"Who am I?"
Personal Accounts of the Dementia Assessment Process and the Impact of the Dementia Label

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ABSTRACT

There are competing models through which a dementia diagnosis can be understood, but what dominates the assessment process for dementia diagnosis is the medical model, which neglects the social, cultural, and political aspects of the diagnosis. In a Western society where value is ascribed to qualities associated with youth, such as good physical health, the rhetoric around older adults and dementia has long been dominated by stories of dependence and burden. Assuming them to be passive and unreliable, little research into the opinions of those diagnosed with dementia has been undertaken, but studies eliciting first-hand accounts suggest that the practice of diagnosis is inconsistent and often fails to meet the needs of the people receiving the diagnosis. Aiming to add depth to this research, four people aged over 65 with a dementia diagnosis were interviewed to evaluate the impact of socio-cultural discourse on their experience of being assessed for and living with a dementia diagnosis. Narrative analysis was then used, attending to the performative, descriptive, and contextual elements of the accounts. The study revealed the narrative abilities of people diagnosed with dementia and showed that hegemonic discourse on dementia alongside personal philosophies affect how the label is received and understood, and whether it is accepted or rejected. Participants also demonstrated value in interdependence, and a variety of post-diagnostic needs, reflecting the heterogeneity of those who receive the diagnosis. The implications of this study are then discussed, considering the impact that utilising the social model of disability could have on the treatment of people diagnosed with dementia.

CONTENTS

ACKNOWLEDGEMENTS

Dedicated to Maureen Golden (1933-2009)

I could have known you for 1,000 years, and it still wouldn't have felt like long enough

"People think that stories are shaped by people. In fact, it's the other way around."
Terry Pratchett, Witches Abroad (1992:12)

"...someone needs to tell their bits of overlapping narrative. There's magic in that. It's in the listener, and for each and every ear it will be different, and it will affect them in ways they can never predict. From the mundane to the profound. You may tell a tale that takes up residence in someone's soul, becomes their blood and self and purpose. That tale will move them and drive them and who knows what they might do because of it, because of your words. That is your role, your gift."
Erin Morgenstern, The Night Circus (2012:482)

1. INTRODUCTION

"Who am I? Come closer, come closer and you'll see me."

(Reid, 2016)

1.1.   Overview

In 2018, there are over 850,000 people in the United Kingdom (UK) who have been diagnosed with dementia, and this is projected to increase to two million by 2051 (Alzheimer's Society, 2018a). These estimates and the current lack of a medical cure contribute to the sense of fear surrounding dementia. Despite initiatives such as Alzheimer's Society's (2017) 'Dementia Friends' aiming to increase understanding of dementia amongst the public, a survey by Saga (2016) of 9,116 participants aged 50 and over found that dementia was their most feared illness, while an Alzheimer's Society (2016) survey found that 62% of people thought that a dementia diagnosis indicated that life was over. This study will seek to explore how the medical and social context of dementia influence people's experience of receiving the diagnosis and the support they receive when the diagnosis is given.

This chapter shall address my personal decision to study this topic, before reviewing models of dementia and the social narratives that surround the diagnosis. I will then review current literature regarding the experience of being diagnosed with dementia, paying particular attention to accounts from those who have received such a diagnosis.

1.2.   Terminology

Terms and categories are socially and culturally bound and have not been used uncritically. To avoid reinforcing the problematic discourses that surround ageing and dementia diagnoses, this section will be used to deconstruct and contextualise the terms used throughout this study.

1.2.1. <u>People with a Dementia Diagnosis</u>

Since labels have the power to shape experience (Hayes, Strosahl, & Wilson, 2011), I will avoid using the term 'people with dementia'. This would impose upon people a dementia label with which they may not relate, and implies a positivist understanding of dementia. I will instead refer to people as having a 'dementia diagnosis', which acknowledges that while the individual has received this diagnosis, it does not necessarily form an essential part of their identity.

1.2.2. <u>Older Adults</u>

Old age is a socially constructed concept rather than a developmental stage defined by biological markers, and ideas around what constitutes old age change over time. Age of receipt of state pension, for example, commonly seen as a marker of old age, changes depending on life expectancy and political and financial pressures (Phillipson, 1982). Furthermore, what a society considers to constitute old age can differ from the definition held by members of that society who fall into that age bracket. Despite this, most Western countries currently use the age 65 and over to define an older person. While this is an arbitrary figure, and 'older adults' are not a homogenous group, the association of this age bracket with old age means that it is linked with wider society's beliefs about ageing (Castro Romero, 2016). As this is pertinent to the aims of this study, the term 'older adults' will be used to refer to those aged 65 and over.

1.3.   Language

Driven by wanting to communicate with those who can at times find communication difficult, I have considered the societal implications of Gergen and Walter's (1998) proposition that the language used in scholarly expression has the power to exclude. I will challenge academic convention and the false boundaries between the personal, professional and political, through writing in first person. This will remind the reader of the role I play in constructing the narratives told through this piece of work (Gergen, 2007), and suggests that listening to those diagnosed with dementia should not simply be restricted to an academic forum.

1.4. Personal Context

No research is value-free, with ideologies being openly or indirectly conveyed through every piece of written narrative (Afuape, 2011; Stevenson, 1988). Through explaining the reasons why I chose to pursue this subject, I hope that the reader can understand what has shaped my approach.

Growing up I lived on the same street as my paternal grandparents, with whom I had a close relationship. Following a stroke in her later life, my nanna found it hard to find support that was appropriate for her needs, and found healthcare professionals to be infantilising and neglectful of her lived experience. Already embarrassed at the impact of the stroke on her memory, this further damaged her sense of pride; she understandably coped with this through dropping out of services. It was hard to see services whose objective had been to provide her with support, struggle to recognise the woman behind the health problem. This narrative was one that I saw replicated when I started to work in the field of mental health. Older adults were consistently underrepresented and often described as a 'hard to reach group' by services who did little to reach out to them and put barriers in the way of their engagement, such as not offering home visits.

Working with older adults, I have found their stories to be rich, and have been amazed by what I can learn from their experiences. This thesis, therefore, offers an opportunity to redress the imbalance and thicken the narratives of those who are marginalised, through sharing their experiences with a wider audience.

1.5. Literature Review Strategy

To find literature relating to experiences of dementia diagnosis, the databases PsycINFO, PsycARTICLES, CINAHL Plus, and Academic Search were searched in August-October 2017 using the terms and parameters listed in Appendix A. Qualitative and quantitative peer reviewed articles were both included. Literature ranged from 1983 to October 2017, however, there were few studies published between 1983 and 2000. This shows how recent it is that research has started to look beyond the diagnosis label. To expand the review,

additional articles were found through searching the reference lists of relevant articles, and exploring 'grey' literature including policy documents and autobiographies.

Relevant returned literature will be presented in a narrative review. This format was selected due to the limited number of relevant studies published, and to allow the diversity and plurality of perspectives in the literature to be explored.

1.6.   Dementia's Context: Competing Explanations

In this section, I will explore three models that contribute to the understanding of dementia within the diagnostic session and beyond, influencing the perspectives of healthcare professionals and the general public.

1.6.1.   The Medical Model

"Our brain scans symbolise the moment of diagnosis, when our life changes forever." (Bryden, 2005:54)

The medical model contributes much of what is understood about dementia, with diagnosis following international standardised criteria such as that of the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-V; American Psychological Association, 2013). This deficit-focused model centres on changes that occur within the brain, and conceptualises dementia as a global cognitive impairment that causes functional decline (National Collaborating Centre for Mental Health, 2007). There are considered to be over one hundred separate dementia disease profiles, the most common being Alzheimer's disease (Botsford, 2015). The symptoms attributed to dementia include a decline in memory, attention, and communication skills, and an inability to complete tasks of daily living (Botsford, 2015).

While the largest body of literature on dementia focuses on predictors, causes and symptoms, it lacks consensus (Harding & Palfrey, 1997); some suggest that dementia is a pathological condition that is more prevalent in those aged 65 and over, and others suggest that dementia is part of a normal cognitive decline

continuum (Brayne & Calloway, 1988). John et al. (2016) state that no biomarkers have been found for dementia, nor have biomarkers been found that distinguish the different types of dementia from each other. Furthermore, neurological markers may present atypically, as the cortical atrophy that is perceived to signify Alzheimer's disease can be present in the autopsies of those who showed no outward signs of Alzheimer's disease (Jacoby & Levy, 1980). It is claimed that without a consistent association between symptoms and biological markers, dementia is not a syndrome, nor is it a disease (Jacoby & Levy, 1980; Terry, 1992).

Despite the aforementioned claims, dementia continues to be considered through a series of vascular problems, neurofibrillary tangles and β-amyloid plaques. Without a standardised test, dementia is diagnosed through brain scans and assessing changes in behaviour, cognition, mood and personality. However, this neglects to acknowledge that the interpretation of behaviour, cognition, mood and personality, is tacitly informed by cultural and societal expectations (Davis, 2004; Fox, Lafortune, Boustani, & Brayne, 2013). Clinical judgement is subjectively weighted and has been shown to be flawed and difficult to quantify (Dawes, Faust, & Meehl, 1989). Therefore, diagnoses cannot be provided with an assurance of certainty.

Despite the difficulties indicated, Herskovits (1995) argues that the medical model dominates because it serves political and economic interests. She suggests that the medicalisation of the difficulties associated with dementia allows for the establishment of services for older adults, has increased the resources and support available for carers and those diagnosed, and increased provision of funding for research. Herskovits argues that it creates order out of chaos and legitimises a therapeutic response, but is this truly therapeutic, or a form of medical and social control? This will be considered further in section 1.6.3.

1.6.2. <u>Biopsychosocial Model</u>

"It seems that when you have cancer you are a brave battler against the disease, but when you have Alzheimer's, you are an old fart. That's how people see you. It makes you feel quite alone."
(Pratchett, 2014:259)

Kitwood (1990a; 1997) argued that the medical model of dementia does not allow the clinician to get any real sense of the person or how to provide effective care. He developed a biopsychosocial model of dementia and theory of personhood, proposing that dementia was not simply a neurological impairment, but also involved interplay of the person's personality, history, physical health, and social environment.

1.6.2.1. Personhood: Personhood has traditionally been derived from Cartesian dualism and connected to cognitive functioning. This suggests that dementia eliminates personhood (Herskovits, 1995), and perpetuates the stigma around dementia, as people fear losing their sense of who they are (see Bryden, 2012). Kitwood (1990a) challenged the capacity-based view and saw personhood as relational; a view that is becoming progressively more established (Baldwin & Capstick, 2007). He suggested that dementia does not destroy personhood, but it is eroded away by the person's environment, as interactions with others devalue and disempower the person with dementia. This was termed 'malignant social psychology'.

Davis (2004) critiques Kitwood's ideas on personhood, suggesting that the concept of malignant social psychology places blame on the carer. He states that dementia subsumes the existence of a person, which leads to aspects of Being[1] disintegrating as the dementia progresses. Davis suggests that we must allow for the loss of personhood to permit carers, who no longer recognise the person before them, to grieve the loss of their former relationship. However, this perpetuates the stigmatising metaphor of dementia as a 'living death'.

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[1] Use of 'Being' draws from Heidegger's (1962/1990) notion of *Dasein*. Existence through 'Being' is self-interpreting, and cannot be extricated from the surrounding world. It is also temporal; based in the past, present and future. In this way, 'Being' is considered to be a contextual and temporal awareness of existence (Davis, 2004).

Assumptions around loss of personhood, agency and citizenship are also demonstrated in Irastorza, Corujo and Bañuelos's (2011) article, which questioned whether those with a dementia diagnosis should retain their right to vote. Through arguing that those diagnosed will not appreciate the consequences of their vote, the authors neglect to consider that that this is a risk for anyone in the population as a whole, and is not just limited to those deemed cognitively impaired (see YouGov, 2017). This augments the current rhetoric around dementia, where ideas around citizenship and personhood are frequently eroded (Baldwin & Capstick, 2007).

In contrast, studies demonstrating personhood include that by Lyman (1989), who explored the views of those with significant impairments and a diagnosis of latter stage dementia. Lyman illustrated that people were 'living with' rather than 'dying from' dementia (see also, for example, Castro & Clark-McGhee, 2013; Hydén & Örulv 2009; Sabat & Gladstone, 2010). Woods, Thorgrimsen, Spector, Royan, and Orrell (2006) studied quality of life in those with a dementia diagnosis, and concluded that it was independent of level of cognitive functioning. Similarly, Sabat (1998) had conversations with people considered to be moderately to severely impaired and found an intact sense of personal and social identity, and a desire to be recognised. There is, therefore, more to personhood and experience of dementia than biology, which illustrates the necessity to include the views of those with a dementia diagnosis within research.

Birt, Poland, Csipke and Charlesworth (2017) and Kontos, Miller and Kontos (2017) advocate changing social practices to allow those diagnosed with dementia to participate in and belong to a community. They suggest that this would alter the discourse around dementia from being deficit-focused, to a discourse that allows for interdependence and supports the individual in shaping their social world; protecting the individual's agency and citizenship status.

1.6.3. <u>Social Construction of Dementia</u>

Many doctors do not work within the rigidity of the medical model, but operate within the biopsychosocial framework, taking into account the influence of

psychological and social factors (O'Reilly & Lester, 2017). From a medicalised perspective, however, the cause of illness is linked to the individual through genetics, biology and physiology. It is argued that the medical and biopsychosocial perspectives co-exist rather than genuinely integrate, and that the biopsychosocial is being pushed back into the 'shadows' with the re-ascendency of biomedical perspectives (Pilgrim, 2002). This is reflected in Kitwood's (1987; 1990a; 1990b) biopsychosocial model, who saw his framework as complementary to the medical model but often moved between conflicting positivist and social constructionist paradigms in his texts, while considering the biological and psychosocial aspects of his model respectively.

With dementia being held in the medical sphere, the associated symptoms become problematised. Harding and Palfrey (1997) argue that the dementia label is used to separate those who demonstrate deviant behaviour in their old age from the rest of society, thus denying them their personhood. Perceived to be symptomatic of disease, their behaviour is able to be addressed and controlled through medical or social means (Harding & Palfrey, 1997). This is supported by Bryden (2012) and Pratchett (2014), both diagnosed with dementia, who postulate that it is the socially unacceptable behaviour of the person with the diagnosis that leads to stigma. Views regarding the dementia construct are historically, culturally, politically and socially bound and, despite healthcare professionals considering psychosocial aspects of dementia, medical and psychological treatments are still sought to return the person to as close a state of 'normal' as possible. Commonly used medical treatments include the use of acetylcholinesterase inhibitors and antipsychotic medication, however, psychosocial interventions such as cognitive stimulation therapy and life story work are increasingly offered to help people come to terms with their diagnosis, maintain quality of life, and support thinking and memory (British Psychological Society, 2014). Such psychosocial interventions are reserved for those considered to be in the 'early stages' of dementia, with psychosocial interventions used in more 'advanced' dementia remaining focused on behavioural change (see Howe, 2008). However, as 'dementia' cannot at present be cured by psychological or medical means, the individual is positioned as 'deficient'; a burden on a normally functioning society (Gilson & Depoy, 2000).

In Foucault's (1963/2003) 'Birth of the Clinic', biomedicine was considered a sociological force bringing the aged body under the medical gaze. Further, Davis (2004) suggests that the collective work of clinicians, researchers, activists and carers legitimises the extension of the medical gaze over the domestic and social lives of older adults. When dementia is considered to be a disease, this offers a more palatable view of ageing. Rather than fearing natural deterioration, society is able to see medics and scientists working to eliminate the 'disease', apprehending processes that deviate from the 'natural' physiology of the body (Davis, 2004).

The rhetoric of the medical model is pervasive across British society and throughout the Western world, separating those with a diagnosis from mainstream society (O'Reilly & Lester, 2017). This portrayal of dementia influences how wider society responds to, understands, and perceives dementia and, therefore, how a diagnosis is both given and received.

1.7. Dementia's Context: Social Narratives

"Maybe at the later stages of our lives we don't need a diagnosis or label of disease at all, but to find ways to accommodate the changes instead."
(Swaffer, 2012)

Throughout this section I will further consider the ideas around dementia that are prevalent in British society, addressing the stigma that surrounds the label.

1.7.1. <u>Dementia and Stigma</u>
A survey by Alzheimer's Society (2009) found that people fear a loss of self if diagnosed with dementia, and consider dementia to be 'a living death'. This fear can affect help-seeking behaviour, as people attempt to avoid the diagnosis, embarrassed and afraid of their own forgetfulness (Ballard, 2010). Terry Pratchett, himself diagnosed with dementia in 2007, felt that to reduce the shame felt around having a dementia diagnosis, society needed to spend more time talking about dementia (Alzheimer's Society, 2008a). However, while raising public consciousness around dementia, awareness campaigns have emphasised the lack of an existing cure and thus contributed to rising societal

fear (Fox et al., 2013). For example, Macmillan Cancer Support ran a campaign in 2017 emphasising that a life with cancer is still a life. Alzheimer's Society's (2017b) simultaneous campaign took an opposing approach, calling dementia 'the UK's biggest killer' and stressing the need to find a cure. The evocative language from Alzheimer's Society used fear to elicit support for dementia research, and supports the narrative around a cure being the only hope for those diagnosed and those who may be diagnosed in the future. This suggests that a life with dementia is not a life at all. Similarly, the National Health Service (NHS) 'Live Well' website ("All Live Well Topics", n.d.) provides information on living with life-changing diagnoses such as HIV and cancer, yet dementia is omitted, even among the topics aimed at those aged 60 and over, implying that there is no way to 'live well' with a dementia diagnosis.

The stigma around dementia in the UK also appears to be cross-cultural, with studies of people from African-Caribbean and Punjabi Indian backgrounds finding dementia portrayed as a 'madness', as shameful, and as being caused by an individual's lack of effort in later life (Botsford, Clarke, & Gibb, 2005; La Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007).

1.7.2. Dementia and Ageing

Stigma around dementia is compounded by stigma around ageing. Rowe and Khan's (1997) pioneering paper on 'successful ageing' considered those with little or no loss in physiological functioning to have aged successfully. While intending to challenge the idea that ageing equates to physical decline, this instead altered the normative framework so that those with health problems or disabilities were considered to have 'failed' (Bülow & Holm, 2016). This concept focuses on individuals to the exclusion of environmental, cultural, social, and political determinants of health inequalities (Katz & Calasanti, 2014; Kendig & Browning, 2016), and establishes that successful ageing involves eluding dementia (Daffner, 2010). However, a 'disease-free' older age is unrealistic for most people (Bowling & Dieppe, 2005), and positive adaptation to age related restraints has been shown to be possible, giving stability despite loss (Baltes & Smith, 2003).

Bowling and Dieppe (2005) investigated lay views on successful ageing and found that psychosocial aspects such as life satisfaction and having a sense of purpose were considered to be of importance. Many older people regard themselves as happy and well, even in the face of health difficulties (Bowling & Dieppe, 2005), suggesting that the biomedical perspective has little relevance for older people themselves. This seemingly contradicts studies that have shown that stigmatised views are internalised by older adults (see section 1.7.4.), but could indicate a state of cognitive dissonance. For some, this could mean thinking that older adults are a burden, while not personally identifying with the 'older adult' label. For others, they might think of themselves as a burden while concurrently considering themselves to be doing better than those more severely impaired.

Seen within the 'successful ageing' paradigm, dementia is constructed as 'failed' old age. Narratives of physical decline dominate consultations between doctors and older patients (Bowling & Dieppe, 2005), and thicker narratives remain unexamined. McParland, Kelly and Innes (2017) suggest that this discourse reduces the complexity of dementia to a dichotomy of either 'catastrophe' or 'living well'. They suggest that there are multiple realities and experiences of dementia, and that this needs to be recognised for social inclusion to occur.

1.7.3. Dementia and Metaphor

Susan Sontag (1989) argued that people project their feelings about evil onto certain diseases, and described how metaphors and myths created through the portrayal of disease and illness can add to the suffering of those with the diagnosis. Common metaphors include portraying dementia as an 'epidemic' (Gubrium, 1986) and a 'rising tide' (Zeilig, 2014), implying that everyone is likely to be diagnosed with dementia due to the unstoppable nature of this threat. Dementia has been said to render people 'empty shells' (Devlin, MacAskill, & Stead, 2007), seeing them as physically present but mentally absent. Despite Kitwood's (1987, 1990a, 1990b, 1997) emphasis on personhood, this Cartesian perspective suggests that the true person is found in the mind. Dementia is often described as a "significant social problem" (see Cantley, 2001:309), suggesting that our social fabric is in danger. These metaphors elicit fear, as

shown in Clare's (2002) use of the military metaphor of 'fighting' dementia. To counteract these reductionist metaphors however, alternatives have been developed. Castro (2011) states that the person is not an empty shell, but a shell with a pearl inside. If the shell is encouraged to open, the person will shine through.

1.7.4. Dementia and the Media

In Western culture, those who do not retain the qualities associated with youth are portrayed to be expensive and a burden on society, unattractive, and even sexless (Castro Romero, 2017). Through assuming that having a youthful, beautiful and functional body is the only way of living a valuable life, the stigma surrounding both dementia and ageing is perpetuated.

Peel (2014) reviewed British print media between October 2010 and September 2011. She found that a discourse of 'panic-blame' dominated national newspaper articles, where dementia was represented in catastrophic terms such as 'tsunami' and 'worse than death'. This was juxtaposed with coverage in the same newspapers of recommendations of individualistic behavioural and lifestyle change to prevent the onset of dementia, which reflects the values of the capitalist and individualist Western world, where health and illness are imbued with notions of self-control and willpower (Grenier, Lloyd, & Phillipson, 2017; Peel, 2014). Media representations, which are dominated by tragedy discourse (Bartlett & O'Connor, 2010), shape how we come to see ageing and dementia.

Headlines such as 'Ageing Britain: two fifths of NHS budget is spent on over-65s' (Robineau, 2016), 'Alzheimer's: A living death both for the patient and their loved ones' (Lefever, 2012), and 'Families need support with burdens of ageing' (Telegraph View, 2014) serve to promote this discourse. The popular social narrative, therefore, focuses on the challenge posed by dementia in medical and social terms, rather than empowering those diagnosed with dementia. This focuses on issues that are important to those who have not received the diagnosis, rather than directly asking about the lived experience of dementia from those who have been labelled in this way.

