

The impact of dementia on the selfhood
and identity of women: A social
constructionist approach

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Abstract

This study explored the impact of dementia on the identity and selfhood of women. It found that, in describing the changes that had taken place, the initial diagnosis had a varying impact. A range of psychological and emotional responses were expressed. The perception of others was considered, in relation to disclosure or non-disclosure. Self-imposed boundaries were set, as participants altered the ways in which activities central to a sense of self were carried out. Continuity between past and present selves was represented through participants enhancing their lives. A rejection of the threat to selfhood posed by dementia was evidenced by participants preserving their independence and maintaining a positive self-concept. Central to the ability to retain a sense of self was the structure of interpersonal relationships; the collective identity fostered by being a member of a dementia support group, and the ways in which family members and others engaged in positioning. Women and their caregivers discussed the changing landscape of relationships, in terms of relinquished roles and responsibilities and outlook on the future.

This thesis used Sabat and Harre's (1992) framework for a social constructionist approach to selfhood in dementia. 12 women who had a diagnosis of dementia, and seven familial caregivers were recruited to participate in the study. Semi-structured interviews were conducted, which were then analysed using interpretative phenomenological analysis (IPA).

The findings contribute to the literature that puts the perspective of the person with dementia at the heart of research. They cast new light on the individual experiences of women, in relation to how selfhood is threatened and maintained in the early stages of the disease.

Thesis outline

This thesis begins with an introductory chapter, discussing what dementia is, and the history of its assessment and treatment – from the biomedical model to social and psychological approaches. It discusses the background to the present study, and my rationale for focusing only on the experiences of women.

The thesis then moves on to a review of the relevant literature in chapter two. The first section of the review explores how people make sense of living with chronic illness. It considers three key theories within this: Biographical disruption (Bury, 1982), narrative reconstruction (Williams, 1984) and loss of self (Charmaz, 1983). These theories are important to the overall aim of the study, because they consider the threat to one's identity and sense of self, posed by the diagnosis of a chronic illness, and how people navigate and adjust to this threat over time.

The second section of the literature review deals with selfhood and identity in relation to dementia. It considers how selfhood is differentially conceived, as well as how it is threatened by a diagnosis of dementia, before focusing on those theories that posit that selfhood can endure.

In the third section of the literature review, I discuss dementia with reference to women. This will look at studies that have recruited women, and what these can tell us about the selfhood and identity of women. It considers the nature of social roles, and the importance of being able to maintain these, as well as comparisons with the findings of those studies that have focused on men.

The third chapter lays out the theoretical framework for the thesis. Here, the social constructionist model of selfhood in dementia is addressed in detail, including situating it within the work of Mead (1934), Cooley (1983) and Goffman (1959). Particular attention is given to William Stern (1938), whose theory of critical personalism conceived of human beings as social and influenced by the world around them. The chapter also considers the role of self-esteem as central to the social constructionist view of selfhood.

Chapter four is devoted to the study's methods. Here, I set out the research design, sampling and recruitment strategy and approach to data collection and analysis. I also discuss the rationale for an all-female sample, as opposed to one that is mixed. As is necessary for a study

that takes as its starting point, the views of people with dementia, the process of obtaining ethical approval is laid out in detail.

Chapter five is the first of three findings and discussion chapters. Chapter five looks at the impact that dementia has on the selfhood of women. Participants described their initial reaction to the diagnosis, and the emotional responses to this and the changes brought about by the disease. Careful consideration was given to the benefits of disclosure versus non-disclosure, and relatedly, to expectations of stigma and discrimination. Women imposed boundaries on themselves – a reflection of the tension between letting go of valued activities and holding on. This chapter concludes that dementia can threaten the selfhood of women in a variety of ways.

Chapter six deals with how women respond to a diagnosis of dementia by resisting its impact on their selfhood and repairing damaged identities. The variety of hobbies, pursuits, or religious beliefs that were described as enriching the lives of participants, convey a message of hope and optimism. Participants are also able to preserve their independence and maintain a positive self-concept, through developing practical coping strategies and minimising the impact of dementia. This chapter concludes that, despite the threat to selfhood posed by dementia, all women had ways of resisting this threat and overcoming the losses suffered as a result.

Chapter seven explores the dynamics of relationships within the social worlds of the women in this study. The ability for dementia support groups to equip participants with a collective social identity is discussed. The positioning of family members is discussed in relation to selfhood – particularly the ability of people to construct a social identity. This chapter also considers the relational aspects of role change and participants' expectations of the future. This chapter concludes that social and interpersonal relationships are important in enabling women with dementia to construct a valued identity beyond that of the dementia patient.

The final chapter, chapter eight, brings together the evidence in the previous three findings and discussion chapters. Based on this evidence, my conclusion is that a diagnosis of dementia impacts on the selfhood of women, but that they can also, in certain situations, and through resistance strategies and social and contextual forces, negate this threat. To enable them to do this often requires the support of those around them and access to the kinds of resources needed to preserve selfhood and identity. This primary finding is discussed and situated in a wider context, of literature that puts the perspective of the person with dementia at the heart of research.

Preface

I studied Psychology and German at the University of Manchester, before undertaking an MSc in Clinical Psychology. At this point, I was interested in social and health psychology, particularly the impact that being diagnosed with a chronic illness could have on a person. Hence, for my MSc project, I decided to explore the experiences of people with Parkinson's disease and their spouses, who had assumed the role of informal caregiver. I particularly enjoyed the qualitative element of this research; the opportunity for interviews to delve into individual lifeworlds, and to deviate from the guide in a way that allowed for new avenues to be opened up, as well as the development of trusting, collaborative relationships with the participants. By accident, rather than design, my sample consisted entirely of men, and within my findings were themes related to masculinity and the threat of Parkinson's to bodily conceptions of this. This led me to reflect on how such an illness would have impacted women, and the role of gender in the experience of chronic illness more broadly. Hence, I believed this PhD studentship would present an opportunity, on a larger scale, to explore the impact of dementia on women.

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Chapter 1: Introduction

Everybody drew their chairs closer to the table. We bowed our heads and clasped our hands. Wendy, however, placed one hand over her face. Her eyes were scrunched up, and she seemed deep in contemplation. Then, to my surprise, she spoke. She removed her hand from her face and began with the words: 'Lord, when I was diagnosed with Alzheimer's, I was so confused'. She went on to describe her distress, her struggle to understand what was going on and why she had been dealt this blow. Then, she remembered the song: 'Count your Blessings'. Wendy said it reminded her of how much she had to be thankful to God for. How it gave her the strength and clarity to carry on, and eased her mental suffering. It was quite a poignant monologue. After the session had finished, the lady sat next to her, said: 'Thank you for that lovely prayer, Wendy'.

The above is an extract from my field notes and describes a prayer meeting I accompanied one of my participants to. It captures the essence of what this thesis is about; the threat that dementia can pose to the order of one's world and sense of identity, and the ability of people to find something – in this case, faith – that can resist its threat and help them to move forward.

This thesis offers a rich account of the threats to women's selfhood and identity that can result from living with dementia. The study also illustrates the multiple strategies through which women themselves, alongside family members and carers, seek ways of maintaining or re-establishing a sense of self in the face of often profound challenges. The study draws from the accounts of 12 women living with dementia and their family members. These are made up of the participants' husbands, and in one case, daughter, who were the main source of support for the person living with dementia. The narratives shed light on how dementia impacts on the selfhood of women – who are under-represented in the dementia literature – in terms of the losses experienced and changes to their self-concept. The introduction will first explore the background to dementia, addressing the dominance of the field of biomedicine, before considering the now well-established traditions of the psychosocial model. It will discuss the theoretical framework used in the thesis, as well as the reasoning for choosing this model and applying it to the study of women, specifically, before outlining the contribution this thesis makes to the wider literature on the relationship between living with dementia, selfhood and identity.

1.1 The biomedical model of dementia

The term dementia refers to a syndrome, caused by multiple diseases, rather than to a specific illness (Rabins et al. 2014). The most common diseases include Alzheimer's disease, vascular dementia and mixed (elements of both Alzheimer's disease and vascular dementia). Dementia is signified by a decline in memory and at least one of the following functions: language, performance of skilled movements, or executive function (Scott and Barrett, 2007). The decline must be severe enough to result in functional impairment and impact on everyday life. Dementia has biological, social and psychological effects, and is associated with ever-changing health and care needs, as people become more dependent on others over time (Murray and Boyd, 2009).

Senile dementia was, for many years, considered an inevitable part of ageing (Lyman, 1989). Premature senility, on the other hand, was considered an illness. The presentation in the early 1900's by Alois Alzheimer, a German psychiatrist responsible for unearthing the neuropathological markers that would come to define the biomedical understanding of dementia, referred to a rare condition affecting middle-aged people (Downs, 2000). However, this theory of dementia was challenged by Katzman (1976), who introduced the idea that senile dementia may in fact be the result of the neurodegenerative disease identified by Alzheimer, and as a result, should no longer be seen as an inevitable part of ageing, but rather as a disease process.

This is what formed the explanatory framework that would become known as the biomedical model of dementia. Models of illness are used to influence the delivery of healthcare and decision-making regarding individual patients (Wade and Halligan, 2004). The biomedical model of illness assumes that all symptoms and treatments etc. associated with a particular condition are biological (Kleinman, 1988). Thus, within this model as applied to dementia, were several assumptions; dementia was pathological and signified abnormal cognitive impairment, dementia was somatic and caused by progressive deterioration of brain regions that controlled memory and other forms of functioning, and dementia was to be diagnosed using medical assessments and treated by the medical profession (Lyman, 1989). Against this changing backdrop and biomedical notion of dementia, the emergence of organisations, such as the National Institute on Aging, led to funds being allocated to dementia research, which in turn identified dementia as a more common condition than had previously been thought (Boller, 2008).

In the 1980's Reisberg et al. (1982) developed a stage-model of dementia, called the Global Deterioration Scale (GDS). The authors proposed that there were three readily identifiable stages involved in the development of the disease: early, intermediate and late dementia, and that these could be further refined into seven stages. Stage one was characterised by no cognitive decline, nor any evidence of memory deficits. Stage two was characterised by very mild cognitive decline, including early signs of forgetfulness, such as misplacing items. Clinical interviews revealed no evidence of memory deficits, however, and the person had no difficulties in social interactions. Stage three, according to the model, was characterised by mild cognitive decline, with noticeable memory deficits – which may reveal themselves in an extensive clinical interview. The person may be unable to retain the names of people they had been recently introduced to, and deficits in the ability to interact in social situations may become more pronounced. Stage four, the stage of moderate cognitive decline, was called the 'late confusional stage' by the authors (Reisberg et al. 1982, p. 1137). Here, the person could be expected to display clear deficits across a range of areas, as identified by a clinical interview, including concentration, short-term memory and knowledge of world events. But they still remained well oriented to time and person, particularly those familiar to them. Stage five, characterised by moderately severe cognitive decline, was presented as the stage of early dementia. Here, the person struggled to recall major aspects of their lives, including the names of significant family members. They may also be disoriented with regards to time. The person still retained knowledge, including their own and their spouses' names, and the ability to accomplish most activities of daily living unaided. Stage six, according to the model, was characterised by severe cognitive decline, and the middle phase of dementia. Here, the person was dependent on others for survival, and was unaware of all recent events in their lives. Personality and emotional changes were also common, including delusional behaviours, paranoia, and obsessive symptoms. Finally, stage seven signified very severe cognitive decline, and involved the person losing all verbal functioning. They were dependent on others for everything, including the most basic aspects of daily living (Reisberg et al. 1982).

Today, there are around 850,000 people – in the UK alone – living with dementia, a figure that is expected to rise to 1 million by 2025 (Alzheimer's Society, 2014). Within the clinical and biomedical literature, it is considered a progressive disease (see the stage model above), for which there is currently no cure, and as such, a significant burden is placed on individuals, family members and health and social care services (Alzheimer's Society, 2018). The biomedical model attributes dementia symptoms to the deviation from biologically defined

norms. It also assigns diagnostic labels to dementia. This is important, because dementia is a disease that invokes cultural anxieties of disability and death (Lock, 2013). The labels present members of the diagnosed group as homogenous, and lead to stereotyping based on these cultural anxieties – representations which can then become internalised by the person themselves (Garand et al. 2009). In other words, this diagnostic labelling has the potential to impact on selfhood and identity, by leading to loss of self-esteem and withdrawal from social life, based on self-perception and the expected experiences of discrimination.

