STORIES OF THE IMPACT ON THE FAMILY WHEN ONE MEMBER HAS BEEN GIVEN A DIAGNOSIS OF DEMENTIA

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ABSTRACT

Biomedical models of dementia dominate UK policy and practice guidelines but can be criticised for neglecting personal, social and contextual factors. The medicalisation of dementia benefits powerful groups whilst shaping the narratives of people with dementia labels (PwDL) in line with dominant discourses of deficit and loss. Personhood has similarly been criticised for neglecting broader sociocultural factors that pervade the experience of dementia. A more recent movement towards understanding the impact of dementia from a relational focus has been narrowly conceptualised, as research usually only involves one significant other and does not consider the interaction of narrative strategies that family members employ.

Taking into consideration the limitations of previous research, this thesis drew upon narrative inquiry using a social constructionist epistemology to interview one family together, including the PwDL, to understand how they have made sense of dementia. By additionally interviewing the family members separately it was possible to explore how the impact of cognitive and functional difficulties has been co-constructed. In this way, it was hoped that the contribution of the family to scaffold or undermine PwDL identity could be discerned. Frank's (2012) Dialogical Narrative Analysis was adapted to incorporate a systemic lens and was used to analyse interview data.

This research suggested that the experience of dementia is shaped by multiple personal, interpersonal and sociocultural factors, which interact to determine the way PwDL and their family members adjust to cognitive and functional changes (Górska, Forsyth & Maciver, 2017). In addition, a dementia diagnosis may be so threatening for some PwDL that their experiences may be best framed using a trauma lens. Clinical implications concern systemic and narrative approaches which may facilitate PwDL and their families to re-story their experiences, retain "empathic access" (Schechtman, 2003:245) to the past whilst re-defining identity, and maintain family connections. Health-care professionals can also advise policy-makers and the media to challenge dominant discourses around dementia and prevent the marginalisation and potential traumatisation of PwDL. Research implications concern further exploration of ways in which the personal, interpersonal and sociocultural interact by interviewing more families, from diverse backgrounds, over the longer term, and using a trauma lens.

CONTENTS

1. INTRODUCTION

This chapter begins with a critical approach to dominant discourses, and the medicalisation, of dementia as well as introducing concepts that frame this research including personhood and positioning theory. It is followed by further contextualising of the research through reflection on my personal and professional experience of people with dementia labels (PwDL) and their families. Next, I review the current literature around threats to self and identity in dementia and what can contribute to difficulties in adjusting to the cognitive and functional difficulties experienced. This section is followed by further exploration of the impact of dementia on family members and their relationships with PwDL, including the way in which they contribute to the co-construction of the self. A critique of the literature is provided, which is used to determine the rationale for the current research and informs the research questions.

1.1. The Medicalisation Of Dementia In The UK Context

1.1.1. What Is Dementia?

As the International Statistical Classification of Diseases and Related Health Problems (ICD-10, 1992) is currently used for diagnostic criteria within the UK, their definition of dementia is provided here:

"a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capability, language and judgement. Consciousness is not impaired. Impairments of cognitive function are commonly accompanied, occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. The syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain."

The Alzheimer's Society (2014) has estimated that 835,000 people in the UK would meet diagnostic criteria for dementia, although a precise figure is not known due to diagnosis rates, for example, this has been approximated at 68% in England (NHS England, 2017). Different sub-types of dementia have been identified, including Alzheimer's disease and Lewy Body dementia. Disease

processes attributed to sub-types of dementia are understood to be diagnosable as they produce different manifestations in the brain and therefore symptoms. However, post-mortem brains reveal that people diagnosed with Alzheimer's disease often display neuropathology expected in someone diagnosed with Lewy Body dementia, and vice versa (Manthorpe & Iliffe, 2016). All forms of dementia are understood to be progressive as they lead to deterioration in cognitive and functional abilities. However, the inevitability of decline is also not clear-cut. For example, Kitwood (1997:4) proposes that social factors, including the culture of care, contribute to the severity of 'symptoms' experienced in dementia; "re-menting" may be possible if PwDL are appropriately scaffolded to reach their potential.

The causes of dementia remain unclear. Kenigsberg et al. (2016) argued that Alzheimer's disease can be clearly distinguished from normal ageing. They posit that disease processes, including the accumulation of toxic proteins, cause the decline in cognitive abilities. Manthorpe and Iliffe (2016) contend that multiple pathological processes interact with multiple protective factors and dementia is the outcome of accumulating exposure to harms or benefits over decades. However, the organic model of dementia has been heavily criticised for being deterministic, essentialist and reductionist, which neglects personal, social and contextual factors and therefore "deprives a neurologically impaired individual of his or her personhood' (Cheston & Bender, 1999; Kitwood, 1997; Kitwood, 1990:177). Indeed, dementia may be better understood within a social model of disability (Innes, Kelly & McCabe, 2012). However, Gilleard (1992:154) argued that psychosocial models of dementia can not be solely based on the notion that "the inner decay of mind is socially constructed; it can, however, assert that the place of that mind, the external significance of that person is indeed the product of the external, social response to the person".

Improved access to education increases cognitive reserve, protecting against cognitive decline (Andrade-Moraes et al., 2013). Reducing poverty also appears to decrease prevalence rates of dementia, which suggests that dementia "may be more tractable by social means than by medical treatments" (Wu et al., 2017; Manthorpe & Iliffe, 2016:10). However, dementia remains understood as a 'disease of the brain' and dominant discourses attribute 'symptoms' to neurodegeneration (Alzheimer's Society, 2013). This is reflected in the

dominance of the biomedical model of dementia in the UK policy agenda. For example, the UK Prime Minister's Challenge on Dementia 2020 (Prime Minister's Office, 2015) prioritises developing disease-modifying therapies.

1.1.2. The Medicalisation Of Dementia – Who Benefits And Who Does Not?

Bender (2003) argued there are numerous factors which have contributed to the persistence of the biomedical model of dementia. In the UK, an ageing population has been positioned as placing additional burden on already stretched societal resources and health care budgets without contributing to society (House of Parliament, 2010, 2015; Hilton, 2010). This has been used to argue that welfare and public service to PwDL must be reduced, for the NHS to be maintained (Walster, 2016). PwDL are portrayed as 'suffering' and by offering the possibility of a 'cure' it is possible to meet the needs of society and appease their fear of 'developing' dementia (Harding & Palfrey, 1997). A more general shift towards understanding mental health using organic 'brain-disease' models in this context has provided an opportunity for old-age psychiatry as a profession, backed by UK policy and practice, to promote itself as the discipline which can manage distress associated with dementia. This has also been used as an opportunity for the pharmaceutical industry to promote old-age psychiatry, thus contributing to their profit-making, and strengthening psychiatry as a profession. Likewise, universities are interested in framing problems in certain ways to ensure their own survival.

Mitchell, Dupuis and Kontas (2013:5) warn that "medical colonisation has seeped into the social and personal fabrics of contemporary society" and has cemented its place in UK policy and practice. For example, Manthorpe and Iliffe (2016:12) suggest that dementia has become characterised as an "epidemic", a "tragic", "defeatable" disease, which encourages a "wartime economy to develop", thus promoting a need for expertise accompanied by the provision of training, expensive diagnostic technology and other resources (e.g., clinic space). Negative media representations of PwDL have perpetuated fear of dementia thus promoting a medical approach, which promises containment and cure (Peel, 2014). Medicine has therefore been framed as a route to salvation, with "promissory science" (Brown & Beynon-Jones, 2012:223) as its source of power (Manthorpe & Iliffe, 2016). Further, Hauerwas (2012) has suggested that technological medicine has become obsessed with eliminating suffering and the

"fetishisation" (Manthorpe & Iliffe, 2016:13) of health replaces religion in an attempt to help people deal with the problems in their lives. The medicalisation of dementia uses expertise to construct a "diseased self" based on a forgetful, muddled individual (Manthorpe & Iliffe, 2016:12). This expertise has been described as part of a technology of self (Foucault, 1982), to "mobilise and be mobilised within political argument in distinctive ways, producing a new relationship between knowledge and government." (Rose, 1996:156). Medical care in the UK is highly organised and well-resourced, compared to social care and public health, and can, therefore, position itself as the means to develop scientific discoveries and new pharmaceutical treatments and overcome the 'epidemic' of dementia. Therefore, it could be argued that for some people there is much to gain by endorsing a biomedical model of dementia (Walster, 2016).

1.1.2.1. *Memory services - an example*

As dementia is a syndrome - a collection of symptoms - it cannot be diagnosed (Manthorpe & Iliffe, 2016). However, one consequence of the medicalisation of dementia concerns the growth of memory clinics commissioned to increase rates of early diagnosing of dementia, which has become a policy priority in the UK and internationally (Alzheimer's Disease International, 2014). Manthorpe and Iliffe (2016:18) suggest early diagnosis is common-sense and "seductive" even though there are few examples in healthcare in which this influences outcome. NHS guidelines, that there should not be any screening for conditions that cannot be treated, have notably been side-stepped. Although Dixon, Ferdinand, D'Amico and Knapp (2015) warn that their economic modelling was limited by the available evidence, they suggest that screening for dementia may be cost-effective, especially considering the effectiveness of psychosocial interventions, including Cognitive Stimulation Therapy (Spector et al., 2003). Currently available medical treatments, for example anticholinergic medications, produce some change in mood and behaviour in some PwDL, but at the population-level it is believed their clinical benefits are negligible (Lin, O'Connor, Rossom, Perdue & Eckstrom., 2013).

The benefits and harms of diagnosis of dementia are not clear and assessments are often deficit-oriented (LeCouteur, Doust, Creasey & Brayne, 2013; Bender, 2003). Potential risks to the individual in early diagnosis include false positives, stigmatisation, marginalisation, diagnostic over-shadowing and

loss of confidence resulting in reduced practice of cognitive and functional skills contributing to further decline (LeCouteur et al, 2013; Spector & Orrell, 2010). The investment in early diagnosis has also been criticised for reducing resources for PwDL and their families in distress (Bender, 2003). Harding and Palfrey (1997) propose that health-care professionals are confused, not PwDL. They recommend uncovering socially, culturally and historically situated linguistic practices, which perpetuate biomedical discourses around the dementia label and serve to 'other' people given this label.

1.2. Personhood

UK policy and practice emphasises putting the person diagnosed with dementia at the centre of care, based on concepts such as personhood (Kitwood, 1997). This is a term used to describe what fundamentally makes someone a person, but which he expanded upon as emerging in interaction with others. Kitwood (1990:46) proposes that "semiotics, sentience and selfhood are necessary to be a person, capable of social being and relationships". This is undermined by the dominance of the medical discourse around dementia, which is so powerful that "its anomalies, self-contradictions and unsubstantiated conclusions are obscured" (Dewing, 2008:9). A Cartesian dualism perspective on dementia, separates the mind from the body and the diagnosis leads to the idea that the mind no longer exists and nor does the self. What is left is a "mere shell of a former self" (Gubrium, 1986:41), which is also considered "dangerous, to be controlled and avoided." (Dewing, 2008:7).

1.2.1. Personhood – A Critique

Higgs and Gilleard (2015) praise Kitwood for ensuring a focus on psychosocial aspects of living with dementia but suggest personhood requires extending. For example, his model of personhood for PwDL can be criticised for being based on Western, cultural assumptions that cognition, autonomy and rationality determine whether someone is a person or not, which may suggest why extreme forgetfulness is so feared in these cultures (Kitwood, 1997; Post, 2000; Dewing, 2008). Kitwood also made limited reference to the way PwDL actively engage with others in accepting or rejecting being positioned in certain ways (Higgs & Gilleard, 2015). Furthermore, Kitwood's ideas around personhood consider self as a continuous personal identity, which Parfit (1984) contests,

suggesting individuals, at any one time, should be understood as more or less themselves. Schechtman (2003:245) suggests that rather than seeking to maintain personhood, as Kitwood proposes, what may be more important is the retention of "empathic access" to the past to provide a continuity and evolving of self. Therefore, personhood should be understood as a dynamic process, rather than a status or position, and something that exists in the here-and-now but also has the potential to evolve over time.

Further, Baldwin (2006) critiques Kitwood's concept of personhood for being apolitical, by focusing too much on the individual without agency. For example, the fear of losing one's identity due to dementia has been framed as a form of "social death" (Sweeting & Gilhooly, 1997:93). Metaphors of dementia frame it in natural disaster terms that we must war against, whilst locating it in individuals in such a way as to leave PwDL feeling terrified and powerless and increasingly isolated from those that do not have the diagnosis (Zeilig, 2014). Societal understanding of ageing is also shifting, influenced by negative representations of dementia (Higgs & Gilleard, 2017). Baldwin (2006) advocates for a citizenship approach to dementia care, using a social model of disability (Oliver, 1990) as its framework, and focusing on social inclusion and power.

1.3. Positioning Theory

Positioning Theory is concerned with revealing the various ways in which people relate to each other and uncover their "multiplicities of self" (Davies & Harré, 1990:49) and those with whom they relate (Harré & van Langenhove, 1992, 1999; Harré, Moghaddam, Pilkerton Cairnie, Rothbart & Sabat, 2009). Four key concepts around the self have been proposed:

> 1) Self1, the 'Self' of personal identity – a person's view of the world, which forms the basis of their actions and sense of personal agency,
>
> 2) Personae – a person's discursively and publicly produced 'Self', which is co-constructed and depends on recognition, response and confirmation from others,
>
> 3) Self-construct – also called 'identity', including personal attributes, and a combination of Self1 and personae,

4) Positioning – the influence of others in determining personae, which can enable or inhibit someone from inhabiting particular versions of Self.

Our sense of self and our worldview can be understood as developing via a number of processes. For example, this includes learning about the categories which include and exclude (e.g., male/female), and positioning oneself in relation to these; and engaging in discursive practices in which the meaning of these categories emerges. Positioning theory explains how behaviour can be understood as a social act, in which people skilfully use language (Burr, 2002) to take positions for themselves (first order positioning), accept or reject positions imposed on them (second order positioning), and impose positions (first order positioning) on others in an ever-evolving fashion. It is through this that one's moral and personal attributes can be defined, strengthened or challenged and through which personal narratives can develop and be acted upon. Third order positioning, which occurs in talk that takes place outside of first and second order positioning, concerns new story lines that are created, i.e. repositioning, which are used by people to re-locate themselves within moral and social space.

1.3.1. Malignant Positioning In Dementia

Positioning theory can explain the filter through which someone observes and attributes the behaviour of PwDL, which may influence the renegotiation of roles and responsibilities and can have a negative effect on PwDL sense of self (Purves, 2011; Sabat, 2003). However, PwDL may be less able to resist being positioned in a "malignant" way due to word-finding difficulties and reduced sense of control in social situations (Sabat, 2003:86). Socio-cultural and historical factors, including gender and poverty, also influence how people position themselves and others (Forbat, 2003).

1.4. Contextualising The Research

Before I review the literature around the impact of dementia on PwDL and their family members, it is important to contextualise the current research by considering my personal and professional experience, as research "can be understood as a tacit and intentional positioning" (van Langenhove & Harré, 1999:31).

I have worked with PwDL and their families across a range of settings, including residential care homes, inpatient units, a memory service, a community mental health team, and within a research context. I have often wondered what influences the experience of living with dementia, how negative representations of PwDL pervade society and who does it benefit to portray PwDL in this way? What purpose does it serve? And why, as a culture, are we obsessed with 'cognition' to reflect who we are as people?

My personal experience has demonstrated how families can be affected by dementia. When my grandmother moved into a care home for PwDL, I witnessed the shift in the way my mother and her brother related to each other. I observed how personal conflicts re-emerged. I noticed implicit assumptions that were made about who should provide care and how this was a source of tension between the siblings when these weren't shared. I have also seen how this experience of dementia continues to affect my mother through statements around not wishing to burden others by losing her independence and on the sibling relationship, which remains strained.

Through this research I seek to use my personal experience as well as knowledge and skills developed through my professional training to explore what it is like for families when one member has been diagnosed with dementia. The literature review below demonstrates there are many questions around this still left to consider.

1.5. Research Exploring The Impact Of Dementia On People With Dementia Labels

The impact of a dementia diagnosis on PwDL is first considered, to position them at the forefront of this research.

1.5.1. Emotional Responses To Living With Dementia

Bender and Cheston (1997) identify four emotional responses to the dementia label: anxiety, depression, grief and despair or terror. Bender and Cheston (1997:518) also suggest that PwDL experience a "profound, existential sense of emptiness and absence which is related to the actual or anticipated damage to their sense of self…[which] may be compounded by the neglect of those around the person." The 'terror' of this influences coping behaviour, but there are few

safe places in which the person can begin to make sense of the experience (Watzlawick, Weakland & Fisch, 1974).

PwDL may experience sorrow, uncertainty, uselessness, embarrassment and shame as well as hope, humour and growth (Holst & Hallberg, 2003; Svanström & Dahlberg, 2004; Imhof, Wallhagen, Mahrer-Imhof & Monsch, 2006; Cheston, 2005; Lishman, Smithson & Cheston, 2016; Aldridge, 2015). However, depression and anxiety are the most commonly reported emotional response in PwDL due to losses, including roles and status and changes in their relationships (Cummings & Victoroff, 1990). Uncertainty about the future and confusion concerning the way others respond to them may reinforce feelings of marginalisation and isolation from ordinary social life. (Svanström & Dahlberg, 2004; Langdon, Eagle & Warner, 2007).

The dominance of the biomedical model of dementia has meant that emotional states are too readily attributed to neuropathological changes (Bender & Cheston, 1997). However, withdrawal and depression may be conceptualised as paths of least resistance when grieving for a lost part of the self (Solomon & Szwarbo, 1992). Alternatively, apathy and withdrawal may be thought of as the withdrawal of social roles by others, leaving only those concerning being a patient. Fears of dependence and burden may be understood in the context of Western cultural assumptions of independence in our "hyper-cognitive" world (Woods, 1999:37). This suggests that loss and emotional responses to dementia reflect the particular meaning associated with the cognitive and functional difficulties experienced. However, in societies in which strong social control is advocated, demonstrating strong emotional responses may be discouraged, which reduces the opportunity for PwDL to assimilate or accommodate changes to their sense of self, affecting continuity of identity, and potentially leading to distress (Sneed & Whitbourne, 2001).

1.5.2. Sense Of Self And Continuity Of Identity

There remains debate within the research literature whether self and identity are retained in PwDL although it may be that pre-existing beliefs influence the interpretation or selection of presented data (Fontana & Smith, 1989). Some researchers argue that self remains intact throughout the course of dementia (e.g. Fazio & Mitchell, 2009), while others believe the self deteriorates "until there is nothing left" (Davis, 2004:375). Others contest that self is maintained to

some extent, although it is compromised due to cognitive difficulties (Hydén & Örulv, 2009).

A recent review found most evidence suggests the self persists throughout the course of dementia (Caddell & Clare, 2010). However, research in this area is further complicated as findings appear to reflect how self has been defined in the study (ibid). For example, Addis and Tippett (2004) found that loss of identity was associated with loss of autobiographical memory. However, poorer autobiographical memory may serve as a protective function against the threat to sense of self (Naylor & Clare, 2008). Bruner (1987) suggests that sense of self depends upon the ability to construct and communicate a narrative, as this allows people to define and update their identity, which creates coherence and continuity when integrating life experiences. Studies, using interviews and conversations to measure this, have found that PwDL are able to construct, to varying extents, a narrative including autobiographical memories, which enables them to preserve aspects of self and identity (Mills, 1997; Usita, Hyman & Herman, 1998).

Sabat and Harré (1992) used a social constructionist model of self to understand how language creates social reality (Gergen, 1985) and identity is constructed in and through interaction. They suggest that 'Self1' - a person's view of the world, which forms the basis of their actions and sense of personal agency - is maintained even in more advanced stages of cognitive decline. 'Personae', the self that is co-constructed, and therefore identity, a combination of 'Self1' and 'personae', can be undermined by other people. This leads to a self-fulfilling prophecy, in which PwDL who are led to believe they cannot contribute, internalise this and then become unable to contribute because others are not willing or able to facilitate their involvement (Sabat & Harré, 1992).

Other research also argues the way people respond to PwDL affects how they: live with their cognitive and functional difficulties; negotiate interactions with others (Beard & Fox, 2008); and sustain a sense of self-worth and positive identity (Burgener & Berger, 2008). For example, stigma associated with the dementia label can lead the diagnosis to become a "master attribute", which presides over any other attributes the person might possess (MacRae, 2011:446). When PwDL are negatively stereotyped and stigmatised, they are

seen as different from others and are subsequently devalued or marginalised as others interact with them less or avoid them altogether (Harris, 2002; Katsuno, 2005); their identity is "spoiled" (Goffman, 1963:90). It is of note that PwDL are more vulnerable to internalising negative stereotypes due to the development of an external locus of control and heightened anxiety, which can also worsen cognitive abilities (Scholl & Sabat, 2008). Proctor (2001) argues the social and political context of women's lives shapes their experience of dementia, which has the potential to 'other' them and elicit feelings of powerlessness, thus influencing their sense of self and adjustment to cognitive and functional difficulties. However, for some PwDL the realisation that they are changed in an objective sense suggests they can not expect others to view them in the same way (Langdon et al., 2007).

