and Moniz-Cook (2006) who suggest that typical experiences of threat, shock and grief remain at around two weeks post diagnosis. However at around twelve weeks post diagnosis people are more likely to experience acceptance, a desire to get the best out of life, positive events and changes in social relationships, as typically illustrated by Kübler-Ross' change curve (1969). As such it was deemed appropriate, and indeed ethical, for the purpose of the proposed research to exclude individuals who had received a diagnosis less than twelve weeks earlier.
- **Individuals with the capacity to consent** to take part in the study in accordance with the Mental Health Act (DoH, 2005).

Exclusion criteria:

- Individuals with **diagnoses that may not be as commonly constructed as a 'dementia'** e.g. Huntington's disease, multiple sclerosis and HIV-associated neurocognitive disorder, were not included in the current research due to these conditions not typically being constructed as a 'dementia'.
- Individuals with **mental or physical health difficulties that may have caused them to experience excessive distress and/or be put at risk during the research process.**
- Individuals who were **not fluent in English**. As the principal data analysis in the study was a detailed analysis of primarily verbal information it was not be possible to recruit participants who did not speak fluent English.

3.3.2 Recruitment Pathway

Two recruitment pathways were utilised in the current research, both will be described here. Figure 4 presents both participant pathways and is provided to illustrate the various stages that each participant in the study passed through.

3.3.2.1 NHS

I initially met with a NHS Younger People with Dementia (YPWD) team in the North of England. This team included psychiatrists, nurses, occupational therapists, and psychologists. I met with the team to outline the aims and process of the research. The team were also provided with recruitment materials including Invitation Sheets (Appendix 13) for potential participants. As a result of working with a large team of individuals with different professional backgrounds NHS REC requested that a Staff Script be developed for NHS staff to ensure consistency. This script highlighted the stages of the recruitment process, who staff should approach, who they should not approach, what to say to those who were interested in taking part and what details to pass on to myself. This Staff Script was also provided to the YPWD team during this initial meeting.

The YPWD team were encouraged to ask any questions about the process of recruitment. Several challenges and concerns were raised including: the competition for recruitment amongst a number of studies looking into YOD, the preference of many service users to take part in studies that include medication trials, worries about overwhelming service users or causing undue distress. One member of the team also highlighted how a number of service users do not agree with their diagnosis of dementia. I explored these concerns and tried to consider how best to overcome such challenges.

Initially, members of the NHS team approached potential participants during routine appointments to gauge their interest. Those who were interested were provided with an Invitation Sheet and consent was then obtained to pass on the participants' information to myself: participants name, address, telephone number, their care co-ordinator's name and contact details, and a second point of contact in the NHS team. I then posted a PIS to those interested in taking part.

A minimum of one week later the researcher then contacted each potential participant to enquire whether they were still interested in taking part. Those who were interested were, at this stage, invited to arrange a first contact. This first contact took the form of an informal conversation about the study, allowing potential participants to ask questions and the researcher to assess capacity. This first contact also allowed for the

development of rapport between the researcher and participant (and in some cases their spouses or partners), which was felt to be beneficial in order to reduce anxieties for all parties prior to the interview taking place.

A further function of this first contact was to provide potential participants with a Media Information Sheet (Appendix 14). This invited potential participants to bring along additional media to the interview, with the first contact allowing for a more informal conversation about what this might include or look like for the participant. The delay between first contact and interview gave participants time to gather any media they wished to discuss, or collect new media, for example through their camera phones.

3.3.2.2 Young Dementia UK Website

Recruitment was extended to include the Young Dementia UK website following difficulties in recruiting solely from the NHS. Young Dementia UK is a registered charity (1085595) that offers support to those whose lives are affected by young onset dementia. Initial e-mail contact was made with Tessa Gutteridge, director of YDUK. Tessa expressed her interest in advertising the study and, following a substantial amendment process with REC, an advertisement was developed collaboratively with Tessa (Figure 3). Website advertisements were also shared on social media platforms by Young Dementia UK. As can be seen in the below advertisement, interested individuals were invited to contact me via email or telephone. I was then able to provide individuals with a PIS via e-mail or post. At this point, those recruited through YDUK then followed an identical pathway to those recruited through the NHS (see Figure 4).

The screenshot shows the Young Dementia UK website. The header includes the logo "Young Dementia UK" with the tagline "Informing Influencing Inspiring". Navigation links include "Home", "About young onset dementia", "Living with young onset dementia", "Find support", "Resources", "Support us", and "Young Dementia Network". A search bar is present. The main content area is titled "What is it like to live with young onset dementia?" and features a "Listen" button. The text reads: "My name is Charlotte Berry and I am a trainee clinical psychologist at the University of Leeds. I am looking for 6-8 people living with young onset dementia to take part in a study. The aim of the study is to learn more about people's experiences, in particular what it's like to receive a diagnosis of dementia at a younger age. By talking to individuals who've received a diagnosis of dementia under the age of 65 years, it is hoped that clinical psychologists, and other professionals, can better understand people's experiences. I hope that this will improve support that services offer younger people with dementia. If you chose to take part I would meet with you at your home or at the University of Leeds. You would be invited to choose a time and location that is convenient to you. When we meet I would be interested to hear about your experiences of living with young onset dementia. You may feel that one meeting is enough, but if you feel that you have more to say we can plan another meeting. This is completely your choice. If you have any questions, or you think you might be interested in taking part please get in touch. You can e-mail me Charlotte Berry at umcefb@leeds.ac.uk or call and leave a message on 07757 808934. Thank you." The page also includes social media sharing options (Tweet, Like) and a "Print this page" button.

Figure 3. Recruitment advertisement from the Young Dementia UK website

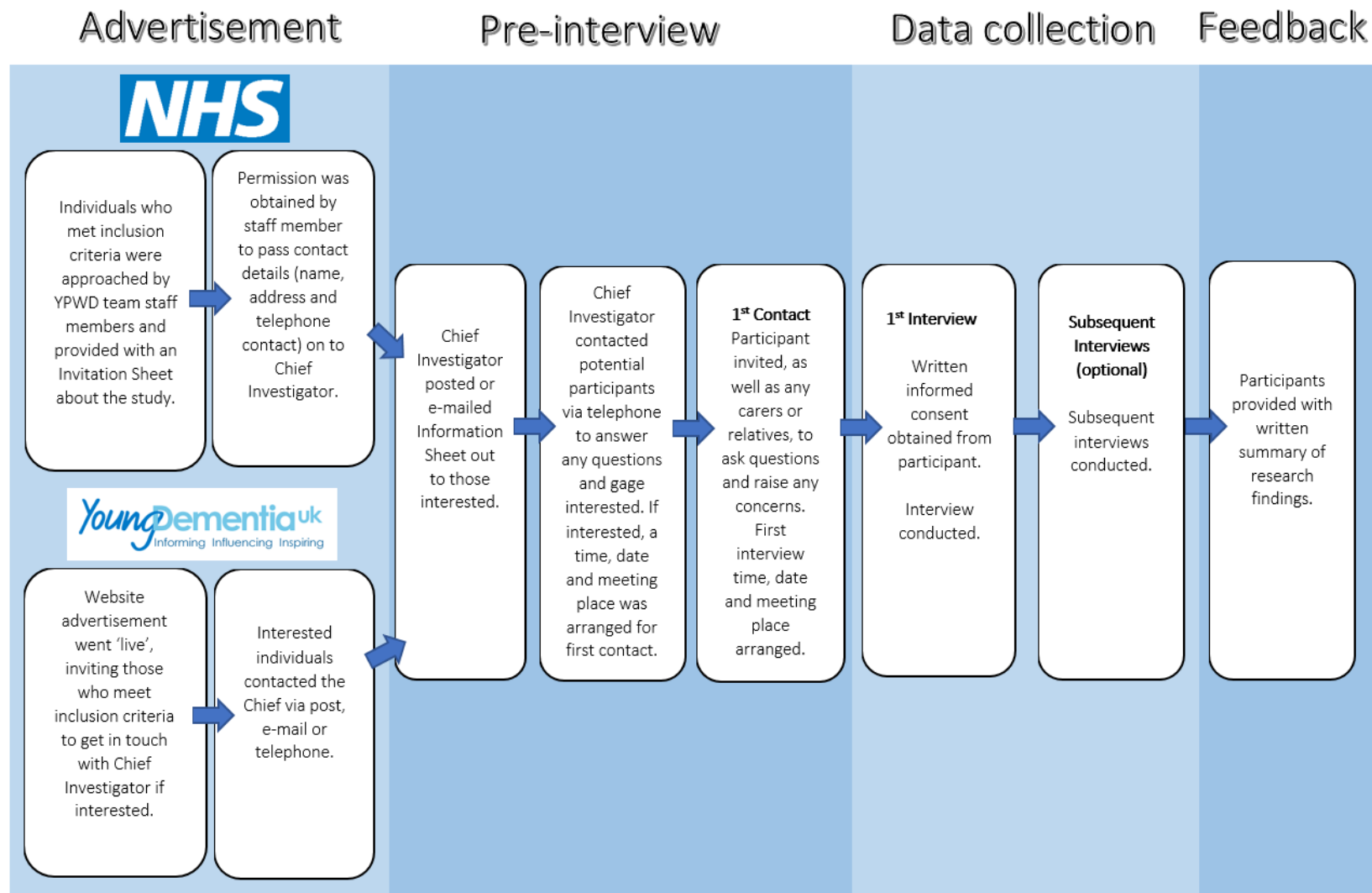


Figure 4. Participant pathways through the research process.

3.3.3 Sample

Smith et al. (2009) suggest that sample size of around three to six participants is suitable for an IPA study. Typically, researchers using IPA aim to recruit a homogenous sample, as such a purposive sampling method allows for a “more closely defined group for whom the research question will be significant” (Smith & Osborn, 2008). The current research recruited a sample size of five. One potential NHS participant was approached by staff from the YPWD team and expressed initial interest; however I was unable to contact this individual despite several attempts. Another potential participant was unable to continue through the recruitment process as it was deemed that they did not have capacity to consent to taking part.

Participants were aged between forty-seven and sixty-five years old at the time of interview, all identified as White British and resided in the UK. Four males and one female were interviewed. All had received a formal diagnosis of a dementia and all were aged under sixty-five when they received their diagnosis. Two participants were interviewed twice, totalling seven interviews that progressed to the analysis stage.

3.4 Data Analysis

Although IPA is noted to not have a prescriptive method of data analysis, it does have a set of common processes and principles (Smith et al., 2009). First and foremost IPA involves in-depth analysis of participants’ experiences, in the case of the current research this comprised of data collected during interviews. The steps taken during analysis are outlined by Smith et al. (2009):

- Step 1: Reading and re-reading
- Step 2: Initial noting
- Step 3: Developing emergent themes
- Step 4: Searching for connections across emergent themes
- Step 5: Moving to the next case
- Step 6: Looking for patterns across cases

The process of data analysis, in line with the above steps, is presented in more depth here.

Reflexive Box 2: The novice IPA researcher.

As a novice, first time IPA researcher the prospect of taking those first steps in the analysis process was a daunting one. My fears were those of being overly rigid with the data, overly systematic and superficial. Alongside these fears, the ongoing debate within the IPA field around exactly how 'interpretative' a researcher should be made it hard for a novice approaching their first (relatively large) data set to know what they should be aiming for. On the other hand, having attended two training courses with Paul Flowers, I found that I was simultaneously eager and excited to get stuck into the data set. During these courses Paul had encouraged creativity, free association, the use of doodles and imagery. This felt in stark contrast the feelings of anxiety and wanting to do things 'by the book'. One way of managing these conflicting feelings was to ensure I continued to ask myself questions, remaining open and curious to the notes, comments and interpretations I was making. Questions such as "*where has this come from?*" allowed me to take a step back and consider what of my own experiences was influencing the analysis. This process allowed me to become much more confident in my analysis and, hopefully, do justice to the experiences of the participants.

3.4.1 Stages of Analysis

Transcripts produced during interviews were initially read in-depth. At times this included revisiting audio-recordings in order for the researcher to become wholly immersed in the data and essence of the interview. The re-visiting of images obtained from interviews also offered an additional medium through which the researcher could connect with the data; Smith et al. (2009) highlight how such approaches can aid in contextualising and developing the analysis stage.

A second reading then took place in which a process of initial, exploratory note-taking took place. Such note-taking (as in Smith et al., 2009) took the form of descriptive comments (key words, phrases, descriptions, emotional responses), linguistic comments (pauses, tone of language, use of repetition, use of metaphors) as well as more abstract conceptual comments or questions. Different types of comments within the transcript were identified through the use of different coloured highlighter pens, with researcher comments written in the wide

margins on either side of the transcript. An example of an annotated transcript can be seen in Appendix 15. Throughout this process the researcher attempted to be as creative, reflective and as exploratory as possible, attempting to move away from Husserl's 'natural attitude' towards the 'phenomenological attitude' in order to connect with the essence of the participants' lived experience.

Following this stage each transcript was revisited and emergent themes arising from both the transcript and the researchers initial notes were identified. Smith et al. (2009) identify how this stage can often take you further away from the participant as the researcher adds their own interpretation to the data which begins to reflect the collaborative efforts of both the researcher and the participant; a reflection of the hermeneutic process. Tentative themes were written onto the transcript in a different coloured pen to initial notes (again, see Appendix 15), these were then transferred into a typed document that aimed to capture initial emerging themes for each participant.

I considered how best to analyse the data of those participants who took part in more than one interview. It was felt that it would be most appropriate to combine interviews for these participants, analysing data by participant rather than by transcript. It was felt that analysing this data separately to participants' first interviews may have been reductive and would not have reflected an analysis of the participants' experience as a whole.

Once initial themes had been identified the researcher aimed to explore connections across these themes. A lists of themes for a participant was printed out, cut up, and tentative connections and links between themes were identified by physically grouping themes together. This offered a strong, visual representation of emerging themes for each participant. This process resulted in the emergence of a number of superordinate themes, either as a result of 'abstraction' or through 'subsumption' of existing themes that were better understood as superordinate (see Smith et al., 2009, pp.96-97). Connections were also identified between themes that appeared oppositional in nature, and those that appeared to be related to a similar key event or narrative. This exploratory approach allowed me to consider how best to understand and group themes that appeared to relate to similar core experiences.

This process was then repeated for the next participant. Once initial themes and superordinate themes had been identified for each participant, patterns across cases were examined. This involved a mass bringing together of the data and a thorough examination and exploration of patterns across the participants' experiences. This stage involved the researcher searching for shared experiences, physically clustering together those themes that shared an

underlying experience. Again, this was done physically through the use of printed out themes, colour coded for each participant for ease of reference. This process involved re-visiting transcripts at times, re-evaluating relationships between themes and re-considering interpretations and assumptions. This iterative process continued until it was felt that the resulting themes and superordinate appropriately reflected the lived experiences of the participants.

3.5 Ensuring Data Quality

Elliot, Fischer and Rennie (1999) propose a number of quality control guidelines that are considered 'pertinent' to qualitative research. These guidelines are designed to ensure methodological rigour, to offer a framework against which the validity of qualitative research can be reviewed and to allow researchers to maintain a reflective position throughout the research process. As such, throughout the current research process I aimed to work within this framework.

Qualitative research, in particular that which calls for an element of interpretation, requires the researcher to be aware of their own "values, interests and assumptions and the role that these play" (Elliot et al., 1999, p.221). They highlight the importance of 'owning one's own perspective' in order to maintain a reflexive stance throughout the research process. The use of aforementioned 'Reflexive Boxes' in this case offered a means of ensuring data quality throughout. Further strategies that were implemented in the current study to ensure data quality, including the use of credibility checks and attempts to situate the sample, will be reflected upon in chapter 5.

CHAPTER FOUR: RESULTS

In the following chapter I will present the results of an IPA analysis exploring participants' experience of living with young onset dementia. Each participant will be presented in a brief pen portrait that aims to provide the reader with additional context from which to view the results. Results will then be presented along with a diagrammatic overview of the major superordinate themes and corresponding subordinate themes that emerged. Direct participant quotes will be provided to help bring the themes to life, provide a richer context and enable the reader to see the relationship between the raw data and the subsequent themes that emerged.

Table 1. Demographic details of participants.

Pseudonym	Age	Gender	Diagnosis	Number of interviews
Mr Vermont*	65	Male	Alzheimer's	2
John	63	Male	Vascular & Prominent Frontal Features	2
C3PO*	65	Male	Posterior Cortical Atrophy	1
Jackie	47	Female	Alzheimer's & Posterior Cortical Atrophy	1
Rich	57	Male	Alzheimer's	1

**Another person present during interview*

4.1. Pen Portraits

The pen portraits presented here will aim to introduce the reader to each participant as a unique individual, in line with the idiographic nature of IPA. Information will then be provided in relation to the structure and content of the interviews themselves. Finally, the pen portraits will incorporate a reflexive element, commenting on my initial impressions and experiences of participants in order to provide the reader with a transparent understanding of my position as a researcher during each interview.

4.1.1 Mr Vermont.

Mr Vermont was 65 at the time of our interviews. He had received a diagnosis of Alzheimer's disease. Mr Vermont lived in his own home with his wife. At the time of interview, Mr Vermont had recently retired. He had previously worked in the car industry.

Mr Vermont chose to take part in two separate interviews that took place in his own home; he requested a second interview when the option was given to him. Mr Vermont's wife was also present during the interviews, also at his request. The first interview lasted around 1 hour and 24 minutes, with the second lasting around 1 hour and 39 minutes. Mr Vermont produced a number of photos during the first interview. One of these images was taken in the week prior to interview on his smart phone. In the second interview Mr Vermont brought along a number of older photographs that he had taken out of storage with the help of his wife. Most of Mr Vermont's photographs were taken during various holidays that he and his wife had taken. During the interviews Mr Vermont also spoke about a number of items around his home, including a trophy, model cars and vinyl records.

Reflexive Box 3: Interview #1

Mr Vermont's interview was my first ever research interview, bringing with it a combination of excitement and anxiety. As a result I found myself sticking more rigidly to the interview guide than perhaps I would have liked, worrying that any deviation would result in me being unable to get through all of the questions I was keen to ask. This potentially shut down some avenues of conversation that could have been much richer than the ones I pursued. Thankfully, Mr Vermont chose to take part in a second interview. During the second interview I afforded myself more flexibility with my questioning and exploration, maintaining much more awareness of my tendency to stick rigidly to the interview guide. As such, I felt that the data became much more genuinely participant led. This allowed Mr Vermont to talk about the things that were important to him, ultimately giving him a voice.

Mr Vermont presented as a clearly well-educated gentleman, who was able to articulate his experiences well and was very keen to be involved in the research process. He

felt it would be an opportunity to talk through his experiences with somebody. Both he and his wife appeared slightly anxious during our first meeting (prior to interviews) and, to some extent, during the first interview. Nonetheless, the interview itself lasted over an hour and was rich in content, with Mr Vermont adopting an almost optimistic attitude throughout. During Mr Vermont's second interview he appeared more reflective and less determinedly optimistic, arising perhaps as a result of an altercation with his brother that morning. Mr Vermont became much more reflective during the second interview, reporting that he was able to be much more honest with his disclosures.