Swaffer (2015) notes that there is a tendency, during the diagnostic process, for medical professionals to encourage the relinquishing of responsibilities on the part of the person with dementia. Swaffer called this process ‘prescribed disengagement’ (p.3). This can increase stigma around the disease, threaten self-esteem and increase the isolation of the person with dementia. They are then prone to believing that they cannot speak up for themselves, and take on the role of powerless victim created for them by the medical world. Swaffer, who was herself diagnosed with dementia, stressed the need for people to maintain connections with their pre-diagnosis lives. This is what is at the core of the present thesis, which explores the ways in which selfhood and identity can be supported, and how women can resist the threat posed to aspects of their lives, by dementia and negative consequences, such as stigma.

In line with the biomedical model, people normally report symptoms of dementia to their GP, in the UK, which serves as a first port of call (Samsi et al. 2014). If they report symptoms considered to be consistent with a dementia diagnosis, the GP will refer them to a memory clinic for further assessment. Initially set up as research centres, memory clinics increasingly began to provide for diagnosing and supporting people living with dementia (Passmore and Craig, 2004). It is here that a wide range of testing is carried out, with assessment results typically discussed within multidisciplinary teams and then communicated to the patient (Samsi et al. 2014). Memory clinics are used by people with dementia at a stage when the majority still retain, what clinicians call insight – an awareness of their condition – and so help to raise the profile of the disease (Passmore and Craig, 2004).

Memory clinics test for dementia by obtaining an up-to-date medical and family history, as well as carrying out physical and neurological examinations. Cognitive evaluations will also be carried out, to determine the degree of impairment. The domains to be assessed during this include memory, attention, orientation, language and visuospatial ability (Camicioli, 2014). There are now standardised instruments for assessing cognition, such as the Mini-Mental State

Examination (MMSE), a brief, quantitative measurement tool (Folstein et al. 1975). All participants in the present study went through this standard process of memory clinic testing before they received a formal diagnosis. This could be important in impacting how participants perceive their diagnosis.

The biomedical model has also contributed towards fulfilling the desire of successive UK governments for earlier diagnosis – as advocated in the Department of Health’s National Dementia Strategy (2009). Yet this emphasis on early diagnosis, and the diagnostic process in general have come under scrutiny recently. People widely report unfavourable experiences of the referral process and memory clinics, with a lack of communication about test scores and the meaning of these, as well as a perceived lack of support throughout the process, leaving service users feeling anxious and uncertain (Samsi et al. 2014). Public attitudes towards dementia often tend to be negative and can represent dementia as a stigmatising condition (Cheston et al. 2016). As a result, it is argued that such ‘overdiagnosis’ (Glasziou et al. 2013, p. 1) does more harm than good, exposing people to the harmful effects of stigma caused by the assigning of disease labels.

The pressures on health and social care services, as a result of dementia, have meant that the biomedical model and the ‘politically gripping agenda’ of finding a cure have taken precedence over the individual experience of the disease and engagement with psychosocial factors (Innes, 2009, p.6). The latter have historically been neglected as a result. Yet such focus on the prevention and treatment of dementia is excessive, and more attention should instead be devoted to supporting those living with the disease. The drugs that are currently available, and marketed at treating the symptoms of dementia, do not in fact cure or even alter its long-term progression, and their efficacy has been found to be modest (Robinson, 2016). Therefore, supporting people with dementia to live well, which involves maximising social and psychological resources to enhance wellbeing and life satisfaction, could instead enable people with dementia to manage their condition more effectively (Clare et al. 2014).

This study aims to contribute to the living well discourse, by shedding light on factors that impact on the selfhood and identity of women from different walks of life. It is important to note that the notion of living well, in this case, is taken from the accounts of those living with dementia. Living well, when considered within a policy narrative, has the potential to be problematic, in that it has resulted in such a promotion of the positive elements of living with dementia, that suffering and loss have been erased from the literature (Bartlett et al. 2017).

Thus, there is pressure on people with dementia and their families to live up to this idealistic picture of what living with the disease entails. This thesis, therefore, accepts the importance of acknowledging and understanding suffering, and considers the totality of living well, which does not preclude women from experiencing a range of losses and negative emotions associated with dementia.

1.2 Critique of the biomedical model, personhood and the social constructionist model of selfhood

During the 1970's, the dominance of medicine as an institutional and cultural force within Western societies began to be scrutinised and critiqued for what scholars set out as its varied – if unintended – negative implications (see Illich, 1975, Conrad, 1975 and Zola, 1972). Engel (1977), an American psychiatrist, suggested that an approach that took account of social, behavioural and psychological factors was far more appropriate. The medical model was reductionist and concerned with the study and treatment of disease, to the point that it had become akin to a 'dogma' (p.196). In other words, data was forced into its remit, even when it was unsuitable to do so. Engel instead recommended a biopsychosocial approach, where the personal and social are given as much attention as the medical. As a result of this, researchers began to recognise the need for alternate theories to be applied to the study of dementia, specifically, with the focus shifting to the *interaction* between the different elements: biological, neurological, psychological and social (Downs et al. 2008). Dementia, according to Lyman (1989) was experienced within a social and relational environment. The perspectives of people with dementia therefore needed to be taken into account, so that we could begin to understand how the meaning of individual behaviour was shaped within the context of a social system (Bond, 1992). These views, advocating for a more inclusive and broad approach to the study of dementia, form the basis of the theoretical framework for this study.

The narrow remit of the biomedical model also served to exclude the adoption of a psychosocial perspective for the exploration of psychiatric and behavioural symptoms associated with dementia. Evidence of depression, for example, was studied as a cause of dementia, not as a consequence of impairment, reflecting an emotional reaction to loss and functional decline (Cotrell and Schulz, 1993). This will be important for the present study, which will explore the impact of dementia on the selfhood and identity of women living with the disease, including the impact on the person's self-concept – their perception of themselves and their past and

present attributes. Within this, emotional responses to dementia will be explored, in terms of reactions to losses or threats to selfhood.

It is important, at this point, to note that the biopsychosocial approach proposed by Engel, was not without its critics. Pilgrim (2002) questioned its impact, noting that the biomedical model, by contrast, had endured over time. The biomedical model favoured impersonal, objective management of a condition, and offered ‘biological certainty’ about the processes involved (p.591). If medical practitioners were to distance themselves from a medical model, he observed, this would be considered an unusual stance. Hatala (2012) also noted that little attention was given, in studies purporting to use a biopsychosocial approach, to socio-cultural factors. Specifically, he argued for a more integrative understanding of culture, one that considered ‘what is at stake for particular individuals in particular contexts’, which impacted all aspects of the biopsychosocial approach (p.58).

Within the field of dementia, nonetheless, efforts to challenge the biomedical model, and to advance alternative approaches to researching dementia, paved the way for theorists such as Tom Kitwood and Steven Sabat, and their contributions to reconceptualising dementia as more than a medical problem. Tom Kitwood was a social psychologist and prominent figure in the field of dementia care, publishing a number of key texts on the subject, including his 1997 book: *Dementia Reconsidered*, for which he was awarded the Age Concern book of the year (Woods, 1999). Kitwood developed a theory of personhood, wherein he emphasised the need to consider both the personal and social psychology of an individual, in addition to brain pathology (Kitwood and Bredin, 1992). People with dementia, according to Kitwood, were impacted directly and indirectly by the behaviour of others, and this behaviour – which he termed ‘malignant social psychology’ – stripped a person of dignity and respect (Kitwood, 1997, p.46).

Sabat and Harré (1992), citing Kitwood’s influence, developed a theory of selfhood in dementia that was based on social constructionism. This represented a conceptual shift from the reductionism associated with the biomedical model, towards an examination of the person’s ‘cognitive and social experience of the world and the quality of interactions between the afflicted and the healthy’ (Sabat, 2001, p.23). There are three kinds of self, according to Sabat and Harré: Self 1, Self 2 and Self 3. Self 1 is the self of personal identity. This, the authors claimed, endures well into the latter stages of dementia. It is evidenced in people’s use of first-person pronouns, such as ‘I’ and ‘me’ – their ability to locate thoughts as their own (Sabat and

Harré 1992). Self 2 refers to one's personal attributes, and beliefs about those attributes. For example, a positive expression of Self 2 may involve remembering an achievement from one's past (Kelly, 2010). Essentially, the Self 2 comprises of one's self-concept and is mediated by self-esteem – the evaluative component of one's self-worth (Cotter et al. 2018). Self 3 is the self of social personae that are constructed together with other people within one's social world (Sabat and Collins, 1999). For example, one could construct the persona of a wife, a mother, or a teacher – but in order to successfully accomplish this, at least one other person would have to cooperate in this construction (Sabat, 2001).

Psychosocial approaches to dementia, such as this, are important because dementia affects the whole person, and is not confined to medical pathology (Hughes et al. 2006). In the context of this thesis, treating someone as a whole person means attending, 'not only to their biology, but also to their psychology, their social and ethical concerns, and the cultural and spiritual aspects of their lives' (p.4). Psychosocial factors consider the ways in which the person reacts to the effects of neuropathology, and the ways in which others behave towards them, which influences the subjective experience of dementia (Scholl and Sabat, 2008). While a purely biomedical model does not take into account the perspective of the individual living with dementia, other scholars argue that this should in fact be considered as central to the dementia care discourse (Innes, 2009). Relatedly, selfhood is an important part of the psychosocial literature on dementia, because dementia poses a specific problem for selfhood (Downs et al. 2008). This has been shown in a range of studies (e.g. Cheston and Bender, 1999, Moniz-Cook et al. 2006), and will be explored further in the literature review. Thus, this study will use the social constructionist approach to explore how dementia impacts on the selfhood and identity of women living with the disease. The effect of dementia symptoms on the participants, and the associated potential losses, will be considered, together with the threat posed to social identity.

Sabat and Harré's (1992) social constructionist approach to the study of selfhood in dementia considers how a person actively makes sense of the disease and adapts to the challenges it poses. They take into account the role of other people, and how selfhood can be socially shaped. Just as Kitwood (1997) argues that the greatest challenge for the person with dementia is to continue to be seen and treated as a person, Sabat (2001) similarly acknowledges that having dementia impacts the dynamics of the presentation of the social self within the context of relationships. An important aspect of this thesis, therefore, is the consideration given to how

the social self of participants is impacted, how the ways in which women present themselves changes as a result of dementia, and how interpersonal relationships can also shape these changes.

1.3 Women's experiences and the social constructionist model of selfhood

In this thesis, the social constructionist approach to selfhood in dementia was used to explore the experiences of women, specifically. Women's voices are underrepresented in the literature and they are considered a 'marginalised majority' (Alzheimer's Research UK, 2015, p.1). Indeed, 61% of people living with the disease are women and it is also the leading cause of death for women in the UK (Alzheimer's Research UK, 2015). This can be traced to life expectancy, and the fact that the conditions that lead to dementia are associated with ageing. Women live on average longer than men, and thus will be over-represented in dementia diagnosis statistics (Savitch et al. 2015). And yet, despite the advancement in research over the years that has moved from the biomedical model to the theories of selfhood developed by Kitwood and Sabat, through to Kontos' notion of embodied identity, the subjective experiences of women with dementia have remained largely neglected (Sandberg, 2018). Where they have been discussed is with reference to caregiving – as most caregivers of people living with dementia are also women (Bartlett et al. 2018).