PwDL have been shown to find ways to maintain sense of self (Cotrell & Hooker, 2005) or make adjustments by integrating changes that have occurred into their current sense of self (Clare, 2003). PwDL resist negative views of themselves in various ways. For example, describing dementia as a disease can be one way that PwDL neutralise the potential stigma of the label (Schneider & Conrad, 1980), as when people are not judged as responsible for their condition they are less likely to be stigmatised (Jones et al., 1984). As stigma is related to its visibility (Schneider & Conrad, 1983), PwDL may also find ways to hide their 'symptoms', including avoiding social interaction or attributing their difficulties to, for example, stress. Making comparisons with others who are more affected cognitively is another way in which PwDL buffer themselves against challenges to identity (Langdon et al., 2007). Therefore, a combination of personal resources and the attitude PwDL adopt with regards to their diagnosis as well as a supportive environment can enable them to adapt to challenging life situations and maintain sense of self (MacRae, 2011; Elder, 1974).

1.6. Research Exploring The Impact of Dementia On Families Of People With Dementia Labels

1.6.1. Literature Review Strategy

The purpose of a formal review of the literature relating to the impact of the dementia diagnosis on the family was to broadly establish what is currently

known about the way families co-construct an understanding of the impact of dementia, the effect this has on PwDL sense of self or identity and wellbeing, as well as the relationships within the family.

The following search terms were used to access the literature regarding the impact of dementia on the family. The databases PsychInfo, CINHAL PLUS, Academic Search Complete, Science Direct, PubMed, and Web of Science were searched during August–December 2017 with no restriction applied to the date of article publication. Search terms were initially derived from the academic and health and social policy dementia literature. Synonyms to key terms were also elicited within each database via index thesauruses:

(dementia OR dementia with Lewy bodies OR Alzheimer's Disease OR Vascular Dementia OR Frontotemporal dementia OR (Parkinson's disease AND dementia)

AND

(famil*[1] OR family care* OR family relations* OR relations* OR relatives OR significant others OR family system OR family dynamics OR family conflict OR family therapy).

This literature review was particularly interested in understanding what happens when more than one member of the family is included in the study. Many articles define 'family' more loosely than this and so the articles were also assessed by hand for relevance using:

    1. Titles and abstracts, and if relevance could not be ascertained,

    2. Full article.

All articles which were not considered relevant to the study were excluded, as were those not written in English. Additional articles were found through cross-references, bi-directional citation searches and conversations with colleagues.

1.6.2. Dementia And Families In The UK Context

Approximately, 700,000 people in the UK identify themselves as informal carers of PwDL (Alzheimer's Society, 2014). Caregiving for PwDL is associated with satisfaction, including the opportunity to reciprocate care and to have a good

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[1] The * symbol denotes variations on the search term, for example, family, families etc.

relationship with the PwDL (de Labra, Guimaraes-Pinheiro, Maseda, Lorenzo & Millán-Calenti, 2015; Andrén & Elmståhl 2005; Lloyd, Patterson & Muers, 2014). However, family members caring for a PwDL may also have poor physical health, experience high levels of anxiety and depression, and greater levels of strain and distress than carers of other older people (Gallagher- Thompson et al., 2012; Cooper, Balamurali & Livingston, 2007; Moise, Schwarzinger & Um, 2004). The National Dementia Strategy in England acknowledged that "family carers are the most important resource available for people with dementia" (Department of Health, 2009:12) as they enable PwDL to experience well-being and maintain identity and self-esteem (Livingston, Cooper, Woods, Milne & Katona, 2008). Family carers also save the UK over £11 billion a year (Alzheimer's Society, 2014). NICE (2007) recommends providing family carers with information and skills training. However, Knapp and Prince (2007) have suggested that there has been a widespread failure to support PwDL and their families. Esandi and Canga (2014) also argue that the welfare state has systematically reduced care expenditure for elders and PwDL, and thus located responsibility and burden in families.

1.6.3. A Relational Focus To Understanding The Impact Of Dementia

Research into the impact of dementia has more recently focused on exploring how family relationships are affected - the experience of giving and receiving care usually occurs in the context of a long-standing pre-existing relationship. Ablitt, Jones and Muers (2009) suggested that PwDL are aware of the psychological wellbeing of their family members, some of whom recognise the distress family members experience is a response to their caring responsibilities. Ward-Griffin, Bol and Oudshorn (2006) reported that even in a mostly positive relationship, PwDL engage in strategies to ensure they do not burden others.

1.6.3.1. *Spousal relationships*
Spouses consistently report a decline in relationship quality, specifically concerning intimacy; reciprocity and happiness in the marriage; and overall perceived quality of the relationship (Blieszner & Shifflett, 1990; Eloniemi-Sulkava et al., 2002; Knop, Bergman-Evans & McCabe, 1998). Some partners of PwDL redraw relational boundaries, positioning dementia at the centre of the relationship, and subsequently don't feel the same way about the PwDL

(Walters, Oyebode & Riley, 2010). The shift in roles and responsibilities may be particularly distressing for spouses (Quinn, Clare, Pearce & Dijkuizen, 2008). However, not all aspects of relationships appear to be affected in the same way. Closeness (de Vugt et al., 2003), warmth (Eloniemi-Sulkava et al., 2002) and mutual affection (Schneider, Murray, Banerjee & Mann, 1999) have been shown to increase following a dementia diagnosis. For some, distress may also increase (Ablitt et al., 2009); distancing oneself may be an adaptive strategy for partners of PwDL (Fauth et al., 2012).

1.6.3.2. *Parent-child and sibling relationships*
Adult children of PwDL experience different stressors to the spouses of PwDL, including competing work, family and social demands. They usually provide care based on gendered social rules. For example, daughters usually take on roles in initiating and providing personal care, whilst sons are usually responsible for financial and legal matters (Matthews, 1995). Sibling roles in caregiving are influenced by pre-existing conflicts and historical alliances amongst family members and they may find themselves competing for their parents' attention and approval (Seaman, 2015). Therefore, adult children often find themselves re-enacting old ways of being within the family (Matthews & Rosner, 1988). Siblings with rigid perspectives on the nuclear family are less likely to become involved in care in a participatory way (ibid).

Adult daughters report higher levels of distress than adult sons, which may reflect that males tend to adopt more problem-focused coping styles - associated with reduced burden - or how males express and manage burden differently than females (Cherry et al., 2013). The ability of siblings to provide care for their parents is determined by how well they encourage emotional closeness and work as a team (Seaman, 2015). Therefore, reported burden, stress and lack of social support may reflect patterns of communication within family systems (ibid).

1.6.3.3. *Ethnicity and relationships*
There is a paucity of research looking at the experience of dementia on relationships in minority ethnic communities. In many non-Western cultures, cognitive decline is attributed to ageing rather than disease (Dein & Huline-Dickens, 1997), which influences the way care is provided. Botsford, Clarke and Gibb (2012) found that Greek Cypriot and African Caribbean families continue

to develop ways of relating following the dementia diagnosis, but this is influenced by their culture. In addition, coping strategies that have been developed resulting from their status as an immigrant and minority ethnic person are helpful but new practical and psychological strategies also need to be developed.

1.6.4. The Co-Construction Of The Impact Of Dementia

Research concerning the impact of dementia on family relationships has tended not to interview PwDL and their significant others together, which limits an understanding of the way in which its impact is co-constructed and how discursive practices can shape narratives. Research which does interview family members together has tended to focus on strong, well-adjusted spousal relationships, which may reflect the challenge of recruiting participants who want to talk about less positive aspects of their relationship, especially if they are being interviewed together.

Hellström, Nolan and Lundh (2007:383) conducted interviews with 20 couples and identified three stages in which they attempt to maintain their relationship: "sustaining couplehood" – strategies used to promote shared wellbeing; "maintaining involvement" – strategies used to minimise the impact of dementia; and "moving on" – how spouses cope with changes in the PwDL. By investigating couple's use of we-pronouns, Hydén and Nilsson (2015) demonstrated they work together to navigate the challenge of dementia and re-define the 'we' together, to maintain their collective identity.

Robinson, Clare and Evans (2005) described a shared process of adjusting to dementia. Denial and avoidance of talking together, for some couples, is part of a cyclical process of slowly turning towards the situation in an attempt to maintain and restore self-esteem, whilst gradually adapting to the new situation (Clare, 2003). This oscillating process matches the proposed way PwDL individually adjust to dementia (Clare, 2002; Cowell, Wolverson & Clarke, 2016). Difficulties acknowledging and adjusting to the loss of their previous relationship coincide with difficulties negotiating changing roles and responsibilities. Couples who are able to maintain a sense of their relationship tend to focus on what remains for each person and for the couple. This is facilitated by a joint process of defining the problem as something to be

overcome and navigating a way to maintain a valued social identity, which buffers against low mood and feelings of hopelessness (Husband, 2000).

Molyneaux, Butchard, Simpson and Murray (2012) also conducted interviews with couples, noting they seek to maintain their roles when traditional gender boundaries need to be crossed but perform tasks together to minimise the impact of dementia. Remembering also becomes a shared process. Couples who are able to maintain "couplehood" (pp. 483) tend to view the changes in their relationship as an expected life transition rather than a problem. Couples who: can reflect and draw on their strength and resilience; ally against dementia by separating it out of their relationship: and share their feelings of frustration, make sense of their current situation and better maintain their relationships.

Couples that can continue to employ previously helpful coping styles can maintain an "us identity" despite a dementia diagnosis (Snow, Cheston & Smart, 2016:1517). Couples who can maintain 'normality' through carrying on their routines and actively negotiating their roles, perceive their time together as limited, which orients shared goals towards the present and a focus to completing positive experiences together, and can find acceptance of dementia through a new appreciation of their lives together (Cowell, 2016; Löckenhoff & Carstensen, 2004). This is motivated by their shared history (La Fontaine & Oyebode, 2014). However, the different strategies that PwDL and their spouse use to resist the impact of dementia can be in conflict and are pervaded by sociocultural values and assumptions, including independence, autonomy and burden (Tolhurst, Weicht & Kingston, 2017).

Doing things and being together can also be viewed negatively, when it feels enforced and traps couples together (Molyneaux et al., 2012). Svanström and Dahlberg (2004), who interviewed couples independently, and then combined their analyses to produce a joint construction of their meaning, found that both spouses feel controlled by dementia and completely subject to the other's will. They argue that couples are powerless in the shift in role identity, which challenges their ability to maintain their relationship. Long-standing relational difficulties may re-emerge in caregiving (Forbat, 2003).

Research with couples demonstrates that PwDL continue to value their relationships and actively strive to maintain connectedness with others (Wolverson, Clarke & Moniz-Cook, 2016). Couples use talk to co-construct an

understanding of their situation (Clare & Shakespeare, 2004), challenging societal discourses regarding a bleak future for couples in which one person has a label of dementia. Research has consistently demonstrated that factors such as shared coping strategies, and the quality of the prior relationship, impact upon the experience of dementia for the couple (Ablitt et al., 2009). However, some particularly close relationships may experience a greater sense of loss (Molyneaux et al., 2012; Ablitt et al., 2009). Forbat (2003) proposes we consider relationships as interacting story lines rather than separate ones brought together.

1.6.5. The Impact of Dementia When More Than One Family Member Is Interviewed At The Same Time

Keady and Harris (2009:2) note that "people with dementia have become separated from their family systems within research, practice and policy attention with the weight of these resources being targeted at individual or dyad based methods of support/understanding". This is reflected in the paucity of literature in which more than one member of the family of the PwDL is interviewed together to explore how dementia is co-constructed within a family. Dementia represents a significant life transition for families; differences in the ways that individuals make sense of situations and the extent to which each family member accepts a diagnosis of dementia, has consequences for the whole family (Carter & McGoldrick, 1989; Perry & Olshansky, 1996). The label has the power to modify family dynamics and functioning and requires emotional adjustment (Esandi & Canga, 2014). Research that focuses on a single caregiver fails to account for the dynamic social connections and support in individuals' family systems that underlie the caregiving process (Seaman, 2015; Nolan, Grant & Keady, 1996).

Research that does include more than one family member has found that emotional responses to living with dementia impact relationships and threaten the stability and homeostasis of the family (Vizzachi, Daspett, da Silva Cruz & de Moraes Horta, 2015). However, PwDL were not included in this research which limits interpretation of the findings. By not including PwDL in research, they are denied the opportunity to participate as equals and to speak about their experiences and needs (Cotrell & Schulz, 1993).

Purves (2011) did not interview her research participants but placed an audio-recorder in the home of a PwDL and analysed everyday conversations that took place between the PwDL and her family. This research found that the family were challenged in reconciling constructions of a wife, mother and grandmother, to a person with dementia. This research highlights how family members position themselves and others through their conversations, which allows researchers and clinicians to understand how they attempt to accommodate an ever changing "diversity of selves" (Davies & Harré, 1990:50), not only for the PwDL but for themselves, as individuals and collectively as a family. By focusing on the family as an interactive web of individuals, Purves (2011) found it was possible to see how they function together to manage the changed circumstances and develop storylines integrating dementia into the family narrative. For example, positioning and repositioning of the PwDL was justified amongst the family based on shared moral concerns although this was less comfortable to endure when these shifts were not compatible with longstanding roles and relationships. The use of less morally acceptable strategies, for example, lying to the PwDL, was justified through family consensus, which allowed for these new patterns of support to be enforced. The importance of understanding how family values are influenced by the historical and cultural contexts also emerged out of this research.

Garwick, Detzner and Boss (1994) also conducted interviews with families but unlike Purves (2011) found that agreement of meaning is not as important as how well the family are able to share their experiences and the meaning associated with them. To frame their understanding of the findings they used boundary ambiguity or "a state when family members are uncertain in their perception of who is in or out of the family or who is performing what roles and tasks within the family system." (Boss, 1987a:709). Families who are able to work together and process accommodating to loss and adjust to dementia are the ones who can reduce this boundary ambiguity.

Phinney, Dahlke and Purves (2013) conducted interviews with individual family members, but not the family together, and found that families are tasked to enable the PwDL to sustain involvement and contribute to family life. Their research demonstrated that the more openly shifts in roles and responsibilities are acknowledged, the easier it is for families to renegotiate these. However, it

also showed that families must navigate ethical and moral dilemmas around how to do this, to consider advantages and disadvantages of taking different approaches and potentially face conflict. The meaning associated with dementia for PwDL and their families greatly influences this. However, trust in the family system and perspective-taking, including for one gentleman the recognition that he had passed down family values to his children, compensates for relinquishing power and appears to facilitate these changes.

La Fontaine (2017) highlights through conducting interviews of people with a diagnosis of early-onset dementia and their families, that it can not be assumed that a previously positive relationship will always lead to a current strong relationship or wellbeing, and families have to confront daily challenges that are unique and specific to them. This research also highlights the ways in which family members can support each other emotionally to facilitate adjusting to dementia. La Fontaine (2017) argues that findings in her research are consistent with those from family systemic approaches to illness and disability (Rolland, 1994) demonstrating that family relationships influence the way dementia is understood and managed, and changes associated with dementia influence relationships. The extent to which families are cohesive, can openly communicate and collaborate, manage conflict and adapt to changes in boundaries and roles, influences family functioning (ibid). This is further influenced by 'illness' onset, course, level of disability and likely outcome, health beliefs, the stage of the family in the developmental life cycle, prior experience and responses to adversity (ibid). However, positioning the family as a unit can over-emphasise family ties, which may influence how they construct their contributions (Kirsi, Hervonen, & Jylhä, 2004).

1.6.5.1. *Contribution of family to sense of self of people with dementia labels*
Research with the family has also suggested ways in which they may contribute to PwDL sense of self. Sabat (2003) argues that PwDL are often the target of negative story lines, which frame their attempts to resist being positioned as someone with dementia as dysfunctional. Usually it is 'healthy' people, such as family members, who narrate these negative stories and feel burdened by the effects of their behaviour on the emotional experiences of PwDL. However, the contribution of the family on PwDL sense of self is less clearly delineated and requires further exploration, especially as positive relationships are important to

maintain wellbeing and couples who are able to preserve the personhood of the PwDL, provide a sense of biographical continuity and maintain self-esteem (Seligman, 2011; Molyneaux et al., 2012). La Fontaine (2017) found that selfhood and identity can be supported within their relational context as family members actively attempt to minimise threats to PwDL wellbeing. She suggests that developing scaffolding techniques, including breaking down activities into smaller tasks, can be effective in retained sense of mastery. However, her findings may only be relevant to people with behavioural-variant fronto-temporal dementia and their families for whom there are particular challenges around social cognition and executive functioning and are often diagnosed with dementia at an earlier age.

Purves (2011) found the family she researched worked together to separate dementia from the person and shield the PwDL from negative representations of dementia and stigma by framing conversations about dementia in the language of physical health. Framing shifts in responsibilities as changes in activities rather than changes in roles and identity may be a way the family can help maintain the PwDL sense of self/wellbeing. However, this may be more difficult regarding the kind of role and meaning associated with it. Phinney et al. (2013) demonstrated that families can support personhood through enabling the PwDL to engage in meaningful activity as it provides a sense of social belonging and continuity of identity (Harmer & Orrell, 2008; Menne, Kinney & Morhardt, 2002; Phinney, Chaudhury & O'Connor, 2007). Further, it benefits the family, for as Phinney et al. (2013:365) tell us: "If the father they have always known is 'not really here' who are they are in relation to this man?" However, these studies did not attend to private and public narratives best explored when additionally interviewing family members separately.

1.7. Family Systems Theory And Dementia

Before I discuss the research aims, I would also like to outline that I have used a family systems theoretical approach to guide the current research, in response to limitations of the previous literature. Family systems theory emphasises gaining knowledge about interconnections between individuals within a system, by looking at family members in relation to each other (Hecker, Mims & Boughner, 2003). Patterns in systems are circular, rather than linear

(ibid), meaning problems are multi-causal and reciprocal. Circular patterns are homeostatic and maintain stability of family patterns i.e. feedback loops. Positive feedback loops effect change, and negative ones obstruct it. When change occurs, elements of the system will behave in ways in which to maintain the status quo. Therefore, individual problems can be understood as existing within these interconnections between the individual parts of the system. Problems may emerge from structural factors such as family hierarchy, boundaries and rules, as well as from process difficulties, such as family communication (ibid).

1.8. Research Aims And Questions

1.8.1. Research Aims

The current research drew upon the strengths and took into consideration limitations of previous research. It aimed to incorporate public and private narratives through intergenerational family and individual interviews, including the voice of the PwDL and, therefore, sought to understand the ways in which PwDL and their families story the impact of dementia and how this shapes their interactions, relationships as well as individual and family identity and wellbeing. This might concern family narratives, the way roles and relationships are defined and negotiated, how the PwDL is positioned by family members and how challenges to individual and collective identity are managed. Unlike other research in this area, this study specifically aimed to listen to dominant discourses around dementia, with a focus on the UK context, that might contribute to the shaping of these narratives.

1.8.2. Research Questions

The proposed study is therefore designed to explore the following research questions:

1) What stories do PwDL and families tell about the impact of a dementia diagnosis?

2) Within these stories, what can we can understand about:

a) the ways family members position PwDL and the influence this has on their sense of self?

b) how do PwDL, within the family, actively accept or resist being repositioned negatively?

3) What sociocultural and political narratives influence the positioning of PwDL, and therefore, the impact of dementia, and what implications emerge regarding the support that healthcare professionals might be able to provide to PwDL and their families?

2. METHOD

Within this chapter, I will discuss my epistemological position and rationale for my methodological approach - narrative inquiry and dialogical narrative analysis. I will outline the procedures for recruitment and data collection and the practical and ethical issues associated with the research.

2.1. Why Narrative?

The term 'narrative' covers a range of types of talk and, at its most abstract, refers to knowledge structures and storied ways of knowing (Cortazzi, 2001; Polkinghorne, 1995). Life emerges from stories and storytelling can be a way for people, as social beings, to share with others, and make sense of, key experiences in their lives (Cortazzi, 2001; Coffey & Atkinson, 1996).

Narrative inquiry is an appropriate approach to meet the research aims, as it "seeks to interpret the ways in which people perceive reality, make sense of their worlds, and perform social action." (Phoenix, Smith & Sparkes, 2010:3). People tend to resist researcher's attempts to fragment their experiences into thematic categories through interview schedules, so I used 'unstructured' interviews to allow participants to use their own way of defining the social world (Reissman, 2001; Fielding & Thomas, 2001). I adopted a conversational interview style, so that the research encounter was more authentic, in terms of ownership and voice (Cortazzi, 2001). I anticipated unexpected turns as I followed the particular responses from the participants, so that I was not led by my assumptions around the topic and pre-conceived notions about what I would hear (Kvale, 1996).