Corner (1999) found that the language used by older adults often reflects the language used by the media, such as describing themselves as a 'burden'. Bond, Peace, Dittmann-Kohli, and Westerhof (2007) believe that the notion of 'burden' is one of the most negative stereotypes of old age, and one that is increasingly in the public eye. Bond and Corner (2004) found that most of their participants described ageing using negative old age stereotypes, reflecting the ageist culture within which they were situated. Systematic and institutional stereotyping on the basis of age means that beliefs are internalised and the ageing body and mind are seen through a negative and often hostile lens. This supports an association between ageing and the inevitability of decline (Nelson, 2004).

Through disregarding personhood in a society that reviles and marginalises old age, disability is caused. Those labelled with dementia experience social exclusion, oppression (Oliver, 1996), and the stigmatisation of a 'spoiled identity' (Goffman, 1986). Excluding those with a dementia diagnosis from society can be seen as a defensive reaction; a response to the anxieties of a society that fears ageing, frailty, and our own mortality and, thus, reveres youth. Little sense of community and a focus on individuality at the expense of interdependence serve only to compound this fear. In this way, social processes work to undermine the person with the diagnosis, causing them to be impaired and perpetuating malignant social psychology.

1.8. Giving the Diagnosis

In this section, I shall explore literature pertaining to the giving of a dementia diagnosis, focusing on the skills and attitudes of clinicians and the format of the 'disclosure session', suggesting that the health professionals whose role it is to assess for and give a dementia diagnosis, are not impervious to the above rhetoric.

Formal diagnoses have been increasing since the launch of the National Dementia Strategy (Department of Health, 2009), which set a target to increase rates of early diagnosis. Nevertheless, a theme throughout the literature review was that dementia was considered by researchers to be underdiagnosed and

under-treated, particularly in primary care (e.g., Bradford, Kunik, Schulz, Williams, & Singh, 2009; Connolly, Gaehl, Martin, Morris, & Purandare, 2011; Iliffe et al., 2012; Raicher & Caramelli, 2008), despite Milne (2010) suggesting that most people are in favour of being informed of a dementia diagnosis. Milne's findings were supported in a study by Holsinger, Boustani, Abbot, and Williams (2011) where 86% of people (N=345) were in favour of dementia screening, though those with a friend or family member diagnosed with dementia are less likely to support diagnostic screening or disclosure (Robinson, Canavan, & O'Keeffe, 2014; Turnbull, Wolf, & Holroyd, 2003). This suggests that people with a dementia diagnosis elicit fear in the systems surrounding them, which the systems manage through wishing to avoid hearing the diagnosis themselves. However, the three aforementioned studies excluded people with a dementia diagnosis from their samples, asking people to engage in imagining a hypothetical situation rather than talking to people with lived experience of the diagnosis.

Following a dementia diagnosis, most people are simply discharged from specialist services (Innes, Szymczynska, & Stark, 2014). This is in stark contrast to those receiving a HIV or AIDS diagnosis, where pre- and post-diagnostic counselling is a core element in the diagnostic process (Chippindale & French, 2001; Williams, 2004). While there is a call for post-diagnostic support to be routinely offered to the person diagnosed with dementia and their family, this is not yet standard practice (Department of Health, 2016). The National Institute for Health and Care Excellence (NICE, 2016) recommend that clinicians discuss the diagnosis of dementia and its implications with the person diagnosed, and suggest that ongoing support may be needed. Still, the quality of disclosure skills is rarely addressed, and clinicians consistently report limited skills and confidence in disclosing a dementia diagnosis, leaving them with a sense of discomfort, and fear of causing distress (Iliffe et al., 2012; Kerwin, 2009; Mitchell, Meader, & Pentzek, 2011; Rae, McIntosh, & Colles, 2001). In a qualitative study of the needs of general practitioners (GPs), Foley, Boyle, Jennings and Smithson (2017) found that the 14 GPs interviewed wanted further education on diagnostic disclosure and symptoms.

In the 'Facing Dementia' survey (Bond, Stave, Sganga, O'Connell, & Stanley, 2005), 71% (N=605) of GPs and specialist practitioners stated that they felt uncomfortable discussing Alzheimer's disease with their patients for the first time. In another study, doctors stated that they were reluctant to make a dementia diagnosis, as they feared it would stigmatise their patient (Milne, Hamilton-West, & Hatzidimitriadou, 2005). Clinicians are anxious about their disclosure skills, but stigma can also make it difficult to openly discuss dementia. Brooker, La Fontaine, Evans, Bray, and Saad (2014) suggest that reducing stigma for older people will make diagnosis easier, as more people will come forward seeking diagnosis, however, this suggests that stigma only affects older adults and that health professionals are impervious to social discourses.

Reluctance to diagnose can be ascribed to a belief that nothing can be done to help those with a dementia diagnosis (Alzheimer's Disease International, 2012; Alzheimer's Society, 2008b; National Audit Office, 2007; Phillips et al., 2012; Vernooij-Dassen et al., 2005). GPs in the UK have been found to be less positive about the benefits of treatment and slower to prescribe medication than doctors in other European countries, feeling that diagnosis is a waste of resources (Wilkinson, Sganga, Stave, & O'Connell, 2005). Vince, Clarke and Wolverson (2017) proposed that nihilistic attitudes regarding outcomes impacted upon diagnostic communication, with the psychiatrists studied spending little to no time considering or discussing the wellbeing of the client when providing them with a life-changing diagnosis. This pessimism and lack of attention paid to quality of life was also reflected in studies that referred to those with a diagnosis as 'dementia sufferers' (see Cotrell & Schulz, 1993; Phinney, 1998; Sabat, 1998; Werezak & Stewart, 2002).

Low levels of confidence in making an accurate diagnosis can manifest in avoidance of discussing the diagnosis with the patient (Karnieli-Miller, Werner, Aharon-Peretz, & Eidelman, 2007), and the use of euphemistic language, such as saying 'memory problems' rather than using the term 'dementia' (Kaduszkievwicz, Bachmann, & van den Busscle, 2008). This is understandable given the problems with the validity of the diagnosis, and has been replicated in studies across Europe, including the UK (see Connell, Boise, Stuckey, Holmes

& Hudson, 2004; Gwilliam & Gilliard, 1996; Hansen, Hauge, & Bergland, 2016; Kaduszkiewicz, Wiese, & van den Bussche, 2008; Moore & Cahill, 2013). Karnieli-Miller et al. (2007) suggest that clinicians attempt to dull the impact of receiving the diagnosis through avoiding elaboration, keeping encounters short, avoiding confirmation of comprehension, and avoiding using explicit terminology. However, this fear of naming dementia perpetuates misunderstandings surrounding the label and denies people an opportunity to make sense of the diagnosis (Alzheimer's Society, 2009; Lee, Roen, & Thornton, 2014).

A systematic review by Bamford et al. (2004) found wide variability in diagnostic disclosure practice. The information given during diagnostic disclosure has been shown to differ depending on clinician and recipient, with information on prognosis and available support frequently being provided to family members but not the person receiving the diagnosis (Downs, Clibbens, Rae, Cook, & Woods, 2002; Kissel & Carpenter, 2007). This can have significant implications, as Mental Health Foundation (2011) report that when personhood is disregarded and the individual is not provided with information or included in decision-making, they feel a sense of shame and worry about their future. While there are suggestions about best practice in the conclusions of many studies (see Downs et al., 2002; Mitchell, McCollum, & Monaghan, 2013; Murphy & Gair, 2014; Kissel & Carpenter, 2007; Turnbull et al., 2003), these studies may not be read by those working in the field, and there are no uniform national or international guidelines for practitioners. However, even when local guidelines are in place, a narrative review by Carpenter and Dave (2004) found that clinicians, patients and family members reported that their experiences differed.

Disclosure practice can be impacted by the guidelines for medics on how to break bad news, which portray the diagnostic process as a single event, neglecting the social impact of the diagnosis (Murphy & Gair, 2014). Stage models of the emotional impact of a dementia diagnosis are suggested by Aminzadeh, Byszewski, Molnar and Eisner (2007), Cohen, Kennedy and Eisdorfer (1984) and Keady and Nolan (1995), reflecting that diagnosis is not a single event but is preceded by a period of worrying about changes such as memory difficulties, receiving and coming to terms with the diagnosis, dealing

with feelings of anger, guilt and sadness, deciding whether to be open about the diagnosis with others, and disorganisation or adaptation. Therefore, formally receiving the diagnosis is only part of a process of continual adjustment. These contrasting attitudes contribute to a perceived lack of empathy and support from clinicians during and following diagnosis, with those receiving the diagnosis feeling misunderstood and unsupported by the disclosing clinician (Alzheimer's Society, 2014; Werezak & Stewart, 2002).

Furthermore, Karnieli-Miller, Werner, Neufeld-Kroszynski, and Eidelman (2012) studied 25 memory clinic encounters between clinician, the person receiving a dementia diagnosis, and their family member. While the clinician started the session being focused on the individual being assessed, the results of the assessment and recommendations for continuation of care were discussed with the family member, thus silencing the person receiving the diagnosis, who, upon receiving the diagnosis, is no longer seen to have agency.

1.9.   Dementia in Research

"It is necessary first to accept that people with dementia have a voice that is worth listening to, second to facilitate the use of it and third to hear it."
(Goldsmith, 1996, ix)

A literature review by Downs in 1997 found no literature focusing on the person with a dementia diagnosis. Before moving on to reviewing the studies of most relevance to the current study in section 1.11, it appears pertinent to address that in my literature review twenty years later, little has changed. Most of the studies in this literature review gathered their information through interviewing healthcare professionals or carers about issues around dementia rather than speaking directly to those with a dementia diagnosis (e.g., Bensaïdane et al., 2016; Gooblar, Roe, Selsor, Gabel, & Morris, 2015; Laakkonen et al., 2008). While Brooker (2007) states that there has been increasing recognition that those diagnosed have something important to say, this does not seem to have translated to the field of research. The perspectives of those diagnosed with dementia regarding diagnostic practice remain largely neglected (Cowdell, 2013). Still, there is a wealth of resources on the impact of dementia on family

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carers, focusing on caregiver needs and 'burden' (Keady & Nolan, 2003). Studies in the current literature review asked the individual's carer about the diagnostic disclosure session (see Connell, Boise, Stuckey, Holmes, & Hudson, 2004) or to interpret the mood and behaviour of the person with a dementia diagnosis (see Holroyd, Turnbull, & Wolf, 2002), disregarding the experience of those diagnosed. This is despite differences of opinion having been found when conducting interviews with carers and those with a dementia diagnosis (see Mastwyk, Ames, Ellis, Chiu, & Dow, 2014). Similarly, people without a diagnosis are also asked for their opinions on diagnostic disclosure (see Robinson, Clare, & Evans, 2005).

Dementia is largely understood as a biomedical disease of irrevocable decline, where the 'diseased' are unable to contribute to an understanding of their condition due to memory and language difficulties, and a perceived inability to provide informed consent (Bamford & Bruce, 2000; Dewing, 2002; Rollin-Sillaire et al., 2013; Taylor, DeMers, Vig, & Borson, 2012). Despite this, there is increasing indication that dementia's outward expression is affected by factors such personal history, relationships with others, and culture (O'Connor et al., 2007), reflecting the importance of considering personhood in dementia. Keady and Nolan (2003) and Dalby, Sperlinger, and Boddington (2012) emphasise that those in the early stages of dementia have been shown to be reliable and insightful. This suggests that those in the 'later stages', who are finding traditional communication more difficult, can offer little of value to research, however, Hughes and Castro Romero (2015) found that through taking a narrative approach and employing a processural consent methodology, interviewing those with communication difficulties could be extremely fruitful. Similarly, Cohen et al. (1984) found that people were willing and open about discussing their memory difficulties and its effect on their lives, while Clare (2002) found that acknowledgement in research was one of the few ways that people diagnosed with dementia could feel useful.

1.10. Receiving the Diagnosis: First-hand Accounts

Some people who have been diagnosed have written up their experience of diagnosis in an autobiography or through contacting agencies such as

Alzheimer's Society, taking the onus on themselves to make sure that their voice is heard. I reviewed this material following the main literature review, since only a small minority of the studies returned included people with a dementia diagnosis. Without this, this chapter would have been largely empty of their voices.

First-hand accounts describe mixed experiences of the support received upon receipt of the diagnosis. For example, Christine Bryden (2012), in Australia, describes being informed of her diagnosis in a matter-of-fact manner, where the biological details of what was happening in her brain were explained without consideration of the psychosocial impact. She had many questions about the future and was not provided with support on how to manage these feelings. Her fear and anxiety, which were influenced by popular stereotypes of Alzheimer's disease, had to be managed alone.

Bracken (2017) interviewed Shelagh Robinson, who lives in the UK and is diagnosed with Alzheimer's disease. Similar to Bryden's (2012) account, she recounts "The consultant spent three minutes with me and didn't turn away from his computer. [...] He told me I had dementia, gave me medication and said, 'See you in three months'" (p. 9). She also felt affected by social narratives around dementia, stating "I remember people referring to dementia as 'senile decay' – this concept of decay or dying has entered our consciousness. People are afraid of it" (p. 10).

When Terry Pratchett (2014) wrote about his experience of receiving the diagnosis, he described feeling a sense of rage; he was offered no support because he was too young to access NHS older adults' services. Pratchett felt that had he been diagnosed with cancer, a well-trodden path would have opened up before him. He would have been given appointments with specialists and treatment would have begun. Bryden (2012) feels that upon diagnosis, attention turns toward the impact on the carer. She wondered if those diagnosed were considered "too far gone" (p. 67) to be offered support.

While these accounts are written by people under the age of 65, they reflect feeling distressed and unsupported following diagnosis. This is likely to be

compounded in those who have retired, by the impact of living in an ageist society and the increased isolation often experienced by older adults (Valtorta & Hanratty, 2012).

1.11. Receiving the Diagnosis: Current Research

This section shall critically review each study returned in the literature review that addressed receiving a dementia diagnosis, where the opinion was sought of the person diagnosed with dementia.

Marzanski (2000) found that of the 30 people diagnosed with dementia who were interviewed, 20 felt that they had received little or no information on their diagnosis and 25 were not provided with an opportunity to ask their clinician questions. Marzanski critiques his own study for having interviewed people diagnosed with dementia without verifying their statements, stating that their cognitive impairment and possible use of defence mechanisms may reduce the credibility of the results. This takes a positivist view of dementia and does not consider that the inability to provide definitive reliability may be true of all people rather than just those diagnosed with dementia, as each research encounter offers a particular context for what is said or enacted (Beresford & Evans, 1999). Although this reflects the assumptions that often exclude those with a diagnosis from research, Marzanski declares that comparing their statements with "cognitively intact" (p. 320) peers in a parallel inquiry found no significant differences in the quality of information received or level of insight, thus challenging some of these assumptions.

Pratt and Wilkinson (2001) argue that the way in which the diagnosis is shared may be less salient than the shock of knowing the diagnosis, however, they found that people wanted the diagnosis to be sensitively disclosed over time, and for individual needs to be responded to, including the need for further information and for follow-up. Unfortunately, few of the 24 people interviewed could provide examples of this happening, reporting poor and inconsistent practice where they were seen as passive recipients of the diagnosis, thus supporting Marzanski's (2000) findings. The emotional response to the diagnosis was influenced by the individual's social context, such as the attitude

of family members and beliefs around social stigma. While this is a well-designed and valuable study, use of thematic and case study analyses neglects to consider the larger meaning of the narratives that are being told, looking directly at what is said by participants rather than what may be behind their statements.

Mastwyk et al. (2014) interviewed memory clinic patients and carers, and found that compassion, a direct approach, and written information, were considered to be the most helpful aspects of the diagnosis session. Without written information, being invited to ask questions, or a family member being present, recall from the diagnostic disclosure session was variable. Nevertheless, a family member being present did not automatically mean that the diagnosis was understood or recalled. Barrett, Keller, Damgaard, & Swerdlow (2006) found that 70% of people diagnosed with dementia (N=37) and a significant minority of carers (16%; N=37) were unable to accurately report the diagnosis shortly after disclosure. Both of these studies conducted joint interviews where carers and those diagnosed were present at the same time, however, limited attention was paid to the way in which this may have shaped the stories that were told.

Manthorpe et al. (2013) interviewed 53 individuals and carers who had recently undergone an assessment for dementia. The participants believed that timely diagnosis would lead to improved outcomes, so felt anxious about waiting times and what felt like long delays between appointments. They also felt that communication with professionals was not person-centred. Questions were reportedly not answered, little information was provided, and that which was provided felt generic. Manthorpe et al. used purposive sampling to increase recruitment of under-represented groups such as females, but failed to consider how the individual's context may have impacted upon their interpretation of the assessment. Women, for example, in societies where they are defined by their caring abilities, can find it difficult to adjust to their changing role, fearing losing their identity and becoming a burden (Borley, Sixsmith, & Church 2016). Manthorpe et al.'s interviews used euphemistic language so as not to distress participants, but I wonder how much this perpetuates the stigma around dementia as something too powerful to be named. Furthermore, the results section of the study does not separate the views of carers from those

diagnosed, failing to acknowledge that the assessment will have a different meaning for each.

Husband's (1999) series of case studies showed that when dementia was diagnosed, anxiety was elicited. Participants feared becoming a burden to their partner and 'going mad'. This was replicated by Werezak and Stewart (2002), who also found that participants considered future losses, and worried about how others would respond should they find out, reflecting the stigma around the diagnosis. Despite this, all participants in Werezak and Stewart's study felt that they were still the same person after the diagnosis, especially if they retained the skills and abilities that they felt gave their life meaning. However, having received little support from the NHS or social services, many turned to Alzheimer's Society for support.

How the diagnosis is understood, access to resources, and the coping strategies used, may differ according to psychological and social factors such as gender, ethnicity and social class, moderating individual experiences. This is not, however, considered in these studies.

1.12. Justification, Aims and Relevance

"…my opinion is no longer sought, and I am thought to lack insight."
(Bryden, 2005:40)

Kitwood (1990a) states that to acknowledge personhood, we need to engage with people with a dementia diagnosis and understand their experiences. Through excluding those with a dementia diagnosis from research and disregarding the impact of the diagnosis - as was common in this literature review - those with a dementia label are disempowered and stigmatised, further marginalising their opinions and experiences.

When the views of those diagnosed with dementia were directly sought, the literature failed to consider the impact of the broader socio-cultural context upon how the interviewees framed their responses, despite the profound and dynamic impact this has upon personal perception and how experience is

recounted (Emerson & Frosh, 2004). Few studies in section 1.11. appeared to consider those diagnosed with dementia as being able to give a 'reliable' response, and sought the opinions of others to verify the 'truthfulness' of their responses. This positivist view undermines personhood and neglects the importance of felt experience.

Furthermore, the literature review suggests that people are unhappy with the way in which they are treated during the diagnostic process, and that the care that is offered is not reactive to the opinions of those diagnosed with dementia. Consequently, services may not be useful or meaningful to those who access, or may need to access them.

Contributing to the restoration of the person to the centre of dementia care, this study will aim to explore satisfaction with the diagnostic process and the support received, through speaking directly to people who have received a dementia diagnosis. The study will also address the ways in which the label has impacted their sense of self, alongside consideration of the social context that shapes the disclosure session and the way in which the diagnosis is understood.

1.13. Research Questions

- How do those diagnosed with dementia experience the assessment process?
- How can narratives around the impact of the dementia label be understood within the wider context of 'successful ageing'?

2. METHOD

Within this chapter, I will outline the design and methodology of the present study, explain my epistemological position, provide a rationale for choosing a narrative approach to analysis, and detail the procedures used for recruitment and data collection.

2.1. Qualitative Methodology

A qualitative methodology was deemed to be the most suitable for this research, as it can capture experiences in ways that are much richer than can be demonstrated through quantitative research (Beuscher & Grando, 2009). A further advantage of this methodology is that listening to those diagnosed with dementia in a research setting has been shown to give the individual a sense of usefulness and purpose, emphasises their value and, thus, honours their personhood (Jonas-Simpson, 2001; Katsuno, 2003; Moore & Hollett, 2003). One-to-one interviews and narrative analysis were selected, allowing those diagnosed to actively engage with the study through having a conversation with me, rather than passively engaging through, for example, completing a questionnaire.

2.2. Epistemological Assumptions

The research aims of this study lend themselves to a social constructionist epistemology. Social constructionism assumes that knowledge and meaning are not based on an objective truth, but are constructed for particular purposes and arise through our interactions with the world (Gergen, 2011). Reality is generated within human relationships and is, therefore, historically, culturally, and socially determined, with the belief systems and ideologies of wider society shaping how our identities are constructed (Gergen & Gergen, 2008; Harding & Palfrey, 1997).

Without minimising the importance of biological aspects of ageing and the impact that impaired memory and communication can have on relationships, adopting a social constructionist stance moves the focus away from ideas around disease and deterioration to allow for consideration of individuals' personhood. Instead of postulating whether biological mechanisms are important or relevant, this study will assert that they do not represent an objective reality. Our understanding of their impact determines our response to them, thus rendering them social constructions (Harding & Palfrey, 1997). The diagnostic disease-label of dementia will be acknowledged to be based largely on observed behaviour rather than pathology, and influenced by Western

concepts of medical knowledge in an attempt to bring order to a messy and complicated experience (Harding & Palfrey, 1997).

2.3. Why Narrative?

Killick and Allan (2001) suggest that storytelling is particularly important for those with many years of accumulated experience, who are confronting change and loss, and are at risk of being devalued and dismissed by others. Through being shaped by our socio-cultural world, narratives can reproduce existing forms of oppression through repeating hegemonic stories, or they can challenge dominant narratives through shedding light on subjugated stories (Ewick & Silbey, 1995). As this study aimed to give a voice to those diagnosed with dementia, who are often overlooked and suppressed, narrative interviewing and analysis were utilised. While the discipline of Psychology has exerted its power, and maintained inequality through its claim to be able to measure the objective world of humans (Emerson & Frosh, 2004), narrative analysis' attention toward the social construction of dominant discourses allows it to be a tool of social change (Clandinin, 2006).