This study applies Sabat and Harré's (1992) theory of selfhood to the accounts of women living with dementia. Taking this approach contributes to the existing body of literature by explicitly attending to the ways in which women's selfhood and identity can be both threatened and maintained. The thesis focuses on 12 women living with a diagnosis of dementia. It is concerned with representing the experiences of and giving voice to women living with dementia. A recent Joseph Rowntree Foundation report found that women were missing from dementia research, as well as from policy documents, with men's voices perceived as dominant (Savitch, 2015). This thesis begins to redress the balance. In a similar vein, Hulko (2009) took an intersectional approach to the experiences of people with dementia, although focusing mainly on aspects of disadvantage other than gender (e.g. race and social class). In doing so, she highlights the heterogeneity of the dementia experience, showing how engaging with different groups of people generates a richer, more complex understanding of the phenomenon. This study aims to similarly show the richness and variety of the experiences of women from different social backgrounds.

1.4 Plan of the thesis

This doctoral study forms part of a wider programme of work funded by the Economic and Social Research Council (ESRC) entitled: Improving the Experience of Dementia and Enhancing Active Life (IDEAL). This thesis contributes to the qualitative part of the IDEAL study. IDEAL is a longitudinal, mixed-methods, nationwide study concerned – in line with government policy – with exploring the factors that help and hinder the ability of people living with dementia to ‘live well’ (Clare et al. 2014, p.1). Living well refers to:

‘maximising life satisfaction, reaching one’s potential for wellbeing and experiencing the best possible quality of life in the context of the challenges that dementia presents for individuals, relationships and communities’. (Clare et al. 2014, p.11)

IDEAL forms the largest national dataset of its kind – recruiting over 1,500 people living with dementia across England, Scotland and Wales – to explore living well from a social and psychological perspective. Emphasis is placed on the role of subjective experience in relation to living well. The project aims to provide a set of recommendations to health and social care providers and policymakers, as well as advice to people living with the disease. These recommendations will inform resource allocation discussions, as well as reduce disability and dependence, by allowing people with dementia to live well across the disease trajectory. In addition, the study aims to educate and inform the public, contributing to the effort to reduce the stigma attached to the disease (Clare et al. 2014).

For this PhD project, I recruited women who were already taking part in IDEAL, utilising the same memory clinic sites as a resource through which to identify and contact people living with dementia. Originally, my thesis aimed to explore the relationships between women’s experiences of living with dementia and social class. I aimed to recruit women from a variety of social backgrounds. In the first instance, information recorded as part of the IDEAL questionnaires, including factors like educational attainment and previous occupation, as well as the previous occupation of the person’s spouse, were used to provide some indication of socio-economic status. The latter category was included on the basis that women’s class identity, particularly for older women, may be as much related to their husband’s previous occupation as their own. The interview schedules I developed in preparation for this were kept deliberately open, and were designed to be a guide, rather than prescriptive. They contained a range of questions about the person’s life and upbringing, as well as questions about living

with dementia and interpersonal relationships. My intention was to explore how the individual experience of dementia was shaped by social class and social location more broadly.

Despite having a relatively heterogenous sample, when I interviewed my participants, class and social location did not emerge as strong themes. What was evident, however, was the way in which selfhood and identity were sustained and impacted by dementia. This fitted with Sabat and Harré's (1992) social constructionist model, which I came to as a result of my data and findings. All participants displayed an intact ability to locate thoughts and feelings as their own (the Self 1), and incorporated a diagnosis of dementia into their beliefs about their characteristics and attributes (Self 2). Here, it was possible to observe the varying ways in which people's self-esteem was affected, as well as the strategies used to preserve it in the face of losses. Positive interpersonal relationships (Self 3) had an important role to play in the maintenance of selfhood, whilst negatively perceived relationships could threaten this. Based on the strong evidence of selfhood and identity within the accounts of my participants, this then became the focus of the thesis.

The interview guide, originally developed with the intention of drawing out the nuances around social class and dementia, therefore served an alternate purpose, which was to allow the women in the study to talk about selfhood. I subsequently honed and developed it with each interview, in accordance with a grounded approach to data collection and analysis. My pilot interviews, which were also included in the main dataset, were important in this regard, because it was in these that the strength of accounts based on the notion of a social constructionist approach to selfhood. I deliberately conducted the two pilot interviews with women from markedly different social backgrounds, with both evidencing strong themes of navigating the threat to selfhood posed by dementia.

The questions that this thesis examines are:

- How does dementia impact on how women perceive themselves, in terms of previously valued attributes and role identities?
- Is their self-concept, and importantly, their self-esteem, affected?
- How does dementia impact on social identity and relationships?
- Is there a connection between the impact on personal and social identity? In other words, could the actions of someone in the participant's social world not only affect

the person's ability to construct a valued social identity, but also reflect back on how that person perceives themselves (and vice versa).

The first findings and discussion chapter (chapter five) explores how the self was changed or in the process of changing as a result of dementia. It explores how participants react to a diagnosis, and the subsequent emotional burden of the disease that aligns with how people perceive dementia (e.g. as a disease, or as part of the normal ageing process). Some describe how the reaction of friends and family, through the diagnostic process, has a significant impact on their own ability to emotionally adjust to the diagnosis or potential diagnosis. The chapter then considers the longer-term impact of dementia. Here, the women talk of changes in their personality, of their self-esteem and confidence being damaged by perceived losses. Participants draw comparisons between past and present aspects of their selfhood. Participants also describe how loneliness and isolation brought on by their diagnosis contributed to feelings of low mood and sadness. The chapter goes on to explore stigma and the self-presentation strategies that people engage in, to reflect patterns of disclosure or non-disclosure. The expected reactions of others within their social world – sometimes based on previous experience of adverse reactions – had a bearing on this. Finally, the chapter explores the importance of setting boundaries for people with dementia; the undertaking of valued activities and pursuits that allowed for these to be carried out, but in a modified way. This chapter shows that dementia has a wide-ranging impact on the psychological, social, emotional and physical domains of women living with the disease. Almost all women perceived themselves differently in terms of their attributes, characteristics and roles.

Chapter six discusses resistance and repair. In other words, the ways in which people resist the threat to selfhood posed by dementia, and negotiate the difficulties faced. All participants are shown to engage in enriching and self-sustaining forms of activities, that are usually related to their existing sense of self, but in some cases, have been adopted as new attributes since the diagnosis. These range from volunteering to physical activity and membership of certain groups. The chapter goes on to look at how resistance to dementia is utilised through participants maintaining a sense of control over aspects of their own lives, including exercising choice, retaining their independence and evidencing selfhood through appearance. Practical coping strategies, such as diaries and memory aids are also discussed, along with the ways in which these serve to increase the perception by the person and others of capability and self-sufficiency. Finally, this chapter addresses how women strive to preserve a positive self-

concept in the face of the threats to selfhood posed by dementia. Thus, by emphasising the attributes related to their sense of self, prior to their dementia diagnosis (for example, intelligence), and downplaying their disease-related characteristics, and with the help of positive social interactions, people's self-esteem could be enhanced, even in those who dwelt particularly on the losses suffered as a result of dementia.

In chapter seven, relational aspects of selfhood are explored. Dementia support groups are central to the maintenance of a positive collective identity for many women, and serve to enhance self-esteem and social participation. For some, the support groups, and the relationships forged within them are a source of release and escape from the realities of everyday life and interaction. The next section of the chapter addresses how women with dementia are positioned by others, and how the women attempt to counter-position themselves, to protect aspects of their sense of self that are perhaps called into question by family members. The chapter explores how traditionally gendered roles are subject to change, and how, in many cases where husband and wife were living together, the husband is taking on added responsibilities. The dynamics of role changes are discussed; for example, the attempts by some family members to preserve the gendered sense of identity of the person with dementia. The impact of such changes on husband and wife relationships are also discussed. Finally, this findings chapter considers the outlook on the future, of both women with dementia and their family members. Practical and logistical implications are at the forefront of the minds of some participants, whilst others are fearful and apprehensive about the unknown. This chapter illustrates the importance of relationships in the context of dementia. These can strengthen social identity by enabling the construction or maintenance of valued social personae and role identities.

The experiences of women have been underrepresented in the field of dementia social science. By using the social constructionist approach to selfhood, this thesis considers the ways in which the different constructions of self (as set out by Sabat and Harré, 1992) are impacted by dementia for the group of women who took part in the study. These findings make an original contribution to the literature, by focusing specifically on understanding the experiences of women from differing social backgrounds – about which little is known – and by showing that all women experience some form of loss, or perceive themselves differently to their pre-diagnosis selves as a result of dementia. This threatens their selfhood, causing emotional reactions and lowered self-esteem. However, all women engage in resistance to such threats,

and actively seek ways to preserve selfhood and identity. A range of strategies are used, to deal with the effects of dementia. Some seek meaningful relationships to strengthen their social identity, others withdraw from social life, as a means of self-preservation. The reactions of people within the world of the women with dementia – or perceived reactions – are important. These play a key role, not only in the construction of a valued social identity, but also in mediating the participant's self-esteem and how they see themselves in light of the disease.

The findings also provide further support for Sabat and Harré's (1992) social constructionist theory of selfhood in dementia, by illustrating its scope for application to specific groups of participants; women who come from a range of social backgrounds and are living in different circumstances. It also provides support for the wider literature focusing on psychological and social aspects of dementia. The women in this study are engaged in a constant process of appraisal and re-appraisal: deciding who to disclose their illness to, deciding who to form close relationships with, which aspects of their identity are important to sustain and which could be discarded, and modifying their behaviour and adapting to the challenges associated with this. Finally, the thesis supports the notion of including people with dementia in research, and putting the perspectives of these individuals at the forefront of the development of future theory and practice. It illustrates the retained capacity for people – in the early stages of dementia – to construct rich, detailed and complex narratives, and to reflect on aspects of their lives and experiences.

Chapter 2: Literature Review

2.1 Introduction

The literature discussed in this chapter will explore chronic illness, and dementia specifically, from a subjective standpoint. It will focus on social and psychological aspects of the illness experience, and consider how selfhood and identity are impacted. This will support the overall aim of this thesis, which is to explore how dementia affects the selfhood of women, and also, how women are able to resist the threat to selfhood.

The first section of the literature review is devoted to understanding how people make sense of chronic illness, and how this can pose a threat to the continuity of one's sense of self, leading to changes in self-presentation. Three key theories will be addressed: Mike Bury's biographical disruption (1982), Gareth Williams' narrative reconstruction (1984) and Kathy Charmaz' loss of self (1983), within which the concept of stigma will also be discussed. All of these theories consider how illness poses an inherent threat to the direction of one's expected life-course. As such, this body of work provides a useful grounding from which to explore how people come to terms with a diagnosis of dementia and the threat that disease poses to different aspects of their selfhood. More specifically, the thesis considers how the Self 2, which is made up of one's attributes and characteristics, as well as one's beliefs about said attributes, is vulnerable to disruption after a diagnosis, and how women respond to this disruption. The threat of stigma discussed within Kathy Charmaz' theory also has direct relevance to this thesis, which explores the role played by others in preserving the Self 3 – the social self.

The second section of this chapter expands on the more general concepts related to the loss of self and chronic illness and describes how identity and selfhood have been explored with specific reference to dementia. It will begin by reviewing those theories that purport that dementia causes damage to one's sense of self, on account of the fact that selfhood is equated with things like autobiographical memory, which are indeed severely impacted by the disease (e.g. Fontana and Smith, 1989, Capps, 2008). However, the main focus of this section will be to counter such a view by describing alternative theories that point to the preservation of selfhood in dementia. Embodiment (e.g. Kontos, 2006, Twigg, 2007) has also played a significant role in redefining how selfhood can be expressed, even in people with severe dementia, by offering another alternative to the biomedical model and proposing that selfhood

is maintained in a variety of ways that are linked to personal and social histories and cultural norms.

The third section explores the experiences of women who are living with dementia, specifically those studies that have focused on selfhood and identity. This section illustrates how socially constructed roles, such as family and nurturing roles, are threatened by dementia, and the resulting impact on self-esteem and social identity. The literature – and the evaluation thereof – in this section, is drawn upon to show how differing coping strategies employed by women with dementia, serve to enhance self-esteem.