2.2. Narrative Inquiry And People With Dementia Labels

Narrated experiences can be particularly useful for understanding meaning-making in situations where there is a discrepancy between the ideal and the real (Reissman, 1993). This is pertinent to this study, as ageing has itself been problematised and dementia constructed socio-culturally and politically as detrimental to the public (Gilleard & Higgs, 2014). However, PwDL may be denied agency through the way we conceptualise what constitutes narrative and reduced opportunities to co-construct narratives, further affected by cognitive and linguistic difficulties (Keady & Williams, 2005; Baldwin, 2006; Hydén & Örulv, 2009). Direct and structured questioning with PwDL can result in anxiety and confusion (Killick, 2001). To directly engage with the PwDL's meaning-making process, for example, how changes in self and identity are reconciled, it was important to provide additional time and encouragement to 'tease out' experiences (Robertson, 2010; Killick, 2001). Polkinghorne (1995) describes narrative as a temporally organised whole, with a plot which holds meaning and serves a function and an outcome in mind. However, narratives that are organised temporally and sequentially may be less evident in the speech of PwDL (Castro & Clark-McGhee, 2014) and less focus was placed here. Attention was also concentrated on the moral points of narratives, as these are more important in showing 'what you are' than the 'correctness' of what is told (Schechtman, 1996; Hydén & Örulv, 2009).

2.3. A Social Constructionist Approach To Narrative Inquiry

Epistemology has primarily been concerned with the assumptions that we make about what knowledge is, how we create knowledge, what we know, and how we know what we know (Breakwell, Smith & Wright, 2012). This research was based upon a social constructionist epistemology and was used to move away from 'true or false', to consider how knowledge is used by relatively powerful groups in society to sustain their position (Burr, 1998). Four tenets to understanding social constructionism were used: 1) A critical stance on knowledge; 2) People understand the world in its historical and cultural context; 3) Knowledge is constructed through interaction; 4) Knowledge and social action are inextricably linked. (Burr, 2003). 'Truth' is, therefore, an ideology, "a political formation that shapes how people relate or are socially positioned"

(Walster, 2016:41). However, it was also important not to position the PwDL as inevitably oppressed (ibid).

Biomedical definitions of dementia dominate discourses around the causes of dementia but do not account for around seventy percent of the variance between neuropathology and presentation (Kitwood, 1997). A social constructionist model for dementia research can be used to analyse how a label of dementia shapes the lives of those diagnosed and how accounts of PwDL and their family members are shaped by sociocultural representations and ideals (Harding & Palfrey, 1997; Tolhurst et al., 2017). For example, the value placed on short-term memory has the potential to influence emotional expression and the way PwDL participate in daily life (Benbow & Sharman, 2014).

Narrative inquiry using a social constructionist epistemology was utilised to explore story-telling strategies and examine the ways in which the narrators use devices to present narratives and close down alternative ones, to undermine the status quo and bring about new ways of telling and, thus, of being (Baldwin, 2006; Ewick & Silbey, 1995). A social constructionist model for dementia research was also used to further explore the positioning of PwDL by others, which has the power to influence how they inhabit particular versions of the self (Harré & van Langenhove, 1992, 1999). It moved beyond person-centred models to consider socio-political context, to access cultural expectations, social context, motives and intentions that construct meaning around dementia for the narrator (Adams, 1998; Cortazzi, 2001).

2.4. An Integrated Approach To Analysing Narratives In Context

In approaching the data, I have followed Riessman's (2008) guidance to select an approach to narrative analysis which fitted with the research aims. Mishler (1995), however, advocates combining different analytic strategies to develop a more nuanced understanding of how narratives work and the political power they exert. Therefore, I drew upon Stephens and Breheny's (2013) approach to integrating narratives at the personal, interpersonal, positional and ideological levels, to re-tell and interpret the individual and collective narratives (Murray, 2000).

Phoenix and Sparkes (2009) encourage attending to 'big' stories, or the most significant narratives of a life, as well as what Baldwin (2006:107) describes as the "'small stories', stories that privilege the fleeting and fragmented as contributing to the performance of identity in everyday interactions". I was concerned with retaining the narrator's voice whilst attending to the broader socio-political context, in which stories were narrated (Emerson & Frosh, 2009). This seemed particularly important for PwDL, who are subject to repressive societal narratives (Murray, 2003).

In the analysis of narratives in their context, it was important to identify each person's 'key narratives'. Phoenix (2008) suggests these organise how stories are told and can usually be identified by the repetition of content across stories told in the research encounter. Sarup (1996) conceptualises narrative in two parts: the story is the 'what' and discourse is the 'how'. My analysis of key narratives, therefore, concerned the impact of the dementia diagnosis on the family, as well as paying attention to the way in which this experience was co-constructed within the family and shaped by socio-political and cultural representations and ideals. Repeated re-reading of each interview in its entirety was necessary to identify key narratives embedded within different kinds of stories.

2.4.1. Analysis At The Personal, Positional And Ideological Level

The telling of personal stories allows narrators to demonstrate their identity by shaping and explaining their actions (Skultans, 2000). However, as Somers (1994) outlines, narratives can only exist interpersonally. The family context of these research interviews allowed a consideration of the ways in which narratives are shaped and co-constructed (De Fina & Georgakopoulou, 2008). Storytelling concerned who was able to speak and what could be said; why particular stories had been chosen and the order in which they were presented; and how particular identities could be claimed or resisted (Riessman, 2001). My contribution to the way narratives were shaped, as well as interpreted within my own frame of reference, was considered (Tanggaard, 2009; van Enk, 2009).

It was important to acknowledge the way narratives were constructed with an audience in mind, for example, warding off unfavourable attributions of weakness when narrating 'illness' (Riessman, 2001). Riessman (2001:706) notes that narratives do not reveal an "essential" self but, rather, a preferred

version of the self, which is appropriate to the social context of the telling. Therefore, attending to the positional level revealed the broader social imperative to be a certain kind of person (Stephens & Breheny, 2015) so that power relations involved in these positions could be taken into consideration. By attending to broader social and cultural systems of shared beliefs and representations in which narratives were shared, it was possible to hear how public narratives influenced personal stories and how they could function to subjugate PwDL.

2.4.2. Dialogical Narrative Analysis

Frank (2012:49) encourages researchers to ask what "animates" their work. Like him, I considered whether the medicalisation of dementia increases distress and if so, why this is and how it could change. Frank (1995) proposes people's stories of 'illness' depend on one of three narratives. Restitution narratives constitute a plot in which someone becomes sick, is treated and their life then returns to how it used to be. Quest narratives are transformational, in that illness serves to provide the ill person with the opportunity to learn from their illness. Chaos stories, on the other hand, are anti-narrative, in that the illness will worsen, out of the control of the actors, but so slowly that the end cannot provide relief. Frank (2012) outlines these to determine what narrative resources are available to 'ill' people.

Frank's (2012) Dialogical Narrative Analysis (DNA) does not attempt to become a form of truth game (Foucault, 1997, 2000). It was used to seek to understand how stories impose themselves on people and to ask how the availability of narrative resources influenced the research participants' experience of dementia. However, as it may be better to understand dementia within a social model of disability (Innes et al., 2012), it was also important to consider how other narrative resources could be made available to PwDL.

Frank (2012) suggests questions that can be used to explore interview transcripts from a dialogical perspective. These questions were adapted in this research in line with a family systems theoretical orientation, taking into consideration the contribution of the family:

- What voices can be heard in a single speaker's voice and in the family system in the context of a dementia diagnosis?

- What external voices/narratives (e.g., about dementia, ageing, self, family, care) are being drawn into storying one-to-one and in the family context?

- What resources are employed in one-to-one story-telling and family storying?

- What stakes do family members have riding on telling this story, at this time? How do family members hold their own in the act of storying?

Appendix A presents a sample transcript excerpt which demonstrates my application of the analytic process.

In presenting the data I have used the phrase "I wondered…" to signify the tentative nature of my analysis, so that it is framed within its social, historical, political and cultural context, for example, the current dominant discourses around dementia, which have influenced how these narratives have been shaped.

2.5. Data Collection

The aim of data collection in the present research was to elicit narrative accounts from PwDL and their families regarding the impact of dementia.

2.5.1. Procedure

One PwDL and her family were recruited for the family and individual interviews. Interviews comprised unstructured conversations, following a uniform opening question, to elicit stories about the impact of dementia:

"Has your life changed since the diagnosis was made? If yes, how has it changed?"

I did not use an interview schedule to facilitate storytelling in interviews, so that less imposed and more valid accounts could be shared (Bauer, 1996). I was guided by the conversations, so that they could assume their own patterns (Montague, 2005). Additional interviews were offered to collect potentially fragmented 'small' stories over time (Baldwin, 2006) – the number of interviews that took place for each participant are detailed in the demographics section.

The duration and pacing of interviews were determined by the participants, to avoid tiredness and anxiety (Clarke & Keady, 1996).

The family requested that interviews took place in their family home, due to the PwDL's limited mobility. Individual interviews were held privately. Guidelines for good interview and group research practice in dementia care were adhered to. For example, Wilkinson (2002) suggests that a group is useful when interaction between members is generated and focus on the topic, therefore, maintained. In this regard, each family member was encouraged to contribute, for example, using prompts such as: "I noticed you shaking your head, is that different to your experience?"

The interviews were audio-recorded on a digital device and transcribed by the researcher for analysis. Congruent with my approach to data analysis, including considering how personal narratives are performed for a particular audience and co-constructed in interaction, I transcribed false starts, non-verbal sounds, interruptions, etc. Appendix B presents the transcription conventions used.

2.5.2. Researcher Participation

I minimised my participation in the conversations to allow each participant's narrative to emerge naturally. However, I used self-reflection and reflexivity throughout the interviews so that conversations could take place without being guided by my own assumptions. I used supervision as an opportunity to develop these skills and to consider how follow-up conversations could be explored usefully. I used clinical skills, including emotional validation, when appropriate.

2.6. Participants

2.6.1. Recruitment

The PwDL was recruited from an outer London memory service. This service provides assessment to determine what may be 'causing' the person's cognitive and functional difficulties. In the case of those who are given a diagnosis of dementia, follow up from the multi-disciplinary team includes medication and psychosocial group support.

All those who receive a diagnosis of dementia are invited to be involved in research via the memory service's Clinical Trials Unit. This register of PwDL and their family members, who have consented to be approached to take part in

research, was used to identify potential participants. As the PwDL had consented to be approached to be involved in research, I consulted their electronic health records and discussed their potential involvement with the team clinical psychologist to determine if it was appropriate for them to be contacted. Contact details were gained from the register.

In an initial phone conversation, I provided information about the study, specifically outlining that the interviews were for research purposes only. An information sheet was sent to the PwDL and her family as she made an initial indication that she would be interested in being involved. A face-to-face meeting then took place as the family remained interested, to answer any questions they had.

Recommendations for the appropriateness of small sample sizes in dementia research and the level of detail required in undertaking narrative analysis were used to determine how many participants to recruit (Cottrell & Schulz, 1993; Riessman, 1993). I initially recruited one family to take part in the research and based the decision not to recruit another family according to the amount of data that was generated.

2.6.2. Inclusion And Exclusion Criteria

2.6.2.1. *People with dementia labels*
PwDL who completed the 'Post-Diagnostic' group were targeted as potential participants. These people had been given their diagnosis within the last six-twelve months; they were likely to have experienced the challenges of living with dementia but would also have had the opportunity to make sense of their diagnosis. Attendance at the group also made it more likely that there was motivation to explore the impact of dementia. An ability to express oneself in English was required, to enable the researcher to undertake the required analysis. Cognitive ability was not an exclusion criterion, as interpretative and interactional abilities, identity, values and skills, reflection and self-awareness, and so on, are retained despite cognitive impairment (Wells & Dawson, 2000; Clark-McGhee & Castro, 2015; Castro & Clark-McGhee, 2014). However, an ability to engage with the topic was required and this was decided in consultation with their allocated clinician on an individual basis. To ensure that the experience of living with dementia remained at the heart of their storytelling the allocated clinician was consulted concerning whether the PwDL remained

affected by any recent significant traumatic events, such as a family bereavement. It was a requirement that a clinician remained involved in their care to provide clinical support if necessary.

2.6.2.2. *Family members of people with dementia labels*

Family members were invited to take part by the PwDL, and this could have included a spouse, children, adult grandchildren and siblings. Families demonstrating significant interpersonal conflict, as determined in consultation with clinical staff, were not approached.

2.6.3. Participant Demographics

Participant demographic information in Table 1 provides context of the family situation and was gathered directly with participants. Biographical information regarding the family is provided in Appendix C.

Table 1. Demographics for interview participants

Participant	Age	Gender	Relation to PwDL	Interviews Attended
Lucy	80	F	PwDL	2 x Family 2 x Individual
Peter	80	M	Spouse	2 x Family 2 x Individual
Andrea	53	F	Daughter	2 x Family 1 x Individual
Mary	51	F	Daughter	2 x Family 2 x Individual

2.7. Ethical Considerations

McKeown, Clarke, Ingleton and Repper (2010) reviewed examples of good practice in dementia research and provide guidance on how to actively include PwDL within an ethical framework. The authors recommend process consent methods, whilst the MCA (2005) provides a guiding framework. Consent process methods for family members were not as facilitative as the ones used for the PwDL.

2.7.1. Informed Consent

The processes outlined here are congruent with the aims of the Mental Capacity Act (MCA, 2005) to aid PwDL to make their own decisions. McKeown et al. (2010) suggest that traditional consent approaches, including obtaining proxy consent, exclude PwDL, even though a diagnosis of dementia does not indicate a lack of ability to make one's decisions. Capacity to consent rather reflects the situation and is dependent on context (Dewing, 2007; MCA, 2005). An ethical approach to including PwDL in this research was used to position the PwDL as central in determining whether they would like to be included in the research (Hughes, 2014).

The PwDL was considered by their involved clinician to be able to give consent herself. However, an understanding that decision-making generally is contextual and influenced by cognitive and functional difficulties, guided the development of consent processes with the PwDL. Hughes and Castro Romero's (2015) guidelines for carrying out consent processes in an unhurried, accessible and reflexive way for PwDL were followed. An accessible, illustrative information sheet (see Appendix D) was provided to the PwDL and her family and opportunities to answer any questions were provided. An accessible consent form, in a non-hurried consent meeting, was completed prior to commencement of interviews (see Appendix E). Consent for involvement in research was sought at each conversation with the PwDL, which was informed by their verbal and behavioural feedback (Dewing, 2007). The PwDL was asked to provide her understanding of the purpose of the research at intervals through these conversations, which did not rely upon recall of specific aspects of the study, but which could provide enough information to assume a general sense of what she would be expected to do. Ongoing consent processes with the PwDL were

time-consuming, however, were necessary to ensure a truly person-centred and ethical approach to the research.

2.7.2. Ethical Approval

Ethical approval was sought and granted by London-Stanmore NHS Research Ethics Committee. In addition to formal ethical approval, local Trust and service-level approval was granted by the recruitment site (see Appendix F and G). Recruitment and data collection were supervised by an NHS-employed Consultant Clinical Psychologist and the Director of Studies, who has a Professional Doctorate in Clinical Psychology and is a Senior Lecturer in Clinical Psychology.

2.7.3. Confidentiality And Anonymity

All information was stored in accordance with the Data Protection Act (1998). Consent forms, recordings, and written versions of the conversations were kept in a locked environment at the University of East London. Consent forms were kept separate from other data held. Access was restricted to the researcher, supervisors and examiners. Participants were assigned an identification number and details of names and ID were held on a password-protected document. Identifying features were altered in transcripts, thesis extracts and any resulting publications and different names were chosen by the family members, to protect anonymity. The recordings will be deleted following successful examination of the research. To facilitate future dissemination of findings/publications, all other data will be destroyed after five years.

Research participants were informed that confidentiality would be broken if necessary, to ensure the safety of any of the participants or people they know, in line with trust risk policies. However, this did not need to take place.

2.7.4. Protection Of Vulnerable Participants

Due to the nature of the topic and the family context for interviews, there was potential for participants to become distressed during interviews. Everyone was reminded before the interview, and where appropriate, that they were free to withdraw at any time, to take breaks or reschedule. Potential family conflict was monitored through the whole family interview(s) and clinical skills - including taking a non-judgemental and empathic approach - were used, for example, to provide an open space to speak but also to reduce the likelihood of blaming.

The purpose of the interview was reiterated where appropriate. Participants were offered contact details for further support, including to their clinician. Clinicians were also informed they could contact the researcher if required.

3. ANALYSIS

This chapter details the integrated narrative analysis performed with two family and seven individual interview transcripts, which enabled an interpretive approach responsive to the data. The family interviews were the focus of my data analysis, to understand how the impact of being diagnosed with dementia had been co-constructed within the family. The individual interviews were utilised to understand what could not be said in the family context. I was concerned to make sense of the whole interview context, but I was aware of the need to attend to the 'small' stories and to listen beyond what was being said. However, I was mindful of Bakhtin's (1984:63) ethical understanding of dialogue, to consider what can be said about someone "in the mouths of others".

I wanted to gain insight into the multiple voices that find expression within any one voice, as well as in the family system (Frank, 2012). My intention was to understand how storytellers narrate their own story composed from fragments of previous stories. Polyphony (Bakhtin, 1984), or the way in which narratives are storied by diverse voices, was particularly important to consider for whom stories are told and the intention in their telling. Further, I wanted to understand in what way stories told in the research encounter were heteroglossic (ibid). For example, I was concerned with understanding the way individual's speech was composed of intersecting codes of professional jargon and emotional expression and those which govern how genres are used to represent experiences (Frank, 2012). In this way, I could gain insight into the challenging subject positions, dilemmas and implicit association between ideas that the story-teller navigated (Phoenix, 2008). Therefore, I was concerned, not with gaining truth but to bring together diffuse voices to give shape to the dialogue, whilst acknowledging that sense of self is constrained by the resources available in the telling of the story, including the stories that others tell about

PwDL (Frank, 2012). In presenting the data here, I am mindful to consider the unfinalisability of the stories narrated by the family (Bakhtin, 1984). I did not seek to provide 'findings', rather my intention was to open up possibilities of listening and opportunities to respond to what was heard (Frank, 2012). Where necessary, I have highlighted the way in which the stories I was more receptive to hearing reflected my personal and professional experience of PwDL (Andrews, 2007).

The excerpts that are presented adhere to the transcript conventions that I have outlined in Appendix B. My speech is presented alongside the participant where this is relevant to positioning. Otherwise, interjections, including words of encouragement, which break up the flow of the narrative, have been removed for presentation.

3.1. A Family Saga

Narrative analysis of the family interviews revealed an evolving, co-constructed account of the impact of dementia from the multiple perspectives of the family members. Lucy was the main narrator as well as the lead character. She narrated stories of an ambitious woman who sought opportunities to succeed in life but was now concerned with the threat to family survival as she felt she could no longer provide for her husband and children. The conflict for Lucy was apparent, as she struggled to reconcile her identity, as a wife and mother, with someone who 'had' dementia. The cognitive and functional difficulties about which she narrated appeared to threaten the image that she had of herself and she seemed to find it difficult to understand or make sense of her loss of personal agency. This threat appeared to be demonstrated through alternating between inhabiting narratives of strength and independence and frightening narratives of loss and deficit and between actively resisting and accepting being repositioned as someone with dementia. All interviews provided numerous examples of first, second and third-order positioning, revealing the ways in which Lucy and the family positioned themselves and each other, and attempts the family made, either as individuals or working together, to resist Lucy identifying with a stigmatised version of dementia. However, family interviews also demonstrated the ways in which family members may have inadvertently

contributed to Lucy's challenge to reconciling her identity. The wider impact of dementia on the family more explicitly emerged out of the individual interviews.

Lucy's storytelling, strikingly coherent and organised, concerned a search for meaning, and seemed to tell her audience that living with dementia was no life to live. She was the protagonist and was positioned by the family as the one most in need of change. Suspense and drama suffused their storytelling as the conflict between contesting voices emerged; it was not clear whether Lucy and the family could find the answers to their questions, and find a way forward living with dementia. However, I was struck by the attempts that Lucy made to ask her audience, including her family and me, to empathise with her situation and to support her through these difficult times.

3.1.1. Narratives Of Deficit And Loss - The Threat To Identity Posed By Dementia

The family interviews demonstrated that personal stories are narrated within interactional exchanges and positioned with reference to broader sociocultural factors. Andrea referred to the stigma surrounding the dementia diagnosis and also implied that family storytelling was constrained:

> [463 - 467] Will: Mmm. Do people not talk about these things [dementia]?
>
> Andrea: Well I think, unless it affects you, you tend not to and consequently you don't know much about it. When it does affect you, and you start to speak to other people, you realise there's lots of people [Lucy: Yes] that have either gone through it or know someone that has. But they don't necessarily say. It's weird isn't it?