4.1.2 John.

John was 63 years old at the time of interview and lived alone in supported accommodation. John had received a diagnosis of vascular dementia with prominent frontal features after numerous referrals to the NHS for assessment, at the request of his family. John had been a carer for his mother who had passed away as a result of cancer. John had also been a carer for his wife; following his diagnosis of dementia he was deemed, initially by care staff, as unable to continue his caring responsibilities. This led to his wife being placed into a care home, whilst John was housed separately in supported accommodation.

John chose to be interviewed alone in his supported accommodation on two separate occasions. Both interviews were interrupted by nursing and support staff visiting to administer medication. John's interviews lasted 1 hour 39 minutes and 1 hour 30 minutes respectively. When I first met with John he was quick to explain that he experiences word-finding difficulties. He stated that he preferred that others allowed him to take his time and not to attempt to fill in the gaps in his speech. During the interviews John made reference to a number of items in his home including an alarm he had attached to his mobile phone in case he misplaced it, his music 'studio' in which he wrote music and played his keyboard, and a number of items that related to his spiritual beliefs.

John presented as a very proud man, eager to spread positivity and make others smile. John also presented as a very social person and spoke about his experiences of loneliness and a desire to be around others. John struggled at times to articulate clearly and as a result the pace of the interview often felt slower. At times he would he would introduce new topics that appeared unrelated to living with dementia: he was very aware that he had a tendency to do so and, on a few occasions, would attempt to bring the conversation back to his experiences.

4.1.3 C3PO.

C3PO was 65 years old at the time of the interview and had received a diagnosis of posterior cortical atrophy. C3PO was recently retired and lived at home with his wife.

C3PO chose to take part in one interview that lasted nearly two hours. This interview took place in the living room of his own home. C3PO stated a preference for his wife to be present during the interview. During the interview he made reference to a number of items in his home including a number of magnifying glasses, a bright pink iPad case (this being a colour that C3PO was able to see more so than black), both of which acted as visual aids. He also pointed out adaptations to his home including hand rails on the entrance into the house, and a sign that he placed in the window preventing cold callers.

C3PO presented as a very proud and family-oriented man. During the interview C3PO became very upset on a number of occasions, in particular when discussing his daughters and granddaughters. C3PO also made reference on a number of occasions to the difficulty in truly articulating what it is like to live with dementia, stating that he found it difficult to put into words as it was unlike anything else he could compare it to. Despite becoming upset C3PO was determined to continue with the interview, seeing research as a valuable opportunity to be involved in something important and to make a difference in some way.

4.1.4 Jackie.

Jackie was 47 years old at the time of our interview together; she had been diagnosed with both Alzheimer's disease and Posterior Cortical Atrophy. Jackie lived at home alone with her two cats. Jackie was recently retired from a long career in nursing and spent her free time gardening, walking, writing and painting. When asked to describe herself Jackie stated that she was a "*positive, optimistic person*".

Jackie chose to take part in one interview that lasted 1 hour and 22 minutes. Jackie's was the only interview that was conducted over the phone due to the geographical difficulties of meeting in person. As a result Jackie was unable to produce objects or photos of relevance during her interview. However, Jackie was able to e-mail across a number of photographs and poems prior to her interview. This ensured that both Jackie and I had the photographs and poems in front of us as a discussion point during her interview.

During her interview Jackie presented as someone who had a strong desire to live well despite her diagnosis. Jackie spoke about some difficult and uncomfortable experiences with other people during her interview. It appeared that some of these experiences made her even more motivated to prove that those with dementia can live well and should have a voice in society. For Jackie, being involved in this research was a way for her to help others, as she had done as a nurse throughout her career.

Reflexive Box 4: Pseudonyms.

All participants were invited to pick their own pseudonym to be used throughout the study. No pre-requisites or conditions were placed on the participant's choice as a means of shifting power-differentials between the researcher and participants as much as possible. At the time, participants' choices felt almost random – a picked out of the air name that would ensure anonymity. On reflection, asking a participant to pick a pseudonym was much bigger than a random act. I was also asking the participants to choose a new identity, to be anyone they wanted to be, to be somebody else. Some participants gave an explanation of their choice, often their choice related in some way to a loved one, a relative, a friend whom they admired or a past role that they filled.

One pseudonym that stood out to me was that of C3PO's, a choice that was attributed initially to having watched Star Wars the previous evening but that later seemed a symbolic choice as C3PO spoke about his past role as being on of a helpful, technologically-minded 'gadget man'. As the analysis progressed these pseudonym choices came to enrich the themes that were emerging around identity, the past self and the preserved self.

Jackie was the only participant who did not pick her own pseudonym, asking the researcher to choose this for her. I was encouraged by one of my supervisors to think about why I might have chosen this name specifically for Jackie. Initially I had assumed this was a generic name that felt suitable for someone of Jackie's age. Further reflection, however, encouraged to consider what the name 'Jackie' meant to me. This then led to the realisation that my aunt was named Jackie and was, in fact, a similar age to the participant 'Jackie'. They were also both nurses. Subsequently it felt very important for me to remain aware of these parallels during the analysis, to ensure that I did not get pulled into losing my reflexive stance as a result of any emotional responses to Jackie's experiences.

4.1.5 Rich.

Rich was 57 years old at the time of interview and had been diagnosed with Alzheimer's disease. Rich lived in his own home with his wife and three dogs. As a result of his diagnosis, he had been required to retire much earlier than he had planned.

Rich chose to take part in one interview that lasted around 1 hour and 40 minutes. His interview took place in his home. Rich's wife was at home during the interview, but he chose to be interviewed alone in his music room. During his interview he played a number of songs that he had recorded and presented a collection of drawings that he had made. He also took a

number of framed photographs down from the walls in his house to help him to further illustrate some of his experiences.

During his interview Rich presented as a confident and determined gentleman. He spoke at length about the difficult experiences he had in the lead up to his diagnosis. These experiences made him determined to be a voice for those with dementia. Rich struck me as someone who was angry at the way people with dementia were treated: he wanted to be an advocate of change.

4.2 Analysis Results

4.2.1. Overview of themes

Four major themes were identified: 'Fear', 'Anger', 'Sadness', and 'Contentment' from which a further thirteen subordinate themes were incorporated. A diagrammatic representation of these themes are presented in Figure 5. This diagram aims to capture the complexity and transitory nature of participants' experiences as they appeared to fluctuate between each of the four major themes both between and within interviews. The nature of these transitions will be discussed further in Section 5.2 in which participants' overall experience will be considered. Furthermore, Table 2 is presented to provide the reader with an overview of the contribution of each participant to each theme.

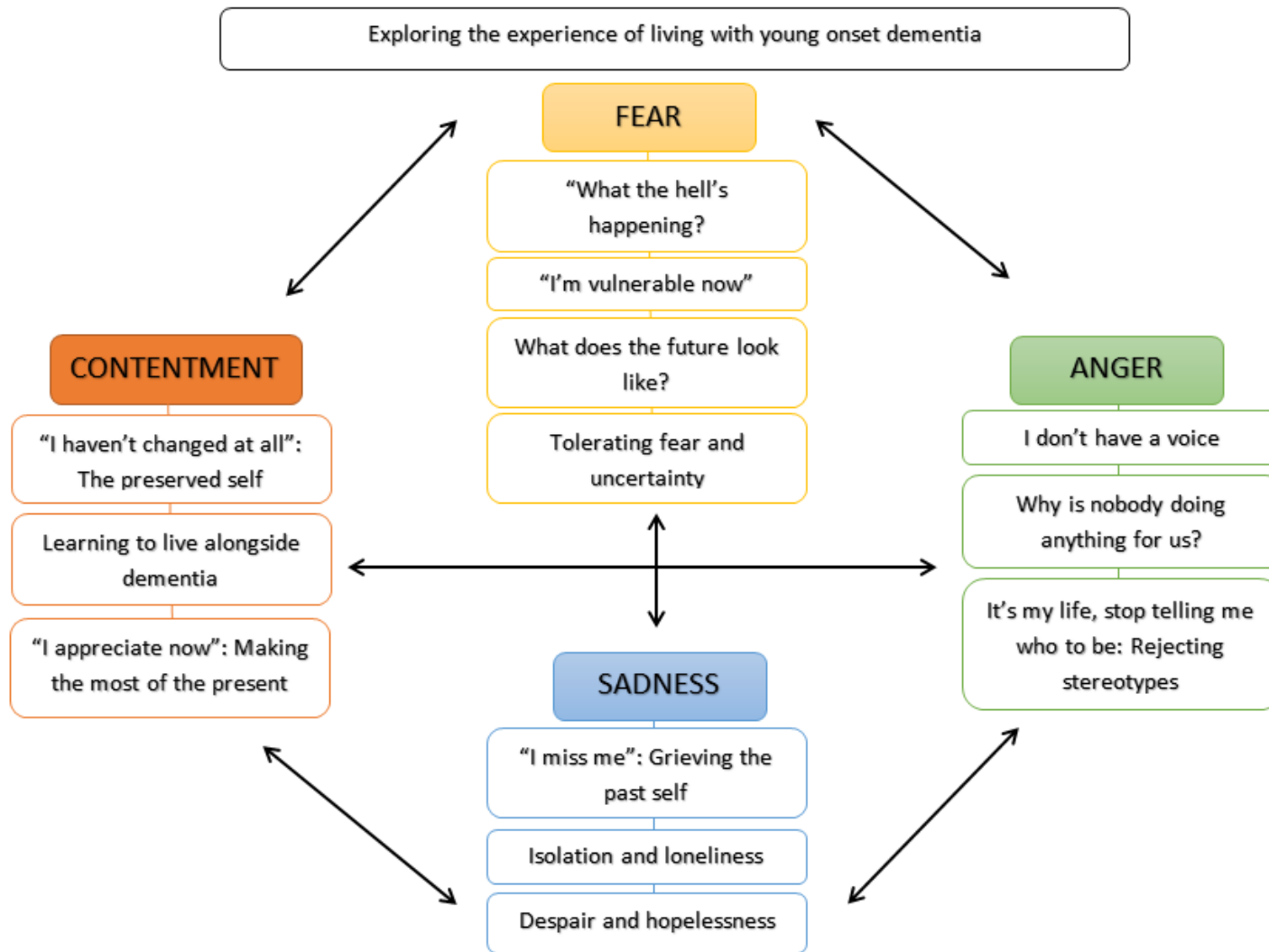


Figure 5. Diagrammatic representation of superordinate and subordinate themes.

Table 2. Distribution of themes by participant.

Theme	Mr Vermont	John	C3PO	Jackie	Rich
FEAR					
“What the hell’s happening?”	✓	✓	✓	✓	✓
“I’m vulnerable now”	✓	✓	✓	✓	✓
What does the future look like?	✓	✓	✓	✓	✓
Tolerating fear and uncertainty	✓	✓	✓	✓	✓
ANGER					
I don’t have a voice	✓	X	✓	✓	✓
Why isn’t anyone doing anything for us?	✓	X	✓	✓	✓
It’s my life, stop telling me who to be: Rejecting stereotypes	X	X	X	✓	✓
SADNESS					
“I miss me”: Grieving the past self	✓	✓	✓	✓	✓
Isolation and loneliness.	✓	✓	✓	✓	✓
Hopelessness and despair	✓	✓	✓	✓	✓
CONTENTMENT					
“I haven’t changed at all”: The preserved self	✓	✓	✓	✓	✓
Learning to live alongside dementia	✓	✓	✓	✓	✓
“I appreciate now”: Making the most of the present	✓	✓	✓	✓	✓

4.2.2 THEME ONE: FEAR

This superordinate theme captures participants' experiences of fear, often underpinned by feelings of anxiety and uncertainty. Frequently, participants' experiences of fear first began prior to diagnosis as they attempted to make sense of scary and confusing experiences that were unlike anything they had experienced before. This theme also reflects participants' experience of feeling vulnerable after their diagnosis in what they perceive to be a dangerous and malevolent world, as well as their fears for what the future might hold for them. It appeared that participants responded to their experiences of fear and anxiety by making attempts to protect the self, through strategies such as minimizing, normalising and denial.

4.2.2.1 "What the hell's happening?"

All five participants spoke of experiencing confusion prior to receiving their diagnosis as a result of difficult and unusual experiences that they could not make sense of. They described this as a time of great uncertainty in which they were making attempts to understand what was happening to them. This often left participants feeling scared and uncertain about what was going on, with a constant sense of things being not quite right.

Jackie: I thought what the hell... didn't quite understand what was happening but now I understand more because I've had it for quite a lot of years now. But that time was soon after my, my diagnosis and I thought what the hell's happening. I don't understand why can't, why can't I walk properly, and I didn't like it.

Rich did not notice that he was experiencing memory difficulties to begin with. His employer took him to one side and explained that he was making mistakes at work. Rich attempted to make sense of this by thinking that there was a conspiracy against him. He described this as a feeling of 'paranoia' followed by a realisation that something was not adding up. He later experienced fear and uncertainty when he went back and realised that he had in fact been making a number of mistakes at work.

Rich: Umm, so when he-he told me that I was making these mistakes and saying... apparently I was confusing people on shift handovers and umm, I didn't believe him. I thought there was a conspiracy against me. I can laugh about it now but that's how I felt; umm [sighs] so I didn't really kind of take it seriously. But then he showed me things I'd done and that was the shock... because I'd not realised I'd done that. So what I did then I, I-I I decided I was a bit worried about that cause I, and then I was still thinking, is somebody falsifying this, d'ya know what I mean? I was just, you know you get all this sort of paranoia d'ya know what I mean. Because I was, at no point of this was I thinking I had got any... any-any problems.

John also reflected on how others began to pick up on his difficulties earlier on, and suggested that he might benefit from seeking more support. He experienced this as a confusing time in which he was conscious of developing difficulties with his speech. John reflects on this time as difficult to clearly pinpoint what was going on.

John: It was a gradual thing, my speech that was very bad because I was conscious of it and also people didn't want to be - with [wife] and family they were aware of how bad I was erm more so than what I thought and I couldn't challenge it or say anything to family and how I felt it first [pause] I didn't realise, it was slow was that [pause] [laughs] I can't honestly remember erm...

All five participants spoke of the long process that they underwent prior to receiving their diagnosis. They all experienced numerous referrals for tests and assessments, with health professionals querying conditions such as cancer or MS. A number of participants spoke about their experiences being attributed to stress or depression which did not fit with their understanding of what was going on for them at the time. Some participants received a diagnosis unrelated to dementia before one of young onset dementia was reached.

Jackie: So I went back to work and then it got worse. I got worse at writing. I couldn't remember what I was supposed to be doing. So I went to umm, see Dr [name] 'There's nothing wrong with you. There's nothing wrong with you. The scan's, the scan's come back fine. You are wasting my time. You're just stressed. Get back to work.'

Furthermore, participants described even more confusion when they were told they had passed memory tests or did not meet the criteria for a dementia diagnosis. This left them experiencing even more uncertainty about what was going on for them.

Mr Vermont: 'Cos at one stage they thought it was cancer and I've been checked for cancer and all these things but it's not. I've been checked for that and they've checked me for the brain and all these things [pause] memory test and all these things and it showed it wasn't there, it wasn't right.

C3PO: He-he [GP] said that he was going to refer me to the memory clinic. Right. And er, he sent a letter to the memory clinic, and the memory clinic er... sent him a note back and said that er, he wasn't um, it wasn't , was it [...] wasn't sev-severe enough. Yeah.

C3PO went through a period prior to his diagnosis in which he attempted to make sense of his unusual experiences. He was repeatedly falling and experiencing problems with his eyesight. He began to question whether he had a brain tumour, which at the time was his worst fear. He described a sense of knowing something wasn't quite right and yet not being

able to put his finger on exactly what was going on. He craved a concrete answer and spoke about needing some evidence such as an x-ray or a professional diagnosis.

C3PO: There were all sorts going through me head [...] to be honest, y’know what I mean. That’s... that’s me only trouble cause everything’s going round. You think well what-what is the problem? And until you get somebody that knows what the problem is or they can see it on an X-ray or what, you don’t know.

For all five participants, it appeared that receiving their diagnosis offered an answer to their experiences. However, this then led them to begin to question why or how they had developed dementia, a process that appeared to be ongoing. For Mr Vermont this left him attempting to find a definitive explanation for the development of his dementia. He wondered whether he had developed dementia as a result of poor sleep, stress, or high blood pressure. He also questioned whether he developed dementia as a result of a genetic vulnerability.

Mr Vermont: But he [Grandad] was, he went funny and erm, but he was very old, but makes me wonder about the genetics ‘cos he was the only one in the family who’s gone bald like me so it’s [laughs]...

4.2.2.2 “I’m vulnerable now”

All the participants described experiencing feelings of vulnerability following their diagnosis. It appeared that they were attempting to make sense of this new part of their identity, with some participants referring to themselves as “broken”, “abnormal”, or “not right” in some way. For some, they began to consider themselves as now disabled (see Figure 6). The concept of being a vulnerable adult was something that participants at times struggled to make sense of. It appeared that this often left participants feeling that the world was a dangerous, unsafe place and that others could not be trusted and would ultimately hurt them.



Figure 6. A photograph of a sign that C3PO purchased to place in his front window.

For some, it seemed that their fears of being vulnerable in the world derived from conversations with others. Jackie relayed an account of being labelled as vulnerable by her GP, followed by her difficulties in accepting this label. She continued to describe the need to ensure her own safety, suggesting that despite her overt rejections of a vulnerable label, a sense of fear and danger remained.

Jackie: so when I got home I was scared of going out thinking, oh, people might tell that I've got dementia and I'm now vulnerable because that's what the consultant said to me. Cause obviously the consultant's God and he knows what he's talking about! I mean I took stock of myself and I think actually, no, I'm not vulnerable. I've never been vulnerable. I've always, I've lived on my own for a very long time. I've always been a bit street umm, streetwise, exactly know how to look after myself out there in the world. And I thought, no, I'm not vulnerable, but I have to put things into place to make sure that I'm safe.

John also relayed an account in which he was told by others that the world is a dangerous place. As with Jackie, it appears that John has integrated a sense of himself as vulnerable into his identity.

John: when I've been out, I feel that people take advantage and I've had people say 'look, John, be careful there's some people who will take advantage of you having erm an illness' and that is something which has been [sighs] when I'm out and about I'm I'm really conscious of it.

Rich stated that he struggled to accept the label of vulnerable as it was something that did not fit with his past identity. He began to experience feelings of vulnerability when out in public situations, such as going to the shop or using public transport. For Rich, it appeared that he reached a point where he did begin to consider himself as being at risk.

Rich: Of course I'm vulnerable because I can't, I struggle with money. So I'm vulnerable to... being confused with money. And there's plenty of people out there who pick up on that, that I'm not counting my money. I'm vulnerable when I go to the shops, if I go, because of the way I am. I'm vulnerable on, on transport because of the way I get. So I am a vulnerable person. And I never ever wanted to say that about myself, but I am. And I've come to realise that now because just... of what I try and deal with, you know...

All five participants spoke about other people being able to pick up on their vulnerability. They felt that others could physically see that they were vulnerable. For C3PO

this related to his visible gait. He described attending an assessment for a Blue Badge during which the assessor instantly saw his physical difficulties.

C3PO: ...and she said. 'I saw you get out of the car when you first came.' she said, 'I saw you struggling'

As a result of feeling that others could see their vulnerability, it seemed that participants feared that others would then use this to hurt or exploit them. Rich spoke about his fear that people would purposely go out of their way to target someone with dementia.