2.2 Lay understandings of health and illness

The term ‘lay epidemiology’ was first conceived in a 1991 paper by Davison et al. (p.2). The authors argued that, while the development of rigorously-tested explanatory frameworks for ill health falls to those within the specialised arena of medicine, the lay person, with no specialised medical knowledge, formulates their own hypotheses all the time. In addition, the authors argued that lay beliefs can never be entirely separated from scientific knowledge, given the way in which science permeates many aspects of our culture and society (Davison et al. 1991). In the study in question, lay beliefs were explored with reference to coronary heart disease (CHD) and ‘candidacy’ (p.5). Candidacy is used to assess the predictability of an illness or disease, and risk to oneself.

Lay beliefs describe an attempt by the individual to relate factual, scientific knowledge to their own personal experience and narrative identity. In other words, such beliefs are ‘socially patterned’ (Blaxter, 1983, p.59). Several studies have explored the concept of lay beliefs with reference to dementia. Andrews et al. (2017) found that most family members did not recognise the link between dementia and death, or other medical conditions. When this was explored further, it was revealed that the manner of family members’ information acquisition about dementia was incidental and not carried out with any kind of intent or process in mind. However, Gillies (2012) found that carers struggled to come to terms with the medical terminology surrounding the disease, which led to confusion and attempts to seek coherence in the familiar. Moreover, the carer was reliant on personal or societal understandings, which were often perpetuated by negative stereotypes. When deciding which source to attribute symptoms and behaviours associated with dementia, the carer therefore often attributed these to the person, rather than the disease (Stokes et al. 2014). This could lead to problems in the

relationship between the carer and the person with dementia. In terms of the present study therefore, it could impact the Self 3 – the ability of the person with dementia to construct a valued social persona, beyond that of the dementia patient.

Quinn et al. (2017), however, found the opposite; namely that caregivers were more likely to attribute dementia symptoms to external (uncontrollable), rather than internal (controllable) factors, and as such, alleviated blame from the person with dementia. The authors found a similar absence of understanding about the cause and timeline of the disease, which is consistent with the above study by Stokes et al. (2014), as well as others (Chung, 2005). Quinn et al. (2017) acknowledged that an apparent lack of awareness on the part of caregivers could also be a way of avoiding confronting the reality of the situation. Caregivers in this study were hopeful, but realistic about the potential for a cure. Whilst some felt that there was nothing that could be done to help the person, others were optimistic about the use of management strategies, such as memory aids. These different perceptions could shape the ways in which carers interact with the person with dementia, and thus has relevance to the present study, in terms of the ability to the women to construct valued Self 3 personae, and maintain social identity.

Whilst much research has focused on lay understandings of dementia from the perspective of caregivers, other studies have explored how the person themselves accounts for aspects of the disease. Belgrave et al. (2004) found that medical definitions were drawn on, but that explanations primarily reflected lived experience. People with dementia also resisted being characterised as having an illness, and instead described their memory problems as ‘forgetfulness’ (p.218). Attempts by caregivers to impose restrictions on their lives were met with anger, opposition and counter-action. A similar tendency to normalise symptoms was found by Sahin et al. (2006), whose participants avoided linking their symptoms with a medical condition. They also displayed a lack of understanding and awareness about what dementia actually involved.

Similarly, Clare et al. (2016), in discussing the illness representations held by people with dementia, found that people reacted to the disease and coped in vastly different ways, and that part of this was determined by their understanding of what dementia is and what caused it. Ways of coping included self-adjusting styles – where people confronted the disease and attempted to adjust their sense of self accordingly, and self-maintaining styles – where people attempted to play down difficulties and maintain continuity with their past self (Clare, 2003).

One, relatively small group of participants, saw dementia as an illness, used diagnostic labels and displayed self-adjusting coping responses. A second group saw dementia as being caused by ageing, did not use diagnostic labels and used a mixture of self-adjusting and self-maintaining coping strategies. Finally, a third group saw themselves as having no problems and used self-maintaining strategies. Those who viewed themselves as having an illness had better cognition and awareness, but lower mood and perceived more practical consequences than those for whom dementia was part of the ageing process – challenging the idea that acceptance of an illness is synonymous with good emotional adjustment. Whilst many participants believed nothing could be done, most used practical and emotional coping strategies, including perceiving the situation as less unfavourable than it was or acknowledging that it would get worse in the future. This made life more manageable, but limited the ability of participants to confront the implications of the disease.

Lay beliefs are multi-layered, complex and central to the link between illness and identity (Williams and Popay, 1994). Lay knowledge invokes different causal attributions to the medical model, by drawing on people's direct experience. This has been illustrated by the above studies, in relation to how people conceive of dementia. Lay understandings of dementia are important for this thesis, therefore, because they impact people's response and coping strategies, which are in turn linked to the maintenance of selfhood. For example, the common finding that people with dementia have limited knowledge and understanding of the disease could serve to protect selfhood and identity, by enabling the kind of self-maintaining approaches described in Clare's (2003) research. Recognition of dementia as an illness, on the other hand, potentially means recognising the realities associated with this, including the knowledge that the disease is a progressive one and that symptoms will get worse over time. Acceptance of this could threaten the Self 2, and lead to a change in one's self-perception and beliefs about one's previously valued attributes, in accordance with Clare's (2003) self-adjusting approaches.

2.2.1 Biographical disruption

One of the most influential theories that emerged with regards to lay understandings of health and illness was Bury's (1982) theory of chronic illness as a form of 'biographical disruption' (p.169). Bury's work was centred on rheumatoid arthritis patients, but has since been applied to a range of health-related problems. The presence of persisting symptoms threatens one's view of the 'taken-for-granted world', resulting in adjustments being made and the need to

incorporate an uncertain illness trajectory (Green et al. 2007, p.525). When confronted with a chronic illness, one is faced with the reality of pain and suffering – potentially also, mortality. The dynamic of relationships and social structures is irrevocably altered, for example, in the way that one person depends on another. Bury (1982) outlined three stages of disruption involved; an initial disruption of taken for granted assumptions and a newfound awareness of one's body, followed by a fundamental restructuring of one's biography, and finally, the response to this disruption.

The patients in Bury's study had a tendency to dismiss or externalise symptoms of the illness (1982). It is often the case that people in the social world of the individual in question will be more aware of these initial changes, which can also hold true for dementia (Williams et al. 1995). However, rheumatoid arthritis patients were able to conceal symptoms from family and friends, and many did indeed attempt to hide their illness. It was also problematic for many to recognise the persistence of particular symptoms as representative of something more serious, when these symptoms could be considered relatively common amongst the general population (Bury, 1982). Similarly, with dementia, people have a tendency to attribute the early signs, such as memory lapses or forgetfulness to part of the normal process of growing older. There is uncertainty and confusion, even in medical circles, around what constitutes normative pathological decline and what constitutes the onset of dementia (Corner and Bond, 2004).

Once a formal diagnosis has been received, however, dementia is extremely hard for many people to come to terms with. One participant in a recent study described it as being akin to having a 'noose around one's neck' – a reflection of the fact that there is no cure (Johannessen and Möller, 2011, p.6). There follows, with any chronic disease, a period of coming to terms with this new reality and the challenges it brings, or as Bury (1982, p.169) observes: 'a fundamental re-thinking of the person's biography and self-concept'. For the rheumatoid arthritis patients in Bury's study, the medical model had an important role to play here, in that access to medical knowledge offered a way of conceptualising the disease as distinct from one's selfhood. This can be empowering, in constructing an objective, and socially acceptable basis for behaviour and intervention. In other words, blame can be apportioned to external forces, allowing one's sense of self to be preserved (Fabrega and Manning, 1972).

Some have argued, however, there is not as straightforward a distinction to be drawn for people with dementia, since dementia is neurodegenerative and impacts on one's sense of self (Eustache et al. 2013). This is because, according to the medical model, selfhood is seen as

being embedded in memory and cognition (Klein, 2010). Episodic memories (one's experiences over time), for example, contribute to identity strength, because they provide a foundation from which personal knowledge is gained. This personal knowledge – or semantic memory – includes trait self-knowledge (knowledge about one's attributes), which is what defines our identity and personality. Poorer retrieval of self-knowledge is thereby associated with reduced identity strength (Haslam et al. 2011). The view that selfhood is embedded in memory inevitably poses a problem for people who have been diagnosed with disorders that impact on memory. This has led Fontana and Smith (1989) to describe people with dementia as experiencing an 'unbecoming of self' (p.36).

There are numerous studies that have since used a biographical disruption framework to situate and explore the experience of chronic illness. Wilson (2007) examined the relationship between illness and identity in the form of HIV positive women, and found that the threat posed by the disease to their identities as mothers, stemmed both from HIV stigma and the moral underpinnings from which it derived. Cayless et al. (2009) explored the biographical disruption that occurred in men following a diagnosis of prostate cancer. A changed sense of self emerged from an altered physical identity, in response to disruption. The uncertainty described by Bury above was evident in the complex process of anticipating a cancer diagnosis and actually being diagnosed with the disease. The study also considered unmet care needs, particularly the assault on identity of treatment side effects associated with intimate and social relationships.

The notion that biographical disruption can co-exist with continuity has also been explored. In a study of osteoarthritis patients, Sanders et al. (2002) found that, on the one hand, symptoms associated with this particular condition were seen as a normal part of ageing. In that sense, the disease was a continuous part of patients' biography. However, their bodies had changed irrevocably and they were hamstrung by persistent pain, which in turn led to disruption to their daily lives and relationships. Locock et al. (2009) found a similar disruption to leisure, work and relationships, caused by motor neurone disease. The fact that this was a terminal illness with poor life expectancy beyond a certain number of years also resulted in what the authors termed 'biographical abruption', whereby life was perceived as being over (p.1047). However, the uncertainty of the disease trajectory was a cause for hope for some patients, and led them to believe that they could confound medical expectations.

Biographical disruption remains a useful concept to consider the effect of dementia on aspects of selfhood, as disruption is likely to be a key feature of the diagnostic process (Tollhurst and

Kingston, 2013). It also focuses on ‘the experiential aspects of chronic illness, with subjective responses articulated via alternations to self-concepts and the mobilisation of resources shaping the experience of the condition’ (p.177). In a study of nursing home residents, some of whom had dementia, Harnett and Jönson (2017) found that residents used biographical comparisons of ‘now versus then’ to portray themselves as fundamentally different (p.5). Residents’ age, frailty and illness made it fruitless trying to compare their past situation with the present, since they were no longer the same self. Thus, there was little point in attempting to maintain their previous lifestyle.

This concept of disruption is important for what follows, because, as will be shown in later chapters, many participants in the present study viewed dementia as an inevitable part of the ageing process, which nonetheless caused significant disruption to aspects of their social and interpersonal lives. They too seized on the uncertainty and lack of clarity surrounding the illness trajectory and turned it into a positive; it gave them hope that things would continue as they were, or at least, would not deteriorate too drastically. The women in the present study experienced transition difficulties, related to having been physically or mentally able to do certain things or fulfil certain roles that they could no longer. All of the women had carved out a sense of purpose since retiring – based around valued hobbies, pursuits or activities – and dementia threatened this. Achieving continuity in these domains helped to minimise the extent of biographical disruption.

The concept of biographical disruption has been robustly evaluated, not least by Simon Williams (2000) who wrote an extensive critique of Bury’s theory. Firstly, biographical disruption does not account for conditions present from birth; it works on the basis that illness strikes in mid-later life. Whilst people born with a condition may still suffer and contend with disruption, their biographies have not shifted in the same way. A further issue concerns what Carricaburu and Pierret term ‘biographical reinforcement’ (1995, p.81), a concept they developed in relation to interviews they carried out with haemophilic HIV positive men. In other words, being diagnosed as HIV positive simply reinforced the identities of these participants as haemophiliacs; there was a continuity between HIV infection and haemophilia. The biographies of these men suffered no disruption because they had already been centred on the negative implications of a chronic illness. Biographical disruption as a cause, rather than a consequence of chronic illness was also undocumented by Bury.

Despite these criticisms, however, biographical disruption remains relevant to the present thesis, as it is centred on previously healthy women, diagnosed with dementia in later life. Tollhurst and Kingston (2013) pointed out that biographical disruption was most effectively applied at the onset of a condition, when, they argued, disruption would be at its most palpable. This is perhaps understandable in the context of many physical conditions, which may not be progressive in nature, but it was not found to be the case with the women in my study. This could be put down to the unique nature of dementia; how it threatens selfhood, and the fact that it gets worse over time, meaning that disruption is a more constant process.