2.3.1. <u>Validity</u>

Rather than addressing averages or themes, narrative analysis focuses on the storied reality as told by the individual, where narratives are viewed as subjective stories of experience rather than objective recounting of events (Squire, 2008). Narratives are not claimed to be representative of a wider population, but they show that an individual's reality is complex, and constructed through language, interaction, and discourse (Elliott, 2005). However, through viewing personal narratives as constructed and contextual, narrative analysis challenges prevailing concepts of validity, which rely on realist assumptions of knowledge. Alternative measures of validity needed to be considered for the current study.

Polkinghorne (2007) and Riessman (1993) argue that the validation of knowledge is an argumentative rather than mechanical process, where trustworthiness rather than 'truth' is what is critical. In order to persuade the reader of the validity of my argument, it needed to be well-founded, presenting

evidence such as quotes and literature alongside the analysis, and grounding conclusions in cited evidence (Polkinghorne, 2007; Toulmin, 1958). To achieve this, I combined my analysis and discussion, utilising current literature to strengthen my reasoning (further described in section 2.7.).

In order to further reinforce validity, I acknowledged reflexivity (see section 2.3.5.) and kept a study journal that detailed my decision making. I have shared an excerpt from this journal in Appendix B. These actions were to ensure transparency, which Riessman (2008) asserts is essential for validity claims to be made. To enhance external validity, add new insight, and assess the soundness of my analysis, I attended a narrative analysis group, reviewing sections of my analysis with other trainee clinical psychologists and my thesis supervisor. I also ensured that participants were provided with an opportunity to provide feedback on the analysis. Further discussion of validity can be found in section 4.1.3.

2.3.2. <u>Analysing Narratives in Context</u>

Narrative analysis has no definitive procedure, with researchers suggesting a number of different ways to approach the narrative form (Elliott, 2005). Based on the work of Labov (1972), some suggest that narrative analysis is concerned with the structure, order, and content of the stories that we tell (Murray & Sools, 2015). Those diagnosed with dementia, however, may need time and encouragement to be able to tell their story, which may not follow a traditional structure (Killick & Allan, 2001). Therefore, my analysis did not focus on structural and sequential features of storytelling, but utilised what Georgakopolou (2006) refers to as second wave narrative analysis; rather than viewing narratives as text, this involves the study of narratives in context. What is considered to be a relevant context for analysis, however, is subject to debate (Phoenix, 2008).

Since narratives develop in interpersonal and sociocultural contexts (Murray & Sools, 2015), Emerson and Frosh (2004) argue that removing a story from its context reduces its meaning, but through narrative analysis, the internal and external world of the storyteller can be considered (Clandinin & Connelly, 2000). This allows for the deepening of research through addressing personal stories

in their socio-historical, political and cultural contexts, and attending to the relational nature of all interactions (Etherington, 2004; Muylaert, Júnior, Gallo, Neto, & Reis, 2014). Therefore, in order to provide a culturally nuanced and active understanding of the narrative, it was important for my analysis to attend to what the narrator said, how they said it, and the immediate and broader contexts in which the account was produced (Gubrium, 2006). In this study, the influence of Western beliefs regarding disease, ageing, and personhood were privileged regarding context, while remaining mindful of other contexts that may have been acting upon myself (see section 2.3.4.) or the narrator.

Through placing an individual's reality in its broader context, narrative analysis demonstrates validity through recognising that knowledge is partial and closely aligned with power (Emerson & Frosh, 2004). However, social power mechanisms mean that some stories will still be silenced, even when they are invited to be shared. Stories are jointly told between speaker and hearer, and are performed differently in different social contexts, with the narrator anticipating different responses from the audience and assessing what is acceptable to say and do (Ricoeur, 1991; Squire, 2008). Since they have a performative function, which can either maintain the status quo, or can be emancipatory (Phoenix, 2008; Plummer, 1995), it was important to consider this performance in the analysis, thus, attending to deeper meanings beyond the words that were spoken (Earthy & Cronin, 2008). This included addressing heteroglossia[2] and polyphony[3], in looking for different voices and ideologies represented within the narrative (Bakhtin, 1981).

2.3.3. Big and Small Stories

There has been debate in the field as to whether narrative analysis should be focused on 'big stories' or 'small stories' (Bamberg, 2006). 'Big stories' are the narratives directly elicited through the questions of the interviewer, while 'small stories' may appear unrelated to the question, incoherent, and without a beginning, middle or end (Bamberg & Georgakopoulou, 2008; Battersby, 2006; Phoenix, 2008). In analysing the words of those who may experience

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[2] Appropriating the language of another for personal use and, therefore, representing two or more viewpoints within a single discourse.
[3] Multiple points of view, perspectives, and voices, represented by different 'characters' throughout the narrative.

communication difficulties, it was important that alongside attending to the events that were being recounted in response to the interview questions, I paid attention to these 'small stories' and their meaning.

2.3.4. Key Narratives

Key narratives emerge from the stories we tell, centring around recurrent content or themes, and showing how we make sense of our world (McAdams, 1997; Phoenix, 2008). They can reflect canonical and personal narratives, be repeated a number of times throughout an interview, and demonstrate how the impact of culture is visible in the context of both 'big' and 'small' stories (Phoenix, 2008). Boenisch-Brednich (2002) suggests that key narratives are developed through the events and processes that the individual considers to be important, and are refined through repeated retelling throughout an individual's life. They become familiar and easily accessible accounts, presenting a particular identity to the interviewer and to the narrator themselves (Phoenix, 2008). There is a risk that when interviewing someone diagnosed with dementia, however, repeated re-telling is dismissed as simply a sign of memory difficulties and, through doing this, key narratives may be overlooked. Returning to the same story or theme can signify the importance of the statement, feeling, or need, so it was important that this be considered in the analysis.

2.3.5. Reflexivity

Accounts are constructed differently depending on their audience (Gergen, 2011). The stories I am told in interviews are created by the participants' experiences and identities, but also co-created through our interactions (Burr, 2003). This includes being shaped by the questions that I choose to ask, the point at which I ask them, my facial expressions and non-verbal utterances, as well as participants' assumptions regarding aspects of my person such as my age, gender, professional background, perceived social class, the colour of my skin, and what they assume I expect from the interview. My beliefs and actions will also impact how the study is constructed and written, so it was important to hold this in mind (Nightingale & Cromby, 1999; Willig, 2013). To attend to this, I kept a personal diary throughout the study and used it to inform the analysis and discussion. Through being open about my positioning, I hope that the

reader will be able to reflect upon the way in which the collection, analysis and interpretation of data was co-constructed.

2.3.6. Analysis Summary

As suggested by Phoenix (2008), the approach to analysis combined descriptive and contextual approaches. To take account of the descriptive aspects of the transcripts, analysis focused on big and small stories, and the key narratives that these represented. Following this, two levels of analysis were undertaken to explore context; performative and sociocultural. Stories are not told within a vacuum, and are influenced by the immediate context of the interview and broader social narratives. These levels of contextual analysis allowed me to consider the narrator's motivation for telling their story, the identity they wished to reflect, the underlying beliefs and values that were represented, and the factors that may be influencing such beliefs.

2.4. Methods

2.4.1. Recruitment:

2.4.1.1. Service context: Recruitment was through an NHS Trust's four London-based dementia services. In these services, the dementia assessment process involves a meeting with a nurse, occupational therapist, psychiatrist or clinical psychologist, brief cognitive testing, and often, a blood test, MRI or CT scan, and ECG. Should further investigation be felt to be required, a clinical psychologist may support the person with in-depth neuropsychological testing, while the diagnosis itself is commonly provided by a psychiatrist. Following a diagnosis, the service may invite the person to join a group for those newly diagnosed, or a cognitive stimulation therapy group. However, these groups use a waiting list system dependent on demand for the groups and staff availability, and are not routinely offered to everyone diagnosed. Both of these groups are run by clinical psychologists, who are also able to provide psychotherapeutic input should the member of staff meeting with the person feel that this could be helpful. Following diagnosis, some are seen by a member of the team for a review of their practical or medication needs, while many are discharged.

2.4.1.2.   Recruitment process: The Trust's register of those who had consented to be contacted regarding suitable research studies was used to recruit four people who had received a dementia diagnosis. Potential participants were initially approached over the telephone by a member of the Trust's clinical trials team. If they expressed interest in the study, I contacted them over the telephone for further discussion of the study. This sometimes also involved discussion with the individual's spouse or other family member.

If they were happy to take part in the study, we arranged to meet in either in the participant's home or their local memory clinic. Cotrell and Schulz (1993) recommend that interviews are conducted in the home of the person with the diagnosis to minimise distress, but I felt that it would be beneficial to provide potential participants with options regarding the meeting location.

It was left up to the individual to decide whether they wanted someone who they trusted to attend the interview alongside them. This was to ensure that they felt as comfortable as possible, while acknowledging that a change in audience would affect the narrative provided by the individual. Two interviews were carried out with the individual alone, while for the other two interviews, the individual's spouse was present.

2.4.2. Inclusion Criteria

The person must:
- Have received a diagnosis of dementia in the last 6-12 months
- Have been informed of this diagnosis
- Express willingness to discuss their assessment
- Be aged 65 or over
- Be an English speaker

Type or severity of dementia was not used for exclusion purposes.

2.4.3. Participant Demographics and Pseudonyms

Demographic context and the nature of the diagnosis will impact upon how the diagnosis is given, the support offered, and the way in which the diagnosis is received, so is provided below (Table 1). These aspects will also shape how the

interviewer and interviewee consider themselves in relation to each other, and, therefore, how questions and answers are constructed and perceived.

Table 1: Participant characteristics

Pseudonym	Age	Gender	Ethnicity	Dementia Diagnosis	Relative Present?	Relative's Pseudonym
Ted	82	Male	White English	Alzheimer's disease	No	
Hugo	71	Male	White English	Alzheimer's disease/ Vascular dementia	Yes (Wife)	Patricia
Fergus	87	Male	White Northern Irish	Alzheimer's disease	Yes (Wife)	Nora
Fran	83	Female	White Irish	Alzheimer's disease with vascular dementia	No	

2.4.4. Procedure

Participants were contacted over the telephone and the study introduced. To avoid inadvertently revealing a forgotten diagnosis, participants were informed that the study was on personal experiences of being assessed and diagnosed with dementia, and asked if they thought this was of relevance to them. If interest in the study was expressed, information sheets were posted to the person's home. The information sheets and consent form were designed based on guidance on developing written material for older adults (National Institute on Aging, 2008), and the accessible and illustrative information sheet created by Allan (2001) and further developed by Hughes (2014). They did not use euphemistic language so as not to mislead participants. As suggested by Allan (2001), different versions of the information sheet were created for the person diagnosed and their family member or carer (Appendix C and Appendix D respectively), with both versions being sent to the potential participant's home.

If they agreed to learn more about the study, I met with participants to discuss this in their preferred location; three chose to be interviewed at home and one in a memory clinic. A reminder phone call the day before the interview was offered, but no one felt that this would be necessary. The meeting involved discussion of the study with the diagnosed individual and, if present, their spouse. Consent to participate was sought from the individual with the dementia diagnosis, who was provided with a copy of the consent form to keep (Appendix E). Each participant agreed to commence the interview immediately following this discussion.

The length of the interview and number of visits needed for the participant to tell their story was determined by the participant, which Clarke and Keady (1996) suggest helps to avoid tiredness and anxiety. Across the four participants, interviews lasted roughly one hour and 15 minutes, and no further visits were needed. If the participant's spouse was present, it was politely emphasised that the interview was particularly interested in the views of the participant, and that if they answered a question on behalf of the participant, I would re-ask the participant that question.

An unstructured narrative interview format was used, and participants were told that the interview would feel more like a conversation than a set of pre-determined questions, so were encouraged to speak for as long as they felt comfortable. I encouraged further talk through affirmations or asking questions, but my input varied across the interviews, depending on the communication style of the participant. Those who preferred to tell shorter stories were, therefore, asked more questions.

I used the guide in Appendix F as an interview prompt, and to ensure that interviews started and ended in the same way each time. Following guidance from Elliott (2005) stating that clear, jargon-free questions can stimulate broad, narrative responses, the interview schedule was based around two main questions: "Can you tell me about your experience of the memory clinic?" and "How has this diagnosis affected you?" Through asking about the impact of the diagnosis, I hoped to elicit discussion of the dementia label without directly asking about ageing and imposing this context upon our conversation. I felt that

this would add an artificiality when later addressing my second research question regarding 'successful ageing' in the analysis and discussion. Instead, through using the second interview question and a narrative interview style, the extent to which ageing arose was intended to reflect the extent to which socio-cultural constructs around ageing were having an impact on the individual.

Once the interview concluded, participants were debriefed, consent re-checked, and they were then thanked for their time. They were offered to be sent an accessible written summary of the study including the analysis of their interview, to which all participants agreed. An example of this can be found in Appendix G. This will be sent alongside a 'thank you' card and my contact details should they wish to provide feedback on the analysis. Further consent will be sought for this to be shared in any further dissemination.

2.5. **Ethical Considerations**

2.5.1. Ethical Approval

Ethical approval was granted by the Camden and Kings Cross Research Ethics Committee (Appendix H) and the NHS Health Research Authority (Appendix I). The study was also registered with the University of East London and the collaborating NHS Trust.

2.5.2. Informed Consent

Upon speaking to potential participants for the first time and explaining the study over the telephone, I posted information sheets to their home. I encouraged participants to read this information and discuss their decision about whether to take part with a family member or close friend. Prior to the start of the interview, I reviewed the information sheet with the participant and explained the consent sheet. At the beginning and end of each interview, participants were informed of their right to retract consent and be removed from the study at any time and asked if they had any questions.

The clinical trials team at the collaborating site deemed participants to have the capacity to make their own decisions regarding their participation in the study. Guided by the Mental Capacity Act (2005), however, which states that capacity

is context dependent and should be considered on a situational basis, consent conversations were ongoing and responsive to the individual. To bolster the written consent form, consent was also monitored verbally and behaviourally. Reflections on these observations were recorded in a journal to provide an audit trail of decision-making (Appendix B; Cowdell, 2008; Hughes & Castro, 2015). At the end of each interview, consent was again sought to use the recorded conversation in my study. This was to check whether the individual had changed their mind about taking part in the study, and to ensure that the individual had retained the information provided to them at the start of the interview and, therefore, could provide fully informed consent. Aiding people in making their own decision regarding whether to participate in the research balanced the individual's rights with the need to protect them (Hughes, 2014).

2.5.3. <u>Confidentiality, Anonymity and Protection of Vulnerable Participants</u>

Before consenting to participate in the study, participants were made aware that written data would be anonymised through removing identifying details including the name of the collaborating NHS Trust, and using pseudonyms. Anonymised transcripts were accessed only by myself, my Director of Studies, and examiners. Data was stored following the Data Protection Act (1998), with the list of people involved with the study and their consent forms being kept separately from the anonymised data, in a locked cabinet at the collaborating site. Documents that identified participants were destroyed once the final analysis was completed and summaries had been sent to participants. Interview recordings and transcribed data were transferred onto a password protected computer on a secure server and stored in separate password protected files. Audio recordings will be deleted once the research has been successfully examined, while transcripts will be stored for up to five years to allow for future publication of the findings. This was explained to participants and their family members verbally and through the information sheets.

The study was not anticipated to pose any risks to participants other than potentially eliciting feelings of tiredness, anxiety or confusion, however, it was explained to them that the interview could be paused, ended or rescheduled at any time they chose. In case risk of harm was indicated, the collaborating service's safeguarding policy would have been followed. Information sheets

also contained the helpline number for Alzheimer's Society and contact information for the relevant Patient Advice Liaison Service (PALS), should participants require further support or have concerns about their care. I also took information on carers' support and crisis support services to the interviews, however, this information was not needed by any participants or their spouse.

2.6. Transcription

The audio from the interviews was digitally recorded and transcribed. Appendix J shows the transcribing conventions used, adapted from Banister et al. (2011). Pauses, emphasis and non-verbal utterances were transcribed to provide additional meaning without artificially slowing down the reading of the text (Brown, 1995).

2.7. Analysis

The traditional format of research studies, through presenting an introduction, method, results and discussion, originated in order to present arguments for claims proposed in behavioural research (Bazerman, 1987). However, this format limits the strength of argument that narrative researchers can produce (Polkinghorne, 2003). Congruent with a synthesis of the different levels of analysis, I integrated narrative analysis with aspects of discussion drawn from current literature. This was an essential part of the analysis as it allowed for the research context and the broader socio-cultural and political context of dementia and ageing to be attended to, as outlined in the literature review. Through doing so, I was able to make a meaningful whole from each individual account.

Each transcript was analysed separately, considering the words of both the interviewer and the narrator. The presence and contribution of the individual's spouse was also taken into account, as this may have affected what the narrator felt able to say or not say, and the performative aspect of their narrative.

Transcripts were analysed using questions developed from Phoenix's (2008) approach to narrative analysis (Appendix K). Appendix L shows a sample of my transcription and analysis, which was formed over multiple readings.

The first reading of the transcript considered the descriptive aspects of the account, identifying key narratives and small stories. This helped me to gain an understanding of the issues that were raised. Subsequent readings took a more interpretive approach, connecting the narrative with the theoretical literature reviewed in chapter one while remaining reflexive and open to new ideas and challenges. I considered the interpersonal and performative context of the account, bearing in mind the audience and the co-construction of the narrative. Finally, I read the transcript considering societal contexts and the broader social narratives within which the account was structured, focusing on beliefs around ageing and understandings of dementia.

3. ANALYSIS AND DISCUSSION

This chapter integrates narrative analysis with aspects of discussion drawn from current literature. Each account will be introduced with a short description of the interview, while section 3.5 will act as more of a traditional 'discussion', seeking commonalities between the individual accounts and considering the accounts in the context of the research questions and the available literature.

3.1. Ted: A Story of Personal Resistance

I met Ted in his home, which he shared with his wife. Before the recording began, Ted joked about the interview and with a warm and friendly nature, teased me about my northern accent. This established a playful environment where my roles as researcher and interviewer were not positioned as dominant. Ted was eager to emphasise his strengths and show me that despite the ageist notions that permeate Western society, he was still feisty and his mind was strong. This narrative continued throughout the interview, with Ted demonstrating his sense of identity to me through focusing on his career rather than his diagnosis.

3.1.1. Disproving Negative Expectations

When asked about the memory clinic, Ted distanced himself from his experience, saying that he had answered the questions he had been asked, but had not thought about it since:

> [14-37] [T]: I've been at least once, that I can tell you. I haven't really bothered myself about it. I've just seemed to go through the process.

> [K]: What *was* that process?

> [T]: I mean, I don't really know. I feel fine; I feel normal. My memory is *pretty* good. I still remember [.] I remember childhood memories. It's the today memories that are the most difficult. Erm, I forget where I put something, that's the sort of thing, or forget where I've put the book I was reading, but my [.] my long-term memory is very good. I mean, I can remember, [2] I can remember at three years old being given a bicycle. All that's still very clear in my memory, and things like that, and of course I remember the war, you know? I remember the area had air raids and all that, and that is very... [2] So, my memory of my youth and er, up to er, up to middle age has been pretty good. Erm, when I was still at work I never wrote anything down for instance. I could remember things. Now, now if I want to remember something I write it down, but I suppose that's not unusual. But erm, you know, for all normal things, normal things I remember. You know, if I want to remember something, I'll remember it.

Ted's response to a question about the assessment process he underwent is to immediately emphasise the enduring strength of his long-term memory. Equally, he seeks to diminish the seriousness of his short-term memory difficulties, and thus protect any sense of vulnerability he may be experiencing. It seemed that Ted felt that I was expecting to hear a negative account of ageing and living with a dementia diagnosis, and meant to prove that notion incorrect, at least with regard to himself. Should Ted be making this assumption, this is likely to be based on an awareness of the stigmatised narratives that Ted has heard, or indeed holds himself, about older people diagnosed with dementia.

Wade (1997) states that people will find creative ways to resist everyday situations in which they are oppressed, helping them to conceive of a stronger self. Ted finds this opportunity in our interview and resists and reverses negative expectations that may be held about his abilities through emphasising his strengths and minimising his difficulties. Aware that his words will be read in an academic context, he repositions himself to show me that he can recall memories from long ago, in detail.

Ted's diagnosis came as a surprise to him, but he tries to de-emphasise this, portraying it as a gentle and manageable surprise, that he has now "got[ten] over" [164]. He stresses that the diagnosis is not important to him and is not part of his identity, instead moving the conversation onto more comfortable topics that he feels have a greater impact on his selfhood:

> [62-73] [T]: I'm aware that at times I forget things that I know I should have remembered, so, but it's erm, I, the memory lasted me until I was, I mean I was working 'til I was erm, 68. I, I worked for [television broadcaster]. I was a cameraman, and then I directed and did hundreds of [television programme] episodes.
>
> [K]: Wow!
>
> [T]: [Laughs] I enjoyed work. I worked 'til I was 68. I could have worked longer if I'd have wanted to. They were quite happy to go on but I thought 68's enough, isn't it! And my memory's still pretty good. Don't remember your name of course [laughs].

Despite having been asked about the origins of his diagnosis and his experience of the memory clinic, Ted quickly moves the focus of the conversation to his career. As someone diagnosed with dementia, society portrays Ted as debilitated (Sabat, 2003). He actively moves the conversation away from this image through emphasising his life before his diagnosis, explaining who he is as a person; something that is often forgotten in the treatment of older people (Clarke, Hanson, & Ross, 2003). Through concentrating on his strengths and achievements rather than his difficulties, he

indirectly comments on the memory clinic's focus on deficit, rejecting this stance as lacking personal meaning. After all, a person's identity is built on their abilities, not the things with which they struggle (Watson, 2010). Instead, Ted emphasises his skill and seniority in the workplace and the field of entertainment. Even when mentioning memory problems, Ted laughs, seeking to show that this does not worry him. Through performing in this way, Ted resists the stigmatised labels assigned by others (Sabat, 2003):

> [460-464] All my family think I'm very wonderful. [K laughs] Well, I, I suppose it is one of those jobs that people, "Ooh, he must be, he must be good", but it's just a job. A job that I enjoyed <[K]: Mmm> [.] and miss to a certain extent.