3.1.1.1. *"I have achieved a lot in my life. I was always, yes. Err [1] and now I am not."* [Lucy:409]

Lucy appeared to use storytelling to self-position as someone who had achieved – she told me and reminded her family of her identity. Although she did not answer my initial question first, her voice dominated both family interviews. I wondered what was at stake for Lucy in asserting herself in this way; an initial storyline consisting of the challenges of living with dementia suggested this was an opportunity for her to control the story being told, so that she could define, for herself, who she was.

Her response to my first question about the impact of dementia was clear and unequivocal. It was characteristic of the polarised language that she used throughout her storytelling and the tragedy that living with dementia appeared to represent for her. Key narratives were dominated by deficit and loss; she listed the cognitive and functional difficulties she navigated in her daily life and how "life is not the same anymore" [15]. By speaking first about how she could no longer work, Lucy prioritised the importance of providing for her family:

> [7 – 10] I used to work, now I don't work. I haven't worked for quite some time. Ummm [1] we don't go out for dinners or so except for birthdays, for something special, for girl's birthday, Peter's, my. I do not drive, I have been driving since 1960 and I don't drive anymore, which upsets me really.

> [59 – 63] Ummm [2] there's many, many things that put me out. I can't cook anymore, can't cook at all. Peter, my husband, never cooked, he could make coffees and things, but he has learnt to cook everything. He does the hoovering, he does the dusting, he makes my breakfast and brings it up to my bedroom every day. He does everything for me now.

Lucy appeared to place great value on being "brainy" [174], independence and autonomy, which had been threatened by being "dopey, because I've not been that all my life" [122-123]. I wondered from where these assumptions had developed as they appeared to have guided Lucy throughout her life and enabled her to achieve through a modelling career and owning a successful business, in an era in which many women were only expected to look after the home and children. Her storytelling resonated with conceptualisations of personhood. I wondered whether notions of dependence due to dementia, for Lucy, were associated with passivity; lack of agency, choice, and connection with people beyond being cared for; and not being a valuable person in society. Perhaps these constructions of deficit point to how Lucy would like to be treated - as someone who contributed and not labelled with dementia and 'defective'.

Lucy explicitly positioned herself as a wife and mother and more implicitly enacted this identity through her interactions with her husband and daughters. However, dementia appeared to have threatened her sense that she could continue to care for her family and enact her female identity, in the context of a dangerous world, perhaps infiltrated by media portrayal:

[895 – 907] Lucy: I haven't got time to get things ready for the family, to get things, I mean, Peter still has his business. He's not working now but he's still got his business, we have to get rid of the, the, business. We have to get Mary, Mary is not married yet so of course yes, erm, we don't want to leave Mary. That that, I don't want to go, Peter, Peter is old too. I don't, we don't want Mary left on her own. Err, she's, she's going to live in this house on her own. Umm, you know, things like that, lots of things come to mind. That time has come [1] and [1] we, we, we have to try and get things ready for her as well.

Mary: But, you're not going to die, you're not dying, so you don't need to worry about things like that.

Lucy: Well, we do Mary, we are parents [1] we are not [1] so many things happening in life now. Things have changed a lot, haven't they? We hear news, bad news all the time and…

However, considering maintained activities, I wondered whether pervasive discourses of loss inherent in medicalised notions of dementia, but not associated with ageing, may have made it difficult for Lucy to recognise what remained. For example, in beginning to develop a narrative about why she had developed dementia (to which I will attend to later), Lucy described how *she* had to support her husband following his head injury, but this did not appear to be recognised by her as contributing to family life. She minimised her role in daily routines. Narration of recent achievements were often followed by stories of deficit. Retained lifelong traits, similarly, did not always appear to challenge dominant narratives of loss. Even happily recollecting recent events were negated by subsequently storying examples of forgetfulness. Lucy's avoidance of household routines may have also contributed to her feeling she was no longer a wife and mother:

[37 – 39] I know we are older, and OK when you get older, you don't do everything, but there are so many things that I can, now I think back on, I can't do it now, but I wanted it.

[16 – 17] But when he drives I have to sit right next to him to make sure, you know, he's alright and everything, although he's a good driver.

[198 – 201] But, you know, Peter has to. I put them in the way I want to put them in, the colours and everything but that's all I do. Then, Peter has to take them out, Peter has to hang them up, Peter has to iron, Peter does everything this man.

[70 – 72] I used to do a lot of things. I used to do a lot of drawings. Still I can't do it. I have cards, I make cards and I can still do it but umm [1] there are so many things I can't do.

[30 – 34] And I don't like to be [1] to be [1] messy. I've always looked after, cared for myself so much. I have been going to the hairdressers, even after my modelling days, when I stopped, I would go twice a week to the hairdressers. For 45 years I have been to the same person. Now, Andrea washes my hair and she does it for me.

[137 – 143] Lucy: I was trying to think of the school, err [1] the school name for weeks. And I remembered. What was it?

Mary: It was the Bush School of Art.

Lucy: Yes. And I was very happy to remember.

Mary: But you've written that down now.

Lucy: I can't remember when Mary was born, and I can't even now, even though we spoke about it, I wrote that down.

[185] Cos they're cooking, I don't go into the kitchen anymore.

Lucy subsequently repositioned herself as a burden. She appeared to idealise her husband taking over all the household chores she had taken care of throughout their marriage. However, I wondered whether Peter had taken on the role of the committed and selfless 'carer', who placed the interests of the 'ill' person before their own, which had further contributed to Lucy feeling dependent:

[738 – 739] Poor thing. You do all the jobs.

[698] I don't think I could have, I could have found a better man, a better husband.

[63- 64] He does everything for me now. I don't like that. I like to do things for myself not to put others out.

> [79 – 80] Yes, I get very sad, very upset, that they have to do everything for me, it's not that I am lazy.

> [217 – 221] Well I love him more and more and more. And I hope we have more years together. He's never, ever told me off. He's never said no. I ask for something, you can have it. He'll buy me the most expensive perfume that I like. He knows, he does everything for me. He does my ironing. He does, my everything. So, I cannot complain.

I wondered what storytelling might have emerged if it were Peter that had dementia; would Lucy have idealised herself and felt Peter was a burden if she were providing care to him? The comparison with Lucy naturally providing care to Peter following his accident was stark; what was different about Lucy and dementia and why it was "unfair" [546] that Peter now cared for her? I also wondered what was at stake for Lucy in talking about her family, to me, in their presence, in this way. Did she hope that by showing how grateful she was for their support they would remain motivated to support here? This seemed a genuine concern for Lucy. However, I wondered whether negative representations of PwDL, for example that they become increasingly incapacitated and burdensome to others, perhaps communicated by the memory service and wider society, and stories in the media about carer's neglecting or abusing elders, may have influenced her narration:

> [628 – 633] Lucy: As long as we don't get worse and you start hitting me or something.
>
> Peter: Well that's what I was going to say, as long as things don't get worse, they will be alright.
>
> Lucy: Why, would you hit me?
>
> Peter: No, no we are not talking about that, we are talking about mentality now. We are not talking about fighting. Yeah but we see, we will see.

Peter's final sentence, here, also alluded to this concern, although it also appeared that this was not something that he was willing to connect to at that moment, or to discuss in the research encounter.

Lucy's preferred identity as someone who had achieved in life and contributed to family life as a wife and mother had been challenged by dementia. Further, she repositioned herself as someone with dementia who had become "silly" [42]:

> [41 – 43] I don't feel old. I still feel young. And I am 80, going on 81, but I still, I don't feel old. I just feel silly, forgetting and not remembering and not being able to do…

In also talking about her age, Lucy moved the narrative towards 'abnormality' and demonstrated her awareness of social norms related to self-control and social deviance. I wondered from where notions of 'normal ageing' emerged and what expectations she had of people as they age. Narratives of dementia as a disease, distinct from the normal ageing process may have contributed to her conclusion that she had become "silly". However, being "silly" due to forgetfulness later became equated with "not functioning" [400], which conjured images of the brain as a machine and Cartesian dualism, and being "mad" [401], which has its own negative connotations. Lucy appeared to use examples of poor memory to supplement her storytelling and argued that "I am not right in the head" [914]. However, it was only when Lucy revisited these narratives of loss, when feeling more hopeful following starting singing classes, that she was able to reveal what all of this really meant to her:

> [195] Yes, it makes me feel I'm not a nothing anymore.

In talking about being "silly" [42] or "mad" [401] or "not right in the head" [914], Lucy appeared to mean that if she could not remember and if she could not provide for her family as she used to, she had nothing to contribute, was a burden and she was "a nothing" [195]. Western cultural assumptions about productivity and contribution were starkly expressed here. However, it may have been that, for Lucy, feeling 'silly', as Mary highlighted, had become co-constructed within the research encounter through her narration of loss:

> [415 – 416] I think, I think the reason you use silly is because you are trying to justify. You don't use the word 'silly'. You never used to use the word 'silly'.

3.1.1.2. *Rejecting and accepting stigmatised notions of dementia*

There were occasions in which Lucy skilfully diverted conversations away from threats to her identity by reminding her family of her life achievements, for example, returning this conversation to her modelling career. However, the way she ended this interaction suggested that her storytelling was suffused with contesting voices and repositioning herself as forgetful made her question the validity of her opinion:

> [53 – 61] Lucy: Yes. But what do I go for this one here?
>
> Mary: For your knee.
>
> Peter: Because you can't walk.
>
> Lucy: No. The other one, the one for dementia
>
> Mary: That's [hospital name]
>
> Lucy: Actually, I did 10 weeks there, cos I didn't want to put weight on and to lose the weight, I did, that's the hospital that I went to then, yes. Umm [1] there's many, many things that put me out. I can't cook anymore, can't cook at all.

Lucy often invited her family and me to comment on their situation. As this risked us agreeing with her that she was a burden, I wondered whether it felt more tolerable to 'know' she was a burden rather than navigate confusing contesting voices of strength as well as loss:

> [555 – 560] Lucy: I have everything I need, everything. But, I depend on them, and on Peter. Don't I darling? You're fed up, aren't you?
>
> Peter: No, I'm not fed up.
>
> Lucy: Are you sure?
>
> Peter: You, you…
>
> Lucy: Tell me, tell me you're not fed up. You must be.
>
> [914 – 915] What else can I say? Just I feel that I am, I am not right in the head. You can tell, can't you, that I'm not right in the head?

Peter's resistance of Lucy identifying with being a burden characterised the attempts the family made to protect Lucy's preferred identity for her. Mary and Andrea drew upon various devices to resist narratives of loss for their mother,

some of which they enacted individually and some together. Mary told her mother that her personality remained intact and Andrea explicitly stated that Lucy retained her role as a mother. Andrea and Mary normalised and validated Lucy's experience of forgetfulness. Mary positioned Lucy as necessary to support her own poor memory:

[758 – 764] Mary: You're always worrying about things.

Lucy: Yes, I always worry. If Mary, if I don't see the car, Mary's car arrive, Mary is not home yet, Mary, because she's working, and then Andrea, I check the car every day to make sure that she's home and you know, I worry about them, they're my children.

Peter: Yeah but…

Mary: But you've always been like that. That's part of your personality. Cos when we were younger, and we would be out, you would be worrying.

[1071 – 1076] Lucy: So, having heard that about Andrea and the man, I said to Andrea, 'No you're not supposed to go through the park for anything anymore.' She says, 'mum I'm not a child'. Yes.

Will: You're still being a mother.

Lucy: I'm still very much a mother.

Andrea: She doesn't stop [Mary: Laughs].

[334 – 340] Andrea: But there are people your age that haven't got dementia and they're not good with memory.

Mary: Remember Sophia. Mum's sister is in America, she died from dementia last year, didn't she? And Sophia, Sophia sometimes when we would skype her and stuff, she lived in America, she couldn't, she wouldn't, she couldn't even talk, could she?

Lucy: No.

Mary: But you're, you like talking and stuff.

[515 – 516] Andrea: I've never. I've never heard you speak to anyone. And I've never had a conversation with you when I don't know what you're talking about.

[1041 – 1045] Lucy: And the other day, I put something on and Mary says, 'mum, you've already put something on already' and I said, 'oh have I?' and yes, I'm wearing two somethings, yes. Err, that was silly wasn't it?

Mary: Do you know what, I put two contact lenses, I put two contact lenses in the same eye before, so everyone does it.

[721] Mary: Mum, you were reminding me yesterday.

I wondered what enabled them to use psychological resources such as these - they were not resources upon which Peter drew. I considered what it was like for them to see their mother experience these difficulties and how important it may have been for them, and their relationship with Lucy, to deny or minimise her difficulties and maintain her preferred identity. However, it did not seem as if Mary and Andrea's attempts to position their mother as retaining these valued roles and characteristics, in this way, were effective in reassuring Lucy that she continued to contribute to the family. Indeed, Lucy seemed to actively reject their attempts and explained away Andrea's own forgetfulness:

[669 – 674] Lucy: Because I'm fussy about myself. I like to be…

Andrea: Well that's why you look nice still.

Lucy: I like to be clean and tidy and everything. But, but, my mouth is not so, so good is it?

Andrea: Well your mouth is fine mum, it's just your memory.

Lucy: And now you have to do my hair.

[253- 254] Andrea: I forget things too. But, you know, I think mum's memory…

Lucy: Yes, that's because of all the work you do.

Peter drew upon a philosophical approach to life to attempt to scaffold his wife's identity. He encouraged Lucy not to consider dementia as a problem, asking her not to worry about being forgetful. This message was reinforced by Andrea's perspective:

[356 – 360] Peter: I think the reason, you have to accept it and forget about everything. Forget about the past and don't worry about this 'I can't send the cards'. I wouldn't worry about it.

Andrea: No, you have to adapt to your circumstances, don't you?

Mary: I think it must be frustrating for mum though.

I wondered whether Peter drew upon a medicalised view of dementia (he later spoke about dementia as an illness) to enable him to take this approach, as it appeared to serve several functions, to: separate the 'disease' from his wife; attribute her forgetfulness to a 'disease' that was legitimised by a diagnosis; and accept these difficulties without blaming Lucy. However, I wondered whether Lucy might have experienced this as telling her to forget who she was, encouraging her to become someone else. Mary's comments, intending to validate Lucy's experience, acknowledged that Peter potentially undermined his wife:

[532 – 536] Lucy: Umm [1] I did so much, so much. And now…

Peter: Yeah, but, forget about those things. It's gone, it's finished.

Lucy: I'm still…

Mary: They're her memories, dad. You don't forget about your memories. These memories are things that keep you going.

Peter often reoriented his wife, which may have reflected an attempt to help her learn or reflected the way he pre-positioned himself as having permission to correct his wife. Likewise, the way in which Mary often filled in blanks in her mother's memory, may have also contributed to feeling dependent on others and 'silly':

[44 – 46] Lucy: They gave me a little chair, the hospital, where I went for dementia, to see a doctor for my legs.

Peter: No, it was the other hospital.

[187 – 190] Lucy: I don't think I know how to put the oven on or anything or what's the thing we put the doo-doo in?

Mary: The microwave.

Lucy: The microwave.

Lucy's protection from ageist opinions may have been undermined by Andrea's comments. I wondered whether Andrea's ideas, that being an elder signalled an end to achievement, had emerged from notions of 'successful ageing' and the broader exclusion and invisibility of older people, as well as political representations of older people burdening the state without contributing:

> [538 – 540] Lucy: I am still [1] umm [1] eager for doing things, for things I have done before.
>
> Peter: Yes, I know that.
>
> Andrea: Well at least you know you've done them all.

3.1.2. The Emotional Consequences Of Dementia

3.1.2.1. *Lucy*

Lucy's emotional response to dementia made sense to me in the context of her repositioning herself. However, whilst Lucy focused on the practical consequences of dementia, it was Mary who introduced how her mother had been feeling:

> [24- 27] Mary: But you do get frustrated when you can't remember things, you are trying.
>
> Lucy: Oh yes, I do of course, I get very frustrated. I'm very lucky to have the girls.

It was not clear whether Mary had pre-positioned herself as the 'voice of reality' or rather felt it was important in the research encounter to provide more of the story. However, Lucy demonstrated, by saying "of course" [26], that she was in control of telling the story, resisting being forcibly positioned by her daughter to provide me with a narrative which she did not wish to tell me. Therefore, Lucy appeared to speak clearly and fluently about how she had been feeling but on her own terms. She expressed shame explicitly, which resonated with moral notions of rationality and a necessity to cope in adversity. Anger pervaded her storytelling, but it was not stated as such, and I wondered whether personal or cultural values made it more difficult for Lucy to express this emotion:

> [485 – 486] I'm ashamed of [2] just talking about me being [1] being what I am now. Not, not, not all there.

[789 – 791] Now I felt very, very [3] ashamed, ashamed with all that I'm saying because I'm not me and still [1] I would have been better off if I didn't care or if I didn't worry. I'm depending on everybody else.

[546] I feel that it's unfair that my brain doesn't work very well.

In telling me about her sister who had also been diagnosed with dementia, Lucy demonstrated fear of further loss of autonomy, which appeared to have been reinforced by attendance at therapeutic groups for PwDL. I wondered whether, for Lucy, the fear reflected the unknown - not knowing how much more loss she might face and whether her family could continue to support her - and losing the possibility to build a future. The way in which Lucy threaded narratives of achievement throughout her storytelling suggested this was an attempt to protect herself from these fears. I wondered whether she also 'othered' people with more advanced cognitive decline for this purpose:

[83 – 88] My sister also, she's been in a wheelchair for four years, with dementia. And I go to see her. We've got a house abroad, a beautiful house that we enjoy so much. We go to see my sister twice a year and she doesn't know me, she doesn't remember me, she just doesn't because of her dementia. And that upsets me, that she doesn't remember me, and it makes me wonder if I'm going to be like that.

[810 – 813] You couldn't understand what they said. They couldn't understand what was going on anyway. They were too far gone I think. Then of course I got scared, you know. Am I going to be like this? And I think I'm becoming like one of them, aren't I?

[1024 – 1030] Well on the other hand I felt very sorry for my, the other people that were there because I felt that the two of us, the one that came here, the one we went to see, the English man that was there, and I, we were slightly more, able to, to talk, whereas one of the others was just going [imitates snoring] all the time. I felt so sorry for him. The other looked a goner, he couldn't speak at all. And a lot of them were very, very slow. But, us three, I think we were more understanding and more able to talk

It seemed that her fears mostly concerned what other people may think of her. I wondered whether internalised stigma around dementia - the threat to being

labelled as 'defective' - influenced her decision-making, for example, to not attend social events:

> [634 – 641] Lucy: I was dubious whether to go or not because we went for Mary's birthday last year and I had to leave them there, err, and come home because I wasn't well. And I think it's because of the…

> Mary: And that's what you are worried about this year. Because my birthday is on Tuesday, so we've booked to go out in the evening. But mum's just remembering last year, and she is getting upset that, she's kind of…

> Lucy: But there's lots of people that come, and I'm worried I can't speak to them well enough.

3.1.2.2. *The family*

I wondered what dementia meant to Lucy's family, what images the diagnosis conjured up for them and whether it was possible for them to fully express these ideas in the family interview setting. In particular, I considered whether Andrea feared dementia too, when she asked me a direct question, about the heritability of dementia and expressed her perspective that PwDL deserve sorrow:

> [446] Andrea: Does dementia run in families?"

> [569 – 571] Lucy: I feel sorry for anyone with dementia.

> Will: Do you agree Andrea?

> Andrea: Yeah because so many people seem to have it.

In speaking about dementia in this way, which may have reflected an attempt for Andrea to protect herself from her own anxiety about developing dementia, I wondered whether discourses around dementia as a tragic epidemic co-constructed fear of dementia for Lucy. I was also particularly struck by Lucy's assertion that we should feel sorry for PwDL and yet she had shown little self-compassion; why did she not feel she also deserved sorrow?

Whilst Lucy focused on how she had been feeling, it was Mary, again, who introduced the idea that it was not possible to speak about the emotional impact of dementia on Lucy without considering Peter too:

[229 – 230] But the thing is, we know it's frustrating for the both of them. It's kinda like upsetting for both of them.

For Peter and Mary, it appeared that dementia was not positioned as the 'problem'; rather it was the way that Lucy had been feeling, as a response to living with dementia, that caused the most difficulty for them. However, I wondered whether the family's attempts to challenge Lucy's repositioning of herself may have inadvertently located responsibility in Lucy for her emotional responses to dementia, thus contributing to feelings of guilt and shame and low mood. Although the word 'depression' was not used at any time throughout the interview - Lucy spoke about feeling "upset" [10] – Peter introduced occasions when Lucy had expressed thoughts that she would be better off dead:

[874 – 880] Peter: No, the worst, the worst thing is, for me, when she says, 'I'd rather die instead of being here'

Mary: It's not worth living.