2.2.2 Narrative reconstruction

Bury describes a period of ‘explanation and legitimation’ following onset of a chronic illness, whereby the longer-term impacts are assessed, and the person seeks an explanation (Bury, 1991, p.455). Medical explanations are often not sufficient, and need to be supplemented with a process of what Williams defined as ‘narrative reconstruction’ (1984, p.177). In this study too, the focus was on rheumatoid arthritis patients, and the author initially offered a rebuke to the capacity of medicine to account for the psychological and social upheaval that occurs when chronic illness attacks a person’s identity (Williams, 1984). He also describes how his own theory of narrative reconstruction is strongly linked to Bury’s (1982) theory of biographical disruption. Incorporating Bury’s notion of the person as social agent, complete with biographical identity, to which chronic illness poses a pertinent threat, Williams states that:

‘...an individual’s account of the origin of that illness in terms of putative causes can perhaps most profitably be read as an attempt to establish points of reference between body, self and society and to reconstruct a sense of order from the fragmentation produced by chronic illness.’ (Williams, 1984, p.177).

Some people find the medical model an inadequate explanatory framework for chronic illness. Causal models of chronic illness, therefore, invoke, through narrative reconstruction, moral, religious, political and sociological factors. These were shown in Williams’ (1984) study as being central to elucidating the illness experience and navigating the resulting biographical disruption. Rheumatoid arthritis ‘assaults the taken-for-granted world’ of the person, and requires explanation (p.197). Dementia, too, can be seen in the same way – as a disease that creates a ‘rupture’ between one’s body, self and the world, and requires the person to reconstruct their experience and make sense of it. Moreover, dementia, like rheumatoid arthritis

(Williams, 1984) carries an 'existential gravity' (p.197), whereby participants in the present study had an awareness of the progressive nature of the disease and recognised its implications for their future health.

Similar to Williams, Robinson (1990) draws on the significance of personal narratives as a vehicle through which people understand chronic illness. He identified three types of trajectories in illness narratives: 'stable', 'progressive' and 'regressive' (p.1178). When illness strikes, it is invasive and a threat to the order of one's life. It therefore requires a complex interpersonal and social interpretative framework to make sense of the process, through assessing the meaning that illness holds for one's goals and objectives and its relationship to one's values in general. Reconciling this involves 'subjectively placing the nature of illness in the temporal context of an individual's life' (p.1174). For the multiple sclerosis patients in this study, stories served a social function, 'generated in and through social settings and interactions' and were subsequently redeployed to others as a means of indicating and reinforcing appropriate responses to the disease (p.1184). Personal control over the illness process was also prevalent in many narratives, which were threatened when the individual was forced to surrender control.

Robinson's view that illness accounts are implicitly written as narratives is supported by the present study. The women involved were encouraged to talk freely and openly, in a way that allowed them to story their lives within the context of dementia. Although the interviews were structured around questions, these formed an overall narrative of what it was like to live with dementia, how selfhood was threatened, and the ways in which the threat could be resisted. The study supports some of the findings by Hillman et al. (2018), whose participants provided counter-narratives in response to potentially stigmatising representations of the disease, as well as offering a rebuke to the pervasive biomedical model highlighting loss and decline. Dementia was also found to be impacted by relationships and one's environment. Finally, biographical reinforcement was also in evidence, as participants navigated the challenges posed by the disease, to reinforce continuity between past and present identities.

People with dementia still possess the ability to story their lives (Mills, 1997). This narrative identity might be retained for longer in some patients, compared to others, on account of the variability of the disease trajectory. However, the fact of sharing their experiences with others means that the narrative never dies. This matters for this thesis, because of the implications it has for subsequent interactions with carers and family members, in terms of fostering an

understanding of the person with dementia and the things that are important to them, even in the latter stages of the disease. Ultimately, this contributes to research examining how people with dementia can live well. Karlsson et al. (2014) concluded that the narratives of people with dementia reflected a positive approach to life, evidencing strong belief in their abilities and ‘an ongoing quest for personal growth’ (p.2796). Thus, it was important for others to support this outlook, through techniques such as life story work, to ensure that selfhood and a strong sense of identity continued to flourish.

The above cases serve to highlight the variety and individuality of people’s experiences of illness. Most will suffer an assault on identity and embark on a process of meaning-finding amidst the turmoil. The theory of narrative reconstruction to explain lay beliefs thus has intrinsic value, and contributes towards viewing disease as being related to identity and sense of self. This thesis aims to use the narratives contained within women’s interviews to explore the ways they experience dementia and reconstruct their identities in the face of the disease. In this study, the women who took part all expressed hope that by sharing their stories, they would be contributing towards a greater understanding of dementia. Whilst some stories reflected experiences of a ‘rupture’ created by dementia (Williams, 1984, p.197), others offered resistance and focused on those aspects of the person’s selfhood that were preserved. In other words, by maintaining continuity with previously valued pursuits or roles, the biographies of the women in this study remained intact. The presence of strong, supportive relationships was central to enabling this continuity.

2.2.3 Loss of Self

The impact of chronic illness on one’s sense of self and identity has been explored by the American sociologist, Kathy Charmaz, who is best known for her work on the development of grounded theory as a means of qualitative enquiry (2006). Charmaz was interested in what happens to the self in chronic illness, and purported that suffering is a social and psychological process, comprising the ‘crumbling away of one’s former self-images’ (1983, p.168). Combined with a heavy burden of negative consequences, including familial strain, stigma, loss of productive function and financial trouble, the individual suffers a critical assault on their identity and experiences a ‘diminished self’ (p.169). Central to this loss is the impact on self-concept, which Harré (1998) defined as being self-aware; having a perception and set of beliefs about one’s personal attributes. However, when diagnosed with a chronic illness, aspects of

one's self-concept may become incompatible with those images of self reflected back in the behaviour of others (Charmaz, 1983).

Charmaz studied chronically ill adults with a variety of diagnoses, including cancer and cardiovascular disease. She found that exposure to suffering stemmed from a variety of sources, each contributing towards loss of self. Firstly, many individuals led a significantly restricted life, which revolved around the illness and everything that came with it. It was important, therefore, that at least some degree of perceived control was maintained, in terms of making adjustments to the ways in which formerly enjoyed activities could still be fulfilled (Charmaz, 1983). Otherwise, there was a danger of the restrictions becoming 'daily reminders of the lessened freedom and, often, diminished self' (p.173). Social isolation also fosters a loss of self, with the risk of friendships being affected on account of the fact that the ill person and others no longer share the same worlds. Indeed, chronic illness leads to greater dependency on others for 'self-definition and value', while at the same time producing situations in which relationships become strained and isolation is more likely (Charmaz, 1983, p.191). There occurs a discrepancy in the traditional rules of reciprocity, requiring that others make more effort to step up and support the ill person. If this does not happen, then isolation – which is compounded as the illness or disease worsens – leads to loneliness and a feeling of being excluded from the normal realms of social life (Charmaz, 1983).

The above study, although considered widely influential within the field of illness experience, has been criticised for presenting an almost exclusively negative account of this, focusing on the losses that occur and neglecting to show how new, equally valued selves can emerge in response to a chronic illness (Garrett, 2001). Charmaz herself attributed this to the fact that, among this group, self-worth was measured almost exclusively in terms of independence and hard work – which often conflict with diagnosis of a chronic illness (1983). Thus, several years later, she undertook a study with a deliberately different cohort of participants (Charmaz, 1991), finding that loss and transcendence characterised accounts of chronic illness, with autonomy being key to this.

A number of studies have explored Charmaz' (1983) theory that aspects of selfhood are impacted by dementia. Holmen et al. (2000) observed that women were in fact more likely to experience isolation and loneliness throughout the course of the disease than men. Whilst the reasons for this are unknown, it could be reasoned, certainly based on evidence from the present study, that women have particularly close interpersonal relationships – the loss of which, as a

result of dementia, may be keenly felt. Relatedly, research shows that the impact of the subsequent disability associated with dementia can be managed, by implementing positive strategies to cope with ‘rough spots’, which includes ‘staying busy’ (Beard et al. 2009, p.230). This comprises small, enjoyable periods of relaxation – nothing that is overly strenuous or taxing. These seemingly innocuous, mundane activities are vital in retaining a sense of normality and calm when life can become consumed by illness-related hurdles.

However, Karner and Bobbitt-Zeher (2005), while acknowledging that dementia had a ‘social reality’ (Vittoria, 1998, p.92), reasoned that selfhood was expressed and maintained through the efforts of others. The authors claimed that theories such as biographical disruption, narrative reconstruction and loss of self – theories that suggest the need for the ill person to reconstruct their identities and adapt to the condition – were not suited to people with dementia, since they are unable to engage in such restorative work (Karner and Bobbitt-Zeher, 2005). Instead, it is the caregiver who goes through this process, trying to create order from disorder, as their pre-existing relationship with the person with dementia transforms into one that is dependency-based and the relational selves of both parties suffer. As a result, the caregiver has to negotiate the terrain of illness and uncertainty, and attempt to recreate valued selves and relationships. Moreover, because the person with dementia has lost the ability to engage with the social world, the caregiver is constantly involved in managing the *presentation* of self, not the actual self of the person in question (Karner and Bobbitt-Zeher, 2005).

This assertion that such theories are unsuited to people with dementia, however, is challenged by the fact that a vast amount of research has been conducted, showing that people living with dementia themselves are heavily involved in the process of negotiating threats to their identity and selfhood (e.g. Caddell and Clare, 2011, Kontos, 2004). Indeed, such claims would suggest a denial of the person living with dementia the capacity to navigate the hurdles facing them. What this study aims to show is that women with dementia retain considerable meaningful engagement with the world around them. They displayed both recognition of the losses suffered, but crucially, in accordance with Charmaz (1991), deliberate attempts to successfully navigate these threats and make adjustments to their lives that enabled selfhood to flourish. Whilst the quality of interpersonal relationships and the social environment were undoubtedly crucial to these efforts at transcendence, they could not be considered in isolation, and served a supportive function to the identity work of the person themselves. This is relevant for what follows in the present study, which considers not only the importance of social environments,

but how women living with dementia can themselves strive to maintain a sense of self and identity.

Within the above literature, it is also important to consider the emotional impact of loss of self, which Charmaz (1983) argued arose as a result of the isolation experienced as the dynamics of social relationships changed. Other research, however, has suggested that the emotional impact of loss is more nuanced and not solely related to the assumption of a stigmatic social identity. Aminzadeh et al. (2007) found that people with dementia mourned actual and anticipated losses and experienced a vulnerability of self. Similarly, Bender and Cheston (1997) found that losses associated with dementia fuelled a range of emotional responses, including anxiety, depression, grief and despair. The person experienced a 'profound, existential sense of emptiness and absence' (p.518), relating to the anticipated and actual loss of self. This supports Solomon and Szwabro's (1992) theory that loss of self triggers a grieving a process, wherein the person moves from denial, to disorganisation, to reorganisation. However, the authors noted that people with dementia could not easily transition into this final stage, which meant that they remained in a state of disorganisation. As a result, they withdrew from life and were at risk of depression.

As mentioned earlier on in this section, self-concept, which is vital to sustaining a positive sense of self, is vulnerable to discreditation – or stigmatisation – in chronic illness. Those with whom the person shares a close interpersonal relationship hold a particularly powerful influence in this regard (Charmaz, 1983). It is now worth engaging with the concept of stigma more closely, since it is central, both to Charmaz' (1983) theory of the loss of self, and to more positive conceptualisations of selfhood in chronic illness that nonetheless stress the importance of the social interplay, and the role of others in enabling the ill person to sustain a positive sense of self.