Rich: That's what, and that's what makes you vulnerable. People will see it, you know there's plenty of crooks in this world who will notice somebody like that. Let's face it, people with dementia get phone calls; they will target people with dementia... to get them to agree to things. They'll send them letters and then, y'know what I mean? They know the game.

Mr Vermont worried that his younger brother was able to pick up on his vulnerability. He described how his physical appearance was different following some drastic weight loss and that this in itself made him appear more vulnerable to his younger brother who would hurt him by calling him names or making fun of him. In this quote, taken from Mr Vermont's second interview, he speaks about his feelings of vulnerability around his brother following an altercation with him directly before our interview.

Mr Vermont: ...I used to take it out of them when they were younger kid-younger people. And it's their time to get revenge on me now; and this, for my youngest brother is how it's coming out now yeah, because I'm er, I'm vulnerable now and he-he's finding a way and also, since I lost all this weight, I'm physically a lot less now so he's... he's got lots of ways... lots of ways and lots of reasons for getting back at me.

Many participants spoke about a sense of self-consciousness around others. They made attempts to 'put on a mask' with others in order to hide their vulnerability and protect themselves. John spoke about adopting a second "mode" when he was with other people, one of positivity. Initially, this appeared to be through a desire to make others happy, although later in his interview John described how this was in actual fact an attempt to protect himself from others taking advantage of him.

John: ... umm, at home and in my own surroundings, Charlotte, it's just totally different, if somebody comes in... I'll, I'll [pauses] put on a... [sighs]...a show or, or

not show my full self [pauses] cause I don't want to and then [pauses] I think... [sighs] it's...

Interviewer: what is it you don't want to show to people?

John: [sighs] I didn't... because... I can see that people can take advantage

Rich also felt the need to present himself as a person who was not vulnerable as a way of protecting himself from others. In this example, Rich describes his attempts to be seen as a confident man when out in public, but later goes on to appear conflicted and wonder whether this may actually make him a bigger target.

Rich: I, I, I know I can walk through a shopping centre cause I've got quite big shoulders and I can walk through shopping centres, people will leave me alone. Umm, but when I started to have my problems, I'm like a bigger target. I'm like a... I'm like 'Look at at him,' d'ya know what I mean? So er, because you notice me; if I was a slim, little thing, out of the way, you might not bother me so much but umm... yeah, I am aware of people around me sometimes. Umm, and I do worry.

4.2.2.3 What does the future look like?

All five participants described a sense of fear, anxiety and apprehension in relation to the uncertainty of their future. Participants struggled between wanting concrete answers about what their future might look like and simultaneously not wanting to know; both options bringing with them an element of fear. For some participants the need for answers related directly to wanting to know how long they might live for. In this illustrative description by Jackie, she fluctuates rapidly between wanting answers and not wanting answers even in the space of a few seconds. Jackie does not want to imagine what the future might look like.

Jackie: I mean I, I don't want to know how long I've got really. I mean it's always nice to know. I don't want to. I want to be able to enjoy my life and live it. Rather than focus on what might happen. We never know what's going to happen in – I mean I say to people live in the moment and don't worry what's gonna happen in the future. The future hasn't happened yet. I don't wanna know what's gonna happen in the future or of things of, you know of what might happen with when I lose my mind and when I can't remember anything.

For others, the uncertainty of the future meant that it was difficult to live in the present. Mr Vermont worried about losing his driving licence, reflecting on how this would mean the end of his 'freedom' and loss of a substantial part of his identity (see Figure 7). For Mr Vermont the uncertainty of his future meant that he continuously searched for answers and direction. During his interview Mr Vermont was noted to ask a number of reassurance-seeking questions. He regularly spent time on his smart phone reading about Alzheimer's

disease and felt frustrated that health professionals were unable to manage his anxieties about how long he would live for.



Figure 7. A photograph of Mr Vermont's model car collection.

Mr Vermont: 'Cause no one's told me how long I've got to go because you can plan, plan things and once you've been diagnosed with this you can't go on forever so it's, nobody said to me, 'Oh, you've got so many years. So many years.' It would, it would be whilst not, it's not a health thing but I can get things more organised er, and sort things out if I knew any ideas about the length of time I've got to go. Yeah.

For many participants their anxieties of the future were brought to life further by fantasies about who they might become. These fantasies were often based on their experiences of others with dementia or stereotypes about what it meant to be a person with dementia. For others, their fantasies of the future were based on their experiences of family members during the end of their life.

C3PO: ... I don't want to be a... a cabbage... y'know what I mean?

Rich: ...but I feel real, I dread not being able to speak. I-I, that's my biggest fear. That's my biggest fear. So umm [sighs] yeah.

Mr Vermont: Because he [Grandad] started to go really funny as he got old, yeah. He started to lose things and erm wasn't diagnosed as this but he he erm [pause] he started to go strange and couldn't talk about things and even me mum fell out with him a lot of the time and it was awkward, but he was – well, when he went I remember going down to the hospital to see him and he was just talking absolute gibberish. He was talking about he he'd gone how he'd gone down there erm in a cart? A horse and cart, telling me about the horses and things like that. He'd completely lost it, he was lying in hospital, he didn't last long.

Rich was particularly fearful about becoming violent in the future. He trained for many years in martial arts and worried that this might mean that he would become violent, fearing that he would become a person who would cause harm to his family. During his interview he presented me with a photograph of himself participating in martial arts based combat with another person.

Rich: See I was always worried because of this [shows interviewer photo]... right, this was me when I was a young man and that, well, not so long ago I started reading about dementia and started reading about people getting violent... and what they can do, and I was thinking, you know I don't want to be the one who starts to get violent because that could be really bad.

For Rich, Mr Vermont and C3PO their fears about what the future might hold became, at some point, intolerable. Fears about the future and a lack of certainty meant that they came to consider ending their lives as their only concrete means of control over their lives. For the most part, they spoke about this option in the past tense. However, during their interviews there was reference to this option being something that would always be in the background. It appeared this means of control offered them a sense of reassurance.

Rich: ... but all of a sudden I felt helpless and I'd never really experienced that in my life. And I never spoke to [wife] about it but I, I worked out three different ways of killing myself. I knew how.

C3PO: ...he [doctor] said to me, he says, 'Do you ever think about-about death?' I said, 'Well... [sighs] ...' that particular time I thought well... yes. But then actually... as I've got to know it better [becomes upset]

Mr Vermont: So my thoughts are er, this is, this is what the psychiatrist was on about: my, my thoughts are if I, if they say I have to go in care I'll commit suicide... it's not something I'm going to do now but I'm... lots of easy ways of doing it. It's not something I... I've had to look into but I know how to do it, yeah. And that's the best. There's no way I'll go into care. No way at all. It's er, if I'm at the stage where I'm still all right to be able to do things, there's no way (I: mm-huh) no way. No.

4.2.2.4 Tolerating fear and uncertainty

All five participants made attempts to manage their often overwhelming experiences of fear and anxiety. One of the most common strategies that people used was that of normalising. Participants appeared to fluctuate between experiencing themselves as 'young' and experiencing themselves as 'old' and dementia as a normal part of the ageing process. Mr Vermont felt that his diagnosis was not a certainty and could not be proven. He believed that

many of his friends of a similar age also experienced memory difficulties at times and that this was a normal part of the ageing process for most people.

Mr Vermont: Well, it's not something you can prove 100% is it, but, no it's just the memory issue but, as I say, so many of my old friends have got the same thing it's just that I've got one that's five years in front of most old people. It's, at 65, I've got what 70 year olds have got so...

Reflexive Box 5: What does my future look like?

As I entered the data analysis stage I began to spend some time considering what my future might look like. As a trainee clinical psychologist I was coming up to the end of three years of employment and training that felt very certain and contained. I had been receiving a steady financial income for three years, I knew what the structure of my weeks and months looked like, I had become familiar with the rest of my cohort and course staff, I knew exactly which client groups I would be working with and on what placements. I suddenly began questioning the uncertainty of my own future: Where will I be living? Where will I be working? Will I even have a job? Will I have enough money to cope financially? What kind of psychologist will I be? All of these questions made me feel that the future would involve some big life changes, some that felt subjectively more positive than others. I found myself reflecting on what felt like the end of a chapter in my life, with a mixture of sadness and regret, yet excitement and a sense of opportunity. This resonated with a lot of things my participants spoke about, questioning what the future would look like. This seemingly parallel process left me feeling guilty at times; my future seemed full of changes but was underpinned by a sense of excitement. My participants, on the other hand, spoke about futures filled with changes underpinned by fear. There was a real risk that the guilt I was experiencing would in some way influence my analytic approach to the data. For example, I considered how I may have wanted to avoid or downplay themes that related to the participants' futures as they were too difficult for me to accept or tolerate. By maintaining my awareness of the guilt I was experiencing I was able to maintain a more reflexive position. During the write up stage I made attempts to remain reflexive and ensure that the themes that I presented were as true as possible a reflection of the participants' experiences.

After receiving his diagnosis Rich did not want to accept it, he felt that dementia was something 'old people' had. He received leaflets about dementia but refused to read them, he did not want to know anything more about his diagnosis.

Rich: I didn't want to accept that it was anything like that. Because I didn't know anything about the disease, at that time, and I was just, you know I was just ignorant as a lot of people. It's an old person's disease. It's not going to be me. Cause every time I went to the clinic it was always old people. There wasn't, there was only like me sat there d'ya know what I mean. So er, so once, I mean I did know what they were looking at but I suppose I was just in self-denial at the time... d'ya know what I meant. And umm, er, as I say, when it when it came out I just didn't, I didn't know how to, I didn't know how to believe it because I didn't think it happened to younger people, d'ya know what I mean. I was 54 and it was just before me birthday [chuckles] but, you know so and I was just thinking, you know, 'No, this can't be right. Can't be right.'

Jackie made sense of some of her experiences of dementia by relating them to aspects of the way she had always been. She was able to minimise the emotional impact of her frequent falls by thinking that she had always been clumsy, so her experience of falls was something to be expected. She also spoke about feeling unsafe to be away from home, but rationalised this by thinking that she had never really liked being ill away from home, so this was nothing new.

Jackie: I was having, I was having lots of falls, I was having lots of falls umm, and I mean I've always been a bit clumsy. I've always been a bit clumsy.

All the participants except John at some point externalised dementia as separate to the self. For some they referred to their dementia as an 'alien' or a 'ghost'. For others the externalisation was more subtle, referring to their brain as broken or faulty in some way, but the brain as ultimately being a separate part of themselves.

Jackie: You're fighting against um, whatever, I mean I call the dementia, the alien that's in my brain. It's like um, a black entity you can't see.

Rich: So, so [laughs] but, you know I used to think it was like living with a ghost. That's how you used to describe it, because I, I don't... *where's that come from*, d'ya know what I mean?

Through the use of externalisation participants were able to reject dementia as a part of themselves and were also able to direct their anger at a more external object. For Rich and Jackie, being able to externalise their dementia meant that they had somewhere to direct their frustrations.

Rich: I don't want dementia. I would choose, if it was a man I would punch his face in.

Jackie: I mean with cancer, most people have a lump somewhere. You can probably feel it. and people, I mean I've known people who give it, give their tumours names and things like that from when I was a nurse; and they get angry at it. But I, with dementia it's invisible. It's like an invisible entity. You can't have, you wouldn't have a go at it say, 'Get out of my head!' Huh! 'And disappear,' and you know but you can't. So it feels a bit, you feel a bit of a cheat because you can't, it's something you grasp, get hold of to get it out of your head or something!

John used perspective-taking in order to manage his experiences. He compared his situation to others who were worse off than him.

John: I always think that I'm lucky and there're always people... worse off... than me.

Having a sense of control over their future was important to participants. This was obtained by some participants through practical means including putting Power of Attorney (PoA) in place. Others made plans to ensure that their loved ones would not be left in a difficult financial situation in the future. Some participants, for example C3PO, ensured a degree of certainty in their futures by ensuring that their partners or family members knew their preferences and wishes.

C3PO: Erm... er, she [wife] knows what my... thing is with umm... death erm... I want to be cre-cremated and umm... er, and wherever my ashes go... I wanna be er, with hers. That's it.

Other participants managed the uncertainty of their future by trying to desperately keep their dementia at bay. This ranged from taking prescription medication, eating healthily, taking regular cardiovascular exercise, and completing mental 'puzzles' such as crosswords to more complementary approaches such as drinking coconut oil. For some participants they also spoke about considering taking part in drug trials, hoping that this could 'hold off' the dementia for as long as possible.

Mr Vermont: I'm doing all the, all the right things it says about exercise and stimulation, and doing as much as possible from that point of view.

C3PO: Er, umm, 'I want to put you on these patches.' 'Okay, fair enough.' Umm, he said, he says, 'It, it won't cure ya er, but it might slow it down.' So-so, 'Okay, fair enough. I'll try out ought'.

4.2.3 THEME TWO: ANGER

This superordinate theme captures the experience of anger. Much of the anger that participants experienced appeared to be underpinned by a sense of unfairness and injustice, and was often directed externally rather than at the self. This theme reflects the anger that participants felt about feeling silenced and not having a voice. Anger also stemmed from feeling that not enough was being done for those with a diagnosis of dementia in general, but specifically for the participants themselves. Finally, this superordinate theme captures a sense of anger, at times bordering on fury, in response to stereotyping that people with a diagnosis of dementia can experience.

Jackie: In the early days I got angry because actually that's normal behaviour, the bereavement part, and you have the bereavement process and anger is part of the bereavement process.

4.2.3.1 I don't have a voice

All five participants made reference to experiences of anger in response to feeling silenced by others. Often this experience related to feelings of powerlessness during interactions with others. Jackie spoke specifically about her experience of being silenced by others when she struggled to articulate, with others attempting to be her voice. This led her to feel frustrated.

Jackie: I hate it when people speak for me... as if they're trying to help me out it makes it easier, it actually doesn't. It makes me quite sensitive when people do that. So I say, 'You don't have to speak for me. I will get the words eventually, I just need time for you to, you know have to have patience with me and then the words come out eventually. But don't speak for me 'cause I hate that.'

Participants felt that there was reluctance to speak about dementia in society in general. This led them to feel even more that they did not have a voice, so much so that it was considered 'brave' when somebody did speak out. Participants spoke about being involved in the current research as a forum through which they could have a voice and talk about their experiences. Some participants also made reference to wanting to give voice to those with dementia who were not able to speak up. For Mr Vermont being involved in a research interview was a medium through which he was able to have his voice heard and to speak openly and honestly about his experiences of living with dementia. This was not an opportunity that he felt he had, but felt that it was right that he should be able to do so.

Mr Vermont: Yeah, but the-the whole thing, it's er, it's just very much, very much of a down and-and a depression and things like that. And as you see, it's been stimulating for you to come and talk to me and lift things up. It's different; and the fact that I can give you the honest and truth about things is, is, is right.

Jackie compared her experience of wanting to talk about dementia to her experience of people openly talking about cancer. Jackie felt that it was not right that people were reluctant to talk about dementia or give those with dementia a forum in which to speak.

Jackie: There's a huge stigma about dementia still. I mean you can talk openly about cancer, no problems, but you mention dementia everybody starts to be quiet on it. And I say, no, that's not right.

More often feelings of being silenced and not having a voice arose as a result of interactions with memory services, GPS and other health professionals. Rich felt particularly angry about an occasion during which he felt abruptly silenced by confidentiality statements. He recalled an experience in which he was experiencing suicidal thoughts but felt unable to share these after he was told that it would not remain confidential. As a result he 'bottled up' his thoughts and feelings.

Rich: I said it to the bloke, the doctor, I said 'do you know what your biggest problem is when the first time you talked to us you said 'if you tell me anything, tell me anything that might be of concern I cannot guarantee I can keep that a secret'. So basically 'shut the fuck up and don't say nothing to me'.

Other participants spoke about their experiences of feeling dismissed by health professionals. For C3PO his experience of not having a voice was most apparent in the lead up to his diagnosis. He had numerous GP appointments in which he was told there was nothing wrong with him. C3PO spoke about feeling that he knew that something was wrong, but that he could not 'voice' his disagreement with health professionals as they held positions of power and were ultimately the experts.

C3PO: I wan't ha-happy about it but I thought well fair enough, you know. He, he's the er GP... you know but I knew me-self that I wasn't right... cause I've always said, you know your own body.

Jackie spoke about a similar experience during which she felt that her own understanding of her body was dismissed as unimportant. Again, Jackie felt that her voice was not being heard.

Jackie: ... umm anyway so umm, I said, well what about my memory cause I can't remember anything. He said, 'It's because you're stressed.' And I thought... he's just brushing me off and I hate... I know my brain and I know my body. Something's not right but nobody'd listen to me.

For Jackie, her experiences of being silenced and dismissed impacted massively on her subsequent appointments with health professionals. Jackie spoke about an expectation that, as a 'patient', she would instantly be ignored.

Jackie: I went on my own to see the consultant because I have a fear that in the past I've been a nurse, I saw sometimes consultants speak to the person that they were with rather than the patient, which is, I think it's really wrong to do that. And I didn't know whether [consultant] would be like that or not so I went on my own to start with.

4.2.3.2 Why is nobody doing anything for us?

Participants spoke about their experience of anger in relation to feeling abandoned or neglected by others. There was a sense of being treated as a lesser person following their diagnosis, of being forgotten about and of not enough being done to support and help people. Mr Vermont felt that he had been 'written off' by health professionals, a term of particular relevance considering his career in car restoration. He felt angry and as though health professionals had given him a diagnosis and then forgotten about him. In particular, his frustrations stemmed from feeling that not enough was being done to help to treat his dementia. He also spoke about anger surrounding a general lack of research into finding a cure for dementia.

Mr Vermont: I feel that they could do more. They just don't seem concerned, yeah. Have I been written off? Mm-don't know. Just saving money? I don't know.

Mr Vermont's roles throughout his life had always been practical in nature. He found it particularly difficult to understand why nothing more was being done for him. He went on to make comparisons between the treatment options that were available to people with a diagnosis of cancer in comparison to those who had a diagnosis of dementia. Rich was also noted to make reference to what appeared to be high levels of support for people with a diagnosis of cancer, in comparison to those with dementia.

Mr Vermont: When you see for instance with cancer what they, what they've done and what they can do. With this, no one says we can do this, we can do that, they don't do it. And yet when you read and see it online they can but they're not. So that's the big frustration.

Rich: If you get cancer, you get a lot more support. There's loads of support there. But dementia, it's this horrible little thing that nobody really wants to talk about it; 'that that and put that over there.' Discovering that people are being refused other medication because they've got dementia. How wrong's that?

Rich felt particularly angry that there was not enough being done to help people post-diagnosis. He felt that services did not offer enough support or offered the wrong kind of support. As a younger person, he spoke about services not being tailored to his needs.

Rich: I mean Alzheimer's society love talking about singing for the bloody brain. I say, 'listen, do I look like I go singing for the brain? I don't want to go sit in the rooms singing 'Knees up Mother Brown', d'ya know what I mean?

Rich spoke about feeling angry that people with dementia were being overlooked when it came to sending out reminders for flu jabs. He felt that nobody had considered the needs of people with dementia who were living alone. For Rich, he felt that this was a way for services to save money, and that people with dementia were overlooked.