Peter: And that, that's been going on all the time.

Lucy: But then, you can have a free life.

Peter: No, that's not free life.

Lucy: Now you realise how silly I am.

Lucy's response suggested this was also at the forefront of her mind, and she took the opportunity to argue why it would be better if she were no longer living. However, I wondered whether it was the way in which Peter and Mary worked together in broaching the subject that alerted to Lucy the importance of speaking about this issue. In this interaction, Lucy appeared to be alluding to the notion that people with dementia could not have a satisfying life and could only burden their family; family members were "free" [878] when they did not have to look after somebody with dementia. A solely negative perception of dementia was characterised by Lucy's request to her daughters:

[1046] Well, don't take after your mum please.

3.1.3. Searching For Meaning

Narratives of deficit and loss were accompanied by questions from Lucy asking why she 'had' dementia and what she understood about the world. The task for Lucy appeared to reflect whether she could find meaning in her situation and a

way forward to living with cognitive difficulties. Lucy's assertion "my brain has gone funny" [428] revealed the pervasiveness of the organic model in her understanding of what had caused the difficulties she was experiencing. This was co-constructed by her husband's perspective:

[74] Yes, but it's all because of this illness.

I wondered whether the medical model constrained their storying of dementia by focusing on deficit and made it difficult to find meaning in their situation. However, this was not the only explanation upon which Lucy and Peter drew. They co-constructed an explanation that encompassed physical illness, stress and trauma:

[470 – 477] Lucy: I had breast cancer. That upset me a lot. I had a heart, umm, umm, [Mary: Valve replacement] valve replacement, yes. That, that, a lot of things that happened hurt me. And I think, I think that's why I've got the dementia.

Peter: That was the beginning because they happened all at the same time.

Lucy: And the accident. Peter's accident.

Peter: All at the same time. They happened all at the same time. Cancer, heart replacement, her knees, I mean [1] of course they all have a place in your mind. You can't forget it, what you went through.

A search for an explanation about why she 'had' dementia appeared to connect with philosophical arguments around the meaning of life. Lucy appeared to ask herself whether she had done something in her life to deserve dementia; was she really a 'bad' person and had brought this on herself? For me, this resonated with arguments about religion and faith and whether we are to blame when we experience difficulties in our lives. This was pertinent as Lucy had a religious upbringing and it remained an important aspect of her life:

[504 – 508] Lucy: There's so many things that I have done, and I think, I think about it now, look at me now.

Will: I see, I see how happy you are when you are thinking about these things.

Lucy: Yes, yes because I had a good life. I had a good life.

[888- 890] I've done a lot of things. I have travelled to many, many countries. I have a good family and I have a good husband. Why am I like this? Why am I feeling like this?

However, I was struck by the way in which the dementia label became the focus of this search for an explanation. Lucy narrated physical health difficulties, including reduced mobility, but its contribution to difficulty maintaining valued roles often appeared overlooked. I wondered whether holding in mind the complexity of the situation was too difficult and it was easier to position dementia as the problem. Or perhaps, dementia was positioned as central to their search in the absence of an explanation for forgetfulness. However, I also considered whether a deficit-oriented cognitive assessment may have overshadowed other factors contributing to functional difficulties in a holistic way.

3.1.4. Stifled Hope

At times, especially in the second interview, a more hopeful voice emerged through the storytelling, one which did see opportunities for achievement. Attending a singing group appeared to represent continuity with her identity and suggested life may carry on despite dementia:

[1085] Maybe I will change.

[13] I'm still doing a lot of things that I have done.

[48] I feel I have achieved something. I don't just sit there, you know.

[140 – 141] So, I am thankful, and I am sort of gaining, recently, sort of these past two weeks maybe.

Lucy's hopes for the future concerned improving her physical health, not improving her memory. Although dementia was positioned as the cause of her difficulties, improving her mobility was the route to a better life. However, I wondered whether focusing less on improving memory may have reflected messages received from her assessment and broader discourses of decline, resulting in little hope to effect change here:

[504 – 511] Will: Are there things you hope you will be able to do in the future as well?

Lucy: In the future? Yes. First of all, I would like to walk. Secondly, I would like to sleep. Thirdly I would like to put my house, you know make it decent, instead of just everything. Erm [2] I still have my driving licence, maybe I will get back to that as well because I have been a good driver. I would like not to forget things, help more around the house, be able to cook for you again Peter.

Despite a more hopeful tone in the second interview, a voice from the first interview continued to emerge, in which she repositioned herself as dependent on Mary and a burden and she resisted her family's attempts to protect her:

[210 – 213] Yes, I mean, where I used to go with Peter only because Mary was working, she hurt her foot and is not working now so she goes with me, and she reminds me of everything because I would never err, I could ever remember everything.

[323 – 329] Peter: Yes, but you see when you get old you change, you just…

Lucy: I am useless…

Peter: No, you feel you are useless because you can't do the things you used to be doing.

I considered whether this more hopeful approach represented a way for Lucy to protect her family from how she had been feeling. However, I wondered whether the threat of dementia was so strong that it was too difficult for her to hold on to this intention.

3.2. Individual Interviews – Providing Context To Family Interviews

The family and individual interviews were dominated by stories of how Lucy had been affected. It may have been that placing Lucy at the heart of the interviews focused the impact of dementia around her. It may also be that Lucy's role at the head of the family may have been enacted in the interviews, thereby focusing the interview on her. Lucy's emotional response to difficulties adjusting to dementia were so heightened that it may not have left open an opportunity for family members to connect with or express the losses they too have experienced (Kotkamp-Mothes, Slawinsky, Hindermann & Strauss, 2005). It could also reflect that the lives of the family have not yet so fundamentally

shifted, or the challenges have not been experienced over time, that this is a concern for them at this time. Alternatively, family carers may bury their guilt about being 'healthy' (ibid). The individual interviews, however, provided context to what was narrated in the family setting.

3.2.1. Lucy – The Wronged Protagonist

The family interviews demonstrated the ways in which Lucy, the protagonist, had been wronged by dementia. In her individual interview, she appeared more connected with the emotional aspects of the impact of dementia, which was reflected in her response to my first question. She also appeared to more clearly describe how she had been feeling, including how "sad" [222] she felt that she would die. Further, she introduced the concept of "depression" [52], a word that was not mentioned in the family interviews. Dementia as a death sentence to her was also more clearly expressed:

> [2 – 3] I feel guilty that I can't do anything in the house anymore.

> [49 – 57] Lucy: Cos I don't think I would be here if it wasn't, if they weren't as nice to me, like that. I mean, not to go away but you know probably, finish me.

> Will: How do you mean?

> Lucy: Well, maybe die. Depression and so on, you know. Now we're really…many things, and I feel sad. I say to Peter, "oh Peter, I would be better off if I die, then you wouldn't have to, put up with me and err and the children also". But he doesn't like to hear this at all and I am sorry that I said it. But then I would say it again some other day when I feel very depressed for some reason. And what reason can that be? It happens that I have dementia.

> [344 – 345] Now I've got the dementia, I'm ready to go, I don't want to leave Peter, I don't want to leave my children. And I think it gets me [1] it gets me.

Lucy's use of metaphor and imagery throughout the individual interviews, which was less apparent in the family setting, highlighted the depth of her experience in living with cognitive and functional difficulties, as well as suggesting she limited her expression, perhaps to protect her family from how she had been

feeling. In describing a situation, in which she sat in the car whilst her family bought a hoover, she stated she "felt like a dog" [199], before moving on to describing herself as a beggar, dependent on the good will of others:

> [357 – 358] I didn't have any difficulties, I didn't have any, I feel like the old man that used to sit outside the theatre, that used to wait to be given something.

This demonstrated to me the desperation that Lucy felt in her situation, but I wondered again whether she drew upon discourses that dementia steals one's humanity to use such strongly emotive imagery. To me her stories resonated with narratives that PwDL have nothing to offer other than to burden their loved ones and they should be thankful for the support when it wasn't merited.

Lucy expressed how she felt about Peter not being able to do what he enjoyed, as well as her attempts to maintain a preferred identity as matriarch in the family setting. However, she also located blame in herself, and suggested that there was only so much that her family would ever be able to do to support her, which again seemed to reflect discourses about not wanting to burden them:

> [174 – 175] Yes. Peter used to love going to the sea every day for a walk. And now he won't let me on my own, which is sad.

> [203 – 204] Which was very naughty of me really because it wasn't their fault.

> [209 – 210] But then I don't blame them, I blame myself for feeling like that.

> [514] But I mustn't have bad thoughts, but I can't help it. I just can't help it.

> [377 – 378] Everything. It's changed my life completely. I don't feel like I'm living a full life. Erm, but nothing to do with the family or my husband.

3.2.2. Peter – The Anxious Mentor

Peter appeared to play the role of Lucy's conscience, voicing the lesson that she must learn from dementia and ways to change if she wanted a fulfilling life. In his individual interviews, perhaps because he was given more space to speak, he more clearly outlined how difficult it was for him to see his wife respond to forgetfulness with sadness and anger, especially because he felt

that Lucy's identity had not changed, and he was happy to take his turn with tasks around the home:

> [39 – 40] I mean especially with my wife, this, it's, it upsets me to see her unhappy.

> [61 – 63] There's nothing really that she does that I mean is out of [1] out of what [1] you know I mean, where normal people and whatever, she's the same person, she just has, now she has this problem she thinks about everything now.

Peter's attempts to find an explanation for dementia resonated with discourses around its unpredictability as well as a battle with dementia with which to engage. However, other resources upon which he drew, including his personality, his experiences of moving to the UK, his accident and the recent deaths of some friends, appeared to allow him to take this more philosophical approach to "accept" [12] dementia:

> [99 – 101] And I think that upset her a lot. But I don't think that's why she got the dementia, it was just, it was just one of those things, you don't know it's, if it's going to hit you.

> [55 – 58] She thinks, she thinks all about these things, she doesn't forget things that happened before, and I always say, I always say [Laughs] "just forget about the past, think from now on". But she can't, that's just her character. She thinks about everything.

> [33 – 34] You see, last year, we had six of our friends err [1] much younger, they passed away because of the cancer, not because of, they all died from cancer just like that.

> [149 – 150] Everybody's got, their life comes to an end, no matter who you are.

> [338 – 342] I survived so [1] so you take the attitude that, it's life, you meet people, you get on and you [2] I always had these things, I never believed [1] everything is going to be alright, no matter what happens. That's the only way you can get on with life. You can't worry about things that might happen, they never happen, it's how you, it's, it's how you

proceed with your life and what you do. You mustn't think about, always think that it's going to, you're going to do better.

His concern to support his wife extended to thinking about what the children could do if he were to die first, which may have reflected an attempt to reassure himself she would be well cared for. However, his storytelling appeared pervaded by negative media portrayal of PwDL, especially those in care, and more importantly, reports of elder abuse, which usually characterise representations of dementia:

> [28 – 32] I mean I see some of the homes, the private ones, they seem to be alright. When you go to homes that [1] is not, they are not private, obviously the council pays for it, they don't treat, they don't get treated right, and that worries me a lot. So, that's why I always say, I say to the girls "if anything happens to me, never put your mother in one of these places. Sell the house, get the money and put her in a private home.

Peter's key narrative was the importance of family. He accounted for the value he placed on supporting the family through an understanding of his cultural background. It was this which enabled the family, as he told me, to be able to speak together and to navigate dementia together as a unit. Further, it was a life philosophy that he suggested allowed them to find a way forward together, comprising what he enjoyed, whilst taking into consideration his wife's needs:

> [198 – 199] And that's how families should be personally, err, that, that's what family, whatever you have kids or husband, wife, it's a team. You work as a team and life is easier.

> [371 – 382] Peter: I enjoy my walks, but I don't do it anymore.

> Will: And is that OK?

> Peter: Yeah, yeah, it's alright because we go to the park and when we are in the park there we sit in the garden and whatever. We don't sit in the car all the time, we've got friends up there, but she knows where I am, I talk to people there and whatever, she can see me, I'm in the garden there, we go round the garden and we chat to somebody or whatever.

> Will: It sounds like you've found a way of being able to carry on doing…

Peter: Yeah, because she can see where I am. So, it's err, it's OK even when we go, if we go to the park or whatever, she sits there, she reads her book, but she can see where I walk.

For as Peter summarised:

[183] My life is still the same, as it always was, all my life with, with my wife.

3.2.3. Mary - The Logical Sidekick

Mary's role in the story appeared to be Lucy's unconditionally loving sidekick. Although she appeared to get frustrated at times, she stated she would always stand by her mother, but it was difficult for her to explain how or why she took up this role. Her approach was also logical in that she responded with matter of fact answers, in which the head ruled over the heart.

Mary brought another perspective to understanding the impact of dementia on the family. Mary stated: "dad doesn't understand" [12]; the life philosophy which Peter reported he used as a resource to help him support his wife may, in fact, have been a preferred identity. She appeared to suggest the mentor himself was also flawed. Therefore, I wondered whether Peter's advice that Lucy forgot about her past may have reflected the anxiety that he faced in adjusting to their changed life circumstances and represented attempts to avoid hearing about their happy past together:

[117 – 118] But, now that, because he's got his injuries as well, his emotions have intensified as well. So, that's why they like bounce off each other.

The family interviews demonstrated ways in which Mary supported Lucy to resist Peter inadvertently undermining her. The individual interviews provided additional insight into the resources upon which Mary drew to support her family, including her own personality, life philosophy and cultural background:

[224 – 225] If there's something I can do for them, if they say they need something, then yeah, I'll do that, but I've always been like that.

[272 – 279] Mary: We are close, and I think that's, that's culture as well, that's the Greek thing. We've, kind of like always been, we are really

close. But I think you find that with a lot of Greeks, and I'm sure you find that with other nationalities as well.

Will: What is it about Greek culture?

Mary: I think it's family is really important. Family is really important, so [1] that's, uh, I don't know how to explain it, but everyone is just like really close.

In this way, Mary appeared able to "take one day at a time" [136], used "trial and error" [146] and distracted Lucy from threats to her sense of self by reminding her of her achievements. She also explained that holding onto certain pieces of information may have been a helpful way of managing the emotional impact of dementia for Lucy:

[391 – 398] Cos I've spoken to my cousin as well, the one in America and it's funny cos the medication mum is on now is the first medication my aunt was on, but I haven't mentioned that to mum, I haven't said that to mum, but it got steadily worse and in the end she was in and out of hospital cos of like different illnesses and at the very end they brought her home and umm, they said that was it and she had carers at home, but I didn't tell mum that and it was only when she died, I hadn't told her that she'd gone through this whole, cos I knew it would upset her and she would think about herself.

However, Mary placed considerable emphasis on the importance of being able to remember one's past; she suggested losing your memories was akin to death. Therefore, her own sense-making in dementia appeared to be pervaded by Western assumptions around cognition and productivity in determining self-worth. I wondered what stories of coping might emerge for Mary, if Lucy were to find it increasingly difficult to remember her past:

[151 – 154] Mary: Well usually it does, especially yeah, well that's where it comes back to the memories, doesn't it. It kind of just, your memories make up your existence in a sense…

Will: So, what happens when you don't have memories?

Mary: You're dead, I don't know [Laughs], I don't know.

Mary appeared more able to access her own assumptions and fears around dementia than her father and sister, which may have reflected a middle ground between being physically closer than her sister but able to have more distance emotionally than her father. She demonstrated insight regarding the greater impact of dementia on her than Andrea as she lived with her parents. But Mary spoke in a more concrete way than her sister and father about drawing strength from speaking in the family about the challenges of dementia. She also suggested that it was not always possible to discuss with Andrea what had been difficult, and I wondered whether it was their shared fear of the future, pervaded by dominant discourses of decline and burden in dementia, that prevented Mary from having these conversations:

> [332 – 336] Yeah, yeah, cos even with like her sister in America, we'd skype her and stuff like that and sometimes she would just be looking at you, she wouldn't be talking and stuff like that [2] it might be something completely different, it's just what I'm thinking myself or maybe, they are my own worries and putting them out there, so I don't know.

> [232 – 233] I think it's because, I think it's because I live with mum and dad, you're there 24/7, so like you see more things and they [1] they say more things [1] than they would do to Andrea. I think that's the only difference.

> [169 – 170] Will: So, so you do have conversations about these sorts of things?

> Mary: Oh yeah, yeah. I think you'd go crazy if you didn't.

> [238 – 239] Umm [1] I think some things that are going to upset her, I wouldn't, I would never tell her [2] you wouldn't want to upset anyone.

Mary suggested that explicitly telling Lucy she was not silly, may be something that the family were doing which made the situation worse. She argued that for Lucy and other PwDL, family can only provide a certain level of support. Perhaps she was implying the onus of locating responsibility for care in the family may have been too much for them to bear. This was also captured in Mary's recommendation for other sources of support, such as the singing group, of which Mary was talking about here:

[375 – 380] Will: So then, do you think her saying she's silly is a good thing for her or a bad thing?

Mary: Do you know what if it kind of [1] in a sense, it gives her peace and it kind of like, in her head, it justifies what's going on, cos that's the confusing thing, that's the frustrating thing, she doesn't actually, I don't think she realises sometimes that she is forgetting things.

[34 – 39] Mary: But if it's someone outside of the family, she seems to listen more, yeah.

Will: Why do you think that is?

Mary: Do you know what? Where it kind of like, we, we're kind of like her comfort and she's used to us. If it's an outsider saying it, it's just, she doesn't want people to think that she's [1] she's doing something wrong.

[357 – 368] Mary: I think family is important but it's like an all-consuming thing. When we first went there you actually see the people who were with carers and from the hospital and they seemed like really withdrawn on the outside. The ones with family were like talking to them and stuff but then when singing starts everyone really came out and so you can see like the change.

Will: So, people with families…

Mary: You did see them talking to them, like the ones with the carers you'd like seen them on their phones or they were out, like the person just had a cup of coffee in their hands and some biscuits and it was just like…

Will: So, there's just something really important about that social support.

Mary: I think, I think so yeah.

Will: But then something like music brings everybody…

Mary: Together.

3.2.4. Andrea - The Silenced Sceptic

Andrea's character in the family saga is less clearly outlined but the tragedy of dementia that pervades her mother's storytelling also characterises her own narration. She is a sceptic because she so strongly disagrees with the way her

mother has reacted to dementia, which may reflect the distance and perspective living outside of the family home offers her. But, she is silent because she doesn't voice this to Lucy or the rest of the family. She is presented last here because her voice is less strong amongst the family interviews. In agreement with Mary, she also argued that there had been less of an impact on her than the other family members:

> [11 – 13] Umm, but obviously it's not changed as much for me as it has for Mary and dad cos I'm not living with her. But yeah, I can see it's changed massively.

However, the emotional impact for her was strong, and not only reflected dementia, but seeing both her parents ageing, their physical health declining, and I wondered too her fear of their death, in the context of their close family bonds:

> [136 – 141] I just find it hard watching. I just find it really hard, not only, but just seeing both of them get older. Seeing them both not able to cope, you know, anymore. It's just hard to watch. Seeing my dad walking around, he has to hold something, and I know some of it's his age and some of it's the accident but for me, it's just hard to see it. Cos it's like watching them deteriorate. And like we are just a really close family.

The impact of dementia also appeared to concern, for Andrea, a sense of tragedy surrounding how someone who had achieved so much could be affected in such a way. Therefore, I wondered what stories might have emerged for Andrea if her mother had not achieved so much in her life. Would dementia have been so cruel, if her mother had not been a model or had a successful business? This resonated with me regarding cognition, productivity and independence and a meaningful life construed through someone's achievements or material gains:

> [309 – 311] And I think because, it's like because she has done quite a lot, it is, you know, she is really talented, so it's even harder to watch, cos she's gone from there to there.

Andrea appeared aware of the stigma that surrounded dementia, that this had been internalised by her mother, and perhaps reflected in Lucy storying a version of their situation, which may not have truly reflected the difficulties they

were experiencing. Andrea's relative silence in the family interview appeared to reflect a desire to maintain their relationship but may have constrained opportunities for the family to speak about how they had all been affected:

[29 – 31] I mean I've seen her, she does, she won't say it to you because she won't want you to know, cos you see her whole thing is, she doesn't want people to perceive her as loopy, or silly as she keeps saying or mental.

[42 – 43] But you know she doesn't want that stigma of being perceived as anything but normal

[96 – 107] Andrea: I think we, yeah [1] we just all need to be careful around her, you know if she heard me say these things to you now, like that would be a massive, that would make a massive difference to our relationship, she would not just accept that.

Will: What do you think would happen?

Andrea: Oh, I don't know, I just don't know, I just think she would burn her bridges with me a little bit. I honestly do think that. As close as we are because she's not forgiving of someone that hurts her. She's not. That's the thing. I mean I do, I do try to say things to her, but I do try to be diplomatic because otherwise it's not, it's not, going to work and it doesn't particularly work anyway but I can't just let her say to me 'I'm not having my tablets, I'm not eating'.