2.2.4 Stigma

Stigma was first theorised in detail by the sociologist Erving Goffman in his 1968 book: *The Management of Spoiled Identity*, which described the micro-level interactions at play through which categories of persons are established, to which new members are assigned and thus a social identity ascribed. Should it be revealed that a new member possesses 'an attribute that is deeply discrediting', that individual will be reduced 'from a whole and usual person to a tainted, discounted one' (p.3). The process of socialisation is illustrated by various patterns,

one of which includes the person who becomes stigmatised in later life – for example, as a result of a dementia diagnosis. In this case, it is common for a wariness and discomfort to develop, in dealing with pre-stigma acquaintances, or those who knew the person with dementia before the diagnosis. It is easier to be seen simply as a stigmatised person – as by those who came to know the person post-diagnosis – rather than having been known before the stigma. The latter allows for an uncomfortable contrast between pre and post stigma to be visible (Goffman, 1968).

The stigmatised individual may respond to his or her situation in a number of ways, including by ‘passing’ – pretending to have a less stigmatic identity (Goffman, 1968, p.42). The intention is that, by erasing all traces of incriminating evidence, or by attributing anything that cannot be erased to a less stigmatic condition, the person will become part of the ‘normal’ group (Joachim and Acorn, 2000, p.245). They are therefore engaged in a process of continual management, of ‘undisclosed discrediting information’ regarding who and who doesn’t know about their stigma (Goffman, 1968, p.42). Individuals to whom the stigma is disclosed are carefully chosen and relied upon to withhold the information from others (Joachim and Acorn, 2016). Due to the high stakes involved – successful transition into the perceived normal group – passing can cause stress and anxiety, as the person worries about being found out (Goffman, 1968).

Since Goffman’s early work on the subject, a number of studies and new research have emerged over the years, in which the definition of stigma expanded. Link and Phelan (2001) attempted to reconceptualise stigma as a relationship between interlocking components. Firstly, people distinguish and label differences, the salience of which is dependent on culturally designated processes of social selection. The label is associated with a negative stereotype, which allows for an ‘us’ and ‘them’ dynamic to set in, whereby the treatment of the stigmatised individual is justified (p.365). The individual then experiences status loss and discrimination. Status loss is a consequence of the labelling and attachment of a negative stereotype and is a product of social hierarchy theory (which states that some individuals are afforded a more privileged position within a group than others) (Link and Phelan, 2001).

Discrimination can be both individual and structural. Individual in that a person’s attitudes predict their behaviour, and structural in that, as with institutional racism, it is woven into the fabric of a particular set of societal practices. Finally, stigma depends on a power dynamic. A

group of stigmatised individuals can come together and share the same negative opinions about a person or group that results in them labelling and treating said person/group accordingly. But they do not possess the necessary power to convert stigma to discrimination, which is an inherent part of this updated redressing of the issue (Link and Phelan, 2001).

Link and Phelan's (2001) reconceptualisation of stigma is important for this thesis. Status loss and discrimination occur when stigma interferes with a person's ability to participate and engage in social life, whereby a power differential favours those who are not stigmatised (Garand et al. 2009). Participation in social life is considered integral to the maintenance of selfhood, with the resulting status loss and discrimination threatening this. Discrimination, for example, impacts on a person's ability to construct a valued social persona, as this requires the support of others. Moreover, this thesis considers how women with dementia are vulnerable to their symptoms and to feeling disempowered, but also how this can be offset, such as in a study by Gove and Rohra (2014) that found that membership of an advocacy group painted people with dementia as active and empowered – and crucially, as having equal citizenship.

Graham Scambler, (1989) in his research into stigma in epilepsy, distinguished between two distinct kinds of stigma: enacted and felt. Enacted stigma describes the experiences of discrimination based on the cultural unacceptability of an attribute that a person possesses. Felt stigma can refer to two things: the shame a person feels about having a particular condition; or, the fear of encountering enacted stigma (Scambler, 1989). It is similar to Corrigan and Watson's (2007) notion of self-stigma; the internalisation by the individual in question, of public stigmatic attitudes towards them, which are then turned on oneself. As such, these concepts are important for this thesis, with felt stigma having been found to be closely related to low self-esteem (Jacoby, 1994). One of the central concerns of the thesis is the threat to one's self-esteem posed by dementia, and how this impacts one's overall self-concept.

Dementia has only recently come to feature in government policy – for example, in the Department of Health's National Dementia Strategy and the Social Exclusion Unit – which have a vital role to play in challenging stigma (Milne, 2010). Within policy initiatives is a push to increase awareness of the disease. Hence, the visibility of public figures, such as Terry Pratchett and Barbara Windsor, speaking out on the issue, is important (Rouse, 2014). However, we need to move from awareness to understanding. Within the latter, dementia friendly initiatives have been introduced, to help people with dementia and caregivers feel part of the community, and to help communities themselves become dementia friendly.

Research has shown that symptoms of dementia are deeply stigmatising, and this has a range of consequences, including that people avoid social interaction with the individual diagnosed, and perceive him or her as having no capacity for quality of life or pleasure (Graham et al. 2003). Dementia has become a feared disease, with people avoiding seeking a formal diagnosis, or attempting to present their memory problems as part of the normal process of ageing (Rasmussen, 2014). A diagnostic label, after all, signals certain cultural stereotypes, and the ideas that someone has previously held in relation to this label become personally relevant (Garand et al. 2009). In other words, by acquiring the label of dementia, that person may regard themselves as a 'social liability' on the basis of this (Scambler, 1989, p.57). There follows then, the expectation that others will reject them, which fosters defensive strategies, such as non-disclosure. This thesis, relatedly, explores how people react to a diagnosis of dementia, and the intentions that lie behind strategies of disclosure or non-disclosure, in terms of protecting oneself from the effects of stigma.

The fear of enacted stigma fuels a 'policy of non-disclosure' (Scambler, 1989, p.57), which can be achieved so long as the person is 'discreditable' and not yet 'discredited' (Goffman, 1963, p.4). Enacted stigma, after all, enhances loss, and it is traumatic for a person to realise how they are viewed by others, with such experiences creating a lasting impression, prompting the person to conceal their stigmatic identity in the future (Charmaz, 2000). Therefore, opportunities for enacted stigma are subsequently minimised, resulting in felt stigma dominating and potentially posing a serious threat to a person's wellbeing (Scambler, 1989). Earnshaw et al. (2012) supported this view, claiming that anticipated stigma – expected experiences of discrimination and stereotyping – from family, friends and acquaintances plays a major role in determining quality of life in chronic illness. Moreover, if the stigma is concealable, and the person has experienced stigma, or anticipates experiencing stigma, it is likely that they will socially isolate themselves.

This matters for this thesis because research has shown that there is evidence of both felt and enacted stigma in people with dementia. Dobbs (2008) found that residents in an assisted living facility held stigmatic views of fellow residents with dementia, declining to associate with them. In society in general, people with dementia are constructed as somehow different; a distinction is drawn between those who are 'afflicted' and those who aren't (Behuniak, 2011, p.86). Drawing this distinction enables the marginalisation of such groups to be perceived as justifiable. It is unsurprising, therefore, that people with dementia describe feeling 'socially

demoted', as if they are no longer a part of normal life – which in turn leads to them developing specific strategies to cope with this (Beard and Fox, 2008, p.1517).

This highlights the fact that people with dementia are acutely aware of and sensitive to, the reactions of others. They express a desire for others to be genuine with them, rather than to conceal or withhold things, as this merely reinforces felt stigma and the notion they are being excluded (Langdon et al. 2007). If they experience negative reactions, in the form of avoidance, on the part of social contacts, this leads to feelings of isolation and fuels the cycle of stigma. It is then likely that the person themselves will engage in voluntary withdrawal, in anticipation of what will follow, based on their experiences thus far (Nolan et al. 2006). Relatedly, some people are so aware of the stigma surrounding dementia that they display an aversion to seeking a formal diagnosis, for fear of the social consequences and the anticipated isolation (Phillipson et al. 2015). This was evidenced in the present thesis, although others in the study painted a more promising picture – voicing a desire to share their diagnosis and to be involved in normalising the disease and eradicating the stigma associated with it (Reed and Bluethmann, 2008).

Taken together with Charmaz' (1983) theory about social influences in chronic illness, it is possible to observe the distinct differences between those behaviours of others that discredit the ill person and those that contribute to an enhanced sense of self, through maintaining continuity with the past, pre-illness self. Much discrediting is also subtle, including the 'tacit devaluation' implicit in being interrupted in conversation or ignored completely (p.184). This is linked to Tom Kitwood's (1997) theory of personhood, which will be discussed later on in this chapter. Recurring discrediting experiences eventually lead to the permanent damaging of the self-concept, wherein the ill person sees themselves as being a failure and burden. Hence they have learnt to accept their discredited self (Charmaz, 1983).

Stigma is important to the study of dementia and selfhood, specifically with regards to women. Women face a 'triple jeopardy' of age, gender and dementia-based discrimination (Bamford and Walker, 2012, p.123). The evidence discussed above describes how enacted, but particularly felt stigma, can have a significant impact on a person's life, as they become fearful of social interactions and subsequently isolate themselves or engage in non-disclosure. Given that, traditionally, women have closer interpersonal relationships and larger friendship groups (Clancy and Dollinger, 1993, Antonucci and Akiyama, 1987), the impact of such anticipated stigma may be more keenly felt. This is an issue that is directly explored in this thesis, as it is

a further example of how women may experience stigma and discrimination as a result of dementia.

In conclusion to this first section of the literature review, the importance of chronic illness as a significant life event has been illustrated by numerous theorists. Literature has explored how chronic illness constitutes a major disruption to life as the person has known it, and how they must reframe their personal narratives to accommodate it. Illness poses a threat to selfhood and identity; indeed, these can be lost or damaged irreparably. A sustained sense of self is heavily influenced by a person's vulnerability to the stigmatising aspects of the disease. Hence, the importance of the social reality of the illness experience. Encountering discrimination, or indeed anticipating discrimination from others can have a profound impact on the self-concept of the ill person.

The application and adaptation of these concepts contributes to the key themes addressed in this thesis. Lay beliefs offer an alternative way of exploring chronic illness, and dementia specifically, distinct from the medical model. They impact one's understanding of illness and response to it. Disruption is an inevitable part of dementia, in terms of the uncertainty of being able to plan for the future and attempts to maintain continuity with previous aspects of one's biographical self. For example, dementia poses a threat to role fulfilment, which is central to selfhood, both in terms of having a sense of value and pride attached to different roles, and in terms of constructing a persona as something more worthwhile than that of a patient. Narratives allow women with dementia to make sense of the disease and its impact, through the construction of stories, which help to navigate the threat of selfhood loss. Within this potential for loss, stigma is an important concept, as a dementia diagnosis can impact both the way one is perceived by others and also, one's overall self-concept. This has implications for one's decision of whether or not to disclose the diagnosis.

Finally, this thesis contributes to and expands upon the literatures discussed within this first section. It shows that selfhood is preserved in women with dementia, in a variety of ways, and that a positive social environment and interpersonal relationships can support women in successfully navigating the numerous threats to selfhood and personal biographies posed by the disease. In this way, it contributes to the wider policy narrative on increasing the understanding surrounding dementia and dispelling the myths that it is something to be dreaded. Similarly, it aims to combat the stigmatic attitudes that are still prevalent, and to show that people with dementia are not to be avoided, for fear they cannot participate in social life.

Instead, it explores how experiences of felt and enacted stigma reflect back on the person, impacting their self-esteem and desire to maintain or form new relationships.

2.3 Selfhood and identity in dementia

There has been much debate as to the impact that dementia has on the selfhood and identity of the person afflicted, which is complicated by the fact that researchers have based their definition of selfhood on different models (Caddell and Clare, 2010). Relatedly, a range of quantitative and qualitative techniques have been used over the years to measure selfhood, including questionnaires, interviews and observational methods. For example, some models measure self by autobiographical memory, and thus use a questionnaire tool to assess performance on a memory test (Naylor and Clare, 2008). The social constructionist model, which is the framework for this thesis, uses qualitative techniques to measure self. Historically, selfhood and identity were assumed to be severely impacted by dementia, as illustrated by such studies as Fontana and Smith (1989), who contributed to the narrative of deterioration by describing an ‘unbecoming of self’ (p.45). This loss was marked by an inability to perceive and interpret phenomena and a capacity to understand only simple ideas. They took their theory further, however, by conceiving of caregivers as assuming that there was still a person behind the presentation of the self as victim and of attempting to normalise their loved one. In fact, according to Fontana and Smith, there was no person; only ‘emptiness’ where the person once was (1989, p.45).