Rich: This year [sighs]... just gone we didn't get... a reminder. [Wife] remembered, I didn't. [Wife] went down to the doc-to the doctors now don't give reminders because people who, if you want one... you have to remember it. So everybody with dementia then... living on their own, don't get one. How is it cost-effective because when they develop flu they'll cost more than the flu jab. So it's false economy. It's false economy. But why they're, why doctors are doing that, because it's trying to save money and paperwork.

For some participants their frustrations that not enough was being done to support those with dementia led them to want to take part in research. Becoming involved in the current research was, for some, a way to 'do something'.

Jackie: I think the more research we can take part in it helps much more for the future.

4.2.3.3 It's my life, stop telling me who to be: rejecting stereotypes

For Jackie and Rich in particular there was a real sense of anger and frustration at the stereotypes that were projected on to them following their diagnosis. They experienced others

as pigeon-holing them into an outdated 'dementia patient' stereotype. C3PO, Mr Vermont and John did not appear to experience this sense of anger in relation to stereotyping to the same degree as Rich and Jackie, although they were consciously aware of the stereotypes that others may have about them.

Jackie experienced a lot of stereotyping from others, including her family and friends. Following her diagnosis, others appeared to make sweeping assumptions about Jackie's abilities and needs. For Jackie, this was an extremely frustrating experience. The assumptions that others made about her life did not fit with her experience.

Jackie: At first my mum said to me, 'Oh you'll have to come and live with me.' I went, 'Why?' 'Cause you have dementia. You can't live on your own now' And I, 'No, mum, I can live on my own. I'm not going to come and live with you.' There's the whole – in the old days, if you got diagnosed with dementia you couldn't live on your own. You'd get together with someone, didn't you? In, in the old, the old days. Whereas now people live well with dementia, you know it's one of those things.

Jackie: When I first got diagnosed umm, I remember going to, I bumped into a person I used to, I'm not saying a friend because she's not a friend but a person I used to know and umm, we got talking and she, 'Oh, I haven't seen you for ages and how are doing?' and that sort of thing. And I told her she looked, huh! she looked around me and said, 'Where's your carer?'. I went, 'What do you mean my carer?' and she went, 'Well surely somebody like you who's got that diagnosis needs to have a carer with you' and I went, 'No!' I thought she was joking cause they... umm, they've... they've... they have perhaps that sort of attitude had gone out of the window because - and er, I said, 'I haven't got a carer. I don't need a carer. I'm quite able and living with dementia' and she went, 'Aren't you supposed to be locked up though?' umm, I said, 'What do you mean locked up.' And she went, 'Surely people with dementia need to be locked up for our safety' and then I sort of looked at her sort of laughed and then she was just, she was quite serious and I said 'Unfortunately, no. those, those attitudes went out of the window a long time ago and people can live well on their own with dementia.'

Rich was aware that the way he presented did not always match with other people's stereotypes about what a person with dementia should look or act like. He felt others feel more comfortable when categorising and stereotyping a person with dementia.

Rich: People when they see me don't always think 'That's a man with dementia.' And that's a good thing... and I'm glad, you know when people say to me, 'I wouldn't know,' well that's good thing. I wouldn't want you to know really, you know, you know when-but I sometimes think people just want you to sit in a chair, slobbering outside not being able to talk. Cause then they'd feel better about themselves.

Following their diagnoses, Rich and Jackie experienced others as pitying them and focusing on the things that they were no longer able to do. It appeared that they felt angry that people no longer saw them as a person who was still able to function and live well.

Jackie: When people say to me, 'Oh, you poor thing,' I went, 'No, I'm not poor thing. Not poor thing at all!' [Chuckles]

Rich: Now that's because doctors tell you when you're diagnosed, 'Oh, you can't drive. Don't do this. Don't do that.' They ought to tell you, you can live'

Both Jackie and Rich spoke about their experiences of others reacting to their rejection of stereotypes. In particular, it appeared that Jackie and Rich were angry that other people appeared to condemn them for wanting to live well with dementia. They felt judged by others and spoke in depth about having to fight to maintain their right to live their life how they wanted.

Jackie: Yeah, it's caused a lot of problems, it's caused a lot of problems when you say it to people cause people are the main carers of people who are umm, at the end stage of their dementia. They say, 'Oh, how can you say that?!' On the rampage. I say, 'It's my dementia so I can say how I want it. It's my life.'

Rich: I'm a man diagnosed and carry on doing things. But some people would condemn me for this... and criticise me for it. But, but why should they do that, d'ya know what I mean? It's like criticising me for the daftest reasons, you know?

Rich: I've said to people before, 'Do you want it? You're judging me. You have it. No, no, you don't want it, d'ya. Why not? Because... so don't criticise me' trying to smile. And I cope with things by laughing and joking because it's in my nature to be like that.

4.2.4 THEME THREE: SADNESS

This superordinate theme captures a more depressive state of mind that participants appeared to experience at times, often underpinned by a sense of loss. During interviews participants spoke about a sense of slowly losing parts of themselves and the subsequent experience of grieving for their past selves. This superordinate theme also captures participant's experiences of isolation, which resulted in feelings of loneliness, as well as their experiences of hopelessness and despair.

4.2.4.1 "I miss me": grieving the past self

All participants spoke about a sense of loss during their interviews. Some conversations related to themes of loss in relation to specific skills such as being able to drive, being able to cook, do the gardening, or use a knife and fork. Moreover, participants spoke about loss in relation to parts of their identity. All five participants had lost their roles in employment. For many this related to a major part of their identity, for example as a nurse, or "the boss". They also experienced a sense of loss in relation to other parts of their identity including their roles within the family.

Mr Vermont: I can't say and think and do things. I was always very sharp and-and bright and things. I didn't have to ask about memory things because I had a really sharp memory and-and things were working and it's, and I used to do so much things, so many things that just norm-that are normal for people but now it's, now I'm abnormal.

C3PO: Mmm. I mean, you know at the end of the day, when I was at work umm, I used to be a [role] and used to stand up and talk to people. But I couldn-couldn't do it now... but that's just the way it's, it gets you.

Jackie: Oh, I miss me when I go dancing 'cause I don't dance any more and things like that.

C3PO: Well it's just that things that I used to be able to do I couldn't do, and it gets bloody frustrated [voice indicates upset].

For participants, discussions about their 'past self' included an element of loss and sadness. Jackie described how she experienced loss in a number of areas of her life, describing this as a bereavement process in which she lost a part of herself.

Jackie: I mean I have, went through the whole bereavement process 'cause obviously I'd to lose a little part of me.

John spoke about his relationship with loss as an important one. He spoke about the loss of his mother following a period during which he cared for her, and the loss of his wife. His mother and his wife were each placed in different residential homes. For John this made the impact of repeatedly losing items around his home on a day-to-day basis even more difficult to manage.

Interviewer: What is that like, misplacing something?

John: It's, it's loss [pause] is quite important to me, whether it's a human or an item. You think once you learn something then don't do it again, but you do.

Rich and Jackie both made attempts to capture parts of their identities through creative means. Rich spoke in depth about recording a music album in which he attempted to capture his life experiences. During the interview Rich played one of his songs and described how it aimed to capture his experiences of being a teenager.

Rich: [plays song] I never wrote until my diagnosis made me think about it, when I was 17 I used to be in a club and on Fridays used to go out clubbing. Well that's what that is.

Jackie, on the other hand, used a diary to capture her everyday experiences. She reflected on how she used the diary to re-visit experiences of her past self.

Jackie: It's an open diary sort of thing so I can look back, 'Oh, I can't remember doing that, but that sounds interesting!' and things like that.

Mr Vermont in particular spoke about the importance of being able to take time to remember his past self. Mr Vermont often listened to old vinyl records that he had kept from his childhood. He listened to The Beatles in particular and reflected on how they transported him to a different time and place, a time during which he was 'right'. He often spent time listening to the lyrics of songs and found that they 'took him back'. Mr Vermont also spent a lot of time speaking about past holidays, and chose to bring a number of photographs to look through during his second interview.

Mr Vermont: ...pop music and I don't know whether it makes, takes me back to the past when I was, when all these things were coming out, when I was right and growing in the right way.



Figure 8. A photograph of a collection of photographs that Mr Vermont presented during his second interview.

4.2.4.2 Isolation and loneliness

All participants spoke about isolation in some sense. For many of them their experience of isolation was the result of overt rejection by those around them. Often this related to being excluded from social groups which they were once a part of, even feeling excluded by members of their family. For some this took the form of not being invited out to social events, whilst others experienced friends or relatives as actively avoiding them. This often left people feeling upset and alone.

Mr Vermont: My son has got no time for me at all. He's not any background, any thoughts er, and my youngest brother: no time for me at all. He doesn't even go, we used to go out for a drink regularly but don't even do that now. Er, and me other brother he, I upset him... regularly (the one I went walking with) but he, he's better most of the time in that way, mm and they've just, and their wives have no time for me at all. They don't want to, don't see us socially and things like that so...

Jackie: Well in the old days they [friends] used to invite me. They would be, 'Oh, we're going out do you fancy coming dancing?' I would say, 'Yeah, okay' But 1) I can't dance because I lose my balance quite quickly and 2) I wouldn't enjoy it so and - I'm used to it now. Um, I don't get, sometimes I do get a little bit hurt if I see on Facebook that they've gone out as a group but it - I would - I suppose but I know that I couldn't go out so therefore I have to say to myself you can't go out because you don't enjoy it so therefore, you know.

Rich: Umm [sighs] so yeah, so people around me: the first thing that happened with my friends disappeared. All my friends disappeared. I lost loads of friends. Just vanished out of my life, 'ughh, got the lurgy,' run away, d'ya know what I mean? And it was, that was hard. That was hard because once I was diagnosed, that's when I became down. That's when I really got down.

The experience of isolation was not always quite so explicit. In some instances participants spoke about feeling isolated even when they were present at a social event. For example, Jackie and John experienced a sense of separation from the rest of their friendship groups as they struggled to follow conversation and respond appropriately.

Jackie: So you can go to the noisy pub and then it's just the noise is so bad and I can't close the noise off anymore to focus on what my friends are saying. I can't understand what they're saying because the noise is too great. But, and then I feel quite isolated as well because they're still talking amongst themselves and not realising that I can't actually hear, know what's going on, and then it's just my brain, it feels like it's going to explode.

John: ...if you're watching television or watching or going somewhere you say 'oh have you been there' and 'oh wasn't that lovely' and talking about simple things like what's on television and [pause] topics of discussion after that first bit of conversation [pause] I dry up.

As a way to manage difficult experiences in social situations, some participants reported that they actively isolated themselves. This allowed them to avoid uncomfortable or difficult situations with others.

John: That's awful, yes, it is because I've no knowledge about what they're talking about and can't inter-react. You see all lads going out into a pub erm and they're laughing and joking and talking about sport and other things and I don't know anything [laughs]

I: How do you manage that in the moment, when you're there?

John: Erm [pause] I'll leave that group and obviously there's some times when you can't but erm find somebody who can talk to.

Mr Vermont: it's the way that people deal with me. It's really bad, really bad... and the way people talk to me and deal with me is er, bad, making it worse in my opinion, yeah. So I just... for people who are not, keep away from it. yeah. Yeah.

Jackie: So I don't have, I don't put myself in that situation anymore. Most friends who know understand don't ask any more so I've lost that a little bit but I haven't, I get enough social-socialisation in a day so and I can please myself but we go out for lunch I try not to go anywhere where it might be too noisy.

John spoke about loneliness and isolation much more extensively than other participants. He reflected on his move to supported accommodation and spoke about wanting to advertise for someone to come and visit him a few days a week. He also spoke about feelings of isolation in relation to his interactions with members of the public. John relayed a number of examples of speaking to people in public situations, for example on the train or in a café. During these interactions he experienced people retreating from the conversation as they sensed that he was different to them in some way. For John, he experienced this as rejection and this was often a very upsetting experience for him. Later on John spoke about going out of his way to try and include people who he felt were unjustly marginalised as he knew first-hand what they must be going through.

John: And people, not even not even talking. Charlotte, it is awful to have that sense where 'woah stay away' a-and th-the [sighs] it's fear.

Interviewer: You think people are scared?

John: Yes.

Interviewer: What of?

John: Human beings that - nobody likes rejection or or fear of – they don't know I've [pause] they don't know how to handle... [wells up]

Feelings of isolation and loneliness also appeared to arise from a sense of participants being alone in their experiences. Many participants spoke about feeling misunderstood by others around them, or not having the words to describe their experiences. In some cases having a diagnosis at a younger age made them feel even more misunderstood and isolated.

C3PO: it's... it's something that you just can't explain [voice emotional] apart from getting a new brain huh! And that won't happen.

Jackie: I've known people who - people who I'm now friends with, who have, who live with dementia umm, and they lost quite a few friends as well. So I think people just don't understand it, how it affects young people.

4.2.4.3 Hopelessness and despair

At times, participants felt a sense of hopelessness or despair in relation to their current situation. They spoke about experiencing days in which things felt extremely difficult and overwhelming, often during times when their awareness of their difficulties was much more pronounced. For example, Mr Vermont experienced periods during which he was more aware of having a 'funny feeling' in his head. During these episodes he would take himself off to bed.

Mr Vermont: The times when I feel erm when it starts to go off and I get this funny feeling in the head or I get a bad feeling in the stomach from this blinkin' IBS its really just – that's really depressing and that's when I just feel like going and lying down in bed and think pfft, really. Definitely [...] really bad. I just, I go to bed. I can't be bothered.

Jackie also experienced days during which things felt upsetting. Again, like Mr Vermont, this often related to her symptoms of dementia become difficult to manage or adjust to.

Jackie: But I have to laugh at it otherwise, otherwise you cry. And then it's all quite upsetting sometimes when you can't get your words out and you can't walk properly and you fall down the stairs and you over, but we, if I fall over with my friends there, we just basically laugh out of it and it's easier that way.

Rich too reflected on days when he became more aware of the difficulties that his dementia brought. At these times he experienced feelings of hopelessness.

Rich: Umm, you know when I see things and I just think 'oh, what's the point' but I think that's just part of it

For others, a sense of hopelessness was experienced as a result of them feeling that they would not see a cure for dementia in their lifetime. Mr Vermont in particular spoke about a feeling of hopelessness due to any cure being *"too late"* to be of benefit to him.

Mr Vermont: They're doing things in other countr-as I said before in other places and they probably will come out with a cure but after I've gone. So it's er, it's too late. That's the er, I think they will come up with a cure for it eventually because they do with everything, don't they, eventually. But it won't be saving my day. So, that's how it goes. Mm.

John underwent a number of assessments prior to his diagnosis, including an MRI scan. Here he describes how he was willing to undertake such assessments in the hope that it would mean he would be able to receive treatment. John then had to face to realisation that his diagnosis had *"no cure"*. John was aware that a cure might be developed, but acknowledged that this would be something that would happen in the future.

John: I took it okay the erm [pause] going through the tunnel [MRI scan] and things like that – no it didn't – because I thought 'oh I'm going to get better' [laughs] and looking into it rather than doing nothing.

I: You thought, if I get a diagnosis of something they can treat it and I can get better?

John: Yes, but I didn't realise there's no cure, but there is going to be in a bit [pause] which is – will be good.

4.2.5 THEME FOUR: CONTENTMENT

This superordinate theme captures participants' experience of contentment. This was often in relation to a sense of being at peace with how things were in the present moment, in contrast to their fears and anxieties relating to the future. It appeared that contentment was not experienced as an end point for participants, but was experienced as a transitory sense of things being 'okay' in the present moment. This theme also reflects participants' experiences of their current self as still able and as having worth. Participants also spoke about feeling that they had developed a better understanding of their current selves and, as a result, felt that they were able to live alongside dementia rather than constantly battle with it. Finally, this theme captured the value that participants placed on living for the moment and appreciating the here and now.

Reflexive Box 6: Harsh realities.

During the research process my best friend's grandmother was diagnosed with dementia. I heard first-hand my best friend's struggles to come to terms with this, her difficulty in accepting the changing family roles and the every-day challenges that her grandma and the rest of the family faced. My curiosity about the possibility of personal growth was somewhat challenged as I began to see the devastating impact that dementia was having on her grandma. I came to feel that to even begin to explore the possibility of positivity in anyway would be both patronising and invalidating for participants. I managed this somewhat by seeing my best friend's grandma's experience as an experience in its own right. I made attempts to bracket these experiences in an attempt to open up each participant to the full spectrum of lived experience.

4.2.5.1 "I haven't changed at all": the preserved self

All of the participants spoke of a sense of preserved self in which they experienced themselves as the same person they had always been. This realisation led participants to consider the things that they were, in fact, still able to do. For many participants this realisation that they were still themselves led to a sense of consolidation of their self-worth. John spoke about his current self as one who was still able to bring joy to others and to make them feel included. He also spoke about he is still able to provide knowledge and useful to others. In one example he spoke about receiving a phone call from his son asking for advice about work related issues.

John: ... and... he says... phones me up for advice [chuckles] even now!

All five participants spoke about still being able to take on valuable and important roles in society, roles which brought them pleasure and purpose. Jackie, was unable to continue working as a nurse after her diagnosis. However, she was able to find new roles that allowed her to live to the values she cherished by continuing to help others , and so make a difference to people's lives.

Jackie: It helps, makes me feel like I've been a nurse again really cause I, the whole reason for being a nurse is you want to help other people in every way you can. Umm, now I feel I'm helping other people but in a different way.

Mr Vermont was retired from working in the car industry, but continued to visit the garage that he once worked at to help out. He spoke about this role as being one that brought him enjoyment, but one in which he was also able to pass his knowledge on to others.

Mr Vermont: I don't work but I do even go into work to help them, I occasionally go in two or three times a week to help them at work.

Others spoke less explicitly about their current or preserved roles, but their preserved identities shone through during interview. For example, C3PO spoke with delight about his role as a grandfather. He spoke about a future holiday with his family and how he would be taking on the responsibility of caring for his grandchildren, allowing his daughter to have some free time.

C3PO: Well, hopefully there'll be er... the waterparks and stuff like that, y'know what I mean? Umm, and then obviously we'll probably be, let them go, the mum, mum and their dad, umm, and we'll probably be babysitting, you know so...

Rich spoke about protecting his family from the difficulties that he has experienced. A massive part of Rich's identity was one of a 'family man', and this identity was one that remained. Rich reflected on his desires to make sure that his family were okay, to ensure they were looked after.

Rich: If I was to sit around being miserable about it and constantly dwelling on it, that wouldn't help anybody; wouldn't help me and it wouldn't help them. So... my priorities at the minute is for me to live well... so that they live well.

Alongside participants feeling contented with their preserved selves, there was also a sense of the importance of that preserved self being able to do things that they had always done. Mr Vermont in particular, placed a high value on experiences that brought him pleasure and that he considered to be "normal". He described a trip to the pub after a long walk with his friend. For Mr Vermont, this was an activity that he had always enjoyed and allowed him to experience continuity of the self.

Mr Vermont: ...it worked out very well and when we got back in the sun and it was lovely sunshine; we sat outside the pub and in [town] and lovely. Just had a pint outside in the sunshine. Really good.