The individual interview allowed a greater understanding of the resources that Andrea used to make sense of the difficulties that were experienced by her mother and her response to them. Some of these emerged, for example, her fear of dementia, in the family interviews, but were more clearly expressed here. Andrea also appeared to reflect on her mother's personality, her experience of her reactions to challenging situations and Lucy's tactics to try and remain in control:

[281] Well it's scary, yeah. I mean it's scary, cos it can only get worse, we know that. It can only get worse.

[26 – 29] So, I think part of it, her dependency, is [1] what's the word [1] she's not calm about things, and she's not optimistic about things. She's

more of a pessimist. So, she's just not laid back about things at all. But that's how she is. And I think, because she's like that, it's made the symptoms of her dementia worse.

[110 – 117] It's like she's so childish, she's trying to blackmail you that she's not going to eat and she's not going to have her tablets. And for me, it's like dealing with a child. I shouldn't have to say to my mum 'mum, you're not going to die, I'm not going to let you die, I'm going to make your Weetabix, cos you know you are going to eat it' because dad made it and she wouldn't eat it. You know because she wants, because I think part of it is that she does get a little depressed, then she tries to blackmail everyone. But she can't, she can't do that.

However, like other 'sceptics', Andrea appeared to seek ways to support her mother to continue to feel she inhabited roles as a mother and wife and contributed to family life. She appeared to do this in such a way to not "overload" [167] her mum with too much information, which might have made Lucy worry:

[154] As a family I think we just try and make her feel like, you know, she is still important in our family.

[159 – 160] But I think we try to, just try and treat her as normally as we can so that she doesn't feel that she's different.

However, Andrea was quite clear, in line with her thoughts that her mum's 'problem' was her response to having dementia, that improving her memory was not the answer, although, again, this may have reflected discourses around memory decline in dementia. Like Mary, she also suggested the family may be an obstacle to getting support and as with her sister, I wondered whether she too felt the burden of responsibility for care being located in the family. However, she felt professional help might maintain family bonds:

[324 – 327] I think that was a good thing because again, I think it got her back into the swing of being with strangers and not having one of us as support. You know, you know cos Mary is very quick to jump in and answer something instead of my mum.

[236 – 238] Yeah, but I think if it came from someone outside and said, 'you know I think this is going to help you a bit, 'blah blah' then she would

be much more accepting of it. If it's someone else's idea, not us going and saying…"

[283 – 293] Andrea: It's like that auntie in Cyprus that's obviously quite a bit, but umm, I can't remember what my cousin does, but you know he works in a field where they sell medication to hospitals and clinics and things like that [I: yeah] and consequently, the boys have got her on these happy pills. The one thing I think when I see her is she's always happy. She doesn't know who we are, and she might not know that her husband has died but she is always smiling, and she is happy. And I think that makes a difference, it does.

Will: Mmm. A difference in what way?

Andrea: A difference in the way her life is for her. At least, she's not, she doesn't know who we are but at least she's not miserable and crying and wants to die. You know, there is a difference. So, I think if mum's mood was lifted a bit she would cope better, I just do.

4. DISCUSSION

Within this chapter, I will discuss the results considering existing literature and the challenges and limitations posed by the methodology. I will end by exploring the implications for theory, policy, practice, and research.

4.1. Summary Of Analysis And Links To Existing Research

This section will explore what emerged from the interviews and this will be related to existing literature. I will aim to address the research questions proposed at the start of this study:

1) What stories do PwDL and families tell about the impact of a dementia diagnosis?

2) Within these stories, what can we can understand about:

a) the ways family members position PwDL and the influence this has on their sense of self?

> b) how do PwDL, within the family, actively accept or resist being repositioned negatively?

> 3) What sociocultural and political narratives influence the positioning of PwDL, and therefore, the impact of dementia, and what implications emerge regarding the support that healthcare professionals might be able to provide to PwDL and their families?

4.1.1. A Devalued Self

4.1.1.1. *Lucy's adjustment to 'dementia'*[2]

Family and individual interviews highlighted the challenge that Lucy faced in reconciling constructions of her identity as an independent and resourceful woman, wife and mother who had achieved throughout her life with constructions of someone with dementia, who felt she could no longer rely upon her own sense of agency. The value Lucy and the family placed on her abilities and achievements and the meaning associated with their felt loss appeared to contribute to her cognitive and functional difficulties being experienced in a different way to other life transitions, including Lucy's reduced mobility, and this seemed to be influenced by negative representations of PwDL. This appeared to contribute to the challenge she experienced in making sense of and adjusting to those cognitive and functional difficulties and resulted in the emotional consequences expressed, including shame, guilt, anger and sadness. This chaos illness narrative pervaded Lucy's story-telling, even amongst a more hopeful voice that emerged at times (Frank, 1995).

Lucy's storytelling suggested that a dementia diagnosis can be so threatening that assimilating losses inherent with cognitive and functional difficulties may be very challenging for some PwDL, echoing previous research (Cheston, Jones & Gilliard, 2004; Lishman et al., 2016). She described herself as stripped of the very sense of herself and a non-person; this lack of a "coherent narrative" (Schechtman, 2003:100) was associated with lack of continuity to past interests, social roles and relationships and supports prior findings (e.g. Gilmour & Brannelly, 2010; Langdon et al., 2007; Beard, Knauss & Moyer, 2009). Lucy's expression of dependency and burden, common amongst PwDL, resonated with conceptualisations of living in the fourth age, with which dementia has

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[2] 'Dementia' from herein concerns cognitive and functional difficulties, shaped by dominant discourses, in their social context.

become acquainted (Ward-Griffin et al., 2006; Higgs & Gilleard, 2017). Lucy placed great emphasis on Western cultural assumptions about the value of the productive, autonomous self, in a "hyper-cognitive world" (Woods, 1999:37) to determine her self-worth, which may have contributed to a devalued self, loss of identity, and the challenge to adapt to cognitive and functional difficulties (Birt, Poland, Csipke & Charlesworth, 2017). However, it may be that a critical inner voice was a self-protective strategy that Lucy used to hold on to hope and increase her motivation to improve her life (Cheston, 2005, 2013).

Sabat and Harré (1992) suggest that the 'Self' is retained even in advanced stages of dementia, but it is the discursively and publicly produced 'Personae' which is undermined, influencing the repositioning of PwDL, and contributes to shifts in identity. However, Lucy's 'Self' – her view of the world, which is the basis of her actions and personal agency (Harré & van Langenhove, 1992, 1999) – appeared to be fundamentally altered by dementia. Her assumptions about the world, for example, as a fair and predictable place, appeared to have been shattered by her experience of dementia (Janoff-Bulman, 1992). The challenge for Lucy to her sense of her identity appeared so difficult for her, i.e. she felt she could no longer recognise who she was, that she appeared to feel she could no longer rely upon herself to provide for others, which seemed to have resulted in her chronic lack of feelings of safety. Intrusive memories of times when she had forgotten, hypervigilance to forgetfulness and loss of identity, avoidance of triggers of this and emotional responses such as low mood, anxiety, anger and guilt, may therefore have reflected trauma and grief in response to the cumulative effects of an "ambiguous loss" (Herman, 2015; Boss, 2010:139).

Rather than push dementia away through lacking awareness or oscillating between self-maintaining and self-adjusting levels of awareness, it seemed that Lucy was consistently confronted and continually challenged by her cognitive and functional difficulties. Lucy's search for meaning in this context appeared to contribute to the affront to her identity this engendered, and this is consistent with other studies (Cheston, 2005, 2013; Clare, Roth & Pratt, 2005). Lucy's heightened awareness of the impact of cognitive and functional difficulties may have reflected her life-long reliance upon cognitive and problem-solving skills in managing adversity, and she had, therefore, become acutely attuned to her

sense of loss. Chronic illness research argues that an individual's ability to cope with a health condition depends on their perception of a threat to control as this is required for self-efficacy (Paterson, 2001). This loss of control may have further contributed to changes in identity, adding to the challenge of adjusting to dementia. However, Lucy's avoidance of social interactions and contributing as much as possible to family life limited her opportunity to demonstrate the agency that does remain.

Chronic conditions, such as dementia, are marked by diagnoses, transitions and changing demands (Birt et al., 2017). The experience of being pre- and post-diagnosis is an example of liminality, which is "essentially ambiguous, unsettled and unsettling" (Turner, 1974: 274); during this time people are often structurally invisible (Turner, 1967). However, a post-diagnosis state for Lucy did not appear to reduce uncertainty; a world in which her identity and self-esteem were constantly threatened may have meant liminality had become a permanent state (Little, Jordens, Paul, Montgomery & Philipson, 1998).

Hulko (2004) argues that older women are more accepting of 'illness' encountered in later life because they have been socialised to structural disadvantage. However, Lucy had overcome oppressive notions of being a woman throughout her life through running a successful business with her husband. It may be that access to financial resources and "social capital" (Bourdieu, 1968:23) buffered Lucy from being marginalised; but, having lived a more privileged life, may have made it more likely that she would view dementia negatively (Hulko, 2004). Indeed, unlike the women in Hulko's study, who had resigned themselves to having dementia, Lucy enacted and forcibly expressed that she could not accept it. Gender roles for Lucy also did not appear to have become "less distinct and mellowed" (Girdham, 2002:8) in ageing and the onset of cognitive and functional difficulties, nor had she been "liberated" (ibid) by her family taking over valued roles and responsibilities (Ginn & Arber, 1995). She appeared to refuse a socialised experience of becoming a "dotty old woman" (Hulko, 2004:95). However, it was also important to acknowledge that these different aspects of identity could not be easily separated out, as gender is also constructed in relation to ethnicity, class, etc (Yuval-Davis, 2007). Nonetheless, it may be that structural forces contributed to a devalued sense of self; lacking

in agency appeared to prevent Lucy from accommodating her cognitive and functional difficulties (Charmaz, 1991; Hulko, 2004).

4.1.1.2. *Inadvertent contributions*

Lucy's identity appeared to be discursively constructed in conversational interactions, which could not be separated from the family's experience of her in the past, present or the anticipated future (Graham & Bassett, 2006). To her family, Lucy's identity did not appear tied up with her cognitive abilities and ability to complete household chores; to them, it remained because she continued to contribute to the family in other ways and her personality was retained (Jannusch & Huisman, 2015). Attempts to resist the impact of dementia for Lucy demonstrated this (Clare & Shakespeare, 2004).

Like the family interviewed by Purves (2011), this family faced a struggle, individually and collectively, to come to terms with dementia in ways that could integrate their constructions of Lucy as a wife and mother with their constructions of her as a person with dementia. However, successfully navigating societal narratives around the dementia label and shielding Lucy from the stigma associated with it appeared more difficult for this family. Negative representations of PwDL appeared to have been internalised by all family members, 'inadvertently' influencing the way they interacted with each other and Lucy, thus contributing to her repositioning (Purves, 2011; Scholl & Sabat, 2008). The word 'inadvertently' is used to denote that family narratives were polyphonic and also appeared pervaded by sociocultural representations and ideals (Bakhtin, 1984; Tolhurst et al., 2017). Interactions with PwDL may, therefore, represent a family member's own struggles to adjust to dementia, rather than negative perceptions of PwDL or a spoiled identity per se (MacRae, 2011; Goffman, 1963).

This research extends other findings to consider how different strategies employed by all family members, in the context of these ideals, interacted and challenged Lucy to retain her preferred identity (Tolhurst et al., 2017). However, it may have been that any shift in roles and responsibilities, whether negotiated or not, may have been difficult for Lucy to accept, because of how strongly she valued, for example, completing household chores, in determining her identity and self-worth. Lucy's role in these interactions also needs to be considered. Although she appeared to have found ways to reduce the impact of stigma and

retain her identity, she also oscillated between rejecting being negatively positioned as someone with dementia and accepting it, as if to say that being repositioned in such a way was justified (Higgs & Gilleard, 2015).

4.1.2. Family Adjustment

Consistent with findings from family systemic approaches to illness and disability, being diagnosed with dementia constituted a transition in the family life cycle, as form and function of family roles, status as well as planned life trajectories were threatened, which challenged homeostasis and attempts to maintain "familyhood" (Rolland, 1994; Birt et al., 2017; Carter & McGoldrick, 1989; Vizzachi et al., 2015; Roach, Keady & Bee, 2014:173). Like other research with PwDL and their families, this family's relationships were characterised by "resistance and acceptance, cooperation and conflict, unity and detachment, and negative and positive reciprocity", in which they called upon old and new ways of coping with dementia (Graham & Bassett, 2006:346). This research highlighted the challenge for the family to adjust to cognitive and functional difficulties and to continue to adapt (Beard, 2004a; Rolland, 1994; La Fontaine & Oyebode, 2014). A previously positive relationship may not necessarily mediate the experience of grief and loss (Ablitt et al., 2009; La Fontaine, 2017), especially in the longer term, in which personal and family resources are stretched.

4.1.2.1. *Protective factors*

The nature and quality of the family's previous relationships appeared to influence their current relationships and motivation for providing support in accordance with their values and goals, for example, the family retained a sense of togetherness and commitment despite Lucy's less active role (Ablitt et al., 2009; La Fontaine & Oyebode, 2014; Tretteteig, Vatne & Rokstad, 2017; Wadham, Simpson, Rust & Murray, 2016). The 'family-centred' nature of Greek-Cypriot relationships, reflecting a collectivist culture in which close family relationships are emphasised, acted as the main source for the family to: engage its resources; maintain the quality of their relationships; and adjust to dementia (Botsford et al., 2012; Papadopoulos, Leavey & Vincent, 2002; La Fontaine, 2017). Ongoing support from Andrea and Mary was seen as a natural evolution of their relationship to their mother, which was welcomed by Lucy and Peter, and served to reinforce their closeness (Botsford et al., 2012).

The family drew upon a range of other psychological and narratives resources, including normalising and validating Lucy's experiences, which were influenced by life events, personality traits and personal worldview.

4.1.2.2. *Risk factors*

However, as other families, this family appeared challenged to openly communicate and resolve difficulties and negotiate shared roles and responsibilities (La Fontaine, 2017; Wadham et al., 2016). For the family, "working together" (Keady & Nolan, 2003:15) may have been more difficult because although dementia was not positioned as the problem, holding dementia apart from the relationship while managing its impact on their day-to-day lives (La Fontaine, 2017) was challenged by the family locating the problem in Lucy's emotional response to her cognitive and functional difficulties. This appeared to contribute to her sense of shame and burden.

4.1.3. The Unique Contribution Of This Data

The current research develops the literature around the impact of dementia by demonstrating further nuances to our understanding of the factors that challenge or support PwDL and their families to adjust to cognitive and functional difficulties. A trauma lens could be applied to the experience of PwDL – heightened awareness of difficulties may make some PwDL more attuned to loss, in the context of fixed beliefs about the world and self, and coping strategies that may no longer be helpful, leading to avoidance of triggers, intrusive memories and chronic feelings of lack of safety and disconnection. This research also highlights that even in the context of retained closeness and good intentions, sociocultural values and assumptions pervade the narratives of all family members, which challenges their ability to scaffold and maintain PwDL identity. Different strategies employed by all family members, influenced by these ideals, interact to challenge PwDL and the family's adjustment to dementia, which can threaten their relationships. The research elaborated on how PwDL and family strengths and resources can buffer them against the demands of dementia.

4.2. Critical Review And Limitations

This next section will outline some of the key challenges and limitations of this study, as well as my personal reflections.

4.2.1. Quality Of Analysis

Narrative analysis allows for the systematic study of personal meaning-making and how events have been constructed by active subjects (Riessman, 2008). Traditional conceptualisation of validity and reliability in research rely on realist assumptions of 'truth'. Reliability concerns the repeatability of findings, which can thus be generalised to other people, settings, contexts, etc. Reliability does not apply to narrative studies. This thesis attempts to present the narratives that emerged from the family and individual interviews and how they were told. Narrativisation assumes point of view and, thus, the data analysis presented here is grounded as a product of the interpretive process (Riessman, 2008). The unfinalisability of the data is placed at the forefront of the analysis, acknowledging that narratives emerge out of social discourses and power relationships, which do not remain constant over time (Bakhtin, 1984; Riessman, 2008).

However, the quality of the analysis remains important; validity and ethics are key methods for evaluating narrative research and the trustworthiness of interpretations (Riessman, 2008; Mishler, 1990). Theoretical coherence, persuasiveness and transparency can be used to evaluate trustworthiness of data analysis (Guba & Lincoln, 1994). These refer to whether interpretations are reasonable and convincing, the theoretical argument is consistent and different parts of an interpretation create a complete and meaningful picture (Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 1993).

4.2.1.1. *Persuasiveness*

To frame the interpretation of the data as reasonable and convincing, peer review and feedback has been used throughout the development of the research questions, design and methodology (Riessman, 2008). I have provided direct quotes from the transcript to support my interpretations; alternatives have also been considered (ibid). Persuasiveness depends on the "analyst's capacity to invite, compel, stimulate or delight the audience…not on criteria of veracity" (Gergen, 1985:272). To improve persuasiveness, I have considered different rhetorical devices and the way the reader may respond to the interpretations (Riessman, 2008).

4.2.1.2. *Correspondence*

Riessman (2008) argues that taking one's interpretations and conclusions back to participants strengthens trustworthiness of the research and is ethically sound; the credibility of the analysis is also increased (Lincoln & Guba, 1985). Congruent with a social constructionist framework, taking stories back to the family was not an attempt to corroborate the analysis; it sought to determine whether my telling of their stories resonated with them. It was an opportunity to triangulate multiple interpretations, including reflecting upon the way the research encounter co-constructed meaning, instead of uncovering a final 'truth' (Gubrium & Holstein, 2002; Riessman, 2008). The family were encouraged to provide feedback; their responses were viewed as a "source of theoretical insight", whilst acknowledging the unfinalisability of stories (Riessman, 2008:66; Bakhtin, 1984)

Selecting what to feedback constituted another form of interpretation, and for transparency Appendix H contains a written summary of what I chose to re-tell. The family agreed that their feedback could be included in this written thesis. This feedback reflects freely-made comments, body language as well as responses to direct questioning. In line with the focus on the impact of dementia for Lucy, she provided most feedback. There were moments when she cried upon hearing her stories re-told, and nods of recognition were provided by all family members. Lucy particularly agreed with interpretations based around the conflict she appeared to experience in reconciling her identity with someone who has dementia. In talking about meaning around dementia, Mary provided further information regarding how difficult it was for Lucy not to blame herself for having dementia because it had not been possible to provide her with an understanding of why she had developed cognitive difficulties. The feedback allowed me to reflect upon the ongoing impact of dementia on the family, which enabled me to develop a better understanding of challenges to living with cognitive and functional difficulties.

4.2.1.3. *Theoretical coherence and knowledge claims*

The coherence of my interpretations constitutes a further validity test (Crossley, 2000). I have attempted to achieve a broadly social constructionist theoretical coherence throughout, beginning at the research rationale, thus enabling the reader to understand reasons for the chosen methodology and arguments

presented for the interpretations (Yardley, 2008). I also described how the interpretations were produced and recommendations made; I was concerned with making clinical recommendations guided by coherent theoretical approaches (Riessman, 1993).

I was not concerned with gaining the truth or making knowledge claims, rather, I aimed to open possibilities of listening and opportunities to respond to what was heard (Frank, 2012). By focusing on, for example, socio-political storylines the family members drew upon, it might have been possible to more fully elucidate current discourses around dementia. However, I was most concerned with understanding the interaction of different levels of context.

Narrative data can contribute to empirically based theory; a key tension concerned not imposing my own position on their telling of the story and I have attempted to base interpretations grounded in the data to enable a bottom-up theorising of the sense the family made of living with dementia (Squire, 2013).

4.2.1.4. *Transparency*
I have attempted to produce a transparent written narrative of the research that reflects the processes used to develop the research topic, including my epistemological assumptions and biases, and how these guided the development of the research questions, as well as my interpretation of the data. I have documented the processes by which I recruited the family to the research and the ethical considerations that were involved throughout this. Further, through the process of reflexivity, I have positioned myself in relation to the research questions and I have outlined how my professional and personal experience have contributed to my interpretation of the data, which have led me to connect to the existing literature, as well as fostering new perspectives. An excerpt from my reflexive journal (See appendix I) elaborates upon this.

4.2.2. Ethical And Methodological Considerations

4.2.2.1. *Critical review*
In critically reviewing this research, I am drawn back to thinking about Frank's (2012) concern regarding what has animated this study. As I explained, I have personal experience of the negative impact that dementia can have on the family. My interest in dementia has also originated out of recognising the value I have historically placed on cognition to determine my self-worth. Through

conducting this study, I have become increasingly aware that I would want a supportive social environment to scaffold any cognitive difficulties I might experience in the future. This research was further animated by recognition that current social discourses and services, predicated upon a medical model, have the potential to undermine people and the value that creating a more supportive context may provide for PwDL and their families.