Ted's career was still a big part of his identity, much more so than a dementia diagnosis. This is consistent with Teuscher's (2010) findings that the more positive the perceived value of the job, the greater the importance of the professional identity post-retirement. A diagnosis of dementia, however, has been suggested to lead to an identity crisis (Bryden, 2005). It is understandable, therefore, that Ted would strive to hold onto his professional identity rather than the stigmatised identities associated with ageing and a dementia diagnosis.

> [126-132] I don't know if I've told you already, every birthday I see if I can still prove Pythagoras' theorem. [Both laugh]. That's my big test. <[K]: Yeah?> About the square of the hypotenuse equals the sum of the square of each side, I can still do the erm, no, prove it. So, I do it every year. [Laughs]

Through stating that he is aware that he may be repeating his story, Ted addresses his memory problems before I can, protecting himself from any judgement. He then laughs when mentioning Pythagoras' theorem, knowing that perhaps because of his age, his diagnosis, or simply for being an unusual habit, I will find his statement surprising. Recounting the theorem, Ted seeks to prove that despite his diagnosis, he remains knowledgeable, cultured, and capable. This gives him a 'footing' in our exchange, where Ted aligns himself alongside me, as someone within academia, and distances himself from his

perception of dementia (Goffman, 1981). The suggestion that he is 'different' from those normally diagnosed with dementia is strengthened when my surprise and laughter validate his position.

[155-157] Oh, I'd noticed a change, yeah, but I think that's as much as being not in that environment <[K]: Yeah> [.] where you have to take things in.

[244-245] Probably if I'm still working the bad bits would show, but erm, not now.

Ted wonders if it was leaving a working environment where he relied on his memory every day that led to having difficulties. This corresponds with the popular 'use it or lose it' notion, which suggests that engagement in complex tasks can prevent dementia (Alzheimer's Society, 2018b). The evidence for this, however, is currently lacking, and positive trial results are often incongruent with observational evidence (Alzheimer's Society, 2018b; Coley et al., 2008).

In his post-retirement life, Ted felt that he remembered enough not to cause him any problems, stating that if he was back at work, he would perhaps be experiencing greater difficulty. Aligning with the social model of disability, it is, therefore, the environment rather than the diagnosis, that causes disability. This challenges the medical model's understanding that the 'problem' lies within the individual, instead representing disability as the "social, financial, environmental and psychological disadvantages inflicted on impaired people" (Abberley, 1987:17). This suggests that adaptation of the environment can lead to an improved quality of life.

3.1.2. Discourses of Ageing and Dementia

[282-289] It's only in the last [.] few months that I realised that I need to write some things down. Not everything. But I write some things down, yes. But my wife is very good and she, she makes sure that I go where I'm supposed to go. [Laughs] <[K]: That's good> Yeah, yeah, no, [2] it, [.]

it's fine, [.] I don't erm... I enjoy all the things that I do. I read and I write, and I suppose that over 80, [2] I'm, I'm in good nick really.

[371-376] [...] I really haven't got any grounds for complaints, er, I feel happy in myself, I've got peace in myself, and I've got a nice wife who looks after me, and I try and look after her, but she's much better than me at everything. [Whispers conspiratorially] She's very clever. [Both laugh].

Ted has been reflecting upon his life and has achieved the task for this stage, having found peace and satisfaction (Erikson, 1994/1959). Challenging previous findings (e.g., Bond et al., 2007; Corner, 1999), he does not appear to have internalised the notion of 'burden' in old age. Instead, writing notes and his reciprocal relationship with his wife support him to live a life without disability. This interdependence defies ageist connotations of 'uselessness', showing that even those who may be dependent on others can give as well as receive (Thompson, 2016). Strong relationships are, therefore, of great importance to Ted's continued resilience.

[588-592] [T]: Well I've never told [friends], or talked to them as such, but [.] they know. I talk about what's happened and [2] erm [.] but I, I don't feel that I'm odd or ill or... I can still read, I can still write, I can still think, I can still do the crossword, and I can still solve Pythagoras' theorem. [Both laugh]

[627-630] I think most people my age accept the fact that their memory's not gonna be so good. You see, my memory of the past is really good. I can remember things that happened 60, 70 years ago, even more.

While they do not perhaps know about his diagnosis, Ted's friends may be aware of his memory difficulties. However, he frames these as an understandable and inevitable aspect of 'normal ageing'. In contrast, Ted associates 'dementia' with the words 'odd' and 'ill', and does not feel that he is represented by either of these terms. While not explicitly disagreeing with his diagnosis, Ted does not feel he has experienced any real changes that would

lead to him being labelled with 'dementia'. His sense of self remains and he emphasises that his intellect is still present, suggesting that he thinks that these would be absent in someone with a dementia diagnosis. This reflects Ted's stigmatised understanding of the dementia label, replicating wider societal constructions (Devlin et al., 2007).

Ted sought to show that he still had value, something that is often stripped of those diagnosed with dementia (Swaffer, 2012), yet did not afford this sense of value to others of the same age:

> [100-114] [T]: I rarely write things down, so I think I'm very lucky in that respect. I mean, I'm over 80, so I've seen people over 80, and thank goodness, I'm not like some of those poor people.
>
> [K]: What do you mean by that?
>
> [T]: Well, they don't really seem to know where they are, some people, or you see them, I go to the hospital every now and then, and there are people there and you know they're not, they're not with themselves. I don't know how to describe it. But I think I'm very lucky. I think I'm very lucky indeed at my age to, to remember so much and still be able to cope <[K]: Mmm> with reading and writing and opinions <[K]: Yeah> and being bossy and... [Laughs]

Foucault (1963/2003) suggests that people police and discipline their own bodies due to the regulating pressure of the medical gaze. Here, showing awareness of this pressure, Ted 'others' older adults and also perhaps those diagnosed with dementia, seeking to preserve his own health in spite of his diagnosis. This safeguards his sense of identity and selfhood, situating their absence within others and reiterating the stigma that pervades society (Downs, 2000).

> [184-203] [K]: You said that you had it in mind that as you get older, you start to decline, erm, what, what kind of things [.] were you expecting?

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[T]: I was expecting to lose memory, certainly of the past, but my memory of all the things I've gone through and been through, I remember pretty well. I'm not very good with names, erm, if I meet someone new and they say, "My name is Albert", 20 minutes later I won't remember his name's Albert, you know. <[K]: Mmhmm> So it's, fresh memories, I do find are most difficult, are most hard to stick, but then I suppose I've got no more room on the paper you see. [...] I don't know how the brain works and if it does get full up, but erm, or whether it's just that I don't remember. [Laughs]

Ted had pessimistic expectations of 'old age' and appears to have expected to lose his memory of his past in its entirety. His experience, however, had been better than this, which had surprised him, and he hopes surprises me too. He uses an analogy of running out of room on the paper, positing that over the course of his life, his memory has reached capacity. Through doing so, Ted's memory problems are aligned with a natural process rather than being explained by 'dementia'.

The term 'dementia' conjures up a vivid image for Ted, where the individual becomes unpredictable, dangerous and frightening:

[221-226] You know, where you put some poor old man, like they did in the nineteenth century, if you were a nut case, they, [laughs] as they called it, they'd put you in an asylum and you were left to scream and shriek with the rest of them. But it doesn't mean that, I know that, and it, it has a very specific [.] meaning, I, I assume.

[796-855] The trouble, the word has such overtones with the word 'demented'. I mean, that's a descriptive in so many novels, the word 'demented', isn't it? So, you don't really, I don't really know what it means. [...] when you're in a bad way and, you're worried, and you, you can't quite cope, that's what I think of somebody who is demented, or isn't thinking properly, or isn't behaving properly, that's what I think. But er, but obviously the medical word is much more, er, er, directed, isn't it? [...] You know, you see people behaving oddly or strangely, or streaking

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or whatever, or hitting children, that sort of thing. You think, "They must be demented". [...] I mean, the word demented that people use who are not medical, er, you think, "They're going nuts", you know. But it is very specific the word in medicine, isn't it? [...] I realised quite quickly, my brother told me when I, he explained it to me, and it is very specific, I understand that. Erm [3], I, don't, I don't really feel [.] *demented* [laughs]. In all every form, I feel quite normal, but then everyone feels normal I should think.

In the image Ted creates, people are defined by thoughts and behaviour that breach social norms relating to self-control and social deviancy, showing a sharp awareness of society's normalising gaze (Foucault, 1963/2003). The word 'dementia' was formed from the Latin for madness[4], only strengthening these stereotypes. Portrayed as forgetful, confused, and aggressive in Ted's image, the person behind the label is disregarded. Awareness of stigma is frequently apparent in those with a dementia diagnosis (Burgener & Berger, 2008; Devlin et al., 2007), but Ted casts this stigma outwards rather than inwards.

Ted draws from 'dementia's' history, when the label was applied to those with an acquired intellectual deficit and was also largely synonymous with the modern term 'schizophrenia', another highly stigmatised label (Hill & Laugharne, 2003). Despite the medical meaning of the term changing over time, this does not stop the term from carrying with it the baggage of the previous two centuries, where dementia, particularly advanced dementia, was and still is, linked with the loss of the mind, incapacity, and behaviour outside of the social norm. This image of being 'old' and 'demented' threatens many people diagnosed with dementia (Harding & Palfrey, 1997). Perhaps fearing for his future, Ted seeks to prove to me and reassure himself that he has not 'lost his mind', is able to control himself, is coping well with life, and his self-identity remains unchanged, thus distancing himself from the stigmatised image that he holds.

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[4] *De* - to depart from; *Mens* - the mind.

Ted was respectful of the medical understanding of dementia, associating it with professionals and assuming it to align with my own understanding, however, the medical term cannot be understood separately from its colloquial meaning and can, therefore, be equally stigmatising and damaging (Downs, 2000). He suggests the presence of multiple truths around 'dementia', resonating with Harding and Palfrey's (1997) proposal that dementia is socially constructed, but while Ted does not fit his own definition of dementia, where the person is unpredictable, senseless and has no sense of memory, he finds that the medical definition also holds little meaning.

> [1034-1049] [T]: I just think this has been a nice conversation. Very open. [2] I don't know what normal is for instance. I don't know whether I'm normal or anything. I just, I am what I am, and I'm not inhibited. I mean I don't, you know, go out onto the street and flash women [both laugh]. No, no, I don't really think about it. I just get on with it. And I'm lucky that I've got good friends, and also, of course I've got so many friends at [television broadcaster], and we all knew each other then and we got on well, and they're very much like me I think. They become the same, we all became similar. I've got good friends, a lovely wife, and [.] I'm a happy person really.

> [K]: I'm really pleased to hear that, Ted.

> [T]: I bet you don't hear many people say that.

Ted believes that the other people I will be interviewing will provide very different and much more pessimistic accounts than the one he has given me, showing that he perceives his experience to be different to the norm. While this represents commonly held stigmatised beliefs about dementia, it also shows how Ted rejects a stigmatised identity.

3.2. Hugo: A Story of Activity

This interview took place in Hugo's local memory clinic. He attended with his wife Patricia, who sat in on and occasionally contributed to the interview[5]. Before the recording began, she said that Hugo had been reluctant to attend as he felt that he had little to contribute, reflecting the belief in society and in the research field, that those with a dementia diagnosis have nothing to offer (Sweeting & Gilhooly, 1997). By the end of the interview, however, he was pleasantly surprised by how much he had engaged with my questions and how long he had been able to speak.

3.2.1. Keeping Moving

Hugo went to his GP following an incident while waiting for his wife outside a shop. He had forgotten her whereabouts and left the area to look for her, ultimately contacting the police. He was referred to the memory clinic, where he underwent an MRI scan and cognitive testing. Hugo recounts the difficulty he experienced trying to answer the questions posed by the clinician in his cognitive assessment:

> [313-322] Right, here I go. "What's that? What's that? That? That?" And the more I done, getting these, pieces of papers and this and that, the more I was getting a headache, and after that, [2] it was just er [2] carry on, carry on.

After receiving his diagnosis, Hugo says that he had to "carry on". The notion of 'carrying on' is repeated throughout the interview[6], showing Hugo's resilience following his diagnosis and his attempts not to let his diagnosis hold him back, but also his fear of 'standing still'; trying to keep moving lest his diagnosis catch up with him and rob him of his personhood. This would indicate that Hugo feared the end of his happy life; a common fear in those with a dementia diagnosis (Alzheimer's Society, 2009).

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[5] Patricia verbally agreed for her views to be included in the analysis.
[6] Lines 64, 66, 316, 335, 510, 757.

Hugo was surprised at how quickly he received his diagnosis, and found it to be a shock:

> [434-437] No, it was a shock actually. Cos, it, as I say, up 'til then, I was alright, you know, it just came along and then hit. I was alright and then suddenly bang [claps hands], gone. That's it.

> [487-493] No mess[ing] about or anything. He just says [...] what you're gonna do, get through, and [...] it's along the way, change.

> [522-529] To them it's quite normal to find dimension in 'em. Because that's what they do, you know, they went in here, and knew there was something wrong. And you know, when I went in I said "No, I'm alright, I'm alright! Yeah! Nothing wrong with me!" Bang, bang, bang, and that's it!

Throughout the interview, Hugo used the term 'dimension' in place of 'dementia'. Perhaps Hugo has had little schooling or gets his words muddled, or perhaps there is greater significance in his use of this word. It has been suggested that those with a dementia diagnosis face an altered reality, where past memories interact with present day experience (Social Care Institute for Excellence, 2015; Spector, Davies, Woods, & Orrell, 2000), but the label also excludes people from wider society (Oliver, 1996), changing their reality. For these reasons, a dementia diagnosis may make Hugo feel as if he is in another dimension. It could conceivably, however, be professionals who are in a different dimension due to giving Hugo a diagnosis that at the time, did not fit with how he understood his reality. The term 'dementia' is often evocative due to its negative associations (Langdon, Eagle, & Warner, 2007), and Hugo's use of 'dimension' may also be a way to actively remove the term from our conversation.

Hugo felt that dementia was common enough to be frequently diagnosed at the clinic, but suggests that staff may, therefore, lose sight of the gravity of the diagnosis. The voice of the clinician in his assessment is in contrast to the voice of Hugo, who strongly proclaims that he is fine, showing that he perhaps felt

unprepared for the diagnosis or that the diagnosis is something he was not willing to accept. In cancer diagnoses, research has shown that denial of the diagnosis can be a positive coping strategy and, if treatment is not rejected, can lead to more favourable clinical outcomes (Garssen, 2004; Rabinowitz & Peirson, 2006). This could be the same in dementia, as denial is cited as a common coping strategy (Aminzadeh et al., 2007), but similar research into whether denial can lead to an improved prognosis has not yet been conducted. Hugo's immediate experience of shock at his diagnosis corresponds with Aminzadeh et al.'s (2007) stage model of the emotions associated with dementia, but Pratt and Wilkinson (2001) suggest that the diagnosis being disclosed over time and preparing the person in advance of the diagnosis may go some way in mitigating against this shock. This upholds Hugo's belief that the speed in receiving the diagnosis can be problematic.

Following his diagnosis, Hugo had been given information[7] and prescribed medication:

> [4-18] It comes all anew for me. [...] And they just turned around and said, "Well, we've got, er, something on top" [gestures to head], you know, and they gave me tablets to do it. It doesn't know whether it, does it work good for ya or bad. It keeps in the middle. [...] You got this item that I have to take every night, and er, it keeps me [.] stable. I don't go any further. You know, I don't want to go anywhere, suddenly turn around and go, "Ooh", and I'm walking out the door or something out there. And er, it just, leaves it as it is. [2] I look after it. And she [nods toward wife] looks after it. And er, she keeps me er, doing bits and pieces. <[K]: Yeah?> Yeah. You don't wanna be stagnant.

Those with an Alzheimer's disease diagnosis are often treated with acetylcholinesterase inhibitors to temporarily alleviate or stabilise some of the associated symptoms (Farlow, 2002). Hugo thought of the medication as 'pausing' his dementia; not improving it, but not allowing it to deteriorate. He used this to ameliorate his fear that dementia would remove his ability to control

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[7] The exact nature of this information was unclear.

or understand his own actions; a common fear (Alzheimer's Society, 2009; Fox et al., 2013). Hugo also tried to keep active, drawing from medical discourse as well as the 'use it or lose it' notion recounted in the analysis of Ted's interview. Through remaining active, Hugo attempts to care for his mental and physical health, which Gunnarsson (2009) suggests is seen as important by retired older adults in preventing deterioration and dependence; both feared consequences of ageing.

Hugo uses the word 'stagnant'; a word that embodies lifelessness. This reminds me of the 'living death' metaphor that is often associated with dementia (Alzheimer's Society, 2009), and shows how important Hugo feels it is to 'carry on' and keep moving away from what he sees as a predatory and devastating disease.

Ideas of 'burden' are rife in society and internalised by this age group (Bond et al., 2007; Corner, 1999), but Hugo and Patricia demonstrated a sense of interdependence that perhaps protects the couple from these perceptions. They checked the accuracy of their statements with each other throughout the interview, reflecting the reciprocity of their relationship, and welcomed support from family, friends, and professionals. While government policy (NICE, 2013) advocates promoting independence in those diagnosed with dementia, Hugo demonstrates the importance of *inter*dependence for his sense of wellbeing and security. This has been shown to strengthen family bonds and maintain personhood (Smebye & Kirkevold, 2013); as stated by Kitwood (1997:3), "no one can flourish in isolation".

3.2.2. Comparisons with Others

Opposing Werezak and Stewart's (2002) assertion that little post-diagnostic support is offered by the NHS, Hugo had accepted medication, been assessed for a place on a research trial for new medication, and was invited to attend a cognitive stimulation therapy (CST) group. He had been much more sceptical about attending 12-weeks of CST than about taking medication: "I was very sceptical about that one." [857]. The medical view of dementia focuses on cure and deterrence (Fox et al., 2013; Sabat & Gladstone, 2010), so perceiving dementia to be a biological disease, Hugo perhaps questioned the value of a

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non-biological intervention. This trust in the medical model is demonstrative of its power. It is also likely that Hugo was unfamiliar with psychological therapy, which was not commonplace during Hugo's formative years, particularly among working-class men (Milnac, Page, & Hinrichs, 2017).

Hugo was surprised by the format of the group, which aims to enhance cognitive functioning through engaging in stimulating activity (Clare & Woods, 2004). He found it fun and "a laugh" [880], and passionately recounts the sessions he has attended. Marino (2016) states that 'social recovery' involves having a space where one can feel both vulnerable and competent. It seems that Hugo experiences this environment in his CST group, where he was able to find humour in situations that outside of the group, he would find embarrassing:

> [898-900] They say, "Who's that over there?", and I say, "I don't know!"
> [Laughs]

This shows the value of joining with peers who have also been diagnosed with dementia (Dupuis et al., 2012), although Hugo felt young compared to the other group members. He perhaps wondered whether he belonged in the group, with his age causing him to feel like somewhat of an outsider, or he may be realising the heterogeneity of what is considered to be 'old age':

> [934-935] But the only thing I was, I'm a bit, *young*, to what they, they are.

> [1020-1021]: I keep it quiet. I keep it quiet. Because, at my age, it's not age to the people out there.

Despite his friend, who was of a similar age to Hugo, having also been given a dementia diagnosis, Hugo associated dementia with very old age and felt a sense of injustice and frustration at his diagnosis: "Why did *I* catch it?" [1060]. These feelings might typically be associated with those diagnosed with young-onset dementia, as expressed by Bryden (2005) and Pratchett (2014), yet Hugo was clearly distressed in his posing this question, showing that these feelings can be present at any age.

A dementia diagnosis was seen as a source of shame for Hugo, and something to be hidden, yet he felt that once dementia progressed, it could no longer be concealed and would be visible in a person's behaviour:

> [1072-1082] I don't go round, walking round the streets saying, "Look, I've got dimensions! I got dimensioned! Yeah, seriously, excuse me, I've got dimension!" No, no, no. You don't! In some ways, should cover it. The bad ones can't. One of my best, my best friends, he's had [...]. He's [mid-seventies], right. And he's gone. I don't know how to explain it. But dimensions. He's been told.

> [1160-1164] But he went so quick! It was, I think it was about approximately about three months, [.] when he started to get ill, and then, and started to go on and on and on, and then [.] he seemed to hit a barrier, where he goes over it, and that's it.

Reassured by my professional capacity, Hugo spoke openly about his dementia diagnosis despite this being something he tended not to divulge to others. For Hugo, dementia was perceived as something that worked quickly. He generated an image akin to a person going over a clifftop to their death, where his friend's identity and personhood were eradicated by an unforgiving disease. With this in mind, it is understandable to see why Hugo wants to 'carry on', hoping never to reach such a point.

The previous excerpt shows that the specific diagnostic label had little impact for Hugo. Indeed, after the interview, some uncertainty was shown over whether Hugo had been diagnosed with Alzheimer's disease or vascular dementia. His worries for the future and sense of shame and stigma were not drawn from his understanding of certain medical diagnoses, but from his understanding of the term 'dementia', social discourse, and the impact he has seen 'dementia' have on others.

It is also apparent, through Hugo's use of the word 'dimensions' rather than 'dementia', that his sense of language has changed. Killick and Allan (2001) suggest that those diagnosed with dementia can experience difficulty finding the

right word, using words in the correct way, and in adhering to conventional narrative structure, but this did not discourage Hugo from communicating. Through doing so, Hugo shows the importance of not underestimating people diagnosed with dementia, and allowing them to engage in research (Alzheimer Europe, 2011).