4.2.5.2 Learning to live alongside dementia

Participants appeared to experience a transitory sense of acceptance of their diagnosis in the present moment. They spoke about learning to live alongside dementia as an unwanted, yet tolerable 'other', rather than as a part of their identity.

C3PO: I've come to terms with it... me-self. And I think you've got to have a, have a positive attitude to it, otherwise I think it'll just... take you further and further down. And I've tried to look at it a positive way that I-I've adapted to the things that... umm... I'm doing now that I couldn't do before; and that's what, I think that's all you can do, you know. Yes, I'd like to be like normal, well I say normal, you know... it won't happen so I've got to live with it.

All five participants spoke about developing better self-understanding following their diagnosis. In particular they spoke about increasing their knowledge of their limitations. For many these limitations were new and a journey of discovery through use of trial and error was

undertaken in order to learn how to manage them. Participants spoke about the need to 'adapt' to their dementia, the importance of putting things in place to live well and to be able to live alongside dementia.

For Jackie, adapting meant having a better understanding of her dementia and the way that it impacted on her on a day to day basis. She became more aware of the need to pace herself so that she didn't become exhausted. She made adaptations in her home to reduce the impact that dementia had on her life.

Jackie: I have a checklist on the front door: don't forget your keys; don't forget to close windows, you know that sort of malarkey. Umm, but and I have, I have a key safe outside now as umm... just because in case in emergencies, in case if anybody needs to come in; if I fall over an hurt myself and they can, you know it's easier for people to come in with a key safe.

Both John and C3PO brought objects to the interview to illustrate how they have learnt to adapt to their difficulties. John placed an alarm on his phone so that he could locate it should it be misplaced. This meant that he spent less time searching for his lost phone and less time feeling frustrated as a result of it. C3PO brought along his magnifying glasses that compensated for his vision difficulties. This meant that he was then able to continue reading, an activity he had always enjoyed. He spoke at length about the importance of adapting.



Figure 9. Photographs of items brought to the interview by John (left) and C3PO (right).

Participants developed a better understanding of the things that caused them stress and made attempts to reduce the likelihood of these in their lives. For some participants this

meant avoiding activities or social situations or even certain people who might increase their stress levels.

Rich: Umm, so... so for me, my main, my main ambition now is for me to live as well as possible. And that means to live well, I've got to have no stress. So I have to avoid stress and that's the thing: avoiding stress.

John: I think through [pauses] helping, or being helped with nice positive people and... I don't want to be around negative and that - that can make so much difference...

Mr Vermont: ...yeah, things, things that are right and er, right for me, yes, I do. And I-I I stick with things that are right for me and things that aren't, don't; it's as simple as that.

All five participants also spoke about the experience of being completely immersed in the present moment. This appeared to be an extremely valuable experience for all participants who described it as an important way of creating some distance between themselves and their fears, worries and concerns. They spoke about this in relation to having a better understanding of themselves, and of having a better awareness of the things they could do to enrich their lives.

For Mr Vermont he experienced a sense of being 'right' when he was out walking, driving or doing more physical activities. This allowed him to experience a time during which he was able to forget about his problems.

Mr Vermont: While I'm doing things I can feel 'right', its [pause] it maybe sounds a bit pathetic this but when I'm doing things I feel 'right', I don't feel any problems at all. I don't feel the funny feelings in my head, I don't feel – the memory works as I'm going along.

For John, he placed a high value on the importance of music in his life. This permitted him to have time during which his mind was free and provided him with a sense of accomplishment.

I: Does something feel different when you play music?

John: Accomplishment and notes and [pause] having free mind and nothing on it err it's [sings] 'didn't you know that you hmmmmm hmmmm'...

John also described how, for him, meditation allowed him to reach a state in which he had a free mind. John described himself as an extremely spiritual person. For John, spirituality

and the practice of meditation allowed him to experience a sense of peacefulness and a feeling of acceptance. This experience for John was one that was extremely moving.

John: Just that . . . few moments. It only takes a minute of silence and I'm thinking it's good now so tears of joy are coming [wells up], it somehow works that your day everything flows better because you've just taken that time to think and...



Figure 10. A photograph of John's collection of items that related to his spirituality.

Jackie valued the experience of gardening as a time when her dementia did not seem to exist. She also spoke about the value of spending time with her pet cats. For Jackie, her cats made her laugh every single day and offered a distraction to her worries.

Jackie: When I do my gardening my dementia doesn't really exist because I don't have to think about it.



Figure 11. A photograph taken by Jackie of her garden.

For C3PO, spending time with his family and in particular with his granddaughters allowed him to feel completely distracted from his worries about dementia.

I: How does it help your mood when you're with your granddaughters?

C3PO: Quite, quite good. Because it's like... you don't think about it.

Rich spoke about a number of activities that he was able to become completely immersed in. Rich was a keen drawer when he was younger and had begun to take up drawing again and described it as "a therapy". Rich also found himself immersed in his music and gardening, times in which his dementia doesn't exist.

I: What's therapeutic about drawing for you then?

Rich: 'Cause I just forget everything. I haven't got time to think about anything else. You have to concentrate so hard on this you don't think about anything else. All I'm thinking about is this so while I'm doing this I haven't got dementia. 'Well you've got it now.' When I'm playing my music I haven't got dementia [...] while I'm doing my garden I haven't got dementia because I'm doing my garden.

4.2.5.3 "I appreciate now": making the most of the present

Although participants spoke about the realisation of what the future holds as being fear provoking, there was also a sense of participants experiencing genuine acceptance in which it appeared they were able to find peace with the concept of mortality. This then led participants to want to make the most of now. For John his desire to live in the present moment meant that he was extremely appreciative of what each new day brought.

John: I'm glad... that [pauses] I can't think of the words [sighs] er, I appreciate now. And that, that's all there is and I guess I can't comment or think about what might have been or... in future. I think of today and, wow! [Chuckles]

Mr Vermont spoke a lot about how important it felt to him to do as much as possible while he still could. It was "crucial" to him to fill his life with positive, pleasurable activities. Whilst this included making a lot of plans for the future, such as booking holidays, it also included the importance of spontaneity. Mr Vermont placed a lot of value on his personal freedom and the opportunities that he had to take spontaneous trips.

Mr Vermont: Just every one of the beaches, when you look at the beach ones [photo] it's just great.

Interviewer: What does it mean to you to be able to go out doing those things?

Mr Vermont: Crucial. It's crucial to me, I just – that day I saw the weather forecast in the morning I thought 'that's it', and we'd not planned anything I just said right we'd like to and he loves -[dog]- he loves it.



Figure 12. A photograph of a spontaneous day trip to the coast by Mr Vermont.

Jackie spoke about the value of letting go of the past and trying not to worry too much about the future. Like Mr Vermont, Jackie spoke about the importance of continuing to experience joy and pleasure in the present whenever possible.

Jackie: People always worry about umm, the future. Always. They seem to hang on to that. I say why would you do that because it hasn't happened yet. And that you've to think of all the things you're doing now and things. And the past: it's good to look back into the past but you don't want to remain there.

C3PO described the joy he derived from simple day-to-day activities, such as spending an afternoon at the garden centre or watching his wife tend to the garden. He described a sense of appreciating the present moment, of becoming more aware of his surroundings and allowing himself to become completely absorbed by it.

C3PO: Sometimes I sit out front if it's... a nice day. Er, one, one of days umm, we sat out back didn't we? It were a glorious day M-M-Monday or Tuesday er, and it were so, so nice er, so we both sat ou-out there. Umm, and then er, we've got a like a little umm, water-wheel er, umm, watermill it's called, in't it? [...] but er, it's nice cause it, you hear the water goin-going round and it's sort of like a bit of er, relaxation as well, you know just sat there and you can just hear it going round, you know.

Towards the end of his second interview John offered a poignant reflection that illustrated the importance of living in the present.

Interviewer: What feels important for you right now in your life?

John: To wake up [pauses /sighs] and be here and, and... be happy. [Pauses] Nothing more.

CHAPTER FIVE: DISCUSSION

This study aimed to explore the experience of living with YOD. Data was collected through the use of semi-structured interviews, incorporating the use of additional media through which participants were encouraged to give voice to their experiences. In the following -and final- chapter of this thesis, I will present the main findings of the study in relation to its initial research questions:

- What is it like to live with young onset dementia?
- What is it like to receive an 'off-time' diagnosis?
- Is there possibility for personal growth amongst people with a diagnosis of young onset dementia?

Following IPA analysis, four major themes were identified: 'Fear', 'Anger', 'Sadness', and 'Contentment'. The main findings will first be summarised, followed by attempts to understand these in relation to existing literature and psychological theory. In particular, frameworks to understanding provided by Erikson's (1959) stages of psychosocial development, Janoff-Bulman's (1992) shattered assumptions theory and terror management theory (Greenberg, Pyszczynski, Solomon, 1986) will be drawn upon. The experience of an 'off-time' diagnosis and the occurrence of personal growth will be considered throughout this chapter. A critical appraisal of the current research will then be presented, including its strengths and limitations. Finally, I will consider the clinical implications of the findings and possible areas of future research.

5.1 Main Findings: What is it like to live with young onset dementia?

In the lead up to their diagnosis of dementia, participants were confused and scared by the unusual experiences they were having. They described this as a scary time and one in which they desperately sought answers. Even after their diagnosis, they continued to try and make sense of why they had developed dementia. Participants struggled to make sense of their new identity as people who were considered to be vulnerable. This new sense of vulnerability led participants to feel that the world was a dangerous place and that people had the potential to harm them. In response to these feelings, participants often felt that they had to put on a mask in social situations and maintain a façade as someone who did not appear vulnerable. Participants were scared about what their future might hold. They fantasised

about intolerable futures in which they imagined themselves as incapacitated. For some, these fantasies were so intolerable that they had considered ending their own lives. Participants managed their experience of fear and anxiety through normalising their difficulties, externalising dementia as separate to the self and maintaining a sense of control wherever possible.

Participants experienced anger as a result of feeling that they did not have a voice. They felt that they were silenced by a society in which there is a reluctance to talk openly about dementia or to a person with a diagnosis of dementia. They also spoke about interactions with health professionals during which they felt that they were not heard. Furthermore, they felt angry because they felt that they had been abandoned or neglected by others. They felt frustrated that more was not being done to find a cure for dementia or to support people post diagnosis. Often, participants compared this to the care, funding, and amount of research that is provided for those with cancer. For many, taking part in the current research was a way of 'doing something' to improve services and care. Jackie and Rich also felt angry that they were stereotyped by others. They felt extremely frustrated that others expected that they should behave in certain ways in order that they conform to out-dated 'dementia patient' stereotypes. They also felt angry that others wanted to condemn them for living well with dementia.

As well as experiencing fear and anger, participants also reflected on a more depressive state of mind that was often underpinned by feelings of loss. This included loss of objects, memories, roles, and parts of their identities. At times participants experienced a sense of grief in relation to their past selves, this led them to reminisce about times before they received their diagnosis. They also experienced sadness in relation to feelings of isolation and loneliness. They experienced loss of friends and family post-diagnosis as people began to exclude them from social events or actively avoid them. Participants even experienced isolation in social situations when they could not follow conversation or did not feel able to contribute. Some participants even chose to isolate themselves as it felt easier than facing difficult social interactions. Isolation was also experienced as a result of participants feeling alone with their experiences and misunderstood by those around them. At times, they also felt a sense of hopelessness and despair as their experiences of dementia became overwhelming.

Participants experienced contentment, often relating to sense of being at peace with the present moment. They spoke about how they were still able to be themselves in the present, this included their abilities to fulfil roles and feel that they had worth in society. They

experienced a sense of acceptance in relation to their diagnosis and subsequently learnt new ways to adapt and manage their difficulties so as to better live alongside dementia. This included finding activities that permitted them to become fully-absorbed in the present. This sense of acceptance that participants spoke about brought with it a desire to make the most of the here and now and a genuine appreciation of the present moment.

The findings from the current research offer insight into the experiences of people living with YOD. This research approach allowed participants to bring along anything that helped them to talk about their experiences of living with YOD. When participants were permitted to be creative in their means of sharing experience this opened up avenues of conversation that felt deeper, richer, and more meaningful.

The results of this study have highlighted the role of 'fear' in those living with YOD, and in particular highlighted experiences of vulnerability that those living with YOD have, by their own admission, been reluctant to discuss at length with others. These findings highlight the uniqueness of the current research in that the experience of vulnerability has not been highlighted by any previous studies exploring the lived experience of those with a diagnosis YOD (e.g. Greenwood & Smith, 2016). There is no evidence to suggest that those with a diagnosis of YOD have previously spoken about their sense of vulnerability around others, their views of the world as being dangerous, and the need to 'put on a mask' in social situations.

In addition, the findings here are unique in that they suggest that those with a diagnosis of YOD are angry; an experience that may be understood in the context of recent empowerment movements in relation to dementia. As with the experience of vulnerability, it appears that no previous research has highlighted such experiences. Furthermore, the findings highlight the transitory nature of experience in those living with young onset dementia, and reflect a continuous process of meaning making and coping. This suggests that the current research adds new and unique insights into our understanding of what it is like to live with YOD.

5.1.1 'Fear'

This super-ordinate theme captured participants' experiences of fear in the lead up to their diagnosis, feelings of vulnerability and fears about what the future might look like. Existing literature and psychological theory will be explored as a means of making sense of participants' experiences.

As highlighted in chapter one, Erikson (1959) proposed that human beings are faced with a series of crises throughout their lives. It is also proposed that there are critical periods when

specific issues may become more central (Whitbourne, 2008) and during which individuals may face multiple crises simultaneously. Existing literature suggests that it is common for people faced with a life-limiting diagnosis to move through a number of Erikson's adult stages of development (Merriam, Courtenay, & Reeves, 1997). The findings of the current study suggest that participants' experienced a number of Erikson's crises following their diagnosis, including those associated with much earlier psychosocial stages.

The crisis of trust versus mistrust for example is expected to occur initially from birth to eighteen months of age and is considered one of the most vital. Successful transition through this stage sees individuals develop strong and stable attachments to others and come to see the world as consistent and predictable. Participants in this study spoke about their fears in relation to feelings of vulnerability and being hurt by others or being taken advantage of or exploited. These experiences suggest that participants' diagnoses led them to question whether they could trust others or not, a question that Erikson considered particularly relevant to this early stage of development. Indeed, it is possible that many participants had not experienced such powerful feelings of vulnerability since their early childhood.

Furthermore, participants' fears in relation to their current experiences as well as their fears of the future could be seen to relate to Erikson's second psychosocial stage; that of autonomy versus shame. Erikson proposed that during this stage (associated primarily with infancy) we come to develop autonomy, control and self-assertion. Difficulties in transitioning through this stage may result in experiences of shame and self-doubt. Participants in this study experienced doubts in relation to their degree of autonomy and control in relation to their current situation. They expressed feelings of embarrassment when they were unable to cover up their cognitive problems in front of others. In particular, participants' fears in relation to the future related largely to anxieties surrounding fantasies of being without autonomy. Participants feared that they would become dependent on others or would need to be taken in to care; bringing with it feelings of shame and fear.

An additional way of making sense of participants' experiences of fear comes from Janoff-Bulman (1992) who proposed that, as human beings, we hold some basic assumptions about the world that allows us to function and see our existence as meaningful. These assumptions include:

- The world as benevolent;
- The world as meaningful;
- The world as predictable;
- The assumption of invulnerability;

- The self as worthy.

Janoff-Bulman proposed that these assumptions are shattered during times of trauma or adversity, for example bereavement, as our psychological equanimity is disrupted. We then come to experience the world as malevolent, meaningless, unpredictable, and thus experience ourselves as vulnerable and unworthy in some way. This theory, known as the shattered assumptions theory, is interesting in that it shares a number of parallels with the experiences of participants in the current research. Although this theory was originally developed to help make sense of trauma responses, it appears that participants in the current study did experience a sense of disruption to psychological equanimity following their diagnosis. They then came to see the world as a dangerous place in which they could be hurt and they experienced feelings of despair (some considering ending their own lives). They came to see the world, in particular their future, as unpredictable. They experienced a sense of vulnerability and periods of low self-worth.

Shattered assumptions theory has since been criticised for its overgeneralisation of complex responses to trauma (see Mills, 2010) but its underlying concept has gone on to inform further theoretical understandings of how we experience the world following a challenging or disruptive experience. One such theory is that of Terror Management Theory (TMT, Greenberg, Pyszczynski, Solomon, 1986), an approach underpinned heavily by existentialism. Existential thought proposes that there are five essential realities:

- That death is both inevitable and final;
- That achievement of independence and autonomy is limited and temporary;
- That life is essentially meaningless;
- That each of us is inevitably alone;
- That our identity as unique, valued individuals is a construct we impose on the world (Cheston, 2012).

TMT proposes that we seek ways to manage our awareness of these essential realities; particularly when we are faced with reminders of mortality. Cheston (2012) proposed that TMT is a way of understanding the existential threat encountered by those with a diagnosis of dementia who are faced with constant reminders of their own mortality.

Participants appeared to manage their experiences of fear and anxiety in response to existential threat in a number of ways. For example, they appeared to fluctuate between feeling too young for dementia and normalising their experiences by identifying as older; this is consistent with findings from previous research with those with a diagnosis of YOD such as in Clemerson, Walsh, and Isaac's (2013) study. Gillies (2000) also highlighted how older adults

with dementia are more likely to implement normalising strategies, for example attributing declining memory function to a natural process of ageing. It appeared that participants who were in their sixties in this study were more prone to normalising as a means of managing fear and anxiety, whereas the two younger participants were less likely to do so, showing the particular issues of coping with off-time diagnosis of dementia.

Participants further managed their anxieties through protecting themselves from vulnerability and threat from others. They put on a mask around others in order to shield themselves from harm, actively avoided reading anything about dementia, or turned to spirituality as a means of maintain a positive attitude. All of these responses to fear and anxiety could be understood in terms of terror management theory in the face of constant reminders of one's own mortality.

Most strikingly, some participants responded to a sense of existential threat by considering ending their own lives. Studies that have explored the relationship between dementia and rates of suicide have highlighted a number of risk factors, one of which was receiving a diagnosis at a younger age (Haw, Harwood, Hawton, 2009). Furthermore, it has been suggested that risk of suicide is considered to be highest immediately following diagnosis (Draper, Peisah, Snowden, & Brodaty, 2010), a finding that shares parallels with experiences of participants in this study who spoke of considering ending their lives shortly after receiving their diagnosis.

Literature around the wish to hasten death in those with a diagnosis of a terminal nature may offer some insight into the reasons for those with a diagnosis of dementia considering suicide. In a study by Kelly, Burnett, Pelusi, and Badger (2003) a wish to hasten death amongst those with a diagnosis of terminal cancer was associated with perceptions of being a burden on others. Participants in the current study spoke about their fears of becoming a burden on their families, in particular their spouses.

In addition, terminally ill cancer patients with a wish to hasten death in Kelly et al.'s (2003) study spoke of further fears in relation to their futures. As well as perceiving that they would be a burden to others, they feared a loss of independence and freedom. Ultimately, it appeared that individuals feared more than anything an intolerable future in which they did not have control.