Although I have framed the interpretations presented here transparently, this critical review is concerned with how my own assumptions shaped narratives in the study and my interpretation of the stories that the PwDL and their family told. For example, I was aware of the relative power that clinical psychology plays in advancing research, clinical practice and policy, and I was keen to uncover socio-political discourses which have shaped these dementia narratives. This will have affected the types of questions I asked, thus limiting choices the family had to narrate their lives in a way that made sense to them. However, through keeping a reflective journal (See appendix I) and drawing on supervision, I have attempted to stay open to uncovering stories that might not fit with my assumptions about what was important to tell.

4.2.2.2. *Balancing the role of the researcher and the clinician*
During the interviews, there were occasions when the family asked me direct questions about dementia and its heritability, and I became aware of being drawn into taking on a role of a clinician. I wondered what motivated the family to be involved in this research; I don't know the answer to this question, but I thought that, for them, it might have been their way to gain further support from services. I was concerned that being drawn into this position indicated my difficulty in balancing a clinical and research role, but I did feel it also influenced how I conducted myself during the interviews. For example, there were occasions in which I recognised that I stopped myself from asking particular questions in order to avoid being drawn in to the clinician role. To some extent, this will have shaped the narratives that were told and the data analysis, although it is not possible to say what stories may have otherwise emerged.

In reflecting on this, I wondered what the boundary was between the researcher and the clinician. Hart and Crawford-Wright (1999) described how both roles concern being told an experience by a participant, whilst listening empathically, with the view to interpret and understand the narrative. I reflected upon the

clinical value of this but, to ensure that the research aims were achieved and to reduce my participation in co-constructing the narratives shared, I felt better able to engage the family members in dialogue about their experiences, knowing to guide them towards the mental health nurse, who had been supporting them, to answer their questions.

4.2.2.3. *Recruitment*

Inclusion and exclusion criteria were created and were motivated by ethical concerns as well as the importance of meeting the research aims, but which will have filtered out some people from participating in the research. However, I was also aware that recruitment to this study may have been influenced by clinicians who acted as gatekeepers to the population and may have been concerned to suggest participants who could provide positive feedback about the service they have received. This will have influenced the stories that were told, silencing the voices of some PwDL and their families, especially those for whom dementia has placed considerable pressure upon their family relationships, which is an under-reported area (La Fontaine, 2017). Again, whilst this research did not seek to determine truth, this is another demonstration of the importance to examine the interpretations here in their context.

4.2.2.4. *Power and participation*

Research which facilitates the hearing of stories of marginalised people may not be emancipatory (Elliott, 2005). This research was intended to balance my personal and political will to improve the lives of PwDL and their families with empathically listening and responding to their stories. Despite my intentions, this research will have reproduced existing power relations for PwDL simply by my researching a group to which I do not belong. Although I have attempted to maintain a position of curiosity about, for example, stories that might have emerged if Lucy were male, my gender and age make it difficult to interpret stories of what it is like to be a mother and wife and the challenge that Lucy faced to maintain a valued self.

Lucy and her family may have been motivated to express narratives of support from the memory service, believing that I was representing the service which she was receiving, fearing that negative reports may later exclude her from receiving further support if she needed it. Despite my assurances of anonymity and confidentiality, Lucy and her family may not have felt entitled to criticise or

even comment on the way in which their experience of being assessed for dementia and supported has negatively affected Lucy and their relationships. This may have shaped the narratives that emerged from the interviews and influenced the interpretations that I made in analysing them.

4.2.2.5. *The silencing of narratives*

Limitations on the number of words for this thesis further constrain and silence narratives that were important in answering the research questions. There were occasions in which I had to prioritise which narratives to feature, thus privileging my own voice and limiting the reader's opportunity to appraise the narratives' meaning (Riessman, 1993). Whilst it was important to analyse the whole transcript, this may have privileged the 'big' stories over the 'small' ones, thus neglecting the subtleties and intricate or less easily described (due to their emotive quality) stories.

4.3. Implications And Recommendations

This research highlights that "the personal, interpersonal and the institutional/structural are inter-related through the stories we tell and are told about us, whether by individuals or collectivities." (Baldwin, 2008:224). Crucially, this has the potential to determine how PwDL and their families adjust to cognitive and functional difficulties (Tolhurst et al., 2017). This next section will discuss implications for theory, practice, policy and research with PwDL and the family.

4.3.1. Theoretical Implications

Recommendations first concern the need to use alternative theoretical frameworks to understand the impact of cognitive and functional difficulties on PwDL and families.

4.3.1.1. *A family systems model of dementia experience*

The impact of cognitive and functional difficulties should be understood in relation to a network of social relationships within which PwDL are "deeply interconnected and interdependent" (MacDonald, 2002:195). By focusing on the interaction of family members as a network of individuals experiencing a significant ongoing life transition, it would be possible to discern the demands of living with cognitive and functional difficulties as well as the resources upon

which they each draw, which influence each other in a circular fashion and maintain homeostasis (Purves, 2011; Carter & McGoldrick, 1989; McCubbin & Patterson, 1983; Hecker et al., 2003).

4.3.1.2. *A trauma model of dementia experience*

Models of trauma have been applied to caregivers of PwDL (Burke, 2014) and could be useful to frame the difficulties some PwDL experience when the challenge to reconcile the experience of their cognitive and functional difficulties with their identity appears to overwhelm them. The cumulative impact of dementia may have the potential to disrupt a person's worldview and assumptions about themselves, as well as compromise coping strategies that were once effective (Janoff-Bulman, 1992; Herman, 2015). Hyperarousal, intrusions and constrictions may, therefore, be evident in the stories narrated by PwDL, reflecting challenges to the PwDL's sense of control, connection and meaning (Herman, 2015). Although dementia can not be understood in terms of an immediate threat to life, the accumulation of threats to psychological integrity may provoke a similar trauma response. However, assuming constructs such as 'trauma' are universal may be incompatible with the meaning individuals have given to adversity and may further contribute to the experience of marginalisation (Ghezai, 2017).

4.3.1.3. *A shift away from personhood – citizenship models of dementia care*

This research also points to shifting away from individualised biomedical and personhood models towards a citizenship approach, which can provide the language required to discuss the experiences of PwDL and their families in terms of power relations (Bartlett & O'Connor, 2007).

4.3.2. Clinical Implications

In line with theoretical re-conceptualisations of the experience of living with cognitive and functional difficulties, supporting PwDL who may be 'traumatised' concerns establishing safety, helping them to re-story their experiences and promoting connections within their immediate and wider systems (Herman, 2015). To do this, Bronfenbrenner's Social Ecological Model (1979) may be one way for health-care professionals, including clinical psychologists, to frame supporting PwDL and families at different levels of context from the micro to the macro. In particular, clinical psychologists will have developed the relevant assessment and formulation skills, through their training, to guide individual and

family interventions, attending to the personal, interactional and socio-cultural domain when exploring the shaping of a person's Self-construct (Hughes, 2014; Castro & Clark – McGhee, 2014; O'Connor et al., 2007). They will have also developed the skills to advise policy-makers and commissioners regarding policy and service delivery. Recommendations for supporting PwDL and their families are balanced with acknowledging the political agenda to locate responsibility for care and burden on individuals and the family (Esandi & Canga, 2014).

4.3.2.1. *Enhancing the resilience of people with dementia labels and their family through systemic and narrative approaches*

Enhancing PwDL resilience by increasing sense of safety and connectedness would be best achieved by involving family members. Drawing on systemic and narrative approaches may be one way in which to enable the PwDL and the family to hold on to what remains, i.e. cognitive abilities and identity, and to utilise their strengths and resources to facilitate the process of making sense of and adjusting to what has changed i.e. the cognitive and functional difficulties experienced. This has the potential to engender hope for the future and reduce the likelihood of ongoing anxiety, depression and other difficult emotional responses. Narrative approaches are theoretically well-established (White & Epston, 1990) and their effectiveness in therapeutic work with PwDL and their family has been demonstrated (Stott & Martin, 2010).

Using the principles of systemic and narratives approaches, PwDL and their family members could be supported by jointly naming and storying their experiences and fears and to search for meaning in their situation (Frank, 2007). Rather than providing the 'correct' story, the role of the clinician might be to help make other stories available, which would allow PwDL and family members to retain "empathic access" to the past and enable their relationships to evolve in the most helpful way for all of them (Schechtman, 2003:245). The social constructionist framework of the narrative approach makes it possible to trace the history of the 'problem' and allow PwDL and family members to stand back from socio-political ideals, situating these culturally and historically, thus providing space to elaborate more hopeful yet still marginalised alternative narratives. This may help the family to tolerate and hold on to the anxiety they are all experiencing. Stories could be thickened by looking for 'exceptions', for

example, times when the PwDL has contributed to family life, to increase PwDL agency and provide them the power to inhabit alternative, more hopeful versions of themselves (Harré & van Langenhove, 1992, 1999; Bartlett & O'Connor, 2007). Helping the family to communicate openly, resolve conflicts, negotiate roles and responsibilities and support one another would enable this (Esandi & Canga, 2014; Wright & Leahey, 2009; Tatangelo, McCabe, Macleod & Konis, 2018; Tretteteig et al., 2017). Encouraging the family to facilitate PwDL engagement with meaningful activities may be particularly helpful to resist the threat of loss in dementia and enable PwDL to tolerate uncertainly due to living in liminality and redefine their identity (Birt et al., 2017; Genoe & Dupuis, 2011). Meaningful activities for PwDL may also be therapeutic in a different way than support from the family can offer, whilst it can provide the family some time apart and reduces the burden on family members.

4.3.2.1.1. *Practice considerations*
When supporting PwDL and their family members, their unique needs as well as their resources should be taken into consideration. How they define who is family is also key (Morgan, 1996, 1999). The potential for further cognitive and functional decline indicates PwDL and their family members should be equipped to continue to adapt to their changing circumstances. Practice implications regard engaging the family that is concerned with maintaining their relationships whilst communicating that individual problems exist within interconnections in systems, are constructed through language, maintained through shared narratives and resolved through the relationships and contexts in which the family is engaged (Hecker et al., 2003; Combs & Freedman, 1996; Dallos & Draper, 2015). However, PwDL and family members could also be provided with opportunities to re-story their experiences as individuals, according to their needs.

4.3.2.2. *Moving beyond the therapy room: challenging negative representations of people with dementia labels*
In a dementia context, the personal is the political. Clinical psychologists and other health-care professionals have an ethical responsibility to help PwDL and their families to successfully navigate the impact of cognitive and functional difficulties. This can be facilitated by: challenging dehumanising practices that objectify, exclude and silence PwDL; and, preventing PwDL and their families

from being traumatised by societal discourses (Mitchell et al., 2013; Caplan, 1964; Baldwin, 2008; Bartlett & O'Connor, 2007).

Therefore, health-care professionals have a role to play as policy advisers, in which they can acknowledge the challenges of living with cognitive and functional difficulties whilst paying attention to remaining PwDL agency. By facilitating a shift from a deficit, medicalised model to a rights-based discourse, marginalisation through structural forces can be prevented (Bartlett & O'Connor 2007; McParland, Kelly & Innes, 2017). To reduce stigma around dementia, health-care professionals could also advise on 'successful ageing' campaigns, which emphasise remaining physically and cognitively active, to allow PwDL to define for themselves the kind of life they would like to lead (McParland et al., 2017). Another role may concern working with the media to encourage shifts in the language used to describe the experience of living with dementia, which perpetuates fear (Peel, 2014).

Health-care professional can also enable PwDL to practice agency and enact narrative citizenship through campaigning for social justice via political lobbying and raising awareness of living with dementia. This also has the potential to increase the availability of alternative personal narratives, alleviate public fears and stigma, challenge dominant discourses around dementia and contribute to the re-valuing of PwDL in society (Baldwin, 2008; Birt et al., 2017; Hughes, 2014; Bartlett, 2014). Challenging dominant discourses has implications for influencing the way families and others interact with PwDL, increasing their agency, which further contributes to challenging dominant discourses and so on.

To support this, relevant British Psychological Society practice guidelines, for example, "Psychological dimensions of dementia: putting the person at the centre of care" (BPS, 2016), which should be praised for placing PwDL at the forefront of care, would benefit from additional emphasis on the impact of the sociocultural and political context on the experience of dementia for PwDL and their families. This would not only endorse its impact but provide a platform from which to consider how to implement these interventions.

4.3.3. Research Implications

4.3.3.1. *Further exploring the interaction of the personal, interpersonal and sociocultural*

Further research with more families from diverse backgrounds, in which the range of interactions between personal, interpersonal and sociocultural factors is explored, is warranted (Górska, Forsyth & Maciver, 2017). By focusing on family systems, it would be possible to develop a balanced account of the experience of living with cognitive and functional difficulties, which does not prioritise one person's account over the other's (Tolhurst et al., 2017). Consideration of family dynamics in research encounters would ensure that all members are heard. Conducting research with families over time would also allow for a better understanding of how they navigate the shifting nature of cognitive and functional difficulties and make sense of dementia in the longer term. A longitudinal design would permit an exploration of how PwDL and family resilience may need to be enhanced as their resources become challenged in the longer term.

Using a trauma lens to understand adjustment to cognitive and functional difficulties also warrants further exploration. This may consider whether 'well-adjusted' PwDL shift their assumptions about the world and self, which allows them to find meaning in their cognitive and functional difficulties? An alternative hypothesis might be that some PwDL 'adjust' to dementia by taking on a socialised version of themselves, in which they enact negative representations of PwDL. Inherent in this is further delineation of what constitutes good adjustment, and linked with this, how is adjustment measured and what outcomes of therapy facilitating adjustment might look like (Cheston & Ivanecka, 2017). A family systems approach may consider how negative representations of PwDL challenge family members to stay connected and successfully negotiate new roles and responsibilities. Further research may explore how to increase family resilience, in particular focusing on the resources that are embedded in the family and immediate social context.

To do this, the current research recommends using a qualitative methodology which attends to the voice of PwDL and their family members concerning how they make sense of their experiences. Similarly, research around therapy

outcomes may explore what was meaningful and useful in therapeutic conversations (Young & Cooper, 2008).

4.3.3.2. *Citizenship and participatory action research*

Citizenship-focused research, incorporating a sociological theoretical base, can help in "advancing the social justice agenda in relation to people with dementia" (Bartlett, 2016:455; Bartlett & O'Connor, 2007). The importance to locate PwDL and their family members at the centre of research processes suggests that Participatory Action Research (PAR), in which researchers work with communities from the development of research questions through iterative cycles of action and research, might be an alternative useful research avenue (Reason & Bradbury, 2001a; Hughes, 2014). The researcher's involvement in the reconstruction of concepts and practices is acknowledged and, thereby, minimised (Parker, 2005). This may also facilitate an iterative approach to developing research questions, in which analysis at one level of context informs more specific questions about other levels (Hughes, 2014). PAR also has the potential to increase PwDL agency and citizenship.

4.4. Conclusion

This social constructionist approach to narrative inquiry with a PwDL and her family offers evidence regarding how they each made sense of dementia and the challenge to accommodate cognitive and functional difficulties into individual and family identity. By interviewing more than one family member at a time it was possible to attend to how an interactive network of individuals function as a unit to develop evolving storylines, in which the repositioning of Lucy was not intentional (Purves, 2011; Davies & Harré, 1990). Narrative strategies used by all family members are positioned with reference to broader sociocultural factors (Tolhurst et al., 2017). Practice and research implications are guided by theoretical conceptualisations of the experience of dementia as shaped by the interaction of multiple personal, interpersonal and sociocultural factors (Górska et al., 2017). Recommendations concern the importance of providing opportunities to the family, including the PwDL, to re-story the experience of cognitive and functional difficulties and to find ways to work together to negotiate their impact. This research also highlights the importance of effecting change at the policy-level in order to challenge negative representations of

PwDL and prevent them from being traumatised and marginalised. Further research exploring the multitude of factors which shape the experience of living with cognitive and functional difficulties for PwDL and their family members would facilitate the further development of therapeutic approaches.

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APPENDICES

Appendix A: Sample Analysis Excerpt

The below excerpt from the analysis of an interview transcript demonstrates how the integrated approach was undertaken. I attended to key narratives (relevant notes in black), broadening with re-reading to attend to positioning (relevant notes in green) and interactional aspects (relevant notes in red) and broader context (relevant notes in blue) to build the content and context of narratives across a transcript. The analytic process was the same for each research encounter whether with the family or in an individual interview setting.

Will: Ok, so first question is, has life changed since the dementia diagnosis?

Peter: Yes.

Andrea: A lot.

Peter: Yes, a lot actually but hopefully things will get better.

Lucy: Everything has changed.

Will: Ok. Can you tell me in what way things have changed?

Lucy: In what way? Yes. I used to work, now I don't work. I haven't worked for quite some time…we don't go out for dinners or so except for birthdays, for something special, for girl's birthday, Peter's, my [1] I do not drive, I have been driving since 1960 and I don't drive anymore, which upsets me really…Peter had an accident himself. We have a holiday home abroad. We arrived, and he went to clean the windows and the last window of the house he fell, and it affected his head. Here, darling.

Peter: No, I'm just listening.

Lucy: He hurt his head and that really upsets me. Life is not the same anymore. He is as lovely as ever. But when he drives I have to sit right next to him to make sure, you know, he's alright and everything, although he's a good driver. We go out every day because we are not, we used to go to the theatre, cinemas, lots of things that we don't do now, we can't do. But we make sure that we go out...besides all the hospitals and problems that we have, we go up to Richmond park every single morning, just to be out, just to have a coffee there and just see people. I don't go into any shops. I have been to Marks and Spencer's the other day, but I haven't been since Christmas, so for almost a whole year <Will: Uh huh>. But the girls do everything.

Mary: But you do get frustrated when you can't remember things, you are trying.

Lucy: Oh yes, I do of course, I get very frustrated. I'm very lucky to have the girls. You know, I will always ask. I used to write beautifully but not anymore. I used to write poems. I can't even write a letter now properly…I have to ask Peter all the time

Commented [WP1]: Peter holding hope for family. Lucy not the first person to talk but dominates storytelling.

Commented [WP2]: Life no longer the same. Polarised language– positioning impact, black and white.

Commented [WP3]: Valued activities that no longer able to complete. Lucy takes main role in describing the impact of dementia – mostly focuses on self, rather than family.

Commented [WP4]: Moral positioning - not to blame for dementia, first explanation that comes to mind.

Commented [WP5]: Meaning-making: reasons for dementia. Multiple voices emerging – one that Lucy is relied upon, another than Lucy relies on others. Integrated into retained self? Asking family to understand challenges?

Commented [WP6]: Burden and dependence. Autonomy and independence valued.

Commented [WP7]: Emotional response to dementia: frustration. Introduced by Mary - voicing reality? Lucy resisting being re-positioned by Mary. Multiple family voices.

Commented [WP8]: Family and personal resources. No longer able to complete valued activities. Dependence and burden. Positioning self as out of control.

'Peter, what day is it?' or 'what time is it?' There are so many clocks in the house but still I can't [1] it puts me out in many, many, many ways. Everything really. Dressing, I love, I just clothes. And now, I can't. And I don't like to be…to be…messy. I've always looked after, cared for myself so much. I have been going to the hairdressers, even after my modelling days, when I stopped, I would go twice a week to the hairdressers. For 45 years I have been to the same person. Now, Andrea washes my hair and she does it for me. I don't bother to go to the hairdressers now because I'm not driving. I don't want to put them out as well. There's lots of things I cannot do. We used to have visitors all the time, people and parties, lots of parties and things we don't do anymore. I know we are older, and OK when you get older, you don't do everything, but there are so many things that I can, now I think back on, I can't do it now, but I wanted it.

Will: So, it's more than just getting older?

Lucy: Oh yes. Being older, really, is very funny, I don't remember this or that, but I don't feel old. I still feel young. And I am 80, going on 81, but I still, I don't feel old. I just feel silly, forgetting and not remembering and not being able to do [1] of course I can't walk now. They gave me a little chair, the hospital, where I went for dementia, to see a doctor for my legs.

Commented [WP9]: Identity that remains, but not recognised

Commented [WP10]: Dependency and burden

Commented [WP11]: Abnormal – successful ageing?

Commented [WP12]: Lost hope for future

Commented [WP13]: Guiding conversation

Commented [WP14]: Feeling younger than age – resisting being positioned as old.

Commented [WP15]: Identity lost due to dementia. Valued cognition and autonomy lost.

Commented [WP16]: Other potential contributing factors to loss of identity not acknowledged.

Appendix B: Transcription Conventions

[1] Pause, length in seconds

[Inaudible] Inaudible; approximate number of words or length of time

(Name: Laugh) Non-verbal communication, used by participant to replace words.