Ward (2015) reported that many caregivers used phrases such as: ‘he is no longer the man I married’ (p.1024). This appears to be indicative of the perceived erosion by dementia of a person’s selfhood, indeed the essence of who that person is. Capps, in a 2008 paper, asserted that the memory and language impairments associated with dementia are evidence of a loss of self. According to the author, one’s memory is based on the identification of the person one was in years gone by, which is the entire basis for one’s sense of self. Moreover, there could be no intact self if the individual was unable to correctly identify himself and others within his social world (Capps, 2008). Similarly, Orona (1990), despite conceiving of identity construction as a social process that was often embedded within close interpersonal relationships, nonetheless presented, in the accounts of caregivers, the notion of the person with dementia as becoming ‘unrecognisable’ (p.1251).

Central to Orona's conception were what she presented as the assumptions inherent in close relationships: reciprocity, social structures and temporality. In reciprocity, people fashion certain expectations of behaviour towards one another, including the negotiating of boundaries. Social structures dictate that people assume different roles in different social situations. Temporality assumes that relationships and interactions occur at specific points in time. These combine to produce a taken-for-granted world, where future events are anticipated and people are constructed 'as before', in line with past expectations (1990, p.1251). However, the person with dementia does not remain as before. Moreover, as the person with dementia changes, so too the caregiver experiences a changing identity, requiring them to redefine the constraints of space and time.

Historically, identity has been theorised as being dependent on memory. As the psychologist Daniel Schacter explained: 'our sense of ourselves depends crucially on the subjective experience of remembering our pasts' (1996, p.34). Autobiographical memories, in turn, 'form the core of personal identity' (p.93). Temporality is at the heart of this assumption; the notion that personal identity is bound to the temporal trajectory of one's autobiographical past, present and future. This trajectory can be viewed as a 'biologically anchored sense of time' – in other words, 'remembered time' (Brockmeier, 2014, p.74). Therefore, we can understand why people with dementia are so often seen as having lost their sense of self and identity. Dementia is a memory disorder, with capacity for autobiographical remembering, impaired (Irish et al. 2011).

The scientific standard for viewing memory was, however, according to some critics, flawed. As Brockmeier (2014) noted, it rejected the conception of identity as rooted in anything other than autobiographical memory. It excluded the role of social and cultural processes, action and interaction. Moreover, many studies that have explored identity in the context of dementia have conceived of it as synonymous with autobiographical memory, which produces an inevitable narrative of loss. Addis and Tippett (2004) theorised autobiographical memory as being the source of trait self-knowledge and narratives. This enabled the 'integration of past and present selves' which allowed for 'the sense of continuity of identity' (p.56). The results of their study supported the authors' argument, in that participants with dementia were indeed found to have impaired autobiographical memory – and hence a loss of self. Brockmeier (2014), however, critiqued the study's focus on an experimental method and use of standardised tools. This was precisely what we needed to be moving away from.

Instead, according to Brockmeier (2014), there was nothing that prevented neurotransmitters from transmitting to intersubjective or cultural constructions of autobiographical memory, identity and time. Memory itself should not be seen as an individual entity, rather ‘a plethora of societally, culturally and historically embedded processes of remembering and forgetting’ (p.76). Similarly, identity should be seen as performative – as realised through action and interaction. In this vein, phenomenological work that explored the narratives of people with dementia represented far more meaningful manifestations of selfhood than memory tests. Thus, Brockmeier suggested ‘decentering memory’, which would lead to a ‘post autobiographical view of identity’ (p.86). In turn, this would enable consideration of the ways in which connections to the world are forged – despite the threat posed by dementia – and the multiple forms and practices through which identity can be enacted.

This thesis, which explores the experiences of people with dementia from a phenomenological perspective, concurs with the Brockmeier critique of associating memory with identity, and studies such as Addis and Tippett (2004), which relied on the use of experimental methods. It assumes that people retain a sense of personal identity and selfhood, despite the inevitable impact of dementia on aspects of their autobiographical memory, and similarly, that methods should be adopted that are suited to people with dementia (Sabat, 2001). Thus, it is important to consider other studies, which have used more of an exploratory approach to the study of selfhood, with a focus on the biographies and personal narratives of people with dementia. These studies, conversely, have largely found identity and selfhood to be intact.

Roger et al. (2014) interviewed people with a variety of neurological conditions, including dementia, to explore the threats posed to selfhood and how identity was preserved. The latter was achieved by patients hiding their illness from others, and avoidance of social situations where it might be exposed. However, they also sought solace and comfort in groups or communities of people in similar situations to themselves. Spirituality, for many people, was linked to a sense of control and direction in life. Importantly, goals were adjusted to account for the condition; patients modified their engagement in previously enjoyed activities – either by engaging less, or replacing said activity with something similar, but more viable. This allowed for a positive connection to be made with past identities (Roger et al. 2014).

Surr (2006) explored the selfhood of residents with dementia living in residential care, and found that people took pride in positive relationships with their family members. However, those whose relationships were damaged, perhaps as a result of family members avoiding the

person with dementia, were painfully aware of this and their sense of self was impacted. Residents' past occupations and social roles also contributed to the ways in which they perceived themselves. Their ability in the present, to construct new, valued roles in relation to past ones was crucial to a preserved sense of self (Surr, 2006).

2.3.1 Self-esteem

Self-esteem is a central tenet of this thesis, because it is part of the social constructionist model of selfhood in dementia (which will be discussed in detail in the following chapter) and it is largely absent from the dementia literature. Sabat and Harré (1992) proposed that a person's perception of his or her attributes was important to the sustaining of or damage to selfhood. The below literature considers self-esteem in relation to chronic illness, although the qualitative arm of this is relatively limited. This is because there are standardised tools to measure self-esteem, for example Rosenberg's (1979) self-esteem scale. However, for the purposes of this thesis, the relationship between self-esteem and selfhood will be explored through women's own stories. The literature below, therefore, considers self-esteem in the context of qualitative studies, which is in tune with the methodology used in this thesis.

The terms self-concept and self-esteem are important in the context of health, yet they have been used interchangeably. Garaigordobil et al. (2008) clarified the difference between the two. Self-concept consists of the cognitive aspects of self-knowledge – for example, descriptive judgements about oneself. Self-esteem concerns the evaluative-affective components – the appraisal of one's characteristics. Since descriptive statements about oneself usually include a degree of appraisal, so self-concept is generally accepted to include both descriptive and evaluative components of self-knowledge.

Drageset et al. (2018) studied survivors' experiences of coping following breast cancer. Among the losses was self-esteem. People expressed feelings of worthlessness and sadness that they were unprepared for and struggled to adapt to. Haahr et al. (2011) looked at the lifeworld of Parkinson's disease patients, and found that the loss of strength and changed body affected both self-esteem and perception of identity. Nicolson and Anderson (2003) studied patients with chronic obstructive pulmonary disease (COPD), and found the impact on self-esteem to be a key theme. For example, dependence on medication, the physical constraints of the disease, and the strain placed upon relationships, all served to lower self-esteem. People were concerned about their changed appearance as a result of COPD, and also, about the social

impact of certain symptoms, such as heavy coughing. As a result, they withdrew from social situations, for fear of embarrassment, which fuelled a loss of confidence and isolation. Moreover, there was a strong sense of blame that ran through participants' accounts. Self-blame led to feelings of being a burden and of self-distaste, which in turn led to lowered self-esteem.

An important paper for the present thesis, and for the literature on dementia more broadly is Cheston et al's (2015) presentation of dementia as an existential threat. The authors proposed that self-esteem, social connectedness and meaning in life were important factors in dictating people's response to such a threat. Those who feel good about themselves, and connected to the world around them are better able to find meaning and purpose in life, which enables them to better tolerate threats to their identity and selfhood. 'Retreating into a cultural worldview' – a way of thinking that holds meaning and allows for a sense of identity to be achieved – is central to preserving self-esteem (p.5). The person with dementia must invest in things that give them worth. For example, they may assert they still do the things they did previously. This was previously assumed to be a psychological symptom of dementia, whereby the person was out of touch with reality. Now, however, it is presented as a way of preserving self-esteem. The authors suggest that those around the person with dementia can foster a caring social environment that enables the person to forge meaningful connections with the world and preserve self-worth.

Gillies and Johnston (2004) looked at the experiences of people living with dementia and cancer, comparing the impact of these on identity loss and maintenance. They found that the impact of chronic illness and memory loss on self-esteem was significant, leaving their sense of who they are and were, vulnerable. Self-esteem could, however, be enhanced by drawing on the respondent's past, which illustrated the importance of bringing aspects of a person's past into the present, to preserve identity. The authors described the challenge, when people were faced with a degenerative illness, of trying to hold on to the certainty of self, that was previously robust, but that was now threatened. Self-esteem is accumulated over a lifetime of both self-appraisal and reinforcement by others. Therefore, if the response of others becomes negative, as a result of illness, for example, this reflects back on the person themselves, causing uncertainty and doubt.

The above studies provide a useful precedence for this thesis because they have drawn on interview accounts to explore the effects of illness on self-esteem. This study, moreover,

includes self-esteem as central to the overall research question, which explores the selfhood and identity of women living with dementia. It takes the view, proposed by Sabat and Harré (1992) that self-esteem is embedded within one's appraisal of one's characteristics and attributes. Additionally, the study aims to explore the interplay between the Self 2 and Self 3, and how self-esteem can affect or be affected by a person's social environment.

2.3.2 The embodied experience of dementia

Another framework that further supports the notion that selfhood and identity can endure, despite a diagnosis of dementia, is that of embodiment. This framework is useful in the context of this thesis, because it also challenges traditional assumptions that identity is dependent on memory. This section therefore offers a brief account of the ways in which embodiment have informed ideas of selfhood in dementia. Much of the work in the embodiment field has been developed by Pia Kontos, who described embodied selfhood as referring to 'the complex interrelationship between primordial and social characteristics of the body' (2004, p.837).

The differing experiences of men and women have been studied within the embodiment literature. Campbell (2012) has studied the importance of the 'sensory experience' of shaving for men with dementia, as way of reinforcing the gendered self (p.90). Buse and Twigg (2015) have analysed how preferences for skirts and dresses, as opposed to trousers, play a vital role in sustaining the gendered biographies of women with dementia. Lindemann (2009) detailed her own relationship with her grandmother, and how, when she was in the latter stages of the disease, her family played a vital role in holding onto her identity – for example, by giving her a manicure and painting her nails.

Ward et al (2008) conducted a study on practices in residential homes found that relatives placed a great deal of importance on how the person with dementia was presented, in terms of their appearance – because this 'supported an expected form of (embodied) biographical continuity' (p.641). In developing the *Hair and Care* project, which was a provision of hairdressing services to people with dementia, Ward and Campbell (2013) emphasised the importance of the sensory and affective dimensions of perspectives on appearance. When participants were having their hair done, the hairdresser themselves would commentate on what they were doing, and, where possible, the participants were asked to describe the sensations they felt. If they could not express themselves verbally, the sessions were filmed, and thus facial expressions and gestures captured in this way. This allowed for a foregrounding of the

multi-dimensional embodied experience. Subsequent unstructured interviews also took place, to gain an understanding of the social and cultural influences on a person's appearance over their lifespan, which was achieved through the use of reminiscence and supported by input from the caregiver and resources such as photo albums. Thus, 'appearance biographies' were created (Ward et al., 2014, p.65).