In response to Hugo's disorganised speech, at the beginning of the interview, Patricia would explain to me that he "can be a bit confused" [68], and would recount other changes that she felt were negative. Later, this changed and she would interject with positives or encourage Hugo to elaborate more on his past achievements. Conversely, Hugo was keen for his difficulties to be acknowledged and understood, and in marked contrast to Ted, feels upset about forgetting my name:

> [218-228] [H]: Yeah. Ooh, well when I was working, all I was worried about, working and then coming back, and by then she's done the housework and that. And she's still doing it. But I, I can't do it as much as I *should* be doing.
>
> [P]: No, he *helps*. He does his certain things. He helps. Shopping.
>
> [H]: But the biggest one is, is that I can't *remember* things. I can *remember* them, but I can't, you know, if it's someone's name, I don't, I don't even know your *name.*

Perceiving dementia as a disease that robs the individual of their personhood, focusing on his difficulties perhaps felt like a vulnerable position for Patricia, who attempts to reassure herself and Hugo that his identity and personhood remain. This protective role has been found in previous research, where difference and despair are denied or minimised by the carer (e.g., Hughes, 2014; Norman, Redfern, Briggs, & Askham, 2004). Being given a diagnosis changes a relationship, as the couple face unique challenges, loss, and changing roles (O'Shaughnessy, Lee, Lintern, 2010), but Hugo and Patricia dealt with loss differently. Hugo sought for the full extent of his difficulties to be acknowledged, while Patricia sought to support Hugo to hold on to his identity.

Ultimately, however, they presented as united, working to preserve Hugo's personhood.

3.3. Fergus: A Story of Acceptance and Personhood

The interview was carried out in the home that Fergus shared with his wife, Nora[8]. Throughout the interview, Fergus was keen to demonstrate that his dementia diagnosis had not changed him and did not cause him any concern.

3.3.1. Support

Fergus said that he had understood his dementia assessment and found it smooth and straightforward: "We went through the thing fairly methodically, and it was fairly reasonable to follow all what they were doing" [87-89]. While this was indicative of the relaxed narrative that Fergus presented throughout the interview, with no complaints or worries, it may also suggest that Fergus perceived me to be a representative of the memory clinic and wished to please me. This would demonstrate values common to this cohort, who often perceive free healthcare to be a privilege (Fredman & Rapaport, 2010). Fergus had a matter-of-fact attitude toward being given the diagnosis, and said that he was pleased to have been informed:

> [136-141] I think it's always good to *know*, if they've actually diagnosed what the problem is. [...] I would rather be that way than not knowing. You know, where it's uncertainty, would be worse than [...] knowing what the actual facts of the matter are.

Fergus' assertion that he preferred to know his diagnosis is congruent with the opinion of many others (see Milne, 2010). He thinks of the diagnosis as 'fact', offering him certainty and an explanation for what is causing memory loss. The receipt of a formal diagnosis allows people to plan for the future (Alzheimer's Society, 2016), however, this planning was being done by Nora rather than Fergus, and she was keeping in touch with the memory clinic through being added to their mailing list. Contrary to the findings of Werezak and Stewart

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[8] Nora verbally agreed for her views to be included in the analysis.

(2002), who suggested that the NHS provide little post-diagnostic support, it seemed that Fergus and Nora had been offered support that they had declined. They instead preferred to remain the dyad they have long been, with Nora using her own knowledge of Fergus to support him. She felt, however, that they may have no choice but to accept support in the future, although her distinct worries remained unspoken. This was perhaps to protect Fergus and maintain his current state of equilibrium, as while she imagined a difficult future for the couple, this did not appear to be a worry for Fergus. This is different to the experiences of Bryden (2012) and Pratchett (2014), and the findings of the Mental Health Foundation (2011), where the person diagnosed experienced fear and uncertainty about their future.

Instead of professional support, Fergus was supported by family, church, and the retirement complex into which they had moved, however, the couple's recent move to London had proved challenging. While it had moved them closer to one of their children, it had removed Fergus from a familiar environment and the social support he had accessed through playing golf and attending church:

> [65-73] Oh, a big change, yes, yes. Yes, cos er, I did a lot of driving where I work, and that obviously, disappeared when we came here, because we didn't bring a car. And er, I er, played a fair amount of golf with a group of friends, who I will have seen several times a week, so that, that sort of, is all stopped. So, that was a change which was, you know, [2] er, difficult enough to er, get used to, but it has worked okay. Don't seem to, find any difficulty now.

Son Hong and Song (2009) state that a familiar environment supports cognitive and functional abilities. Reflecting these findings, Nora felt that the move had facilitated the decline of Fergus' memory, ultimately leading to his dementia diagnosis. His memory problems were perhaps less apparent when in a familiar environment in their family home in Northern Ireland, but the move had made his difficulties become much more noticeable.

Phinney, Chaudhury, and O'Connor (2007) suggest that a familiar environment and relationships promote involvement in activities and maintains quality of life

and personhood. This loss of regular activity, therefore, has the potential to harm Fergus' personhood. Seeming aware of this, Nora, with the support of one of their children, was trying to establish a routine for Fergus, seeking to keep him active and re-establish elements of previous hobbies. Having moved away from his friends, Fergus, as with many people diagnosed with dementia (Alzheimer's Society, 2013), may have felt lonely, but it appears that his family's efforts have been helping Fergus to deal with a difficult transition. Although he may have been saying this for the benefit of his wife, he stated that he had adjusted to the change.

3.3.2. What is 'Dementia'?

Throughout the interview, Fergus' language would move between framing his difficulties as a diagnosable disease, and an age-related problem. While my position as researcher gave the couple permission to share their difficulties, only the couple's children knew about Fergus' diagnosis. Dementia was framed as a private experience, perhaps being perceived as something shameful and embarrassing, as in the findings of Ballard (2010) and the Mental Health Foundation (2011), and the experience of Pratchett (2014). Fergus thought that his children would not be surprised by his difficulties, although he contextualises these in relation to age:

> [714-716] They probably realise that we're quite a bit older and probably er, erm, memory loss is, is one of the things they accept.

Fergus reflects society's assumption that ageing leads to loss and deterioration (Segal, 2013), but through doing this he negates his diagnosis and positions himself as indistinguishable from any other older person. This separates his experience from that of his twin brother, who also has a dementia diagnosis:

> [153-170] [F]: I have a twin brother who's a much [2] further stage in dementia. He's been in a nursing home for/
>
> [N]: Years [...]

[F]: [...] I think, in his later working life, he got very stressed. [...] I don't know why, but he just got very uptight about some of the jobs that he was working in, you know? And I think that led to him er, getting further and further into that condition.

Fergus proposes that stress and poor emotional management have made his brother vulnerable to dementia. This may be an effect of emerging discourse, popularised in national newspapers, that emphasises personal responsibility for dementia prevention through behavioural and lifestyle change (Peel, 2014). Such messages have the potential for further stigmatising people living with dementia through introducing notions of blame. Counter to the discourse around Fergus' brother, the origin of Fergus' dementia was attributed to a transient ischemic attack (TIA). Despite the hospital finding that it had not had any lasting impact, Nora felt this had been the start of a slow decline in Fergus' memory. Reliance on the medical model and ascribing memory difficulties to physical causes outside of his control offers reassurance to the couple; there was nothing they could have done to prevent this from happening.

The 'relaxed' narrative perpetuated by Fergus throughout the interview served to differentiate Fergus from his brother, however, Nora explained that Fergus' laidback attitude had not been present throughout his life, and had begun when he had started to experience memory problems. Perhaps the diagnosis had led to Fergus finding a new way of being in the world, which may have been safer than acknowledging his losses, particularly if stress is perceived by the couple to make 'dementia' worse. However, nearing the end of one's life has been shown to provide some people with a sense of freedom and liberation from fear (ERSO, 2014), so this may be a way of Fergus relativising and re-evaluating what is important in his life.

Prior to his diagnosis, Fergus was described as someone who was quiet, controlled, and who never worried, but also someone who could be sharp and overwhelmed with his work. Regardless of this, his personality was seen to be different to that of his brother, with these differences being further emphasised post diagnosis with Fergus described as "laidback" [24]. Distance between Fergus and his brother was reinforced by Fergus stating that he did not live

nearby, and Nora asserting a genetic approach to dementia and saying, unprompted, that they were not identical twins. This sense of distance protected the couple from the outcomes associated with Fergus' brother:

[182–190] [...] I was concerned obviously and er, [.] my sister and I, we'd have visited him, er, fairy regularly, but it became even less and less. I mean, he recognised us both, but couldn't really converse, or, hold any sort of [.] lucid conversation. I mean, you couldn't get any [.] er, lucid answers from him. Basically, he wasn't able to get to that stage, which was [...] very worrying really in a way, you know, to see someone that you'd known for so long, er, going into that, er, situation.

Personhood is sustained through our relationships and emotional bonds (Smebye & Kirkevold, 2013), yet there is a common assumption that those diagnosed with dementia have nothing to contribute and no desire to do so (Sweeting & Gilhooly, 1997). This and the perceived inability of the individual to express their selfhood in a socially acceptable form, leads to what Sweeting and Gilhooly (1997) term a 'social death'. Compounded by notions that those with advanced dementia are an 'empty shell' (Devlin et al., 2007), this discourse can provide friends and family with a way of psychologically coping with a difficult and at times distressing situation through removing the social and moral obligation to maintain contact with the person (Guendouzi & Müller, 2012). Influenced by these popular narratives and situating personhood within cognitive functioning, visits to Fergus' brother reduced over time.

3.3.3. Personhood

As with Ted, it appeared that Fergus believed that the intent behind my questions was to hunt out the difficulties he had been experiencing as a result of his dementia diagnosis.

[394-398] [K]: How do you find going for a walk?

[F]: Mmm, I quite enjoy [.] walking. No, there's no problem there. [...] I have no difficulty in recognising the places we're going to.

Medical and social discourse around dementia focuses on deficits, and it seemed that Fergus had internalised these messages (Mental Health Foundation, 2015). Fergus tended to offer qualifiers such as "possibly" [262] and "probably" [274] in his statements, maybe indicating that he doubted his memory or feared being misleading. He would check the accuracy of his statements with Nora, who would also offer unsolicited corrections. These actions meant that an awareness of Fergus' memory difficulties was constantly in the room. Nora was interested in the research process and keen that I gained an accurate picture of Fergus, but this meant that at various points, Nora rather than Fergus became the lead narrator. Perhaps influenced by social narratives on dementia, Nora felt that Fergus was unable to tell his own story, performing a dominant role and seeking to protect Fergus. This reflects the dynamic found in the literature review, where voices of carers were more prominent than the voices of those diagnosed with dementia (e.g., Bensaïdane et al., 2016; Gooblar et al., 2015). Nora may be accustomed to professionals speaking to her rather than to Fergus, and being expected to speak on his behalf, as in research as well as in care settings, professionals construct environments that allow carers to dominate, rather than encouraging and giving space to the voice of the person diagnosed (see Connell et al., 2004; Holroyd et al., 2002; Karnieli-Miller et al., 2012). Alongside the societal expectation that those with a dementia diagnosis have deficits that need to be supported (Birt et al., 2017), it is understandable that Nora would seek to protect Fergus and offer me this information on her husband's behalf.

Notably, Nora commented on an aspect of the interview that she had found surprising:

[564–570] [N]: This is the most I have heard him talking in [2] two years.

[K]: Hmm!

[N]: My daughter comes regularly and she hasn't got him to talk as much as that. And he doesn't talk to me at all.

Fergus said that he had always been a reserved person and rarely initiated conversations. This made me wonder why Nora felt there was such a difference in what Fergus felt able to contribute inside and outside of the research interview. At the start, Fergus gave short answers of only a few words, and Nora attempted to fill in the information that she felt Fergus had not covered in his response. With the current social narrative portraying those diagnosed with dementia as incapable, Nora sought to counteract this through ensuring that I was aware of his strengths. However, when given focus and space, Fergus was able to do this on his own. He provided thoughtful answers, showed me evidence of his accomplishments, and explained the strongpoints of his memory, such as when completing crosswords:

> [490-494] I've fairly good command of English, so my memory is obviously good enough to be able to recall what er, words would, you know, are similar to, or the same as, er, so obviously my memory of those must be fairly good.

Resonant with previous research, Fergus could be a capable and independent communicator (see for example, Hughes & Castro, 2015; Langdon et al., 2007; Manthorpe et al., 2013). Yet since personhood is enabled through our relationships with others (Kitwood, 1990a), the wish of family members to protect the individual from the stigma around dementia may have an unintentional negative impact on self-expression and, therefore, personhood.

3.4.   Fran: A Story of Community

This interview took place in Fran's home, where she lived alone, although her son and his family lived in the same building. She was a lively woman, eager to tell me about her friends and her life in the pub trade. Fran grounded her narrative in the importance of community, with her siblings, children, grandchildren, friends, and the church all being drawn into her narrative. This community enabled Fran to demonstrate that her diagnosis was not a matter of concern.

3.4.1. <u>Being Given a Dementia Diagnosis</u>

Fran said that while she had recognised that she was experiencing memory problems, it was her sons who suggested that she get her memory professionally checked:

> [4-19] Well, I didn't, you see, I didn't really notice it that much myself. It was the, the, my sons and that. Well, other people wouldn't tell you! [Laughs] And, sometimes, I used, because I, one time, I'd never need to write anything down if I was going out to the shops. I'd just know what I wanted, and that was it. And you might forget one thing, but then after, you know... [Laughs] Me memory's getting worse. I'd go out and half the time, if I didn't have a list with me, I'd forget what, what I went out to buy! And I think that was the first, and then I noticed, like er, you know, if you'd get a letter from somebody, and I'd forget to reply. Or get a phone call, and they'd leave a message, and I'd forget to reply to it. And then you'd get *another* call, and it said "Ya know, I've left you a message", and *things like that,* that really made me think "God, me memory's getting bad!", you know?

While it is common for people to try to avoid a dementia diagnosis and delay help-seeking (Ballard, 2010), throughout the interview Fran professed not to be concerned about her memory difficulties. It is frequently families who initiate a dementia assessment for older family members, to some extent defining the presenting problem (Zarit & Zarit, 2011), and Fran's forgetfulness perhaps caused greater worry for her children than for herself. Having been found to be one of the most stigmatised and, therefore, feared, illnesses in the country (Alzheimer's Society, 2016; Saga, 2016), it is understandable that Fran's children would wish to seek a professional assessment, however, this shows how the medical model extends its surveillance into the domestic lives of older adults (Foucault, 1963/2003). Once the label of dementia was given, Fran says that her life did not change aside from being provided with aides-mémoires from her children. The label provides her family with a socially constructed understanding of Fran's memory problems, which they perhaps feel provides them with some guidance on how to support Fran.

Fran acknowledges that her memory was never perfect, even before the diagnosis, yet associates forgetfulness with ageing. For Fran, this is not a negative, but something she both expected and accepts:

> [61-69] *Well*, it didn't *bother* me much. Because, [laughs] we've all got to get old and if that's what's going to happen, if the memory's not going to be good, well I thought there's plenty of them [...] to remind me. I've got [five children] [...] But I thought, there's plenty to remind me [.] of anything I forget, so I'm not going to forget to pay my bills or, well that's, I don't think I'd forget that because that's sort of, something that's in your mind, anyway.

> [78-79] I'm getting old and I've had my days, so, it's okay.

Medical, deficit-focused, and ageist messages about ageing pervade Fran's speech, furthered by Fran's notion of her life having been already been lived. While for Fran this led to a calm acceptance of her diagnosis, in the medical profession such attitudes can lead to under-treatment and a lack of support for those receiving potentially life-changing diagnoses at an older age (Macmillan Cancer Support, 2012).

Fran could not remember the details of her experience at the memory clinic, but recalls being told that she was "in the early stages of dementia" [99-100]. Similar to Hugo, the exact nature of the diagnosis has little relevance or significance for Fran, and she draws her understanding from a lifetime of messages she has received about 'dementia' and what it means. It has been suggested that these labels can lead to lowered self-esteem and diminished feelings of control (Rodin & Langer, 1980), however, Fran's confidence in the support of her children and comfort with interdependence appear to protect her from such concerns. Fran wishes to portray a woman who is unfazed by her diagnosis. She is not a 'victim' or a 'sufferer'; language popularised by the medical model (Alzheimer Europe, 2017). While ageing can be associated with marginalisation, denigration and being devalued, and the literature on dementia often cites shame and fear as common feelings in those diagnosed (e.g., Borley et al., 2016; Mental Health Foundation, 2011), this is challenged by Fran. Her

age and diagnosis perhaps provide her with a sense of freedom and liberation, or perhaps her life experiences have made her more resilient to challenges to her identity. Foucault (1982) urges people to "refuse what we are" (p. 216), rejecting the fixed identities that are imposed upon us and struggling against discourse that seeks to control and subjugate. Fran was able to do this, remaining unconcerned about perceptions of what she should or should not be doing or feeling.

3.4.2. Interdependence

Fran wanted to stress that her life had been good and remained meaningful through her contact with friends and family, however, she had found ageing difficult as she felt it had led to a reduction in activity. Fran's main worry was that she would forget a debt, but she was confident that, with the support of her family, this would not happen:

> [861-892] [...] It doesn't, it doesn't [laughs], as I say, it doesn't bother me. It *doesn't* really *bother* me that much because I know I'll be looked after. [Laughs] I keep saying to them, you know, they'll erm, [2] I can't think now who said it, "You know, your memory's getting worse". I said, "I know, but I know you'll remind me if I owe you money and I, you know". [Laughs] So nothing else bothers me, as long as I don't owe any money [laughs], and someone's coming to say to me, "Oh God, you owe me money!" [Laughs] Must be a terrible thing! I hope people now don't, but that was, when *we* were young, that used to worry me *most*, you know, every week, that I had enough money to pay everything and that I didn't owe, that I didn't owe anybody anything. [Laughs] And family, you know when they were young, that you had enough money to buy them clothes and pay them for everything, mmm. [2] Because, I had a good life. I enjoyed me life. I worked hard, but I enjoyed it. And er, I had loads and loads of lovely friends, and I met an awful lot of nice people, yeah! So, I have nothing to, sort of, that I can, [.] *regret*. I don't think I have. Probably getting old. [Laughs] Can't go out as much. [Laughs] But I've not got any worries. I've no worries because I know I'd be looked after, and er, I'm not short of money. And if I do run short, I have [children] [laughs], that I know would look after me, so I don't have any worries! I haven't got any

worries because I get on well with me [siblings], and we all communicate, and if there's any celebration, we all meet up, and really enjoy it. We never have any arguments, so er, there's er, nothing! And I get on well with grandchildren and everything, so I, no, no worries. And I get on, I've got loads of friends, and that I keep in touch with, so yeah!

At many points in the interview, Fran joked that despite her dementia diagnosis, she would not forget about owing or being owed money, e.g., "They said, 'I bet, if any of us owed you money, you wouldn't forget!' [Laughs]" [151-152]. While she joked about it, this concealed a sense of fear that she would one day be unable to look after her finances. Experiencing her early childhood during a time when Ireland was impacted by food rationing and coal shortages (Wills, 2007), being financially secure had been of great importance to Fran throughout her life, as it meant that she could look after her family. A life-long worry, this shows continuity in Fran's identity, challenging claims that the diagnosis equates to loss of self (Kitwood, 1997). Her fear was reconciled, however, by her trust that her children would protect her from financially vulnerability. Their support helps Fran to retain a core aspect of her identity, where she pays her bills and does not let anyone down. Through her emphasis on staying free from debt, Fran performs the 'personally responsible citizen' (Westheimer & Kahne, 2004); a contrast to the 'mad' and 'demented' images encountered in society, which question and erode citizenship in those diagnosed with dementia (Baldwin & Capstick, 2007; Harding & Palfrey, 1997).

This sense of support from family and the importance of frequent contact with friends may be linked with Fran's Irish heritage and her integration into the Irish community in London. Malone and Dooley (2006) state that many first-generation immigrants in this group believe in the significance of family ties, mutual support, paid work, the Roman Catholic Church, and have a deep sense of community. Life within a migrant community offers networks of help and fosters feelings of belonging, identification and meaning, which can support people through the stresses of later life through providing them with collective and individual resources (Malone, 2001; Malone & Dooley, 2006; Sonn, Bishop, & Drew, 1999). The strength of Fran's character and position in her community

is demonstrated in a story she tells about hiring a man from Northern Ireland to work in her pub:

> [504-516] Like, we all met up *yesterday* at a funeral. [.] Even though this fella came from Northern Ireland, and he wasn't a Catholic, and er, I mean, we hadn't, not a lot in common, but the brother came to work [2] with us, and, I can remember somebody coming into the pub, now this is *years* ago, erm, somebody coming into the pub and saying to me, erm, we had four barmen [.] working there, um saying to me, "I hear you have a Protestant working here". And I said, [feigning surprise] "*Oh, God, have I? Which one?*", and they were so disgusted. [Laughs] I thought to meself, "You cheeky sods, you!" [Laughs] As though it made any difference!

Similar to her reaction to her dementia diagnosis, Fran shows power, courage, and defiance.

At the funeral Fran mentioned, she got to meet up with many of her old friends. It is unclear whether she named her difficulties as 'memory problems' or 'dementia' when speaking to them, but she had informed her friends about the problems she had been having with her memory:

> [161-165] But I thought well, if I'm gonna say something wrong, and if they tell me something and I forget it, and ask the same question again, well at least they'll know why! [Laughs] But it didn't, it didn't er, bother me at all.

Contrary to the findings of previous research (e.g., Singleton, Mukadam, Livingston, & Sommerlad, 2017), Fran was not worried or embarrassed about telling her friends this, and was able to speak openly and confidently about her difficulties. She accepted forgetfulness as a new part of her life and wished to confront any awkwardness before it occurred yet, despite her diagnosis, she considered her memory difficulties to be no different to those experienced by other older adults:

[352-361] [F]: Yeah, well some of them are *better* than me.

[K]: Better?

[F]: Better like, memory-wise and that. [2] And some of them are worse! [Both laugh] I don't think much... I know my older sister, I mean, she's got a memory like, I don't know what! She can remember everything. But, my younger sister, she's er, she's close to me in age but her memory is probably not quite as *good* as mine.