Draper et al. (2010) suggested that for some, "the lived experience of dementia differs from the imagined experience" (p.77). The study of phenomenology suggests that experience is a result of an individual's given context. As such, for participants in this study, their experiences of people with dementia and people at the end of their lives greatly influenced

their lived experience and their fantasies about what it meant to live with dementia. Participants spoke about vivid and intolerable fantasies of their future selves, often imagining their worst-case scenarios. It appeared that, following their diagnosis, participants' fantasies regarding their future selves became so overwhelming that suicide was considered as a means of managing such experiences. However, it appeared that as participants spent more time processing their diagnosis they became more able to tolerate fantasies of the future or manage these fantasies through aforementioned 'terror management' strategies.

5.1.2 'Anger'

This super-ordinate theme captured participants' experiences of being silenced and having no voice, anger that more was not being done for those with dementia and a rejection of stereotyping of people with dementia.

A psychological interpretation of participants' experience of anger in relation to being silenced and being stereotyped may relate to issues around identity. Arguably one of the most fundamental of Erikson's psychosocial stages, the phase of identity versus role confusion concerns itself with the establishment of a consistent sense of identity. Previous research has highlighted the unique impact that a diagnosis of dementia can have on a younger person's identity (Caddell & Clare, 2011; Hawkins, 2004), this seems to be consistent with the current findings. In particular participants in this study spoke about the challenges they faced in terms of losing parts of the self, or experiencing the future self as uncertain. It is possible then that anger in response to being silenced and stereotyped emerged as resistance and rejection of further threat to one's identity.

The current context should also be considered in that recent movements have seen the voice of those with dementia become much louder over recent years. For example, recent World Health Organisation (WHO, 2017) initiatives have seen emphasis being placed on rights-based approaches to dementia care. In addition, organisations such as the Dementia Engagement and Empowerment Project (DEEP) have emerged that aim to bring together those with dementia in order to support them in bringing about change to services and policies. In a recent presentation at the University of York (04th April 2017) Kate Gridley and Nava Savitch stated:

“Recently, people with dementia themselves have started speaking up through groups like DEEP (the Dementia Engagement and Empowerment Project) and demonstrating that, far from being hard to reach, many people with dementia want to be heard.”

It appears that those with dementia are finally being permitted to have a voice; bringing with it a sense of anger following years of being silenced.

Social identity theory (Tajfel & Turner, 1979) proposes that a large part of our self-identity is formed through identification with others and group membership. Such identification can lead to a 'them' versus 'us' bias in which in-group identification is favoured over those considered to be out-group members. It is of interest that three of the five participants in this study made explicit reference to 'people with cancer' in relation to the type of support they receive in terms of research funding and treatment as well as the general openness to discuss cancer in society as a whole.

It should be noted that the biggest discrepancy between participants' experiences appeared to be related to the experience of anger. It appeared that the two younger participants were much more likely to speak about feelings of anger and frustration in relation to issues of identity in comparison to the three older participants. It is possible that these individual differences reflect variances in cohort identity, with younger participants having developed a sense of self during the 1970s and 1980s; a period of great social movements and activism. In comparison, the three older participants may be more likely to identify with the 'baby boomer' generation; the first generation to live under a free National Health Service (NHS), perhaps resulting in them being more tolerant of feeling 'silenced' by means of a sense of gratitude.

5.1.3 'Sadness'

This superordinate theme captured participants' experiences of grieving for a lost self, isolation, hopelessness and despair.

In his understanding of existential phenomenology Sartre (1943/1956, as cited in Smith et al., 2009) theorised that "things that are absent are as important as those that are present in defining who we are and how we see the world" (p.19). Participants spoke about their experience of loss in great depth; loss in relation to parts of the self, memories, everyday items, and loss in relation to others, absent friends and family. It is possible that these experiences triggered grief responses in participants during which feelings of despair and depression became more prominent.

Erikson's stages again offer a useful framework from which to understand participant's experiences in relation to the super-ordinate theme of 'sadness'. In Erikson's final psychosocial stage, that of late adulthood, individuals may be found asking themselves the deeply

existential question: is it okay to have been me? Successful transition through this stage results in a sense of ego integrity, in which individuals experience contentment with “who they had been and who they had become” (Merriam, Courtenay, & Reeves, 1997, p.299). However, in the face of an existential threat participants’ experiences of a more depressive state of mind may be understood in the context of ego despair. It is suggested that ego despair brings with it “agonized concern in the shadow of impending death over unrealized goals and unfulfilled potentials, sometimes expressed in disgust at life and other people” (Stevens, 2008, p.54). Participants in the current study did indeed speak of a sense of the awareness of time and unachieved goals.

Erikson (1963, as cited in Stevens, 2008) proposed that ‘fear of death’ compromises one’s ability to develop ego integrity. As such, participants’ experiences of fear may have resulted in difficulty in the resolution of this psychosocial stage, culminating in repeated experiences of hopelessness and despair.

5.1.4 ‘Contentment’

The super-ordinate theme of contentment captured participant’s experiences of a preserved self, a sense of learning to live alongside dementia and a focus and appreciation of the here and now. Again, this theme will be explored in relation to existing literature and psychological theory.

The experience of contentment may reflect participants’ experiences of a transitory sense of ego integrity; a reflection and acceptance of both negative and positive attributes of one’s life with a sense of acceptance in relation to one’s own mortality. Participants spoke of a sense of contentment in relation to who they were at that given moment. Furthermore, the experience of contentment could also be understood in the context of Erikson’s seventh stage, that of generativity versus stagnation. This stage relates to “concern in establishing and guiding the next generation” (Stevens, 2008, p.53). Participants in this study spoke about realising their preserved abilities to fulfil roles and feel that they had worth in society.

One of the experiences that participants spoke enthusiastically about related to the value of a time in which dementia did not exist and during which they became fully immersed in the present moment. It is possible that the experience that participants came to value as important to them could be understood in the context of a state of ‘flow’. Carr (2004) states that “flow experiences occur when we become engaged in controllable but challenging tasks or activities that require considerable skill and which are intrinsically motivating” (p.58). The experience of flow is considered to include the following:

- Intense and focused concentration on the present moment;
- Merging of action and awareness;
- A loss of reflective self-consciousness;
- A sense of personal control or agency over the situation or activity;
- A distortion of temporal experience;
- Experience of the activity as intrinsically rewarding.

For participants the ability to maintain concentration on the present moment and reduce self-consciousness meant that they were able to experience time away from their fears and anxieties about the future. In addition, being able to 'do' and experience a sense of agency was something that participants found rewarding.

In Baltes and Baltes' (1990) model of selective optimisation and compensation it is hypothesised that 'successful' ageing is a result of purposely optimising skills and abilities that remain and compensating for those that are lost. It is possible that this model aids in understanding participants experiences of learning to 'live alongside' dementia. All five participants spoke at length about the strategies they utilised in order to manage the challenges that they faced each day.

It is in participants' experiences of contentment that the possibility of personal growth may be considered. As mentioned in chapter one, Heffernon, Greal, and Mutrie (2009) conducted a systematic review of qualitative literature exploring the experience of post-traumatic growth following physical illness or traumatic events. One of the themes that emerged was 'trauma equals the development of self' within which participants spoke of the development of a 'better self' through spiritual, emotional or psychological transformation. Again, these findings may parallel participants' experiences of 'living alongside' dementia in which they spoke of developing a better understanding of themselves, their limitations but also their abilities and worth.

A systematic review and synthesis of qualitative literature was published during the development of the current research (Wolverson, Clarke, & Moniz-Cook, 2016), reviewing studies in which the subjective experience of older people with dementia contained experiences of positive states, experiences or attributes. Unfortunately, the authors specifically excluded studies that exclusively related to those with young onset dementia; however they did identify a number of significant experiences that could be seen to match those of the current participants.

A total of twenty seven qualitative studies were analysed using thematic synthesis that produced three super-ordinate themes: 'Engaging with life in ageing', 'Engaging with

dementia' and 'Identity and growth'. Many of the findings suggested that people are living positively *despite* dementia, through 'facing it, fighting it', a finding concurrent with the current study in which participants spoke of 'living alongside' their dementia. In addition, results from Wolverson, Clarke, and Moniz-Cook's (2016) review suggested that people with dementia experience a sense of self-worth through the realisation of a preserved sense of self, again strikingly similar to the theme of "I haven't changed at all" in the current study in which participants' were able to experience contentment.

5.2 Considering Participants' Experience as a Whole

In the current study participants spoke of their experiences of fear, anger, sadness and contentment. These experiences appeared to be transitory with participants fluctuating between them both between and within interviews. One possible way of making sense of these experiences is to consider dementia as a diagnosis that challenges individuals in ways that echo the challenges faced at numerous life stages. As such, it could be considered that individuals are facing repeated challenges, as in Erikson's psychosocial stages of development, that threaten their ability to trust others and feel safe in the world as well as their ability to maintain autonomy, initiative, a consistent sense of self, intimacy, generativity and ego integrity. A sense of resolution of any one of these stages appears to bring with it a sense of contentment, growth, and development that is quickly replaced by fear, anger or sadness when a further challenge presents itself. There did not appear to be any resolution per se of Erikson's stages as participants were faced with constant and repeated challenges to psychological equanimity.

Psychological models of bereavement also offer a framework with which to tentatively understand participants' experiences as a whole. For example, in Kubler-Ross's (1969) stages of grief, individuals are proposed to transition between five emotional responses: denial, anger, bargaining, depression and acceptance. Kubler-Ross does not hypothesise that these stages are linear, instead that people move between stages during their own unique, individual journey through which they are processing and making sense of their experiences.

The dual process model of coping (Stroebe & Schut, 1999) provides an additional framework from which to make sense of experiences of bereavement. This model proposes that individuals frequently oscillate between loss-orientated and restoration-orientated means of coping (see Figure 13). Loss-orientated refers here to "concentration on, and dealing with, processing some aspect of the loss experience itself" (p. 212), this type of coping often incorporates emotional reactions such as pleasure from reminiscence to more painful

emotional experiences such as despair. On the other hand, restoration-orientated refers to a focus on “what needs to be dealt with” (p.214), including a range of behavioural responses. It also incorporates emotional responses such as pride, but also anxiety and fear in the face of difficult challenges. Participants in the study could be considered to be implementing both approaches to coping with their diagnosis of dementia. The most important aspect of this model is that of ‘oscillation’; a phenomena that appeared to be ongoing for all five participants.

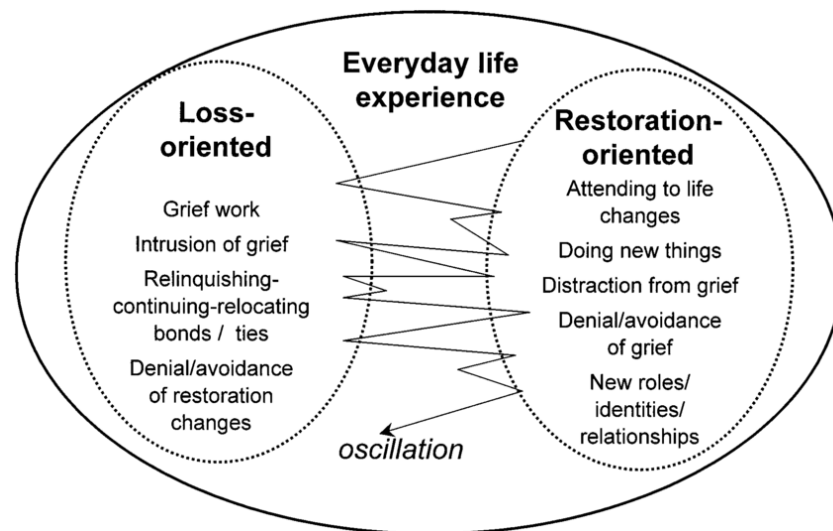


Figure 13. A dual process model of coping with bereavement (Stroebe & Schut, 1999).

Models of bereavement were first developed in order to understand individual reactions to the loss of a loved one, but later incorporated loss in others ways. The participants in this study experienced loss in numerous domains. In addition, it is important to note that dementia itself is a relatively unique experience in that there is a continual shift in sense of self as well as ability to cognitively process and make sense of information. As such, participants appeared to experience repeated losses, perhaps explaining why they did not reach a ‘final’ constant state of acceptance that we might expect to see in some sense-making models.

It is also important to consider the individual experience of participants in line with IPA’s idiographic stance and emphasis on the unique lived experience of the individual. It is highly likely that participants in this study were at various stages of processing and making sense of their diagnosis. In addition, each participant faced their own unique challenges following their diagnosis and each had a varying degree of resources with which to cope.

5.3 Strengths and Limitations

5.3.1 Recruitment and sample

Participants were initially recruited through a single NHS YPWD team. As such, this restricted the sample of participants who were approached. In addition, team members tended to approach individuals whom they felt could 'cope' with taking part in a research interview, which may have excluded individuals who may have had different experiences to those in the current sample. Team members may have also been more likely to approach individuals, with whom they had a good rapport, further restricting the sample. As the research progressed recruitment expanded to include participants who responded to advertisements on the Young Dementia UK website. This enabled recruitment to encompass a much wider geographical area as well as individuals who were not necessarily receiving care from the same NHS services.

Participants from both the NHS and YDUK pathways chose to take part in the research independently. Participants were not rewarded financially for their participation. As such, it should be considered that the individuals who did come forward to take part in the study may reflect a specific group of individuals who, for some reason, saw a benefit in taking part in research interviews. For example, for some this may have been a way of having a forum within which to talk about their experiences, or to advocate for others. The recruitment pathway may thus have excluded those for whom speaking about their experiences did not feel as important or individuals who did not feel ready or willing to talk. As such, it is possible that the sample in the current study included individuals who were more reflective and open to discussing their experiences than may be typical.

The current study was open to include participants of any age so long as they had received a diagnosis of dementia when they were under sixty-five. Although this approach aspired to be inclusive of anyone with a diagnosis of YOD, the resulting sample comprised a wide age range: from forty-seven to sixty-five. This meant that there was an eighteen year age difference between participants, resulting in a less homogenous sample. Ultimately this led the sample to include two separate age groups which may mean that the findings reflect the experiences of two separate cohorts.

Without a doubt, the ethnic diversity in the sample was limited. The results therefore are more likely to reflect the experiences of specific cultural and ethnic demographic, those of White British origin. In addition, four of the five participants were male and so findings may be more heavily weighted to reflect the male experience of living with dementia. Further research gathering a female sample may therefore be valuable.

Reflexive Box 7: Pain, guilt and reparation.

During the research process I was allocated to a clinical placement within an older adult's service. One of my roles there was to conduct neuropsychological assessments for the memory service, this included feeding back the results to patients and their families. I have a vivid memory of having to feedback a diagnosis of dementia to a gentleman and his wife. I spent many hours preparing what I would say, how I would say it, how I could buffer the impact to avoid upsetting or distressing them. This was something that I later came to see as important to remain aware of during interviews as I found myself tending to avoid more difficult conversations for fear of upsetting participants.

None-the-less I found myself falling into the pattern of avoiding difficult and, what I felt might be painful, conversations. One example came from Mr Vermont's first interview in which I found that I had actively avoided asking questions in relation to his fears of the future. Following supervision I was able to identify this and developed a 'things I wish I had asked' list. Fortunately, Mr Vermont chose to take part in a second interview and I was able to push myself to tentatively ask about the future.

During his second interview Mr Vermont asked a number of questions such as "how long do I have left?" and "why isn't more being done for me?". Not being in a position to answer such questions led to further feelings of guilt that I could not offer any comfort or certainty. Adding to this was my guilt as someone who was a part of the service that Mr Vermont was angry and frustrated at. Klein (1937) suggested that we, feeling that we have caused pain to another, in turn experience feelings of guilt. As a way of managing such feelings we then seek to repair. In this second interview with Mr Vermont I noted how, at times, I sought to repair the pain that I felt had been caused. For example, when Mr Vermont spoke about not being told about research or support groups following his diagnosis, I immediately signposted him to the back of his PIS on which a number of websites could be found.

It is possible that my fear of causing pain for my participants may have led to me shutting down certain areas of discussion and exploration. As a result, the findings within the study may not truly reflect the entire lived experience of the participants.

5.3.2 Interviews

Participants were given the option of being interviewed alone or being interviewed with another person present. The rationale for this decision was to ensure that participants felt comfortable, safe and supported during their interviews. Two participants chose to be interviewed with their wives present. At the request of the NHS REC both participants and their chosen support person were briefed prior to the commencement of interviews. They were reminded that I was interested in exploring the participant's experiences, as opposed to the supporting person's experiences. Nonetheless, the dyadic interview set-up brought along its own limitations. For example, a number of conversations may have been shut down by the others present during the interview, as when upsetting topics were closed down by a partner offering reassurance.

In addition, those in dyadic interviews regularly referred to a sense of a shared experience as opposed to their individual lived experience, using the word 'we' and referring to joint experiences. Attempts were made on such occasions to bring the focus back on to the individual but there was a tendency in both cases for shared experiences to be reflected on. It is possible that these experiences would have been spoken about regardless of the presence of their wives; both Mr Vermont and C3PO had been married to their wives for a significant portion of their lives and many of the experiences they spoke about were shared. Indeed, their very request to have their wives present during their interviews may have reflected a type of shared identity.

One of the strengths of the current study was its flexibility to offer participants multiple interviews, at their discretion, in addition to a more informal 'first contact' prior to any data collection. It is felt that this allowed the development of rapport prior to interviews, perhaps allowing participants to feel more comfortable in the context of a research interview which would allow for more open and honest conversations. Two participants also chose to take part in a second interview and the richness of conversation during these interviews felt subjectively more apparent.

5.3.3 Analysis

During the analysis stage I was able to immerse myself more thoroughly in the data through utilising participants' photographs, music and poetry as a means of adding context to raw verbal data. This approach permitted me to more holistically consider the given context of each participant. In addition, attempts were made to maintain conscious awareness of the hermeneutic circle and the impact this may have had throughout the research process but in

particular during stages in which interpretation played a key role. As mentioned in chapter three, steps to ensure data quality were considered throughout the research process in line with Elliot et al.'s (1999) evolving guidelines for qualitative research. Attempts were made throughout to own my perspective and these attempts were presented to the reader through the use of Reflexive Boxes. In addition, the sample was situated with the provision of contextual data and attempts were made to ground raw data in examples to allow the reader to better understand the development of themes and “conceptualize possible alternative meanings and understandings” (Elliot, Fischer, & Rennie, 1999, p.222).

Furthermore, attempts were made to provide credibility checks throughout. Research supervision offered checks through the discussion of anonymised transcripts and emerging themes. Supervisors were able to offer alternative perspectives on the emergent themes. Attempts were also made to promote transparency in relation to the analytic process with an example transcript provided to the reader in Appendix 15.

Elliot et al. (1999) suggest that checking understandings of the data with the original informants is an example of good practice. As such, data quality could have been improved through a feedback session with participants to ensure that themes developed truly matched participants' experiences, thus increasing the validity of the current findings.

5.3.4 Power and collaboration

This research was one of few studies that have explored people with dementia's experiences directly. As such, it aimed to give voice to participants and allow their experiences to be heard. Attempts were made throughout the research to minimise power differentials to encourage collaboration. For example, participants were given choice about when interviews would take place, where they should take place, how many interviews they wanted and how long for. Through the use of a semi-structured interview participants were permitted to lead the conversation into areas that felt important to them. They were also invited to talk about their story in the best way for them. For some this included using photographs to illustrate their experiences, bringing objects from around their home or sharing music, poetry and artwork. Collaboration during the research design stage was also part of the study, through consultation from Wendy Mitchell, a lady living with YOD, and service user groups.