[*name*] name or place

<I: text> Brief interjection/overlapping talk

[18-20] Transcript Line Numbers

… Interrupted speech

Appendix C: Participant Biographies

Lucy and Peter are in their early 80s. She was born in Cyprus, the youngest of four children. Her father died when she was a baby. Lucy recalled a strongly connected family in her early years, in which her uncles and aunts all helped bring her up. Her aunt's family, along with her eldest sister, decided to move to the UK when Lucy was young. Lucy asked her mother if she could go with them for a week, but she didn't return to live in Cyprus. Lucy recalled a happy childhood, although there was not much money. Peter described a similarly closely connected family with many brothers and sisters. He moved to the UK when he was a teenager, to support his family who remained in Cyprus.

Lucy worked as a model and then trained as an air hostess. However, she met Peter during this time and when he asked her to marry him, she decided not to work on the planes. They developed a successful business, which they still own but no longer manage. They described living in many locations across London although they have been settled in their current home, since they got married, over 50 years ago. They have a holiday home in Cyprus and visit at least once a year, for around 2-3 months.

One of Lucy's sisters has recently died; she had been diagnosed with dementia. One of the sisters who is alive also has a diagnosis of dementia, whilst the husband of the other sister had been diagnosed with dementia and died recently. No family history of dementia was described in Peter's family. Some of his brothers and sisters are still alive, although they live across the world.

Lucy and Peter have three children, who were all born in the UK. Andrea is the eldest; she is married and lives next door. Michael was born next. Although he trained to be a doctor, he decided to move abroad following a round the world trip. He has recently got married; Lucy was upset not to be able to attend the event. Mary is the youngest, she is single and lives in the family home. She is not currently working due to physical health problems.

Appendix D: Information Sheets For People Diagnosed With Dementia And For Relatives Of A Person Diagnosed With Dementia

<NHS TRUST LOGO>

<u>Stories of the impact on families when one member has a label of dementia</u>

IRAS ID: 221546

<u>Information sheet for people diagnosed with dementia</u>

I am interested in hearing the stories of people who have been diagnosed with dementia and their relatives. I would like to hear about the impact the dementia diagnosis has had on you and your family.

I would like to do this so that professionals, like psychologists, can better support those affected by dementia and their families.
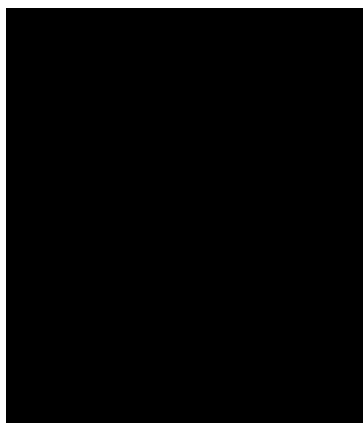
My name is William Pearson

I work for the NHS and I am training to become a Clinical Psychologist

I will be doing this research as part of my Professional Doctorate in Clinical Psychology at the University of East London.

Email:

<u>Requesting your consent to participate in the research</u>

This leaflet provides you with the information that you need to make an informed decision about whether you would like to participate in this research.

Conversations with Will

If you would like to take part, I will begin a conversation with you together with other members of your family. We will speak about your experiences of the dementia diagnosis and the impact this has had on the family.

What you talk about will be decided by you. It might include speaking about some challenges that you have experienced since the dementia diagnosis. But it's also likely to include talking about more positive experiences. I will check with everyone how they are feeling when talking about these experiences. We can stop or take a break at any time.

There may be some stories that you want to tell me which may be more difficult to say in front of your family members. So, I would also like to have a conversation with you on your own.

If it is helpful we can meet more than once as a family and/or individually.

These conversations can take place in:

- a private room at <Name> Memory Service or,

- in your home.

The conversations that we have will be audio-recorded by myself. This is so that I can carefully consider what you have said. Only my supervisor and I will listen to the recordings. I will then produce a written record of the conversation. This will be anonymised so that neither you nor your family can be identified.

Next year I will produce a report to inform other people about what we spoke about. I will make suggestions about how services can support people affected by the dementia diagnosis.

If you have any other problems, please talk to me or a member of staff at <Name> Memory Service.

It is entirely your decision whether to take part.

It is not a problem if you don't want to take part in the research. It's also OK if you start and then decide that you don't want to carry on. You do not have to give a reason for this. Please do let me know or speak with someone you feel comfortable talking to who can pass this information on.

Whatever you decide, your subsequent care from services will not be affected.

<u>Confidentiality of the Data</u>

CONFIDENTIAL

Anonymised recordings and written versions of the conversations will be kept safe. Your name and details, and those of your relatives, will NOT be stored.

The recordings will be deleted following the examination of the research. The anonymised written versions of the conversations will be kept for up to five years as they may also be useful for further research that might take place.

I will keep anonymous notes of all my contact with people involved in the research. Access to this will be restricted to the researcher, supervisors and examiners.

If during our conversations, I am worried about your safety or the safety of someone else I might need to share this information with the service. I want to make sure that you or that other person stays safe. I will keep you informed if this is going to happen.

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 a favourable opinion by:

London-Stanmore Research Ethics Committee

If you have any questions or concerns about how the research has been conducted please contact the research supervisor, Dr Maria Castro Romero.

Address: School of Psychology, University of East London, Water Lane, London E15 4LZ

Telephone Number: 020 8223 4422

Email: m.castro@uel.ac.uk.

Or

Dr Mary Spiller, Chair of the School of Psychology Research Ethics Sub-Committee

Address: School of Psychology, University of East London, Water Lane, London E15 4LZ

Telephone Number: 020 8223 4004

Email: m.j.spiller@uel.ac.uk

Patient Advice and Liaison Service (<Name> Mental Health Trust):

Telephone: <Telephone Number>

Email: <Email Address>

<u>Thank you for your time - It is greatly appreciated</u>

<NHS TRUST LOGO>

<u>Stories of the impact on families when one member has a label of dementia</u>

IRAS ID: 221546

<u>Information sheet for the relatives of a person diagnosed with dementia</u>

I am interested in hearing the stories of relatives of people who have been diagnosed with dementia, in particular on the impact this has had on the family.

I would like to do this so that professionals, like psychologists, can better support those who have been diagnosed with dementia and their families.
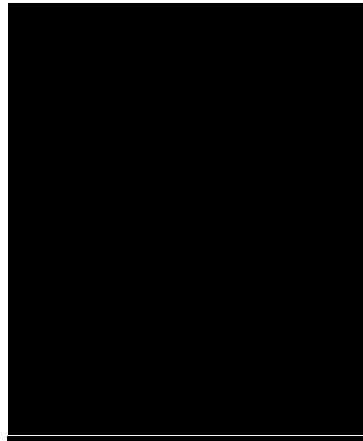
My name is William Pearson

I work for the NHS and I am training to become a Clinical Psychologist

I will be doing this research as part of my Professional Doctorate in Clinical Psychology at the University of East London.

Email: ▮▮▮▮▮▮▮▮▮▮

<u>Requesting your consent to participate in the research</u>

The purpose of this leaflet is to provide you with the information that you need to make an informed decision about whether you would like to participate in this research.

Conversations with Will

If you would like to take part I will begin a conversation with you together with other members of your family to speak about your experiences of the dementia diagnosis and the impact this has had on the family.

What you talk about will be decided by you. It might include speaking about some challenges that you have experienced since the dementia diagnosis but it's also likely to include talking about more positive experiences. I will check with everyone how they are feeling when talking about these experiences. We can stop or take a break at any time.

I would also like to have a conversation with you on your own as there may be some stories that you want to tell me which may be more difficult to say in front of your family members.

If it is helpful we can meet more than once as a family and/or individually.

I will ask where you would like these conversations to take place. This could be at a private room at <Name> Memory Service or in your home.

The conversations that we have will be audio-recorded by myself. This is so that I can carefully consider what you have said. Only my supervisor and I will listen to the recordings. I will then produce a written record of the conversation. This will be anonymised so that neither you nor your family can be identified.

Next year I will produce a report to inform other people about what we spoke about and to make suggestions about how services can support persons and their families when a diagnosis of dementia has been given.

If you have any other problems, please talk to me or a member of staff at <Name> Memory Service.

It is entirely your decision whether to take part.

It is not a problem if you don't want to take part in the research or if you start and then decide that you don't want to carry on. You do not have to give reason for this. Please do let me know or speak with someone you feel comfortable talking to who can pass this information on.

Whatever you decide, your subsequent care from services will not be affected.

<u>Confidentiality of the Data</u>

CONFIDENTIAL

Anonymised recordings and written versions of the conversations will be kept safe. Your name and details, and those of your relatives, will NOT be stored.

The recordings will be deleted following the examination of the research. The anonymised written versions of the conversations will be kept for up to five years as they may also be useful for further research that might take place.

I will keep anonymous notes of all my contact with people involved in the research. Access to this will be restricted to the researcher, supervisors and examiners.

If during our conversations, I am worried about your safety or the safety of someone else I might need to share this information with other people to make sure that you or that other person stays safe. I will keep you informed if this is going to happen.

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 a favourable opinion by:

London-Stanmore Research Ethics Committee

If you have any questions or concerns about how the research has been conducted please contact the research supervisor, Dr Maria Castro Romero.

Address: School of Psychology, University of East London, Water Lane, London E15 4LZ

Telephone Number: 020 8223 4422

Email: m.castro@uel.ac.uk.

Or

Dr Mary Spiller, Chair of the School of Psychology Research Ethics Sub-Committee

Address: School of Psychology, University of East London, Water Lane, London E15 4LZ

Telephone Number: 020 8223 4004

Email: m.j.spiller@uel.ac.uk

Patient Advice and Liaison Service (<Name> Mental Health Trust):

Telephone: <Telephone Number>

Email: <Email Address>

Thank you for your time - It is greatly appreciated

Appendix E: Informed Consent Forms For People Diagnosed With Dementia And For Relatives Of A Person Diagnosed With Dementia

UEL
University of
East London

<NHS TRUST LOGO>

Stories of the impact on families when one member has a label of dementia

IRAS ID: 221546

Consent to participate in a research study – person diagnosed with dementia

Please
Tick

I have read the information sheet relating to the research study and I have been given a copy to keep. The nature and purpose of the research has been explained to me. I have had the opportunity to discuss the details and ask questions about this information. I understand what is being asked and what I will need to do has been explained to me.	☐
I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.	☐
I consent to the interviews being audio-recorded.	☐
I freely and fully consent to participate in the study which has been fully explained to me. Having given this consent, I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun.	☐

<NHS TRUST LOGO>

Participant's Name (BLOCK CAPITALS)

……………………………………………………………………………….

Participant's Signature

………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

………………………………………………………………………………..

Researcher's Signature

………………………………………………………………………………………

Date: …………………..…….

1 copy each for:

- the participant,
- the investigator file,
- the medical records.

<NHS TRUST LOGO>

Stories of the impact on families when one member has a label of dementia

IRAS ID: 221546

Consent to participate in a research study – relatives of a person diagnosed with dementia

I have read the information sheet relating to the research study and I have been given a copy to keep. The nature and purpose of the research has been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being asked and what I will need to do has been explained to me.	☐
I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.	☐
I consent to the interviews being audio-recorded.	☐
I freely and fully consent to participate in the study which has been fully explained to me. Having given this consent, I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun.	☐

<NHS TRUST LOGO>

Participant's Name (BLOCK CAPITALS)

……………………………………………………………………………………….

Participant's Signature

………………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

………………………………………………………………………………………..

Researcher's Signature

…………………………………………………………………………………………

Date: …………………..…….

1 copy each for:

- the participant,
- the investigator file,
- the medical records.

Appendix F: Ethical Approval Letter

NHS

Health Research Authority

London – Stanmore Research Ethics Committee

Health Research Authority
Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 7972 2561

> **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

28 June 2017

Mr William Pearson
School of Psychology
University of East London
Stratford Campus
Water Lane
London
E15 4LZ

Dear Mr Pearson

Study title:	**Stories of the impact on families when one member has a label of dementia**
REC reference:	17/LO/0839
IRAS project ID:	221546

Thank you for your letter 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.

Please include the name of the London-Stanmore Research Ethics Committee as having approved the ethics of the study.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity]	Version 1	11 May 2016
IRAS Application Form [IRAS_Form_05052017]		05 May 2017
Other [REC review provisional opinion response]	Version 1	12 June 2017
Participant consent form [Consent Form PWLD]	Version 1	12 June 2017
Participant consent form [Consent Form Relatives]	Version 1	12 June 2017
Participant information sheet (PIS) [Information Sheet PWLD]	Version 1	12 June 2017
Participant information sheet (PIS) [Information Sheet Relatives]	Version 1	12 June 2017
Referee's report or other scientific critique report [Peer review feedback]	Version 1	25 February 2017
Referee's report or other scientific critique report [███ Peer Review Feedback Letter]	Version 1	14 March 2017

Referee's report or other scientific critique report [Approval of amendments]	Version 1	22 January 2017
Referee's report or other scientific critique report [████ Approval of Amendments]	Version 1	
Research protocol or project proposal [Research protocol]	Version 4	03 April 2017
Summary CV for Chief Investigator (CI) [CI CV]	Version 1	03 March 2017
Summary CV for student [Student CV]	Version 1	03 March 2017
Summary CV for supervisor (student research) [1st supervisor CV]	Version 1	09 March 2017
Summary CV for supervisor (student research) [Second Supervisor CV]	Version 1	30 March 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Research Summary]	Version 1	03 March 2017

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/

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

Yours sincerely

PP
Mrs Rosemary Hill
Chair

Email:nrescommittee.london-stanmore@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Dr Mark Finn*
               ▮▮▮▮▮▮▮ *Mental Health Trust*

Appendix G: Health Research Authority Approval Letter

NHS
Health Research Authority

Mr William Pearson
School of Psychology, University of East London, Stratford
Campus
Water Lane, London
E15 4LZ

Email: hra.approval@nhs.net

07 July 2017

Dear Will

Letter of HRA Approval

Study title:	**Stories of the impact on families when one member has a label of dementia**
IRAS project ID:	**221546**
REC reference:	**17/LO/0839**
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

Page **1** of 8

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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 **221546**. Please quote this on all correspondence.

Yours sincerely

Sharon Northey
Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Dr Mark Finn – Sponsor contact*
              ██████████ ██████████ *Mental Health Trust – R&D contact*

Appendix A - List of Documents

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

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity]	Version 1	11 May 2016
IRAS Application Form [IRAS_Form_05052017]		05 May 2017
Other [REC review provisional opinion response]	Version 1	12 June 2017
Participant consent form [Consent Form PWLD]	Version 1	12 June 2017
Participant consent form [Consent Form Relatives]	Version 1	12 June 2017
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Participant information sheet (PIS) [Participant information sheet - PWLD]	Version 2	29 June 2017
Referee's report or other scientific critique report [Peer review feedback]	Version 1	25 February 2017
Referee's report or other scientific critique report [▉▉▉ Peer Review Feedback Letter]	Version 1	14 March 2017
Referee's report or other scientific critique report [Approval of amendments]	Version 1	22 January 2017
Referee's report or other scientific critique report ▉▉▉ Approval of Amendments]	Version 1	
Research protocol or project proposal [Research protocol]	Version 4	03 April 2017
Summary CV for Chief Investigator (CI) [CI CV]	Version 1	03 March 2017
Summary CV for student [Student CV]	Version 1	03 March 2017
Summary CV for supervisor (student research) [1st supervisor CV]	Version 1	09 March 2017
Summary CV for supervisor (student research) [Second Supervisor CV]	Version 1	30 March 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Research Summary]	Version 1	03 March 2017

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: Dr Mark Finn

Tel: 0208 223 4493

Email: m.finn@uel.ac.uk

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 has not been submitted for this student study taking place at one NHS organisation.
4.2	Insurance/indemnity arrangements assessed	Yes	The applicant has confirmed that the insurance certificate will be renewed by the sponsor after it expires at the end of July. Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			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 and no funding will be available to the site to support this study.
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	No comments
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 one NHS participating organisation; therefore there is one site type.

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.

- The sponsor should ensure that participating NHS organisations are provided with a copy of this letter and all relevant study documentation, and work jointly with NHS organisations to arrange capacity and capability whilst the HRA assessment is ongoing.
- Further detail on how capacity and capability will be confirmed by participating NHS organisations, following issue of the Letter of HRA Approval, is provided in the *Participating NHS Organisations* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections 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's 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).

This is a single site study and the study Chief Investigator will, in addition, act as Principal Investigator (PI). Therefore no additional PI or Local Collaborator (LC) is required.

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.

No access arrangements are expected as all study activity at the participating NHS organisation will be undertaken by NHS staff who have a contractual relationship with the organisation.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England in study set-up.

The applicant has indicated that they <u>do not intend</u> to apply for inclusion on the NIHR CRN Portfolio.

Appendix H: Summary Of Re-telling Of Narratives

- Lucy's stories of strength, independence, agency and achievement vs stories of loss, deficit, dependence and burden,

- Difficulties for Lucy living with cognitive and functional difficulties in the context of identity as a wife and mother,

- Family stories of Lucy's retained identity

- Challenge for Lucy and the family to negotiate negative representations of PwDL

    - Lucy: reduce avoidance, recognise contributions
    - Family: scaffold support, e.g. to recall words

- Emotional consequences for Lucy

    - Shame, guilt, depression, anxiety, worry, anger
    - The 'problem' for the family

- Searching for meaning

    - Lucy not to blame for dementia

- Building hope

Appendix I: Reflective Diary Excerpt

The following excerpt from the reflective journal I maintained throughout the research process details aspects of my personal, family and professional life experiences, including how I have made sense of my identity. This excerpt concerns the challenge I noticed when writing my introduction, whilst ethical approval was being sought:

"I have noticed over the past week that I have been finding it increasingly difficult to write about dementia and critique biomedical conceptualisations of it. However, I realised today that what I have found difficult isn't understanding my position on what I believe are the causes of dementia. Looking at the literature and thinking about power, I feel increasingly confident paying attention to the very-real complexities inherent in dementia, which sit alongside meaning-making and the challenges that this brings. Rather, I have felt increasingly disabled by the dominance of the illness model, which pervades all aspects of dementia assessment, diagnosis, care, and the need to challenge dominant discourses around dementia. Although I acknowledge that this is part of what has animated my interest in this area, at times I have felt worn out in thinking about the scale of the challenge that arises out of disease models of dementia. I think trying to distil this complexity into this thesis in a coherent fashion has felt particularly challenging recently. I think back over my experiences of PwDL in a personal and professional context and I have felt re-animated in my hope to put forward a convincing piece of research, which has real clinical implications. Even with this, though, I have realised a need to temper my enthusiasm and my expectations with regards to the limitations on time and resource engendered by this research.

I have increasingly recognised that I place considerable value on my cognitive abilities in determining my self-worth. I'm not sure why I have placed such emphasis on this, although I acknowledge pressures from society around being able to contribute, as well as being consistently told by my teachers that, as I attended a grammar school, I was part of the top 2% of the country. I think this message stuck with me and I have been trying to maintain this, for if I'm not intelligent, then who am I? I'm confident this has played a significant role in my interest in what happens when our cognitive abilities decline as we age, and in particular what it means about someone when this is worse than would be

expected, i.e. dementia. However, over time, I think I have also developed an understanding that although I may know some things that others don't, this doesn't mean very much when I think about the relationships I have with my friends and family. I have come to realise that maintaining my relationships is more important to me than being 'intelligent'.

I would hope that if I were to develop cognitive difficulties in later life, I might continue to have my relationships to fall back on. Perhaps, this research has emerged out of that, alongside the recognition that it's an under-researched area. Improving services to support PwDL and their families, however they might define this, is something that I feel can be achieved. Perhaps, my hope is that by developing services, I will have secured my own anticipated future. However, I have seen this happen with clients and in my own family. When granny developed dementia, mum travelled two hours each way, every other weekend to look after her, and did this for five years. When granny moved into a care home closer to us and away from uncle Rob, she barely saw him anymore. This placed considerable pressure on mum's relationship Rob, but it never was spoken about. Even now, a few years after granny died, mum's relationship with Rob remains strained.

I also think about caring for mum and dad if they were to develop dementia, and I would like to be there for them, even if that meant moving closer to my family home. I already know they would not want that for me though; they have spoken about not wanting to be a burden. But I don't think I would want to do this out of a sense of duty. I acknowledge it's always difficult to know what will happen in the future and how you might respond to whatever situation you face. I hope though I can make life as easy for them as possible, whatever might happen.

And so, I come back to what I first started writing about. Biomedical conceptualisations of dementia have serious consequences and for people to marginalise others to maintain their own power, doesn't seem fair or just to me. I think what I will need to consider further in future is how I preserve my resources so that I can carry on supporting PwDL and their families in the best way I can. I don't know what that will look like yet but hopefully over the course of this research I might be able to start thinking about this."