Unaffected by the media's panic-blame discourse (Peel, 2014), Fran considered memory problems to be common and outside of one's control. This may be protective, framing her difficulties as a matter of normal ageing rather than a diagnosable difficulty. For Fran, ageing was not a matter of being 'successful' or 'unsuccessful', but was a matter of luck, determined by memory quality, regardless of diagnosis. Fran felt that the majority were unlucky, but this was not a personal failing and did not necessitate a poorer quality of life. However, she recognised that her attitude toward her difficulties may not be one that is shared by others who may be in her position, who may fear the stigma that is attached to ageing and memory problems and, thus, hide their difficulties:

[456-474] It's just age, isn't it? Getting old. It doesn't bother me. It doesn't bother me. I think that's what's happening and that's what's going to happen to most people. [Laughs] So anyone that's very lucky, that's what I'll say to them, I say to my older sister [name], I say "You're lucky, you see. [Laughs] You don't forget anything at all!" [Laughs] [.] Though then again, [older sister], she's the type that wouldn't [.] *say* that she didn't remember. You see, I'm out, everything is out. Straight. Everything is out in the open. Well [older sister] wouldn't er... She's a different type of person. She wouldn't want er, people to think that she couldn't, you see. She'd probably pretend that she had... [Laughs] [Younger sister], she's more like me. She'd be looking at it, *looking*, wondering, "I can't remember that!" [Laughs] [Older sister] is *different.* She'd erm, pretend that she could remember it, whether she did or not. [Laughs] She'd hide

it, but we're open. She'd be more worried about what people will think of her.

3.4.3. Getting Older

Fran said that through working in her pub, she had seen people grow older; their body deteriorating and their memory getting worse:

[747-763] [...] There was a lot of *old* people would come into the pub, and I was used to doing things for them, you know, them forgetting things [...] And er, and because we had a great relationship with the older people that used to come in... And the youngsters that used to come into the pub, they were very good as well. Like for, looking after them, and they'd see them home and all that.

[785-803] Because we used to get a lot, a lot of old people [.] coming in. And you know, you see them gradually [2] deteriorating, say and the er, the memory. And, *as well as* the memory, you know, their erm, their *walk*, and everything gets [2] a bit frail. They're a bit frail, and there's the worry, the worry then that they'd be nervous crossing the road and that, yeah.

[K]: Does that resonate with your experience?

[F]: [Laughs] I don't think it does, really! I don't, no, I cannot explain it, really! [3] I don't know why. [2] I don't know. I can't give you an answer to that. But it doesn't bother me. It doesn't bother me to think that, well if I can't remember something, you know, I can *ask*, and if I forget it, well it doesn't make a bit of difference. The world still goes on! [Laughs] Yes, and it'll come back. It comes back, you know, the memory, or somebody will *remind* you.

Fran was happy to use the term 'old', constructing herself and others in these terms, and was empathetic and understanding toward the experience of older adults: "I think, 'Well that's happening to me now, so it is!' [Laughs]" [450-451]. She held frequently encountered stereotypical views of old age as a period of

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physical ailments, frailty and dependency (Markle-Reid & Browne, 2003; Palmore, 2001), yet did not judge these negatively. Fran felt that these vulnerabilities may cause some to worry, but she did not identify this within her own experience. The importance of community and interdependence for Fran meant that she felt no stigma around receiving or giving support and, with the help of her family, Fran's memory problems did not cause her any disability.

> [325-330]: I like going over there, but the trouble is, there's, see, the people that I was, [.] you know that were *my* friends and that I used to go out with and visit. They're, they're all old now as well! [Laughs] So it's sort of, we have to get someone to *take* us about town. So, it's not as, it's not as nice as it *was*. It's not the *same* as it was.

> [896-907] [...] they're sort of, my age and, maybe they're older, so they're sort of all [2] fading away, or they don't come out. We don't see each other. Like, in the summer time, when the weather's nice and that, if I go out for a walk I might see them, but I don't see some. I see [neighbour], but not as often as I used to, and then er [2] the [neighbour further down the road], they moved down the country. I don't know, I haven't heard from them now, cos we lost touch as we get older. And erm, I don't even see me sister as often as I used to. But we, we keep in touch on the phone and that. But every so often, we *all* meet up, the whole family.

While Fran maintains that she is unaffected by the changes in her memory, she feels more negative about ageing, which she connects to some loss of independence; an experience she believes is shared by many of her peers. She feels unable to be as active as she once was, and the activity she is able to do does not feel as rich. She describes old age as a 'fading away'; disappearing from social life and no longer being visible, which is a feeling commonly reported by older adults (Ory, Kinney Hoffman, Hawkins, Sanner, & Mockenhaupt, 2003). To avoid isolation, Fran adapts her social engagement, finding new ways of connecting with people and working around her obstacles. She has frequent visits from family members but, beyond this, has moved most of her social contact to the telephone. Although she cannot visit church as often as she would like, the priest comes to visit her in her home. Through finding

ways to adapt to and cope with her loss, Fran is able to maintain a sense of community.

3.5. Summary of Findings

Informed by wider social narratives on ageing and dementia, and personal philosophies developed throughout long and rich lives, the narrative accounts elicited in these four interviews showed remarkable diversity in their interaction with their diagnosis, yet each resisted a stigmatised identity. The thoughtful narratives that were shared reflect the abilities of older people with a dementia diagnosis to tell a story and express their thoughts and opinions, particularly when provided with support and facilitation (Hughes & Castro, 2015). Since an extensive array of experiences were recounted in participants' interviews, the research questions were used to provide a general structural framework for analysis and discussion. This section focuses in more depth on the research questions, summarising the findings and reviewing participants' experiences of being given their diagnosis, and how their diagnosis interacted with their beliefs around ageing.

3.5.1. How do those Diagnosed with Dementia Experience the Assessment Process?

Showing the reach of the medical gaze, each participant was advised by a relative to have their memory assessed. For Hugo, the medical model was something that provided hope of keeping 'dementia' at bay, while for Ted it was something that garnered respect, however, the exact medical diagnosis meant little to the participants. Their understanding of the label instead came from socio-cultural beliefs and stereotypes, emphasising Harding and Palfrey's (1997) argument that 'dementia' is socially constructed.

The deficit-focus of the medical model was rejected by all but Hugo, who instead wished for his struggle to be understood and not minimised. This led to divergent attitudes on whether professional support was felt to be necessary, and differing reactions when given the diagnosis; for example, Fergus and Fran professed a lack of concern about their diagnosis while Hugo and Ted felt shocked. Response to the diagnosis was influenced by the individual's socio-

cultural context and beliefs, biomedical, age-related and political discourse, attitude, sense of identity and life-philosophy, as well as the response of family members. With multiple factors acting upon the emotional response to the diagnosis, this supports Pratt and Wilkinson's (2001) assertion that an individualised approach should be taken when giving the diagnosis. Some may reject pre- and post-diagnostic counselling, medication, or psychosocial groups, while others may embrace these forms of support. Rather than taking a medical perspective and focusing on how to 'fix' behavioural and social problems, individuals may need support with whether to reject or integrate the diagnosis into their identity.

While professional support and medication were important to Hugo, other participants were helped by memory aids and pastoral and social support. Contrary to medical understandings of dementia, this support helped each person maintain a quality of life that helped them to cope with their losses and maintain an overall sense of happiness. This concurs with Woods et al.'s (2006) findings that quality of life is independent of level of cognitive functioning.

Similar to the clinicians in studies by Connell et al. (2004) and Kaduszkievwicz et al. (2008), participants fluctuated in how their difficulties were framed. While at times the problem was 'dementia', at other times it was 'memory problems', using euphemistic language to position their difficulties as part of 'normal ageing'. Understanding of their problems was, therefore, fluid and often functional, serving to protect from fear, shame or stigma. Perhaps the resilience this demonstrates may allay clinicians' fear and avoidance of giving someone a denigrated diagnosis (e.g. Bond et al., 2005), allowing the person to decide for themselves what they wish to do with the diagnosis.

Stereotypical and stigmatised views were present across each narrative, and had not been re-evaluated following personal experience of the diagnosis. Stereotypes were often rejected by the individual but assumed to be present in others. Also held by family members, these views could have a negative impact on the support that those diagnosed with dementia receive from others. While interdependence was valued in the individual's relationships, it was assumed that others who were ageing or diagnosed with dementia were frail, dependent,

and their identity had been erased by 'dementia'. Participants in the present study did not feel like they belonged to this stigmatised outgroup, seeing themselves as different and acknowledging an individual rather than a group identity. They perhaps do not consider those diagnosed with dementia to be a homogenous group and separate themselves through level of impairment and, therefore, level of stigma (Deal, 2010). Alternatively, while many people state that they 'don't feel old' due to a continued sense of identity and qualities that challenge old age stereotypes (Thompson, 1992), perhaps participants in this study felt similarly, and did not experience a sense of belonging to a group defined by a 'dementia' label.

Although friends or relatives may say otherwise, participants felt that the only changes they had noticed were in their memory. As with Werezak and Stewart's (2002) study, participants felt fundamentally the same person they had always been, yet it remained important to recognise both the strengths and losses they had experienced, particularly for Fran and Hugo. While some studies (e.g., Corner, 1999; Werezak and Stewart, 2002) state that a dementia diagnosis elicits a strong sense of fear for the future and thoughts of 'burden', loss and stigma alongside negative thoughts regarding ageing, I was struck by the resilience shown by the participants in this study. Even when experiencing fear, interdependent relationships supported participants to cope with this, and powerfully prevented disability. Each participant resisted the label and the diagnosis in different ways; for example, with Ted, this manifested in moving the conversation onto his career, while Fergus emphasised the activities he was still doing. Ted, Hugo, Fergus and Fran strongly showed that they were more than their dementia label and set it aside; they have lived, had a career, some have had children, they have achieved, loved, celebrated, and still stood strong. Their diagnosis does not define them.

3.5.2. How can Narratives Around the Impact of the Dementia Label be Understood Within the Wider Context of 'Successful Ageing'?

Each participant referred to themselves as 'old'. As someone younger than the participants, this may have been caused by my presence, but may also be due to participants' perception of their body as 'deteriorating', and having been told through decades of social discourse, that this is a sign of being 'old' (Rowe &

Khan, 1997). Judging this 'deterioration', the medical gaze was apparent in the lives of all four participants (Foucault, 1963/2003), either through the professional treatment they received, the way in which they were monitored by family members, or in their awareness that the medical definition of dementia differed from their own understanding of the diagnosis. This gaze has many socio-political consequences for those diagnosed with dementia, such as stigma, exclusion, and loss of citizenship (Castro Romero, 2017). Consequently, the focus of doctors on physical decline in ageing patients (Bowling & Dieppe, 2005) not only misleads in presenting a biomedical position that claims to be neutral (Humphrey, 2006), but enforces a perspective that may lack profound meaning for patients, who ultimately imbue diagnoses with their own sense of understanding developed from a lifetime of social conditioning (Harding & Palfrey, 1997). Loss and decline did not dominate the narratives in this current study, and although present, were part of much thicker stories.

An expectation of loss and deterioration appeared to contextualise the dementia diagnosis and to a certain extent, mitigated its impact. Society's fear of ageing was not evident in these participants (Castro Romero, 2017), who accepted ageing and dismissed dementia. However, despite dementia diagnoses being familiar to these participants, as part of their own experience and that of peers, dementia remained stigmatised and viewed with greater negativity than ageing. Contrary to findings that show that older adults hold a stigmatised opinion of themselves (Corner, 1999), the individuals in this study held a complex sense of self-perception, holding views that were at times stigmatised, and at other times liberated, empathetic, and strengths-focused. Indeed, Ted, Fergus and Fran did not distinguish themselves from dementia diagnosis-free peers. Participants did not think of themselves as having failed or been unsuccessful at ageing, and did not view their diagnosis as being something within their control. Rather than a dichotomy of either 'living well with' or 'catastrophe' (McParland et al., 2017), experiences of ageing were complex and fluid, and could elicit pity, empathy, comradery, feelings of togetherness or feelings of separation.

Bowling and Dieppe (2005) previously challenged Rowe and Khan's (1997) concept of 'successful ageing' through stating that its focus on physical health neglects the psychosocial aspects that can enrich old age. Supporting this, the participants in the current study placed great importance on the psychosocial

aspects of their life, such as seeing family and friends, engaging with memory services, or practising hobbies. It seemed that evaluation of 'successful ageing' was also part of a broader review of their life as a whole, and not simply confined to their life post-65 (Erikson, 1994/1959). In this study, participants appraised their lives positively, which contributed to a sense of successful ageing irrespective of their diagnosis. Similar to previous studies by Baltes and Smith (2003) and Bowling and Dieppe (2005), participants showed stability despite loss and suggested that they were happy and well in the face of health difficulties. Aspects of life that had become more difficult in old age, such as remembering names, spending time outdoors, independent activity, and spending time with peers, were adapted or carried out on a smaller scale (Baltes & Smith, 2003). Fran, for example, had noticed no longer seeing her friends in the street when out of the house. Ultimately, she also reduced the time she spent outdoors, maintaining contact with friends over the telephone. This was accompanied, however, with a sense of loss. Like the other participants, Fran attributed this change to old age, yet this highlights that her environment was not facilitating her to live a life as full as she would wish. Through not being facilitated to leave her home, Fran, as with many her age, then becomes invisible to the rest of society (McIntosh & Huq, 2017). Therefore, elders remain marginalised by a society that does not adapt to meet their needs, perpetuating disability and malignant social psychology through undermining personhood and wellbeing (Kitwood, 1997; McParland et al., 2017; Oliver, 1996). Dementia was not seen to be 'failed ageing', but perhaps it is society that has failed the ageing.

4. FURTHER DISCUSSION

This chapter will address some of this study's challenges and limitations, as well as evaluative concepts such as issues of validity and ethical considerations, alongside my personal reflections. Finally, I will discuss the implications of the current study and recommendations for the fields of research, clinical practice, service provision, and the wider socio-political context.

4.1. Critical Review

4.1.1. Recruitment

While the medical model categorises people by their diagnosis, insinuating that people hold only single and limited identities, intersectionality shows that those given a label hold multiple and overlapping identities that shape the individual's unique experiences and worldview, including their experience of being diagnosed and growing older (Settles & Buchanan, 2014). Recruiting only four participants allowed narratives to be studied in depth, but meant that narratives from many different contexts remain unheard. Support from family members, for example, was a source of great value to those in this current piece of research, so a different story may be heard from people who are isolated from social networks, and different conclusions drawn\. Since each individual brings a different context to a research setting, influenced by aspects of their identity such as political beliefs, social class and sexuality, alongside their socio-cultural and physical context, opportunities for further exploration and elevation of the voices of those diagnosed with dementia are plentiful. Future studies may benefit from continuing to broaden the stories that are heard about people diagnosed with dementia, further investigating different experiences.

4.1.2. Data Collection

The study can be said to be limited by its use of single interviews (Riessman, 2002). These provided a snapshot of how participants felt at that moment and allowed for thorough analysis, but stories collected over multiple visits could have shown how narratives and sense of self can change and develop over time, providing deeper and richer accounts.

Meeting participants only once, it was important to hold performance in mind, as this shaped how participants recounted their experiences. Despite my curious stance, for example, it was apparent that Ted and Fergus expected that I would hold negative views about dementia, which perhaps shaped their narrative. Aspects of this performance may change over time should participants become more familiar with my presence and style, however, this may be limited as my status as an 'outsider' in age, cognitive ability, and professional 'power' would remain. This could suggest a distinct power imbalance between researcher and

participant but, albeit from my own perspective, participants appeared confident that there was something important that they could share with me, supporting me with my research project. The most hesitant about this was Hugo, who relaxed into this position rather than holding it initially. There are many negative stereotypes associated with older age, but older adults are also associated with positive stereotypes, such as being 'knowledgeable' and 'experienced' (Chasteen, Schwarz, & Park, 2002), which perhaps led to participants rightfully believing that they could offer me something that I would find helpful. The impact of these positive stereotypes on the understanding of a dementia diagnosis may be a fruitful avenue to explore further in future studies.

While the literature review suggested that potential participants would voice internalised negative stereotypes, I was provided with complex narratives that did not focus on self-criticism. Cotterill (1992) suggests that the portrayed self alters as trust and confidence develop, so perhaps participants would have voiced more vulnerable stories after further meetings. Since interviews are a process, however, where stories are constructed for an audience, an interview on the same day by a different interviewer may also have led to different narratives being storied (Lyons & Chipperfield, 2000).

4.1.3. Validity

Since dominant notions of validity and reliability cannot be applied to narrative studies, Polkinghorne (2007) suggests that validity in such research is determined by the readers, who base their decision on the cogency and soundness of the evidence-based arguments provided by the researcher. Additionally, Riessman (2008) calls for transparency and external validity in narrative studies. While my interpretation of the data will be different to that of anyone else due to the co-constructed nature of knowledge, I have attempted to ensure the validity of my study using the means described below:

4.1.3.1. *Cogency:* Using top-down theorising to make sense of the data that I collected (Squire, 2008), I ensured that my analysis of the transcripts was well-grounded in theory and considered the results of previous studies. Drawing directly from the transcripts also allowed for bottom-up theorising (Squire, 2008), where the sense that people made of being given and then living with a

dementia diagnosis, was considered within each participant's particular context. To support my interpretations, I included direct quotes from the transcripts to allow the reader to see from where I had drawn my conclusions, allowing them to decide whether they felt that these inferences were reasonable and convincing (Riessman, 1993).

4.1.3.2.   *Soundness:* I have attempted to ensure theoretical coherence throughout the study, positioning knowledge as socially constructed. This has necessitated the use of alternative validity tests and led to considering shared and individual contexts in my analysis. Being outside of the group that was the focus of this study, i.e. people aged 65 and older with a dementia diagnosis, and not having prior and in-depth knowledge of participants, means that there may have been aspects of participants' contexts of which I remained unaware when conducting my analysis. To manage this, I chose to be guided by both the research questions and the data, drawing from the aspects of each participant's context that appeared to be pertinent to and prominent in their narrative.

The focus of the analysis was on the interviews as individual stories. I found that each narrative had a different emphasis, with each person interpreting the initial question in different ways. Themes were not drawn across interviews, as this would limit bottom-up theorising and ignore the continuity and contradiction present through individual accounts (Braun & Clarke, 2006). Without minimising the importance of individual perspectives, however, I attempted to summarise the data in order to answer the research questions, showing how the diversity and similarities between the transcripts portray the social construction of dementia. This impacts upon how the diagnosis is understood at the point of it being given, and afterwards when the individual considers how the diagnosis will impact upon their life and that of others.

4.1.3.3.   *External validity:* Riessman (2008) argues that, firstly, qualitative research should have a pragmatic use, therefore, section 4.2. draws practical recommendations from the implications of this study, with particular focus on the field of clinical psychology. Secondly, interpretations should be shown to participants. Thus, participants will be provided with a personal summary of the

study (Appendix F). The ethical issues that this elicits will be considered in section 4.1.5.2.

To further bolster the validity of the study, I attended a narrative analysis group, where I shared excepts from my transcripts and analysis for review. This allowed me to gain new perspectives on the data, and was a way to check the soundness of my conclusions.

4.1.3.4. *Transparency*: The story told throughout a study must be 'trustworthy' for validity to be claimed (Riessman, 2008). Since no research is neutral or value-free (Stevenson, 1988), I have been open about my own position and reason for undertaking this research, my epistemological assumptions, and the reasoning behind my methodology and analysis. This has included sharing an excerpt of my research journal (Appendix I), and taking a reflexive approach to the study. These measures allow the reader to assess the persuasiveness of my arguments, informed by an understanding of the study's context.

4.1.4. Reflections on the Analysis

Participants rarely spoke directly about their experience at the memory clinic, either being unable to recall the details of their experience, or wishing to redirect our conversation to a subject they felt offered a more relevant picture of themselves. As a result, at times during the interview I found it hard to know when a story had moved too far from my question for it to continue to be relevant for the purposes of this study. Aware of my role in shaping narratives, it was difficult to balance the narrative direction of the participant with the focus of the study, and when analysing the transcripts there were narratives that I wished I had pursued further in the interview, although at the time had seemed like unproductive or exhausted avenues of conversation.

When considering my role in shaping the analysis, it was important to keep in mind all sides of a dementia diagnosis rather than favouring the commonly used narrative trope of triumph over adversity; a trope frequently found in stories of disability, set up to alleviate the anxieties of those who are able and well (D. Davis, 2004; L.J. Davis, 2002). Simplifying their narratives in this way would be

an injustice to those who gave up their time to tell me their story. As it was my role to make the reader aware of hegemonic ideologies, challenging what society takes for granted (Elliott, 2005), I sought to keep the complexities of their narrative in mind throughout the analysis.

4.1.5. Ethical Considerations

4.1.5.1.   *Analysis*: Through the process of analysis, I worried that my analytic frame and control over which excepts to present, meant that my own voice was being heard over that of participants. Bearing in mind my research aims and Miles and Huberman's (1994) caution regarding the potential for researcher bias, I tried to account for this through ensuring that, where possible, extended excerpts were presented, allowing the reader to get closer to the words of the narrator. This could not, however, be done to the same degree with every participant, as they differed in the degree to which their narratives were fragmented and how long they wished to speak in response to the question, thus reflecting the reliance of this study on verbal communication.

4.1.5.2.   *Sharing the results with participants:* I will provide participants with accessible summaries of the study including a summary of their interview analysis, ensuring that these remain meaningful to those outside of academia and the social sciences. Receiving such a summary has been shown to be able to help participants feel that their contribution was valued, and can provide validation of personal experiences (Birt, Scott, Cavers, Campbell, & Walter, 2016; Harper & Cole, 2012). As these will be received when I am not present, I wished to minimise the potential for any distress to be experienced through trying to ensure that, albeit based on my own evaluation, my interpretations were respectful and balanced.

In addition to providing summaries, Riessman (2008) argues that to strengthen the credibility of findings and the ethical basis of the study, one should gain feedback on the analysis to ascertain whether it resonates with participants. This adds another perspective to the analysis and gives participants a greater voice in the study (Birt et al., 2016). In this study, provision of feedback will remain optional and may not be received in time to be included in the current write-up, but will be included in future publications. Allowing feedback to be

optional reduces the burden on participants' time and enables them to decide at which point they wish their involvement with the study to end, but Estroff (1995) found that participants tend to privilege the interpretation of the researcher, suggesting that they are unlikely to get in touch to share views that deviate from my analysis. This, therefore, constrains claims that this study elicits a true dialogue with participants and limits validity claims, but could be remedied in future studies through allowing more time to arrange meetings with participants to discuss the analysis.

4.1.5.3.   *Sharing the results on a broader scale:* To ensure that this research is meaningful, it remains important to disseminate my findings in academic, professional, and lay settings, not privileging the awareness of academics over people diagnosed with dementia and their families.