Despite efforts to create relationships in which there was a shared sense of power, there is no doubt that as a researcher I remained in a powerful position. I held the power to make a decision about each participant's mental capacity and was in a position to terminate interviews where I felt appropriate. I also entered each participant's interview with an agenda

in the form of my interview questions, which, despite attempts to be as participant led as possible, may have shut down and silenced participants at times. Participants were also silenced in that they were not able to use their own names in the research and were not able to present images that might compromise anonymity. Although these measures were in place to protect participants there is no denying that this took away a degree of participant autonomy and choice.

5.4 Clinical Implications

5.4.1 Approaches to dementia care

The British Psychological Society's (BPS) guidelines in relation to psychosocial interventions in the early stages of dementia (2014) highlight a variety of approaches to dementia care. Many of these approaches could be beneficial to enable participants in the current research to manage their experiences. For example, advanced care planning in order to manage anxieties around the future, the use of creative art therapies, music therapies, life story work, and reminiscence therapy. However, BPS guidelines do not explicitly advocate the use of more third-wave based approaches that the current findings indicate may be beneficial. For example, the use of mindfulness and encouragement of present-moment mindedness may help those with a diagnosis of dementia maintain a focus on the current moment. Indeed, early research into the use of mindfulness with people with dementia has shown some promising results (Chan et al., 2017). In addition, the use of third-wave therapeutic approaches such as Acceptance and Commitment Therapy with its focus on radical yet empathetic acceptance of current circumstance and a commitment to action where possible, may be indicated. The use of Compassion Focused Therapy may also be beneficial in supporting those with a diagnosis of dementia to develop their soothing system and manage experiences of threat and fear.

5.4.2 Increasing awareness and beginning conversations

Participants spoke about their experiences of fear and confusion in the lead up to their diagnosis followed by difficulties in making sense of their diagnosis as a younger person. Participants went on to feel isolated and alone as a result of a general lack of understanding of YOD and a reluctance to talk openly about it. It would be beneficial for the awareness of YOD to be increased in the general public. It is encouraging to see numerous movements and advocates of those with dementia beginning conversations in public domains, through social media and concepts such as 'Dementia Friends', an Alzheimer's Society initiative that

encourages people to learn “a little bit more about what it's like to live with dementia and then turn that understanding into action” (Alzheimer’s Society, 2017). All five participants also spoke about their experiences of numerous referrals and lack of awareness of YOD amongst health professionals and in particular amongst GPs. Many participants felt that their GPs were unaware of the existence of YOD or were reluctant to consider it as an option. In this case training for front-line health professionals is imperative to ensure that diagnosis is not overlooked and that those seeking support are heard and their concerns are acknowledged. Through increasing awareness in these ways it is hoped that individuals would feel less alone with their experiences, may find making sense of their diagnosis easier to process, and may feel comfortable in beginning more difficult conversations.

5.5 Conclusion

This research aimed to explore the experience of living with YOD. The findings indicated that participants experienced feelings of fear and vulnerability in response to their diagnosis. It found that people living with YOD are angry and are beginning to find a shared identity and voice through which to be heard. The findings also suggested that participants experienced contentment at times as a result of a sense of preserved self and an ability to live in the moment and make the most of the here and now. These experiences could be understood in the context of the concept of personal growth. This research highlighted the transitory nature of participants’ psychological experiences as a result of multiple and repeated challenges to their equanimity. It suggested that participants’ overall experience could best be understood in the context of models of lifespan development, bereavement and grief. The findings highlighted the importance of approaches to dementia care that focus on developing present-mindedness, acceptance and compassion. It also highlighted the need for society to become more open to discussing dementia and allowing people to be heard.

5.6 Future Research

Although the current research findings highlighted experiences related to the concept of personal growth, the method of data collection did not allow for more direct explicit questioning in relation to this construct. This study aimed to explore the full spectrum of lived experience, but future research directly investigating the construct of personal growth may highlight experiences that were overlooked or not explored in as much depth here. In addition, the findings of the current study, at times, appeared to reflect the experiences of two distinct

cohorts. Future research may wish to explore the experiences of a more closely defined age-range of participants to allow for a more homogenous sample.

In line with issues of empowerment, collaboration and giving voice to those with dementia, future research may wish to be much more inclusive of those with a diagnosis of YOD throughout the research process. This may include increased consultation or co-supervision of future research projects by those living with young onset dementia. Future research may also involve developing research aims more collaboratively with people living with dementia, in order to ensure that research is meaningful and explores relevant and important experiences.

This study excluded those who were deemed not to have capacity to consent and so reflected only the experiences of those in relatively early stages of dementia. Future research may wish to consider exploring the experiences of those who may be in later stages of dementia. Issues of capacity may be managed through working with individuals who have completed advanced directives that stipulate their preference to be involved in research. Future research with this group may need to consider more creative and accessible means of involvement, but should not see the challenge of working with this participant group as a reason to exclude and silence their experience.

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LIST OF APPENDICES

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Appendix 2. NHS REC Favourable Opinion Letter.

Appendix 3. Supporting letter from YDUK.

Appendix 4. NHS REC Favourable Opinion Letter following Substantial Amendment 1

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Appendix 6. NHS Participant Information Sheet.

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Appendix 15. Example of Analysed Transcript.

Interview Schedule

Introduction

If participant brings along a person for support:

[To participant] You have brought [support person's name] along today to support you today, which is great. What we need to remember that it's your experiences that I am interested in hearing about today.

[To support person] Thank you for coming along to support [name of participant] today. As you will know, I will not be recruiting you into the study, and will not be asking you questions about yourself. If [name of participant] asks you to join in, please feel free to do so, and we will return to [name of participant]'s answers as soon as possible.

The study is about your experiences of living with young onset dementia. I've got few questions that I'd like to ask you, but I really want to hear about your experiences so feel free to talk about anything that feels important. Remember that you don't have to talk about anything you don't want to talk about, and we can stop or take a break whenever you like.

Questions

1. First of all it might be useful if you could tell me about when you first started noticing [memory] changes?
What changes did you notice? Did others notice any changes? What processes/services did you go through? What was that like? Who did you meet?
2. Could you tell me about receiving the diagnosis?
How did you feel when you were told? What did you think? What did you do? Do you think anything would be different if you were older?
3. How have those around you responded to your diagnosis?
How do people feel? What have people said?

4. Can you tell me about any changes that have happened in your life since you received your diagnosis?
What do you do that's different now? Do you feel differently about anything? Do you think differently about anything? Have your perspectives/outlooks/opinions of anything changed? How do you feel in yourself?

5. What's life like now?
What are your priorities right now? What feels important to you at the moment?

6. Is there anything important that you think we haven't talked about?

Media

- Tell me about this [X]....
- What does this [X] mean to you?
- How do you feel when you look at this [X]?

Prompts

Can you tell me a bit more about that?

How have you made sense of that?

How did that happen?

How did you feel when that happened?

What do you mean by [participant comment]?

Do you have a particular examples of [participant comment]?

Reflection

Is there anything that you wanted to talk about from our last meeting?



Health Research Authority

Yorkshire & The Humber - South Yorkshire Research Ethics Committee

Room 001
Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0207 104 8081

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

26 October 2016

Miss Charlotte Berry
Trainee Clinical Psychologist
The Leeds Teaching Hospitals NHS Trust
Clinical Psychology Training Programme
2.07 Charles Thackrah Building, University of Leeds
101 Clarendon Road
LS2 9LJ

Dear Miss Berry

Study title: Exploring the Experience of Living with Young Onset Dementia
REC reference: 16/YH/0389
IRAS project ID: 198498

Thank you for your letter of 18th October, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Katy Cassidy, nrescommittee.yorkandhumber-southyorks@nhs.net.

Appendix 2.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

Appendix 2.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Invitation_YDUK_V1]	1	26 July 2016
Copies of advertisement materials for research participants [Invitation_NHS_V1]	1	26 July 2016
Covering letter on headed paper [Cover_Letter_V1]	1	18 October 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Supporting_Letter_YDUK_V1]	1	26 July 2016
Interview schedules or topic guides for participants [Interview_Schedule_V2]	2	11 October 2016
IRAS Application Form [IRAS_Form_19082016]		19 August 2016
IRAS Checklist XML [Checklist_18102016]		18 October 2016
Letter from sponsor [University_Sponsorship_Confirmation_V1]	1	26 July 2016
Other [Info_Letter_DClinPsy_Research_V1]	1	26 July 2016
Other [Confidentiality_Statement_Transcribers_V1]	1	26 July 2016
Other [Research_Panel_Constitution_V1]	1	26 July 2016
Other [Research_Panel_Feedback_V1]	1	26 July 2016
Other [Transfer_Viva_Recommendations_V1]	1	26 July 2016
Other [Media_Information_Sheet_V1]	1	26 July 2016
Other [IT_Statement_V1]	1	11 October 2016
Other [Capacity_Statment_Supervisor_V1]	1	13 October 2016
Other [Staff_Script_V1]	1	17 October 2016
Participant consent form [Consent Form_NHS_V1]	1	26 July 2016
Participant consent form [Consent Form_YDUK_V1]	1	26 July 2016
Participant information sheet (PIS) [Information Sheet_YDUK_V1]	1	26 July 2016
Participant information sheet (PIS) [Information	1	26 July 2016

Appendix 2.

Sheet_YDUK_Adapted_V1]		
Participant information sheet (PIS) [Information Sheet_NHS_V2]	2	11 October 2016
Participant information sheet (PIS) [Information Sheet_NHS_Adapted_V2]	2	11 October 2016
Research protocol or project proposal [Protocol_V2]	2	11 October 2016
Summary CV for Chief Investigator (CI) [CV_V1]	1	26 July 2016
Summary CV for student [CV_V1]	1	26 July 2016
Summary CV for supervisor (student research) [CV_Supervisor_V1]	1	26 July 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Participant_Pathway_V2]	2	11 October 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/YH/0389

Please quote this number on all correspondence

Appendix 2.

With the Committee's best wishes for the success of this project.

Yours sincerely

pp



Dr Ian Woollands
Chair

Email: nrescommittee.yorkandhumber-southyorks@nhs.net

Enclosures: "After ethical review – guidance for researchers" [\[SL-AR2\]](#)

Copy to: Faculty Research Ethics and Governance Administrator
Ms Sinead Audsley, Leeds and York Partnership NHS Foundation Trust

Appendix 3.

YoungDementia UK PO Box 315 Witney OX28 1ZN
telephone 01993 776295 mail@youngdementiauk.org
www.youngdementiauk.org



25 May 2016

Dear Colleagues

Re: Exploring the Experience of Living with Young Onset Dementia

We welcome the opportunity to support the research project undertaken by Charlotte Berry, and supervised by Dr. Jan Oyeboke (University of Bradford) and Dr. Carol Martin (University of Leeds).

We are keen to encourage research into the experience of living with young onset dementia. It is an area that is not well-enough understood and hence those people who have young onset dementia are not supported as well as they should be.

We look forward to supporting the recruitment to this study and will be pleased to promote participation via our membership, website and other forums.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Tessa Gutteridge'.

Tessa Gutteridge
Director

YoungDementia UK Company limited by guarantee in England and Wales Company No 4142850
Registered Office: 7 Mount Pleasant Crawley Road Witney OX28 1JE Charity No 1085595

Charlotte Berry IRAS Project ID: 198498 Version: 1 Date: 27.01.2017



Health Research Authority

Yorkshire & The Humber - South Yorkshire Research Ethics Committee

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NE32 3DT

Tel: 0207 104 8124

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

28 February 2017

Miss Charlotte Berry
Trainee Clinical Psychologist
The Leeds Teaching Hospitals NHS Trust
Clinical Psychology Training Programme
2.07 Charles Thackrah Building,
University of Leeds
101 Clarendon Road
LS2 9LJ

Dear Miss Berry

Study title:	Exploring the Experience of Living with Young Onset Dementia
REC reference:	16/YH/0389
Amendment number:	1 - 27.01.2017
Amendment date:	01 February 2017
IRAS project ID:	198498

The above amendment was reviewed on 21 February 2017 by the Sub-Committee in correspondence.

The amendment is to gain approval to recruitment through a second source – that of the Young Dementia UK (YDUK) website (<https://www.youngdementiauk.org/>). A recommendation was made in September 2016 following Research Ethics Committee review, to remove the website recruitment from the study and to resubmit as a substantial amendment in future if required. Due to difficulties in recruiting solely from the NHS it is felt an amendment in recruitment is appropriate.

Appendix 4.

The committee queried whether the submitted document Invitation YDUK V1 the advert which will be placed on the YDUK website?

Miss Berry confirmed that the invitation document is the advert for the YDUK website.

The sub-committee were satisfied with the responses to the queries raised.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Email from Charlotte Berry]		02 February 2017
Letter from sponsor [University Sponsor Support_V1]	1	27 January 2017
Letters of invitation to participant [Invitation_YDUK_V1]	1	27 January 2017
Notice of Substantial Amendment (non-CTIMP) [1 - 27.01.2017]		01 February 2017
Other [Participant_Pathway_V3]	3	27 January 2017
Other [Supporting_Letter_YDUK_V1]	1	27 January 2017
Participant consent form [Consent Form_YDUK_V1]	1	27 January 2017
Participant information sheet (PIS) [Information Sheet_YDUK_V1]	1	27 January 2017
Participant information sheet (PIS) [Information Sheet_YDUK_Adapted_V1]	1	27 January 2017
Research protocol or project proposal [Protocol_V3]	3	27 January 2017

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.



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NE32 3DT

Tel: 0207 104 8124

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

03 May 2017

Miss Charlotte Berry
Trainee Clinical Psychologist
The Leeds Teaching Hospitals NHS Trust
Clinical Psychology Training Programme
2.07 Charles Thackrah Building, University of Leeds
101 Clarendon Road
LS2 9LJ

Dear Miss Berry

Study title:	Exploring the Experience of Living with Young Onset Dementia
REC reference:	16/YH/0389
Amendment number:	Substantial Amendment 2 - 5/4/17
Amendment date:	05 April 2017
IRAS project ID:	198498

The above amendment was reviewed on 20 April 2017 by the Sub-Committee in correspondence.

This amendment is to gain approval for the change of first contact to include telephone contact and interviews to be done over the phone in the protocol.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Appendix 5.

The Committee recommended the subsequent exclusive use of telephone for the taking of consent (audio recorded) and interviews should only be used if requested by the participant. A preference for face-to-face interaction should remain for the research project as a whole.

Ms Berry replied that this recommendation is acknowledged, and that the taking of telephone consent will be used only for those participants who have specifically requested telephone interaction. Face-to-face interaction will always be favoured and used when possible.

The committee also queried how continued assessment of participant capacity will be made only by audio (telephone) contact. Would this involve a set of initial questions before the interview is started.

Ms Berry replied that the continued assessment of capacity will be made in the exact same way as it is in face-to-face interviews at present, in line with the Mental Capacity Act (2005).

At the first 'contact' this is assessed through the use of individualised questions during conversation. These initial questions are structured by the MCA (2005) framework. Furthermore, capacity is continually assessed by the researcher throughout the research process. It is acknowledged that capacity to provide consent fluctuates and, as such, capacity will be assessed during each contact.

The use of telephone contact does not prohibit any discussion that allows for the assessment of capacity.

The committee were satisfied with the responses received.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper	Email from Charlotte Berry	07 April 2017
Notice of Substantial Amendment (non-CTIMP)	Substantial Amendment 2 - 5/4/17	05 April 2017
Other [Participant Pathway]	Version 4	05 April 2017
Other [Sponsor Support Email]	Version 1	05 April 2017
Research protocol or project proposal	Version 4	05 April 2017

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Participant Information Sheet

Research study title: Exploring the experience of living with young onset dementia

You are being invited to take part in this research study. This sheet provides information about the purpose of the study and what it will involve. Please read it carefully to help you to decide whether you would like to take part. You are welcome to talk to others about the research and ask any questions.

Who is doing the research?

Charlotte Berry will be conducting the research. I am a trainee clinical psychologist at the University of Leeds. I am carrying out this research as part of my three year course.

What is the purpose of this study?

I hope to learn more about what it's like to live with young onset dementia. I hope that the study will help those of us who work in dementia services to better understand younger people's experiences.

Why have I been invited?

You have been invited as you have received a diagnosis of dementia and you are under 65 years of age, or were when you received your diagnosis. You have been given this information sheet as a member of your care team felt that you might be interested in taking part.

Do I have to take part?

No. Whether you take part is up to you. If you do decide that you'd like to take part you will be given this information sheet to keep. When we meet you will be asked to consent to the study. This will involve signing a form saying that you understand what the study involves and you are happy to take part. If you decide to take part but then don't want to carry on, you can leave the study at any time. If you do decide to stop this won't affect the care you receive from the NHS.

What will happen if I choose to take part?

I would arrange to meet with you when you are available. We could meet at an NHS location, at the University of Leeds or at your home. This will be your choice. If you would like to meet outside of your home I would reimburse any costs for taxis, public transport or petrol. If you would feel more comfortable with someone else present during your interview then you just need to give permission for them to do so.

I will arrange to meet you to talk about your experience. You may feel that one meeting is enough, and that's okay. At the end of the meeting I will ask if you feel

that you have more to say. If you have, we can plan another meeting. In all, we can plan up to four meetings together if you want them.

Our meetings would be flexible and be as long or as short as you wanted. When we meet we would explore your experiences of living with dementia together. You would also be invited to bring along any images, objects or items that help you to tell your story of living with dementia. We would talk about this more at our first meeting.

What will happen to the results?

I will write up the results of my research in a thesis. My thesis will be printed into a book and will also be available online. I may also publish a report in an academic journal so that the findings can be shared with others working with people with young onset dementia. You will not be identifiable in any of these publications. I can also send you information about the results of the study when it is completed.

Will my answers be kept confidential?

I will record what you say using a dictaphone. It will then be typed up by a professional transcriber who will keep your interview confidential. They won't talk to anyone else about your interview. After this I will take out any information that might identify you. I will draw themes out of the interviews, to show what it's like to live with young onset dementia. Direct quotes will be used within my reports but I will change your name so that you cannot be identified.

The only time I would have to share information with anybody else is if I felt that you were at risk or if another person's safety was at risk. In this case, I would be obliged to contact the local Adult Safeguarding Team. I would always try and talk to you about this first.

When the research is complete your audio recordings will be destroyed. Other information, including your typed up interview and your name and address, will be kept safely at the University of Leeds for three years and then destroyed.

Who else will be able to see my interview?

The typed up interviews will be read by myself and three members of my research team. These are people who work in the University of Leeds, University of Bradford and the NHS.

What are the possible disadvantages of taking part?

Talking about your diagnosis of dementia and the impact that this has had on your life might be difficult. It is possible that you might feel upset or uncomfortable discussing this. If you do become upset that's okay. If you want to stop or postpone the interview that's okay too. You don't have to talk about anything that you don't want to.



What are the possible benefits of taking part?

By talking about what it's like to live with a diagnosis of young onset dementia it is hoped that clinical psychologists, and other professionals, can better understand your experiences. We hope that this will improve support that services offer younger people with dementia. Taking part might help other people going through similar experiences.