4.1.5.4.   *Dementia as a disability:* Led by participants discussing the value of interdependence and a supportive environment, the social model of disability was introduced in the analysis chapter. While considering dementia to be a disability has benefits (further discussed in section 4.2.3.), participants may not wish to identify as experiencing disability. Similar to the 'dementia' label, the dominance of the medical model of disability may mean that participants associate the 'disability' label with dependence, discrimination, and stigma. While I would not wish to impose a label upon anyone, the social model of disability has much to offer our conceptualisation of dementia through focusing on the wider societal context in which a person exists. Through highlighting that disability rights are human rights and must be supported by laws and policies, the model can be a powerful lever for change (Mental Health Foundation, 2015).

4.2.   Implications and Recommendations

The findings of this study are not representative of a wider population, but the narratives elicited by participants challenge the assumptions of the medical model and highlight the importance of individualised, whole-person care, that holds as central the person's broader social context. While particularly pertinent

to clinical psychology, implications can extend beyond this group to all who play a role in dementia-care.

4.2.1. Developing Theory Through Research

The narratives in this study showed that a medical label cannot be extrapolated from the folk tales that are told about that term. Drawing from medical and social discourse, participants often mentioned characteristics that they associated with 'dementia', such as 'old age', 'madness', and 'loss of self'. Current policy and policy recommendations emphasise the importance of further research (Alzheimer's Disease International, 2013; Department of Health, 2015; World Health Organization, 2015), but to gain an understanding of the lived experiences of those with a dementia diagnosis, the research community must continue to take this socio-cultural context into account rather than seeing dementia through a purely medical lens. Clinical psychologists are well placed to use their evaluation and research skills to support services in monitoring the effectiveness of their communication processes and to develop models to further research the process of sharing the diagnosis (British Psychological Society, 2016).

People diagnosed with dementia are able to provide a valuable contribution to research, yet the current study is one of only a minority that directly address their experience (Cowdell, 2013). This emphasises the need for further research that involves those diagnosed with dementia, promoting their voice, thickening narratives, and developing 'bottom-up' theory that holds meaning for those with a diagnosis. Ensuring widespread dissemination of personal narratives may also lead to re-evaluation of those diagnosed with dementia, alleviating the fear and stigma that this study has shown is held by those with and without a dementia diagnosis. This, however, will not be without difficulty. When external bodies checked the proposal for the current study, each suggested altering my inclusion criteria to reduce the timeframe since diagnosis, seeking to elicit greater recall of the assessment process. This realist focus on 'fact-gathering' rather than on experiences, interpretation and understanding, serves only to continue to exclude people with cognitive difficulties, especially those with more severe difficulties, from qualitative research.

This study has shown the value of utilising qualitative methods with those diagnosed with dementia, making use of their experience and social history. Participatory action research (PAR) could take this further through engaging people diagnosed with dementia from a study's inception, to collaboratively influence social change and improve service provision (Baum, MacDougall, & Smith, 2006). This would challenge the power relationships that were replicated in the present study, where I studied a group to which I did not belong.

4.2.2. Clinical Practice

The current participants showed how the medical and social are intertwined. If clinicians consider these to be separate, as with Ted when he distinguished the medical definition of dementia from his own, they will remain blind to how negative social rhetoric influences the way in which they support people diagnosed with dementia. Clinical psychologists should, therefore, use supervision to reflect upon their own views. Providing reflective practice and supervision for team members, as well as training and consultation for other agencies involved with people diagnosed with dementia, clinical psychologists can also aid others to reflect on the biases that may influence practice. This is supported by recent guidance from the British Psychological Society (2018), which additionally suggests that clinical psychologists provide skills training to staff working with those being assessed for or diagnosed with dementia, regarding the psychological impact of diagnosis.

Clinical psychologists can broaden the discourse among professionals who come into contact with people diagnosed with dementia through sharing formulations that consider the biological, social and psychological, and have been collaboratively constructed with the client. They could also share stories in team meetings of people diagnosed with dementia, or invite those diagnosed to do so, increasing clinicians' understanding of the lived experience of a dementia diagnosis. Through doing this, the dialogue in diagnostic sessions may come to have more meaning for people being assessed, amending a system that through rendering people passive, causes dependence and, therefore, oppression (Freire, 1970/1996).

Participants in the current study differed in their attitudes toward the diagnostic label, and their narratives reflected a process that started before, and continued after, diagnosis was given. Following British Psychological Society (2016) guidance, and congruent with the conclusions of this study, psychological assessment should be made available as part of the diagnostic process. Clinical psychologists are well-placed to support people to reject or integrate their diagnosis into their understanding of themselves but, to do so, they need to become core members of fully staffed multidisciplinary memory clinics (British Psychological Society, 2006, 2016). Packages of care can then be offered pre- and post-diagnosis, depending on the needs of the individual, and allowing them to make their own choices (Mental Health Foundation, 2015). As the idea of 'care' might be rejected by people who perceive themselves to be well and able, or who are culturally unfamiliar or uncomfortable with the concept of seeking emotional support, as expressed by some in this study, narrative approaches and groups for those with and without a dementia diagnosis may serve to provide space that is not focused on problems. This has the potential to address loneliness through shared story-telling (Hughes, 2014), and remove artificial barriers between people with a diagnosis and those without. Through 'co-creating' an understanding of 'dementia', this could challenge stereotypes held by the individual and people supporting them, thus creating the potential for personhood to be preserved (Fredman, 2010).

4.2.3. Service Provision

This study suggests that the current policy narrative of disease and burden (see Alzheimer's Disease International, 2013; Department of Health, 2015; World Health Organization, 2015) perpetuates negative discourse regarding dementia, impacting perception and treatment. Psychologists can lobby for continued policy change, but this may be difficult within services that expect work to be focused on the individual and within a therapy room. As psychologists have a duty to act in the interests of their clients (Gauthier, Pettifor, & Ferrero, 2010), with the British Psychological Society (2016) asserting that psychologists are instrumental in upholding the human rights of those diagnosed with dementia, they may have to use the ethical position of their profession to bolster their individual position, preserving and upholding their values and ethical commitments.

Listening to the voices of those diagnosed with dementia in this study has shown that doing so can open up new perspectives. Psychologists should, therefore, challenge existing leadership and commissioning structures to allow people diagnosed with dementia to take more of an active role within services. Advocating for and working alongside elders, clinical psychologists should consider them 'experts by experience' (Barnes, 2009), promoting their involvement in issues such as service design and policy change (British Psychological Society, 2016). Developing long-term partnerships within the field of research and in local contexts may remove barriers and help to alter dominant discourses, utilising virtues that would otherwise be hidden by dominant medical narratives (Martin-Baro, 1994; Mental Health Foundation, 2015).

4.2.4. Socio-political Implications

The narratives in this study recognised and were impacted by hegemonic discourse. Aware of the stigma behind the 'dementia' label, for example, Hugo and Fergus wished to keep it largely secret. Even when rejecting this discourse with regard to themselves, it was considered present in others, affecting how the diagnosis was understood and how others were regarded. The diagnosis attaches a stigmatising 'disease label' to the individual, demonstrated by participants' use of detrimental language inherited from the medical model (e.g., 'demented'; Alzheimer Europe, 2017). This label is seen as defining a homogenous group, set apart from the rest of society (Mental Health Foundation, 2015), but the current study challenges these assumptions and shows the heterogeneity of those diagnosed with dementia. While psychologists mostly work at an individual level, discourse based on stereotypes remains unchallenged, maintaining the status of the medical model and negatively affecting the wellbeing of people diagnosed with dementia.

Patel (2003) argues that clinical psychologists have a responsibility to consider whether they wish to reinforce the oppressive status quo, or support the people we encounter to move towards liberation. This study shows the importance of adopting an activist role, confronting social narratives and attending to issues of equality and justice, which are missing from current dementia discourse

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(Alzheimer Europe, 2017). Taking a political approach to advocacy involves working beyond a one-to one approach, as this is not enough to affect societal change (Martin-Baro, 1994). Through working on a wider scale, psychologists must promote the rights of those diagnosed with dementia and seek an end to discrimination.

Dementia activism has adopted the tagline, 'Nothing about us without us', which is a strong indication that people with this diagnosis wish to be seen as active agents in their own lives (Mental Health Foundation, 2015). While some with a dementia diagnosis will not wish to challenge the stereotypes and prejudice linked with this label, it remains important for clinicians to offer alternatives to the current social response to this diagnosis (Mental Health Foundation, 2015). Psychologists are able to use their status to stand alongside people diagnosed with dementia, recognising them as agents of change, breaking down oppressive barriers, and supporting people to live a life of their own choosing. This becomes of even greater importance for people who are experiencing significant cognitive impairment, who are at ever increasing risk of isolation, marginalisation, institutionalisation, abuse, and systemic inequalities (Mental Health Foundation, 2015).

Recently, taking a 'diagnosis neutral' human rights approach to dementia has been advocated, applying the social model of disability and seeking social justice for and alongside people diagnosed with dementia (Alzheimer Europe, 2017; Shakespeare, Zeilig, & Mittler, 2017). Here, the term 'disability' is used for all impairments that arise from society's response to health difficulties (Alzheimer Europe, 2017; Mental Health Foundation, 2015). Through use of this alternative approach, dementia is moved away from the negative connotations of the medicalised view, reinstating the importance of care and interdependence (Alzheimer Europe, 2017). This is particularly pertinent considering the dominance of interdependence in the narratives of the current study. Extending the scope of care beyond the immediate family and into wider society, this model suggests that each person plays a caring role, including the person diagnosed with dementia. Through 'caring about' rather than 'caring for', dependence is not imposed, eliciting equity in moral status (Alzheimer Europe, 2017; Mental Health Foundation 2015). It is for this reason that in this study I

have used the term 'carer' only in its general sense, and resisted referring to the individual's spouse or children as carers, acknowledging that this suggests dependence and disregards relationships.

Considering ourselves as all being responsible for each other's wellbeing would introduce new values into the public domain (Kittay, 2011), and would enable the individual to participate in a society that is supportive and understanding. Through reducing the separation between people diagnosed with dementia and people in mainstream society, a new understanding could be elicited (Mental Health Foundation, 2015). This has the potential for preventing isolation and eliciting engagement in meaningful activity through developing supportive environments, which Kitwood (1997) suggests can avoid much of the 'disease progression' that is currently perceived to be inevitable in dementia. Recognising the diversity of experience in the present study, the social model of disability acknowledges that those diagnosed with dementia have a multiplicity of needs and interests. While it may be a useful tool in helping to tackle the stigma around 'dementia', these ideas are relatively new, and would require massive change at micro and macro levels.

Change has begun to be implemented through government policy (Department of Health, 2012, 2015), which has seen the introduction of an initiative where 'dementia-friendly' communities are created. This furthers the notion that care about those diagnosed with dementia needs to occur at a community level, however, as this was not accompanied by a programme of sustained investment, the scheme risks being tokenistic. Any change must be meaningful, and ensure that communities are inclusive and accessible for those diagnosed with dementia. For this reason, a large-scale evaluation is currently being undertaken to assess the extent to which this initiative has been successful, in the communities in which it has been implemented (DEMCOM: National Evaluation of Dementia Friendly Communities, 2018). Additionally, psychologists must ensure that the promotion of cross-community care is not at the expense of current health and social care provision, through standing against cuts and austerity measures that may endanger the wellbeing of those diagnosed with dementia.

4.3. Conclusion

While it may appear that the process of dementia diagnosis, rooted in the medical model, is de-politicised and value neutral, this study shows that it exists in and is inextricably linked to its socio-political and cultural context. Clinicians must, therefore, be conscious of the broader impact of the diagnosis upon the individual, recognising the complexity and richness of experience that has been demonstrated in the narratives of people diagnosed with dementia.

The narratives I was provided in this study were at times amusing and at other times saddening yet, for me, they showed that a diagnosis that is portrayed so negatively in the media does not automatically rob people of what gives them their identity, echoing previous research (e.g., Clark-McGhee & Castro, 2014). Retaining a sense of humour or pride, showing defiance or fear, participants demonstrated that their experience can cover a range of emotions, hardships, and strengths. The diagnosis is multifaceted and cannot be understood simply through assumption or asking relatives. Prior to diagnosis and onwards, the whole-person needs to be considered in a clinical setting, yet clinicians also need to think on a wider scale. This research is part of an upcoming movement recognising the voice and the rights of elders with and without a diagnosis of dementia; a movement that I hope continues to gather momentum, getting broader, richer, and leading to genuine social change.

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APPENDICES

APPENDIX A: SEARCH STRATEGY

To find literature pertaining to people's experience of receiving a dementia diagnosis, literature was identified in the databases PsycINFO, PsycARTICLES, CINAHL Plus, and Academic Search Complete using the search terms below:

Search Number	Search Term 1	Search Term 2	Search Term 3	Number of Articles
1	Dementia OR Alzheimer's	Diagnosis OR Assessment OR Investigation OR Disclosure OR Disclosing		85,006
2	Dementia OR Alzheimer's	Disclosure OR Disclosing		954
3	Dementia OR Alzheimer's	Disclosure OR Disclosing	Experiences OR Perceptions OR Attitudes OR Views	390

The initial searches returned too many search results to be reviewed practically. The terms 'diagnosis', 'assessment' and 'investigation' were deemed to return too many irrelevant results, mostly focusing on topics of medicine or biology and the prediction or cure of dementia, so were removed from following searches.

Searches were restricted to English language studies, but incorporated UK and international studies. Dates for the returned articles ranged between 1983 and October 2017. Few articles were returned for the years 1983-1999, but since there were some relevant articles published within these years, search dates were not narrowed further.

To evaluate the applicability of the returned studies, their titles and abstracts were checked. Studies were prioritised if they investigated the experience of giving or receiving a dementia diagnosis, and were subsequently read in more detail. Other prioritised studies investigated the meaning of a dementia diagnosis from personal, social, cultural, medical and psychological perspectives, and the role of those with a dementia diagnosis in research. Studies solely considering mild cognitive impairment (MCI) or physiological aspects of a dementia diagnosis were excluded.

The reference lists of pertinent articles were then checked for appropriate further reading. Grey literature, such documents by Alzheimer's Society, and autobiographies written by people diagnosed with dementia, were also reviewed with the above search terms in mind.

APPENDIX B: STUDY JOURNAL

Participant: Hugo

Initial telephone conversation

[Date] Details given to me by the Trust's research team.

[Date] Called Hugo and explained the study. He was interested in the study and wanted to attend an interview. Hugo was eager to arrange an interview, as the study was of interest to him. Did not wish to receive interview sheets before arranging a time and date to meet. Handed the phone to his wife, saying that he was "no good with dates". Explained the study to Hugo's wife. Booked interview date, making sure that the interview would occur after the information sheets had arrived. This will give Hugo a chance to consider his decision to speak to me and to discuss any concerns with his wife.

Both were keen for the interview to take place at their local memory clinic as they had a family member living with them and felt that the memory clinic would offer more privacy. Hugo's wife was keen to attend the interview with Hugo as she was interested in the study. She understood that I would be interviewing Hugo and not interviewing them together as a couple. She said that they did not need a reminder call prior to the interview date.

[Date] Sent information sheets (two different versions) with reminder of interview date.

Initial meeting – Discussing consent

[Date] – Introduced myself and the study. Talked through the information sheets, using a copy as a visual reminder of the sheet Hugo and his wife had received through the post. Hugo said that he understood that his details would remain anonymous and that he could end or pause the interview at any time. Provided clear verbal consent that he would like for the interview to go ahead today and to audio record the interview. Hugo said that he understood that he could withdraw at any time. I discussed the intended value of the study – in

services for people diagnosed with dementia, and should the study be published, in literature on dementia.

Hugo had been unsure about attending today. This is interesting as had been enthusiastic when arranging the meeting. He perhaps started to worry as the date came closer. He worried that he would have little to share.

Consent form signed.

During the interview

Hugo remained thoughtful and engaged throughout the interview. His wife sometimes interjected. To consider this further in analysis.

Fire drill unexpectedly occurred in the building partway through the interview but it turned off when I got up to check what was happening. Hugo was happy to continue with the interview.

Hugo did not wish to have a break after half an hour.

After over an hour, it felt like we had covered a lot of information. I drew the interview to a close. I asked, "Is there anything else you'd like me to know?". Hugo said that there was nothing else he felt he needed to add.

Consent upon completion

Agreed for the interview to be used in the study.

Agreed to be sent written overview of the final study.

Feedback

After the interview and the audio recorder was switched off, we spent time talking about the local area and Hugo said that he had enjoyed talking to me. He had not expected to talk for so long, but was surprised at how easy and enjoyable he had found the conversation.

Research Study: Personal accounts of the memory assessment for dementia

Participant Information Sheet

My name is Kirsty Golden

I am a Trainee Clinical Psychologist working for the NHS. This research is part of my Doctorate in Clinical Psychology at the University of East London.

This leaflet is to provide you with information on this research study so that you can decide whether you would like to take part.

You were contacted about this study because when you were first diagnosed with dementia, you said that you would like to be contacted about research opportunities.

Contact: **Telephone**: xxxxx   **Email**: xxxxx

About my study

I would like to find out about your experience of the memory assessment process. I would also like to find out how you feel about the support you were offered, and what it was like to receive your diagnosis.

I think it is important to take your experiences and opinions into account so that professionals can think about how to improve dementia services.

What does it involve?

If you would like to learn more about this research, I will meet with you at your local Cognitive Impairment and Dementia service, or in your home, on a day and time that you find convenient.

When we meet, I will explain the research study. **Deciding whether to take part is up to you – It is your choice.**

If you would like to take part, we will have a conversation together. You will be asked about your experience of your memory assessment and how you feel about your diagnosis.

What you talk about will be up to you. It might include the things you have felt happy or unhappy about, or about what has changed for you since your diagnosis.

Why is my interview being audio-recorded?

This is so that everything that is said can be taken into account. No one will hear these recordings other than myself.

How long will it take?

You can let me know how long you would like to talk for. We can take breaks or stop whenever you need. If you would prefer, we can split our conversation over more than one meeting.

Will my details be kept private?

I will write a report on my conversations with people with a diagnosis of dementia. All names and identifiable information will be changed to make sure that you stay anonymous. The report will then be shared with others and if you would like, you will be provided with a summary copy of the study and the analysis of our interview.

Documents containing personal details, such as names, will be stored safely and kept separate from the anonymised records.

Audio recordings will be deleted once the research has been assessed by the University of East London. The anonymous written records will be kept for up to five years to allow publication of the research.

I will keep anonymised notes of all of my contact with people involved in the research. Access to these notes is limited to the researcher, supervisors, and examiners.

If during our conversation I become worried about your, or anyone else's safety, I might need to share this with other people to ensure everyone is kept safe. I will always try and let you know if this is going to happen.
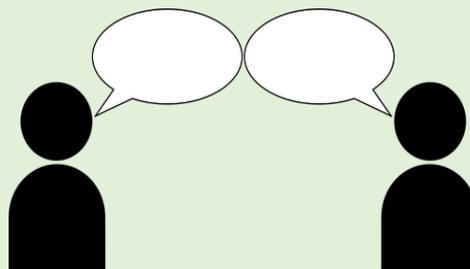
What if I decide <u>not</u> to take part in this research?

That is okay. You do not need to provide a reason for this decision. If you decide that you want to take part in the study but later change your mind, this is also okay. You are free to withdraw any time before December 2017 if you don't want your interview to be used in the study.

Decisions about taking part in this research will not affect any other help that you are receiving.

What if I have questions?

Please talk to Kirsty using the contact details on the front page. If you would like some advice on whether to take part, please contact [Name and contact details of on-site contact]

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Camden and King's Cross Research Ethics Committee.

If you have any <u>worries or concerns</u> however about how the study has been conducted, please contact the **study's supervisor**, Dr. Maria Castro Romero.   **Telephone**: xxxxx   **Email**: xxxxx

You can also contact the **Patient Advice Liaison Service (PALS)**
Telephone: xxxxx
Email: xxxxx

Further Support

While it can feel good to tell someone about your experiences, for some people there may be times when it feels upsetting. If you start to feel upset in the interview, we will put it on hold and it will be up to you if and when you want to continue.

If you would like further support with your concerns about your memory problems or dementia diagnosis, you can:

- Speak to your GP or your named contact at the Cognitive Impairment and Dementia service about being referred for psychological support.

- Call the Alzheimer's Society National Dementia Helpline on
  0300 222 1122

They can provide information, support, guidance and signposting to other appropriate organisations. Callers speak to trained Helpline Advisers. The Helpline is usually open from:

9am - 8pm Monday, Tuesday, Wednesday
9am - 5pm on Thursday and Friday
10am - 4pm on Saturday and Sunday

Thank you very much for your time

.

Research Study: Personal accounts of the memory assessment for dementia

Information Sheet for Family Member/Carer

> **My name is Kirsty Golden**
>
>
>
> I am a Trainee Clinical Psychologist working for the NHS. This research is part of my Doctorate in Clinical Psychology at the University of East London. **Contact**: **Telephone**: xxxx   **Email**: xxxx

> **About my study**
>
> This project aims to listen to the experiences and feelings of people who have been diagnosed with dementia. I would like to have a conversation with your family member / person you care for, to find out about their experience of the memory assessment. I would like to find out how they feel about the support they were offered, and what it was like to receive this diagnosis. This information will help us understand how services can best meet the needs of people diagnosed with dementia.

Why has your family member / person you care for, been asked to take part?

- They have been told that they have a diagnosis of dementia

- They are aged 65 or over

- When they received their diagnosis, they said that they were interested in being contacted about research

- People with dementia are the experts on what it is like to live with this diagnosis. It is important that they are involved in research so that they have the chance to communicate their opinions and experiences

If your family member / person you care for, agrees to involvement in the research:

What will they do?

I will have a conversation with them and ask about their memory assessment, the support they have received, and the impact of the diagnosis.

Where?

This conversation will take place at their local Cognitive Impairment and Dementia service or in their home, on a day and time that they find convenient. If they would like to be accompanied, you are free to attend this meeting.
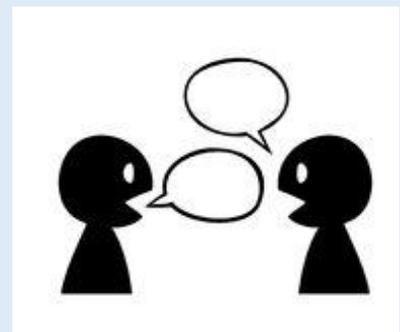
For how long?