What happens if I have concerns about this study?

If you have any concerns about the study or want to make a complaint you can contact Clare Skinner (Faculty Head of Research Support) on **0113 343 4897**. Claire works for the University of Leeds but is not involved in the current research.

What happens next?

I will give you a call in the next few weeks to arrange for us to meet up. When we meet I can answer any questions you might have and to see if you're still interested in taking part.

What if I have more questions?

If you have any questions or concerns about the research please get in touch with me or my supervisor. You can contact us using the details below:

Charlotte Berry
Trainee Clinical Psychologist
E-mail: umcefb@leeds.ac.uk

Dr Carol Martin
University Supervisor

Address:

Doctorate in Clinical Psychology Programme
Room 2.07, Charles Thackrah Building
University of Leeds, 101 Clarendon Road
Leeds, LS2 9LJ

Telephone:
07757 808934

Thank you for taking the time to read this information sheet

Appendix 6.



The Dementia Engagement & Empowerment Project (DEEP) brings together groups of people with dementia from across the UK.

To find out about groups available in your area visit:

<http://dementivoices.org.uk/>



YoungDementia UK is a charity that exists for one reason – to help people whose lives are affected by young onset dementia. For more information please visit:

<https://www.youngdementiauk.org/>

Or telephone:

01993 776295 (general enquiries)

01865 794311 (support-related enquiries)



If you have concerns about Alzheimer's disease or about any other form of dementia, Alzheimer's Society National Dementia Helpline on **0300 222 1122** can provide information, support, guidance and signposting to other appropriate organisations.

The Helpline is usually open from:
9am - 8pm Monday to Wednesday
9am - 5pm on Thursday and Friday
10am - 4pm on Saturday and Sunday



If you need someone to talk to you can call Samaritans, free any time, from any phone:

116 123

They are available round the clock, 24 hours a day, 365 days a year.

Author: Charlotte Berry IRAS Project ID: 198498 Version: 2 Date: 11.10.2016



Participant Information Sheet

Research study title: Exploring the experience of living with young onset dementia

You are being invited to take part in this research study. This sheet provides information about the purpose of the study and what it will involve. Please read it carefully to help you to decide whether you would like to take part. You are welcome to talk to others about the research and ask any questions.

Who is doing the research?

Charlotte Berry will be conducting the research. I am a trainee clinical psychologist at the University of Leeds. I am carrying out this research as part of my three year course.

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I hope to learn more about what it's like to live with young onset dementia. I hope that the study will help those of us who work in dementia services to better understand younger people's experiences.

Why have I been invited?

You have been invited as you have received a diagnosis of dementia and you are under 65 years of age, or were when you received your diagnosis. You also expressed interest in the study that was advertised on the Young Dementia UK website.

Do I have to take part?

No. Whether you take part is up to you. If you do decide that you'd like to take part you will be given this information sheet to keep. When we meet you will be asked to consent to the study. This will involve signing a form saying that you understand what the study involves and you are happy to take part. If you decide to take part but then don't want to carry on, you can leave the study at any time.

What will happen if I choose to take part?

I would arrange to meet with you when you are available. We could meet at the University of Leeds or at your home. This will be your choice. If you would like to meet outside of your home I would reimburse any costs for taxis, public transport or petrol. If you would feel more comfortable with someone else present during your interview then you just need to give permission for them to do so.

I will arrange to meet you to talk about your experience. You may feel that one meeting is enough, and that's okay. At the end of the meeting I will ask if you feel that you have more to say. If you have, we can plan another meeting. In all, we can plan up to four meetings together if you want them.



Our meetings would be flexible and be as long or as short as you wanted. When we meet we would explore your experiences of living with dementia together. You would also be invited to bring along any images, objects or items that help you to tell your story of living with dementia. We would talk about this more at our first meeting.

What will happen to the results?

I will write up the results of my research in a thesis. My thesis will be printed into a book and will also be available online. I may also publish a report in an academic journal so that the findings can be shared with others working with people with young onset dementia. You will not be identifiable in any of these publications. I can also send you information about the results of the study when it is completed.

Will my answers be kept confidential?

I will record what you say using a dictaphone. It will then be typed up by a professional transcriber who will keep your interview confidential. They won't talk to anyone else about your interview. After this I will take out any information that might identify you. I will draw themes out of the interviews, to show what it's like to live with young onset dementia. Direct quotes will be used within my reports but I will change your name so that you cannot be identified.

The only time I would have to share information with anybody else is if I felt that you were at risk or if another person's safety was at risk. In this case, I would be obliged to contact your GP. I would always try and talk to you about this first.

When the research is complete your audio recordings will be destroyed. Other information, including your typed up interview and your name and address, will be kept safely at the University of Leeds for three years and then destroyed.

Who else will be able to see my interview?

The typed up interviews will be read by myself and three members of my research team. These are people who work in the University of Leeds, University of Bradford and the NHS.

What are the possible disadvantages of taking part?

Talking about your diagnosis of dementia and the impact that this has had on your life might be difficult. It is possible that you might feel upset or uncomfortable discussing this. If you do become upset that's okay. If you want to stop or postpone the interview that's okay too. You don't have to talk about anything that you don't want to.

What are the possible benefits of taking part?

By talking about what it's like to live with a diagnosis of young onset dementia it is hoped that clinical psychologists, and other professionals, can better understand



your experiences. We hope that this will improve support that services offer younger people with dementia. Taking part might help other people going through similar experiences.

What happens if I have concerns about this study?

If you have any concerns about the study or want to make a complaint you can contact Clare Skinner (Faculty Head of Research Support) on **0113 343 4897**. Clare works for the University of Leeds but is not involved in the current research.

What happens next?

I will give you a call in the next few weeks to arrange for us to meet up. When we meet I can answer any questions you might have and to see if you're still interested in taking part.

What if I have more questions?

If you have any questions or concerns about the research please get in touch with me or my supervisor. You can contact us using the details below:

Charlotte Berry
Trainee Clinical Psychologist
E-mail: umcefb@leeds.ac.uk

Dr Carol Martin
University Supervisor

Address:

Clinical Psychology Training Programme
Leeds Institute of Health Sciences
Level 10 Worsley Building
Clarendon Way
University of Leeds
LS2 9NL

Telephone:

07757 808934

Thank you for taking the time to read this information sheet

Appendix 7.



The Dementia Engagement & Empowerment Project (DEEP) brings together groups of people with dementia from across the UK.

To find out about groups available in your area visit:

<http://dementivoices.org.uk/>



YoungDementia UK is a charity that exists for one reason – to help people whose lives are affected by young onset dementia. For more information please visit:

<https://www.youngdementiauk.org/>

Or telephone:

01993 776295 (general enquiries)

01865 794311 (support-related enquiries)



If you have concerns about Alzheimer's disease or about any other form of dementia, Alzheimer's Society National Dementia Helpline on **0300 222 1122** can provide information, support, guidance and signposting to other appropriate organisations.

The Helpline is usually open from:

9am - 8pm Monday to Wednesday

9am - 5pm on Thursday and Friday

10am - 4pm on Saturday and Sunday



If you need someone to talk to you can call Samaritans, free any time, from any phone:

116 123

They are available round the clock, 24 hours a day, 365 days a year.

Author: Charlotte Berry IRAS Project ID: 198498 Version: 1 Date: 27.01.2017

Information Sheet

You are being invited to take part in some **research** about younger people with dementia.



Please read this information carefully.

Please ask **questions**.



Charlotte Berry will be doing research.

Charlotte is a Trainee Clinical Psychologist.



We want to learn more about what it is like to have **dementia at a younger age**.

We hope it will help us to **understand** peoples experience more.

Participant Consent Form

Research study title: Exploring the experience of living with young onset dementia

Name of Researcher: Charlotte Berry

Please tick (✓) each box if you agree with the statement

You must tick all of the boxes to be able to take part in the study

1. I have read and understand the information sheet on "Exploring the experience of living with young onset dementia".
2. I have had chance to ask questions about the research project.
3. I understand that I will be invited to talk about my experiences of living with dementia.
4. I understand that it is up to me whether I take part.
5. I understand I can stop the interview at any time and that I don't need to give any reason. If I do decide to stop this won't affect the care I receive from the NHS.
6. I understand that I can withdraw my interview from the study as long as I let you know within two weeks.
7. I agree that if I lose capacity to consent to the research that the researcher can use any previous interviews I took part in.
8. I understand that my name will be changed so that I can't be recognised in the final report.
9. I understand that direct quotes and images might be used in the final report but my name will be changed so I can't be recognised.
10. I give permission for members of the research team (supervisors) to have access to my interview.
11. I agree that my interview can be used in future research and teaching but my name will be changed so I can't be recognised.
12. I understand that if I bring anything along to my interviews to help me tell my story, including photographs, that I will discuss with the researcher what can and cannot be included in the final report.
13. I give consent for this interview to be audio recorded.

Appendix 9.



14. (a) I would like a family member/ friend/ carer to be present during my interview for support. I therefore give permission for

Name: _____

Relationship to me: _____

to be present during my interview.

(b) I am happy to be interviewed alone.

15. I agree to take part in the project.

Name of participant: _____ Date: _____

Signature: _____

Name of researcher: _____ Date: _____

Signature: _____

To be signed and dated with researcher and participant present

One copy for participant and one copy for researcher.

Appendix 9.



Please tick one of the boxes below to let us know if you would like a summary of results of the study:

- I don't want to receive a summary of the results of this study
- I would like a summary of the results of this study

Address I would like the summary to be sent to:

You are invited to choose your own pseudonym – this is the name that will be used for you in the results of the study. If you don't want to choose that's okay and we can choose one for you.

Name that I would like to be used: _____



Participant Consent Form

Research study title: Exploring the experience of living with young onset dementia

Name of Researcher: Charlotte Berry

Please tick (✓) each box if you agree with the statement

You must tick all of the boxes to be able to take part in the study

1. I have read and understand the information sheet on "Exploring the experience of living with young onset dementia".
2. I have had chance to ask questions about the research project.
3. I understand that I will be invited to talk about my experiences of living with dementia.
4. I understand that it is up to me whether I take part.
5. I understand I can stop the interview at any time and that I don't need to give any reason.
6. I understand that I can withdraw my interview from the study as long as I let you know within two weeks.
7. I agree that if I lose capacity to consent to the research that the researcher can use any previous interviews I took part in.
8. I understand that my name will be changed so that I can't be recognised in the final report.
9. I understand that direct quotes and images might be used in the final report but my name will be changed so I can't be recognised.
10. I give permission for members of the research team (supervisors) to have access to my interview.
11. I agree that my interview can be used in future research and teaching but my name will be changed so I can't be recognised.
12. I understand that if I bring anything along to my interviews to help me tell my story, including photographs, that I will discuss with the researcher what can and cannot be included in the final report.
13. I give consent for this interview to be audio recorded.

Appendix 10.



14. (a) I would like a family member/ friend/ carer to be present during my interview for support. I therefore give permission for

Name: _____

Relationship to me: _____

to be present during my interview.

(b) I am happy to be interviewed alone.

15. I consent to my GP being contacted in the event that the researcher feels that I am at risk or another persons safety is at risk. I understand attempts will be made to discuss this with me first.

GP Name: _____

Address: _____

Telephone: _____

16. I agree to take part in the project.

Name of participant: _____ Date: _____

Signature: _____

Name of researcher: _____ Date: _____

Signature: _____

To be signed and dated with researcher and participant present

One copy for participant and one copy for researcher.

Appendix 10.



Please tick one of the boxes below to let us know if you would like a summary of results of the study:

- I don't want to receive a summary of the results of this study
- I would like a summary of the results of this study

Address I would like the summary to be sent to:

You are invited to choose your own pseudonym – this is the name that will be used for you in the results of the study. If you don't want to choose that's okay and we can choose one for you.

Name that I would like to be used: _____

'Exploring the experience of living with young onset dementia'

Chief Investigator: Charlotte Berry (Trainee Clinical Psychologist)

umcefb@leeds.ac.uk

07757 808934

Thank you for offering to approach potential participants for my study. Here is information about what you need to do.

Who to approach

1. Anybody you approach to take part must have the capacity to consent to take part in the study in accordance with the Mental Health Act (DoH, 2005). As such they should have:

- A general understanding of that they are being invited to take part in a research study
- A general understanding of the likely consequences of deciding to take part or not
- The ability to understand, retain, use and weigh up the information about what taking part would involve
- The ability to verbally communicate their decision.

2. Individuals must have a formal diagnosis of dementia.

3. They must be (or have been) under the age of sixty-five at the time of diagnosis.

4. They must be at least 12 weeks post-diagnosis.

Who not to approach

Please do not approach:

1. Individuals with diagnoses of Huntington's disease, multiple sclerosis and HIV-associated neurocognitive disorder.

2. Individuals with other mental health difficulties and or/ physical health problems, if you feel that their other health problems may cause them excessive distress and/or be risk during the research process.

Recruitment Pathway

1. If you know of any individuals who may be suitable and who may be interested in taking part please talk to them using the following script:

"A trainee psychologist, called Charlotte Berry, is conducting research looking at people's experiences of what it's like to live with young onset dementia. She's currently looking for people who might be interested in meeting up and talking to her about their experiences. I was wondering if this might be something you would be interested in? I have an invitation sheet here. If you are interested just get in touch with me or another member of the Young Onset team."

Please provide them with an invitation sheet.

2. If an individual expresses interest in taking part in the study:

"Would it be okay for me to pass your details on to Charlotte so she can send you some more information and get in touch with you? This would include your name, address, telephone number, and details of your care team. This is so Charlotte can post you a letter and give you a call in a week or so."

If the individual consents, please pass on the following details to me by email or phone (see details below):

Name

Address

Telephone number

Care Co-ordinator name

Care Co-ordinator contact number

Care Co-ordinator e-mail address

Name and contact details of second point of contact in YPwD team

Appendix 11.



If you have any questions or concerns about the research please get in touch with me or my supervisor. You can contact us using the details below:

Charlotte Berry
Trainee Clinical Psychologist
E-mail: umcefb@leeds.ac.uk

Dr Carol Martin
University Supervisor

Address:

Doctorate in Clinical Psychology Programme
Room 2.07, Charles Thackrah Building
University of Leeds, 101 Clarendon Road
Leeds, LS2 9LJ

Telephone:
07757 808934



UNIVERSITY OF LEEDS

**Confidentiality Statement for Transcribers
Doctorate in Clinical Psychology Training Programme**

The British Psychological Society has published a set of guidelines on ethical principles for conducting research. One of these principles concerns maintaining the confidentiality of information obtained from participants during an investigation.

As a transcriber you have access to material obtained from research participants. In concordance with the BPS ethical guidelines, the D.Clin.Psychol programme requires that you sign this Confidentiality Statement for every project in which you act as transcriber.

General

- 1) I understand that the material I am transcribing is confidential.
- 2) The material transcribed will be discussed with no-one.
- 3) The identity of research participants will not be divulged.

Transcription procedure

- 4) Transcription will be conducted in such a way that the confidentiality of the material is maintained.
- 5) I will be supplied with the audio-recordings on an encoded USB and will work directly from this USB, not downloading the audio-recordings onto my computer.
- 6) I will ensure that audio-recordings cannot be overheard and that transcripts, or parts of transcripts, are not read by people without official right of access.
- 7) All materials relating to transcription will be returned to the researcher, and no copies will be made.

Signed.....*JMC*.....Date *04/04/2017*
Print name.....*JULIE R CLARK*.....

Researcher: Charlotte Berry

Project title: Exploring the experience of living with young onset dementia

**Do you have a diagnosis of dementia?
Were you under 65 when you got a diagnosis?
Would you be interested in talking about your
experiences?**

My name is Charlotte Berry. I am conducting research looking at what it's like to live with young onset dementia. I hope that my research will help people to better understand what it's like to live with dementia at a younger age.

I am currently looking for people who would be interested in being involved. If you are interested this would involve meeting up with me to discuss your experiences.

If you are interested please let a staff member from the Young People with Dementia team know. I can then send you some more information.

Interviews

When we meet please feel free to bring things with you that help you to talk about your experiences of living with dementia.

This might include:

- **Photographs** – these might be old photographs, or new photographs that you take between now and the next time we meet. These can even be on your phone.
- Other images
- Music
- Drawings, paintings, artwork.
- Objects
- Books
- Anything else that is important to you

If you bring images of other people please check that they are happy for you to do so.

If you don't want to bring anything with you that's okay.

Appendix 15.

Mr Vermont #1 1

1 I: I wondered if it might be useful if you could tell me, if it feels okay,
 2 about when you first started noticing changes, perhaps in your
 3 memory or other changes you noticed before you got your
 4 diagnosis?
 5

6 P: It felt strange. Yes, that's why I went to the doctors because of
 7 the err- because of the lack of memory. The memory going, I went
 8 to the doctors because of the funny feelings in my head. Yep.
 9

10 I: When you say it felt strange?
 11

12 P: Yes, because I've always had a - I've always been fairly clever
 13 and had a good memory. Things like seeing friends and not
 14 recognising their faces at first and er not being able to remember
 15 their names and things like that. It all started to go on more and
 16 more, it's the memory issue all of it and erm that's very much
 17 [pause] yeah, yeah. - difficult to talk about
 18 or no words?
 19

19 I: You gave quite a specific example there about going to see your
 20 friends and struggling to recognise-
 21

22 P: -well, it's very much like you see friends and neighbours on the
 23 street I can't always recognise them. Sometimes I can, but to try
 24 and remember their names is always difficult, it's always difficult
 25 with the names. When we're together [looks at wife] I have to ask
 26 "who's that, who's that?". It's silly. It's very embarrassing when
 27 someone says "now then mate" and I say "who's that" you know.
 28 It's embarrassing to say the least. And like people I've been at
 29 school with and people I've known for years and they've known
 30 me and suddenly it fades away. Very embarrassing. Stressful in
 31 itself. It's like when I was working towards the end when
 32 customers were coming in I couldn't remember their faces and
 33 their names, people I've known for ages, that was another
 34 embarrassment. So much of it is the embarrassment issue from
 35 there. The psychiatrist, interestingly, said probably what set me off
 36 going was the situation with my mum, the stress of that situation
 37 was part of what kicked it off because that's more or less the time
 38 it started wasn't it? That's what the psychiatrists said, that's more
 39 or less what got it going, the stress from that.
 40

41 I: Okay. Just to clarify, was that about two years ago you said that
 42 happened?
 43

44 P: No, about five. Five years ago was when I started and they said
 45 that's probably what it was that kicked it off. And I've been brain
 46 scanned by the psychiatrists and it's shrunk very much. All old
 47 peoples brains shrink don't they? But - and all peoples memory's go
 48 but it's just that mine's going faster [pause] Yeah.

Handwritten notes:

- STRANGE
- Now vs. Then Identity
- PAST SELF
- Embarrassment
- Worse than embarrassing?
- SELF-CONSCIOUSNESS
- 'Strange'/'Funny' - Somethings not quite right?
- Is he different now?
- Things got worse
- It's changeable?
- Repetition/emphasis "difficult"
- Silly - like strange, funny?
- FADING AWAY
- Looking for a reason that this has happened to him.
- WHY?
- MEANING MAKING
- Reasonable seeking? Is this normal? Am I normal?
- NORMALISING?
- Hard to admit or say out loud?