This will be decided by the person being interviewed. They can take a break or end the conversation at any time. If preferred, they can pause the conversation and meet with me again to finish the conversation.

What now?

This envelope will have contained an information sheet for your family member / person you care for, much like this one. If they are still happy for me to do so, I will meet with them to explain the research. I will check to make sure that they have understood and would like to take part. It will be their own choice as to whether they take part in the research.

What if my family member / person you care for, starts to feel upset?

At the start of the conversation, I will check whether they are happy to proceed. I will pace the talking to ensure that no one is put under stress. If they start to feel frustrated or upset, I will stop at once and offer reassurance and comfort. Everyone who takes part in the study will be provided with details of organisations that can offer them support with their diagnosis and how they have been feeling.

If during our conversation I become worried about the person being interviewed or anyone else's safety, I might need to share this with other people to ensure everyone remains safe. I will always try and let the person being interviewed know if this is going to happen.

Why is the session being audio-recorded?

This is so that everything that is said can be taken into account. No one will hear these recordings other than myself. The recordings will be turned into a written record of the conversation. Any identifiable information will be removed.

Will personal details be kept private?

I will write a report on the conversations I have had with people with dementia. All names and identifiable information will be changed to make sure that your family member / person you care for, stays anonymous when the report is shared with others. If they would like, your family member / person you care for, will be provided with a summary copy of the study and the analysis of our interview.

Audio and written records will be anonymised and kept safe. Documents containing personal details such as names, will be stored separately to the audio and written records.

Audio recordings will be deleted once the research has been assessed by the University of East London. The anonymous written records will be kept for up to five years to enable publication of the research.

I will keep anonymous notes of all of my contact with people involved in the research. Access to these notes is limited to the researcher, supervisors, and examiners.

What if my family member / person you care for, decides not to take part in this research?

This is okay, and they do not need to provide a reason for this decision. If your relative/person for whom you are a carer decides that they want to take part in the study, they are free to change their mind about this and withdraw their information at any point until December 2017. Decisions about taking part in this study will not affect any other help that they are receiving.

What if I have questions?

Please talk to Kirsty using the contact details on the front page.

If you would like some advice on whether to take part,

please contact [name and contact details of on-site contact]

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Camden and King's Cross Research Ethics Committee.

If you have any <u>concerns</u> about how the study has been conducted however, please contact the **study's supervisor**, Maria Castro Romero.

Telephone: xxxx   Email: xxxx

You can also contact the **Patient Advice Liaison Service (PALS)**

Telephone: xxxx

Email: xxxx

Thank you for your time!

APPENDIX E: WRITTEN CONSENT FORM

Research Study: Personal accounts of the memory assessment for dementia

Your name (block capitals) ....

This form asks you some questions about your knowledge of the above project.

If you agree with the statements, please tick the appropriate boxes and sign this form:

- I have read and understood my copy of the leaflet giving information about the project.

- I have been able to ask the researcher, Kirsty Golden, any questions I may have had about the project.

- I understand that my participation is voluntary. I am free to withdraw at any time without giving any reason.

- I agree for my interview to be audio recorded.

- I understand that my personal information will be kept safe, and any identifiable information will be removed from the written account of my experience.

- I understand that the decision to participate or not will not affect any help I may receive now or in the future.

Please check that you have answered all the questions.

If you have answered 'yes' to all of the questions, please sign below:

Signature...

 Date......................................

Researcher's Name..

Researcher's Signature.......................................

Date......................................

Date Interview Occurred: ....

Thank you for your time. It is greatly appreciated.

APPENDIX F: INTERVIEW PROMPTS

This does not act as a structured interview schedule but a series of prompts for the interviewer. This is to ensure that a conversational tone is maintained, encouraging narrative responses. The two key questions will remain the same for each participant while the prompts used to elicit narrative responses may differ.

Each meeting with the person:
- Introduce self
- State the purpose of the meeting
- Agree approximate length of your conversation
- Ice breaker – General conversation outside of the research study
- Show a copy of the information sheet. Talk through each section on the sheet, and ensure that key aspects are understood:
    o Audio recording: So as not to miss anything. This will be turned into a written account of our conversation. No one else will listen to the recording. It will be deleted at the end of the study.
    o Anonymity: Your name or any details that could identify you will not be written down in the written account of our conversation or any other part of the study.
    o Confidentiality: If I have any worries about your safety or anyone else's safety, I might need to share this with other people to ensure everyone remains safe. I will always try and let you know if this is going to happen.
    o Withdrawal: You do not have to take part in the conversation. This is your choice and will not affect any help you are currently receiving. If you do take part, you are free to change your mind and withdraw your information at any time until December 2017. You are also free not to answer any question that you do not feel comfortable with.
- Happy to go ahead?

<u>Interview Prompts:</u>

- Introduction: In our conversation, I would like to explore your experience of being assessed at the memory clinic. I will also ask you about the impact of your dementia diagnosis. I am interested in what you feel is important so will be guided by what it is that you want to talk about.

 [Questions should be amended throughout the interview to reflect the language of the participant. Questions below should serve as prompts only and the interviewer should be guided by what the participant wants to discuss around the two key questions. The interviewer must also remember the regular use of summaries.]

Key Questions

- Can you tell me about you experience of the memory clinic?
    - Additional Interviewer Prompts:
        - Are there any particular moments that stand out?
        - Experience of being given a diagnosis
        - Opinion regarding the diagnosis
        - Support received from professionals (What support has been offered? What has been their experience of accessing help? What has been their experience of professional attitudes? May also wish to talk about alternative forms of support – friends; family; cultural; spiritual; environmental; hobbies)
- How has this diagnosis affected you?
    - Additional Interviewer Prompts:
        - What was life like before the diagnosis?
        - Has life changed since the diagnosis? (Changes in sense of self/how they spend their time)
        - How do you feel in comparison to your friends/people the same age?
        - Has the diagnosis has affected how others treat you?
- Is there anything else you'd like to let me know?

<u>Debrief</u>

- Thank you for your time

- How do you feel about the conversation we've just had?

- Is there anything that bothered you about the interview?

- Are you still happy for me to write up our conversation?

- Do you have any questions?

- There are details of a support organisation on the information sheet if you would like to talk to someone later on. [If currently involved with the memory service, can ask the person if they would like to be contacted by their named clinician at the service]

"Who am I?"

Personal Accounts of the Dementia Assessment Process and the Impact of the Dementia Label

In 2018, there are over 850,000 people in the United Kingdom (UK) who have been diagnosed with dementia.

Dementia is commonly understood medically, and is diagnosed after assessment of difficulties, e.g. with memory. However, thinking of dementia as purely medical gives no real sense of the person behind the label.

Research has shown that old age and a dementia diagnosis are stigmatised. Negative stereotypes are all around us, e.g. in the media. For people diagnosed, it can lead to shame and fear. For professionals who give the diagnosis, it can affect how they tell someone their diagnosis.

These stereotypes ignore that there is more to satisfaction in old age than physical health. Many people live well with a dementia diagnosis.

People have reported feeling unhappy with the way they were given their dementia diagnosis. They say that they were not given enough information or emotional support.

There is little research to find out more about this. Research studies tend not to include people diagnosed with dementia.

This study aimed to talk to people diagnosed with dementia to find out about:

- What it was like being assessed for dementia
- If their experience of the diagnosis was affected by negative stereotypes

I interviewed four people diagnosed with dementia and analysed their words in depth.

Summary of Findings

The four people differed in how involved they were with their local memory clinic.

They each thought differently about their diagnosis, which was affected by negative stereotypes and their personal attitude. They all, however, rejected being stigmatised by the dementia diagnosis.

Each person was advised by a relative to have their memory assessed. The exact medical diagnosis meant little to each person. Their understanding of the dementia label instead came from the stories they had heard about dementia.

Sometimes dementia was considered a medical problem. At other times, it was considered part of normal ageing.

Three people refused to focus on their difficulties. One was keen that their difficulties be understood.

Two people expressed shock at their diagnosis. Two said that they were not concerned about being given the diagnosis.

Support came from medication, therapy, family, friends, or church. This support helped each person maintain a good quality of life. It helped them to cope with their losses and maintain an overall sense of happiness.

Ageing was seen as holding many negatives, but everyone showed strength, resilience and adaptability.

Although friends or relatives may say otherwise, participants felt that the only changes they had noticed were in their memory. They felt fundamentally the same person they had always been.

Ted, Hugo, Fergus and Fran strongly showed that they were more than their dementia label and set it aside. They have lived, had a career, they have achieved, loved, celebrated, and still stood strong. Their diagnosis does not define them.

Based on the Findings: Recommendations for Professionals

- Involve people with a dementia diagnosis in developing and taking part in research

- Allow the individual to choose what support they need and when

- When giving a dementia diagnosis, consider the social, cultural, and political impact on the person – What does it mean to the person?

- Emphasise the importance of mutual support rather than independence or dependence

- Professionals should be aware of their own biases so that they do not affect their work

- The experiences of people with a dementia diagnosis should be shared with staff

- Memory clinics should hold sessions including people with and without a dementia diagnosis. This may challenge stereotypes

- Involve people with a dementia diagnosis in policy development, service design and leadership

- The rights of those with a dementia diagnosis should be promoted. Professionals should work alongside those diagnosed with dementia to challenge stereotypes

Fergus: A story of acceptance and identity

The interview was carried out in the home that Fergus shared with his wife, Nora.

Support:

Fergus said that he had understood his dementia assessment and had found it smooth and straightforward:

> **Fergus**: We went through the thing fairly methodically, and it was fairly reasonable to follow all what they were doing.

He had a matter-of-fact attitude toward being given the diagnosis, and said that he was pleased to have been told:

> **Fergus**: I think it's always good to *know*, if they've actually diagnosed what the problem is. I would rather be that way than not knowing. You know, where it's uncertainty, would be worse than knowing what the actual facts of the matter are.

People commonly wish to know a dementia diagnosis. For Fergus, it offers him an explanation for his memory problems. Fergus was not receiving support from the memory clinic, but the couple were on their mailing list in case they needed help in the future. Instead of professional support, Fergus was supported by family and church. Fergus felt relaxed about his diagnosis. His attitude challenges the studies that suggest a dementia diagnosis causes fear to be experienced.

The couple's recent move to London had been challenging:

> **Fergus**: Oh, a big change, yes, yes. Yes, cos I did a lot of driving where I work, and that obviously disappeared when we came here, because we didn't bring a car. And I played a fair amount of golf with a group of friends, who I will have seen several times a week, so that is all stopped. So, that was a change which was difficult enough to get used to, but it has worked okay. Don't seem to, find any difficulty now.

Nora felt that the move had negatively impacted Fergus' memory, but memory problems are often less noticeable in a familiar environment.

Nora and their children were trying to keep Fergus active, establish a routine, and help him to pick up old hobbies. They had helped him to deal with a difficult change.

What is dementia?

Sometimes Fergus would talk about dementia as if it was a disease. At other times, he would talk about it as part of natural ageing. Apart from his children, his diagnosis was kept private. He perhaps thought the diagnosis was shameful or embarrassing. This is a common worry for people with this diagnosis.

> **Fergus**: They probably realise that we're quite a bit older and probably, memory loss is one of the things they accept.

Fergus reflects society's assumption that ageing leads to loss. He sees himself as being no different to anyone else his age. This protects him and shows that his sense of identity has not changed. It also separates his experience from that of his twin brother, who also has a dementia diagnosis:

> **Fergus**: I have a twin brother who's a much further stage in dementia. He's been in a nursing home for
>
> **Nora**: Years
>
> **Fergus**: I think, in his later working life, he got very stressed. I don't know why, but he just got very uptight about some of the jobs that he was working in, you know? And I think that led to him getting further and further into that condition.

Fergus suggests that stress made his brother vulnerable to dementia. This ideas is often found in newspapers. They suggest that dementia can be avoided and that people can be blamed for their diagnosis. This can cause stigma. Fergus' memory was thought to decline after a TIA (transient ischemic attack). This offered the couple reassurance that developing dementia had been outside of their control.

Fergus was relaxed through the interview. Nora said that Fergus was not as laidback before his diagnosis. Perhaps the diagnosis had led to Fergus finding a new way of being in the world. He may have re-evaluated what is important in his life.

Identity:

It seemed that Fergus thought I was trying to find out the difficulties he was experiencing:

> **Kirsty:** How do you find going for a walk?
>
> **Fergus**: I quite enjoy walking. No, there's no problem there. I have no difficulty in recognising the places we're going to.

Memory clinics often focus on what the person can't do. Fergus seemed to have picked up on this message. He often worried about not giving accurate answers. Nora would sometimes step in as she was keen that I gained an accurate picture of Fergus. Nora may be used to being expected to speak on his behalf. People are often told that people with a dementia diagnosis are unable to tell their own story. Professionals often talk to the person's spouse or family member rather than to the person with the diagnosis. It is understandable that Nora would try to protect Fergus, attempting to disprove stereotypes and show the man behind the diagnosis.

Fergus showed he was able to tell his own story. He was thoughtful, showed me evidence of his accomplishments, and explained the strengths of his memory:

> **Fergus**: I've fairly good command of English, so my memory is obviously good enough to be able to recall what words would, you know, are similar to, or the same as, so obviously my memory of those

When given the time and opportunity to do speak, Fergus was a capable and independent communicator. He challenged the stereotype that people with a dementia diagnosis have nothing to say.

APPENDIX H: RESEARCH ETHICS COMMITTEE (REC) APPROVAL

NHS
Health Research
Authority

London - Camden & Kings Cross Research Ethics Committee

Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0207 104 8086

> **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

12 July 2017

Miss Kirsty Golden
Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
Department of Psychology, Stratford Campus
University of East London
Water Lane, London
E15 4LZ

Dear Miss Golden

Study title:	**"Who am I?" Personal accounts of the dementia assessment process and the impact of the dementia label**
REC reference:	**17/LO/0855**
IRAS project ID:	**217958**

Thank you for your letter of 30th June, 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 hra.studyregistration@nhs.net outlining the reasons for your request.

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.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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
Covering letter on headed paper [Cover letter]	v1	01 March 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity certificate - UEL]	v1	11 May 2016
Interview schedules or topic guides for participants [Interview Prompts]	v1	01 January 2017
IRAS Application Form [IRAS_Form_03052017]		03 May 2017
Other [REC response]	v1	26 June 2017
Participant consent form [Consent form]	v2	07 June 2017
Participant consent form	2	07 June 2017
Participant information sh	1	09 March 2017
Participant information sh Carers]	1	14 March 2017
Participant information sh	1	01 January 2017
Participant information sh participants]	1	01 January 2017
Participant information sh relatives]	1	01 January 2017
Participant information sh relatives/carers]	2	07 June 2017
Participant information sh relatives]	2	07 June 2017
Referee's report or other scientific critique report [Proceed letter - UEL]	v1	11 January 2017
Referee's report or other scientific critique report [Detailed feedback]	v1	11 January 2017
Research protocol or project proposal [Protocol]	v2	01 March 2017
Summary CV for Chief Investigator (CI) [Research CV]	v1	11 March 2017
Summary CV for supervisor (student research) [Supervisor CV]	v1	11 March 2017
Summary CV for supervisor (student research) [Secondary supervisor]	v1	14 March 2017

Redacted to remove details of participating organisation

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/

17/LO/0855	Please quote this number on all correspondence

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

Yours sincerely

pp

Mrs Rosie Glazebrook
Chair

Email:nrescommittee.london-camdenandkingscross@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Redacted to remove details of participating organisation

APPENDIX I: HEALTH RESEARCH AUTHORITY (HRA) APPROVAL

NHS

Health Research Authority

Miss Kirsty Golden
Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
Department of Psychology, Stratford Campus
University of East London
Water Lane, London
E15 4LZ

Email: hra.approval@nhs.net

24 July 2017

Dear Miss Golden

Letter of HRA Approval

Study title:	**"Who am I?" Personal accounts of the dementia assessment process and the impact of the dementia label**
IRAS project ID:	**217958**
REC reference:	**17/LO/0855**
Sponsor	**University of East London**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators",* issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

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 research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **217958**. Please quote this on all correspondence.

Yours sincerely

Simon Connolly
Senior Assessor

Email: hra.approval@nhs.net

Copy to: Redacted to remove details of participating organisation

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Covering letter on headed paper [Cover letter]	v1	01 March 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity certificate - UEL]	v1	11 May 2016
Interview schedules or topic guides for participants [Interview Prompts]	v1	01 January 2017
IRAS Application Form [IRAS_Form_03052017]		03 May 2017
Other [Statement of Activities]	1	09 June 2017
Other [Schedule of	1	09 June 2017
Participant consent	v2	07 June 2017
Participant consent	v2	07 June 2017
Participant informati	v1	09 March 2017
Participant informati Carers]	v1	14 March 2017
Participant informati	v1	01 January 2017
Participant informati participants]	v1	01 January 2017
Participant informati relatives/carers]	v2	07 June 2017
Participant informati relatives]	v2	07 June 2017
Referee's report or other scientific critique report [Proceed letter - UEL]	v1	11 January 2017
Referee's report or other scientific critique report [Detailed feedback]	v1	11 January 2017
Research protocol or project proposal [Protocol]	v2	01 March 2017
Summary CV for Chief Investigator (CI) [Research CV]	v1	11 March 2017
Summary CV for supervisor (student research) [Supervisor CV]	v1	11 March 2017
Summary CV for supervisor (student research) [Secondary supervisor]	v1	14 March 2017

Redacted to remove details of participating organisation

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Kirsty Golden

Email: ▮▮▮▮▮▮▮▮▮▮▮▮

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A Statement of Activities and Schedule of Events have been provided for use with participating NHS organisations in England. Exchange of the Statement of Activities will act as confirmation of capacity and capability for a participating organisation to host the research.
4.2	Insurance/indemnity arrangements assessed	Yes	Insurance for the management of the research will be provided by the sponsor. Indemnity for the design and

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			conduct will be provided by the NHS. Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No application for external funding has been made. There is no funding available to participating organisations.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	The study has a favourable ethical opinion from the London - Camden & Kings Cross Research Ethics Committee.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.
There is a single type of participating NHS organisation at which research activities as described in the protocol and IRAS form will be conducted. The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website. If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.
Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research**. • Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix. • The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).
A Local Collaborator should be in place at each participating NHS organisation in England and a suitable individual has been identified for the sole site. GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
Researchers employed by another Trust or a University would be expected to obtain a Letter of Access on the basis of a standard DBS check and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.
The applicant has indicated that they <u>do not intend</u> to apply for inclusion on the NIHR CRN Portfolio.

APPENDIX J: TRANSCRIPTION CONVENTIONS

[.]	Brief pause
[2]	Long pause - length in seconds
[Inaudible]	Inaudible
Italics	Emphasis
/	Interruption
[Laughs][Sighs] [Cough]	Non-verbal utterance
[daughter]	Identifiable information that has been removed and replaced
<[K]: text>	Brief interjection/overlapping talk
[...]	Lines or words of transcript have been excluded
...	Sentence abandoned by orator
[12-13]	Transcript line numbers

APPENDIX K: NARRATIVE ANALYSIS

Areas of Focus:

- Content (Key narratives)

- Context

- Performance

Ask the questions:

- What is being said?

- How is the narrator trying to communicate their story?

- What is the story designed to do? What is being performed? Why?

- What other stories are they drawing on?

- What cultural and socio-psychological influences are acting upon the narrator?

- In what context is the narrative placed?

- How is the narrator constructing their identity?

- What is being forgotten/excluded?

- What is repeated?

- How have you (as the interviewer) contributed to the narrative?

- (If present) How has the family member contributed to the narrative?

APPENDIX L: TRANSCRIPT EXERPT

1 [K]: Can you tell me about you experience of the memory
2 clinic?
3
4 [T]: Well [.] I have to say something [.] but that I've
5 forgotten quite honestly. [Laughs] <[K]: that's alright>
6 Erm, if you remind me I'll remember, er, [.] it [.] it [.] It
7 didn't mean an awful, ya know. I [.] I answered the
8 questions the best I could, but I hadn't really remembered
9 them. It didn't seem necessary for me to remember them,
10 so I didn't.
11
12 [K]: What was the memory clinic like?
13
14 [T]: I've been at least once, that I can tell you. I haven't
15 really bothered myself about it. I've just seemed to go
16 through the process.
17
18 [K]: What *was* that process?
19
20 [T]: I mean, I don't really know. I feel fine; I feel normal.
21 My memory is *pretty* good. I still remember [.] I remember
22 childhood memories. It's the today memories that are the
23 most difficult. Erm, I forget where I put something, that's
24 the sort of thing, or forget where I've put the book I was
25 reading but my [.] my long-term memory is very good, I
26 mean I can remember [2] I can remember at three years
27 old being given a bicycle. All that's still very clear in my
28 memory, and things like that, and of course I remember
29 the war, you know, I remember the area was air raids and
30 all that, and that is very [2]. So, my memory of my youth
31 and er, up to er, up to middle age has been pretty good.
32 Erm, when I was still at work I never wrote anything down
33 for instance. I could remember things. Now, now if I want
34 to remember something I write it down, but I suppose

Kirsty Golden
Distancing self
Trying to put aside experience
Can't remember the detail, but not seen as
an important event
Claims forgetting is due to not deciding to
remember rather than due to dementia –
performance – not inhibited by diagnosis
Protecting vulnerable part of self

Kirsty Golden
Taking control of the conversation

Kirsty Golden
Repositioning. Foucault. Surveillance

Kirsty Golden
Trying to persuade and surprise me

Kirsty Golden
Impressing upon me that he is a capable
person.
Emphasises that memory is good
Aware of what is said about dementia –
social discourse
Trying to disprove any preconceptions I may
have about him based on social messages

Kirsty Golden
Memories from long ago. Detail emphasised
Expectation that people diagnosed with
dementia would not be able to remember
things from so long ago
Identity is protected. Has not lost sense of
self. Countering metaphor od person with
dementia as an 'empty shell'

Kirsty Golden
Difficulties mentioned but emphasises these
less than strengths
Needs to make only small adaptations -
Performance