Much of Kontos' work focused on practices employed by the individual themselves, to maintain selfhood. Observing the activities, spontaneous interaction and mealtime routines at a Jewish residential home in Canada, she found that female residents took great care over their appearance. When one of the residents was seated at the table, in preparation for a meal, she suddenly reached beneath her bib to pull out a string of pearls, so that they were on display (Kontos, 2004). The participants were also revealed to have intact capacity for self-expression and creativity, taking part in organised singing and dancing sessions. Kontos described her participants as having 'agential powers', meaning that they engaged with the world and interacted with others with purpose and intention (p.836). This, she argued was fundamental to their selfhood. The embodied notion of selfhood referred to the body's power for natural expression, which operated below the threshold of cognition.

Whilst the work of Kontos and others emphasises biographical continuity between past and present as a means of repairing the disruption caused by dementia, some authors have queried the intentionality behind this assumption. They have suggested that disruption could, in fact, signal something more positive (Sandberg, 2018). Ward and Price (2016), for example, noted that expectations concerning gendered norms and ways of behaving may be lost when a person is diagnosed with dementia, and that this might allow them the freedom to explore other facets of their identity that might not have been possible before. Similarly, Boyle (2013) looked at decision-making capacity, from the perspective of people with dementia and their spouses. Husbands attempted to preserve their wives' role as homemaker, imposing this on them, even when the wife, now having been diagnosed with dementia, rejected it. Boyle found that some husbands drew negative comparisons between the past and present, with one emphasising that his wife had previously been 'a fairly normal housewife, in getting things ready, or tidying things up', whereas now, there were jobs 'that she never gets done' (2013, p.235). Yet his wife, for her part, professed no interest in doing housework anymore, and insisted she would 'rather be pursuing a hobby' (p.235). Thus, it might well be the case that, in our fixation with emphasising biographical continuity, we are neglecting to consider the other side of the coin;

namely that some people might be actively rejecting this continuity, and might indeed desire a change in identity.

Embodiment should be considered as a resource through which people with dementia can communicate. The fact that a person may have lost all or some of their ability to articulate verbally does not mean they should be assumed incapable of social interaction and excluded on this basis. Research has demonstrated that communication through embodiment is a valuable creative device in preserving a sense of self. Hydén (2013), for example, describes the ‘adaptive compensation’ used by people with dementia who have speech impairments, whereby the relationship between spoken word and gesture is restructured (p.3). This is supported by Hughes (2013), who believes that understanding a person constitutes more than merely understanding what they are saying. Thus, meaning is assigned according to a shared inter-personal context, not words alone. One can therefore interpret the gestures and body language of someone with dementia as subtle forms of communication, even when the person has little or no remaining speech. In this sense, the embodiment framework allows us to ground approaches to care in a process of ‘shared connections’ rather than cognition, and for meaning to be located in the context surrounding linguistic discourse (Hughes, 2013, p.9).

The literature on embodiment and embodied selfhood is important, because it illustrates the myriad of ways in which selfhood can be preserved, even in the latter stages of dementia, illuminating the ‘richness of behaviour that has heretofore gone unrecognised’ (Kontos and Martin, 2013, p.294). Embodied selfhood endures when the person is severely cognitively impaired and unable to communicate verbally. As Kontos explains, it operates ‘below the threshold of cognition’ (2004, p.837). It is inexorably linked to gendered norms and biographies, in the sense that many embodied practices centre on appearance work, or dress. Finally, embodiment appears throughout social constructionist accounts of selfhood, where the emphasis on sustaining the self in social situations reiterates the significance of a gendered past (Sabat and Harré, 1992).

2.4 Women and dementia

As this thesis is focused on the experiences of women, specifically, it is important to consider the existing literature in this domain. Most of the literature on dementia and identity has used a mixed sample. But given that the disease disproportionately affects women, there is a need to understand the impact on the selfhood and identity of this group.

A report by Erol et al. (2016), that reviewed the existing literature on women's experiences of dementia internationally, found that few studies actually included the views of women themselves. They stressed the importance of considering identity as part of the family system, for example, the roles within this system held by women prior to a dementia diagnosis, and how the dynamics of such relationships change as a result of dementia. Spouses have an important role in supporting a continuity of gendered sense of self in women, particularly, as Calasanti and Bowen (2006) have shown, with regards to appearance. Furthermore, identity maintenance was found to be complicated for some women, due to cultural associations of dementia and the meanings attached to the disease. The authors concluded by noting that the majority of research into women's experiences, focused on their roles as caregivers, and moreover, that few studies explicitly discussed gender, which was important to consider with regards to policymaking (Erol et al. 2016).

Similarly, Savitch et al. (2015) stressed the need to encourage the voices of women in the dementia literature, as these were not heard as loudly as men's. In reporting on the experiences of women, they found that many women felt invisible and powerless, due to a lack of control over their lives and roles within their family becoming threatened. There was a paradox in those women who lived alone, in that this group were particularly vulnerable to not being heard, but they conversely had more control over their lives and worked harder to sustain pre-diagnosis attributes. The social construction of roles for women, meant that they were often defined by being a wife, mother, friend etc. Dementia threatened the stability of these. Men, on the other hand, were more likely to be identified by status roles, e.g. doctor, engineer, lawyer. The authors argued, therefore, that society more readily equates the selfhood of men with status roles, and hence their loss of identity is perceived as more visible. Because women are less likely to be identified by such roles, when women withdraw from social life, it is less noticed. Moreover, the tendency to emphasise women's roles in terms of family and home, risked overlooking the significance of their working lives, because of culturally expected norms. Instead, it is important, going forward, that the diversity of roles held by women is focused on.

Frazier et al. (2011) focused on women diagnosed with Alzheimer's disease, who lived alone, to explore whether the absence of a spouse to sustain the social self, made damage to other aspects of selfhood more likely. Many had lost valued roles, including as a mother and nurturer, which led to feelings of isolation. Loss of independence had led to a decrease in mobility, and

associated decline in confidence – for example, no longer being able to drive. Because of this, it was particularly important that the women maintained control in other areas of their lives, such as decision-making. By using specific strategies to cope, the women ensured their freedom could still be preserved, which in turn preserved self-esteem. Self-esteem was also dependent on social situations, for example, in how others reacted to memory lapses or mistakes, which impacted directly on the person's self-evaluation. For some women, home was a sanctuary and they did not venture far afield, thus protecting themselves from the internal threat of forgetting and the external threat of the consequences of this. However, they also desired connections with others. Joining a memory club provided many benefits, although it also served as an admission that this was the group to which they now belonged, and indicated to others that memory loss was a part of that person's identity.

In advocating for a person-centred approach to care, Shenk et al. (2002) studied two women living in rural America, one of whom had dementia. The authors found this woman's self-identity to be present, with similar themes emerging compared to the account of the woman without dementia. They found that memories, cultural and social ties were preserved, despite cognitive losses, but emphasised the role of other people in helping the person with dementia to connect with these and thus retain their identity. This included the researchers conducting the interviews, who were responsible for the co-construction of narratives. Such an approach, based on exploring the answers participants gave, rather than following a structured interview guide, was one that I replicated in this thesis, with the aim of facilitating richer, more personal accounts.

Van Dijkhuizen et al. (2006) explored subjective accounts of coping, self and identity among women living with dementia, and developed the 'Level of Connectedness Model', (p.79), at the core of which was people's relationships with others and their environment. The authors positioned their participants on a continuum of connectedness vs disconnectedness. The former was associated with positive adjustment to changes and acceptance of the situation – including normalising dementia as part of the ageing process and comparing oneself favourably with others, as well as staying active and engaged in life. Threats to connectedness included protective strategies, such as minimisation and avoidance. Finally, the extent to which the participant was connected with family, friends and her environment, and maintained valued social roles, could mediate connectedness. This was in contrast to Pearce et al. (2002), who studied the coping responses of men with dementia, and found that reconstruction of their sense

of self carried more weight, rather than connectedness and interpersonal factors. This supports the notion that there are differences between men and women in coping with dementia. For men, the focus is on autonomy, for women, on the development and maintenance of relationships. These differences are relevant to this thesis, which is interested in considering the identities and coping behaviours of women living alone, as well as women who may otherwise reject the social construction of nurturing/caring identities.

Although not focused solely on women, Boyle's (2017) study explored the gendered sense of identity and agency among people living with dementia, to find out what mattered to them. Women, it seemed, were far more tied to relationships with their spouse and family. They described themselves as being part of a couple, in terms of their love for their partner and the social lives they shared together. The men with dementia were far more tied to a sense of independence, which was hugely important to them. They didn't want to accept dependency on anyone. Their occupational personas were also far stronger than they were for women. Contrastingly, the women emphasised domestic competencies and relational concerns, such as the emotional support provided to friends and family. This thesis is interested in taking these findings further, by exploring the notion of gendered identity with a larger cohort of women, as well as a cohort with different social backgrounds, to see if similar findings are reached. The sample size in Boyle's study was small, and it might be expected that women who lived alone, or had a particularly high educational attainment level, may present a different view of what matters to them.

In a case study by Borley et al. (2016), the experiences of a woman with dementia becoming cared for were explored. In terms of her awareness of her changing health, the woman downplayed the significance of her diagnosis, perhaps to protect her sense of self. When discussing her difficulties in completing certain tasks, she ascribed these to her physical health, perhaps because this was easier to acknowledge and less stigmatic than dementia. Throughout, there was a strong emphasis on sameness. Importantly, her family supported this view of herself as unchanged, affording her the same integral familial role as they had previously, where she was the central caring figure and felt valued. The woman shopped, cooked, cleaned, played with her grandchildren and socialised with friends. Sameness to her was continuity of involvement in such things, and the support of her family enabled her to do this and this maintain her identity. The findings of this study are relevant to the present thesis, where the notion of adjusting to the changes brought about by dementia will be discussed, along with the

roles that different kinds of families play in helping to sustain identity, but also instances where tension may arise between people with dementia and their social environments.

In 2017, Borley and Hardy conducted a follow-up study to the above, exploring the impact of becoming cared for on the identities of a larger sample of women (8). This study found that some women had a negative sense of self, perceiving themselves as different to previously and evidencing an inability to come to terms with this. Those positive attributes from their past weren't carried forward, which led to feelings of uselessness and helplessness. Other women fought to retain their pre-diagnosis identities, aware that certain familial roles were changing, but still trying to maintain these nonetheless, by focusing on the things they could still do. This thesis shows that women deal with the transition to being cared for in a variety of ways. The loss of ability to perform certain tasks – particularly those that were seen as synonymous with being a woman, such as housework – threatened the identity of some participants, and led to low self-esteem. Those women whose past lives had been influenced by such gender-based roles experienced a particular threat to self as a result of such losses.

Robertson (2013) explored quality of life, sense of self and social identity in a woman living with dementia. In common with previous studies, family was central to identity, but the participant saw their own position within the family system as diminished. She made critical comparisons with the past, perceiving others as imposing restrictions on her continued ability to carry out certain tasks, and taking valued roles from her. As a result, her social identity was diminished, and her quality of life affected. The participant, however, emphasised her sense of self as continuous – despite the perceived loss of status within her family. She attempted to resist the restrictions imposed on her, constantly reiterating to the interviewer the range of things she could do, and comparing herself favourably to others of her generation. Her sense of self was supported by the day care centre she attended, where she was able to construct a valued identity as a worker and which gave her life meaning. This study suggests that good quality of life is dependent on a person's ability to make sense of their experiences 'in ways that enable them to continue to be represented as ordinary within their social context' (p.538). In other words, by maintaining connections to one's past, or by 'establishing roles and relationships that bring a new sense of purpose to life' (p.538) – such as the day care centre in this woman's case. This was essential to her sense of status and social identity.

The above literature is important in the context of this thesis, because it is from a small pool that has considered the experiences of women. A strong theme running through the literature

is the notion of role identity – for example, social, familial etc. – and loss or maintenance of this. This thesis will build on these concepts, by further exploring familial roles and their relationship to identity and selfhood, while also exploring how the loss of past attributes and valued roles impacts on self-esteem. It will also consider the importance of occupational and status roles – roles often associated with the identity and selfhood of men – to explore whether these are significant for the present cohort of women. Generally speaking, the literature above mainly focused on case studies or small sample sizes, whereas this thesis has used a larger sample of 12 women. The 12 also come from different walks of life, have differing levels of educational attainment and different careers. They are also living in different circumstances – with some living alone and others with a partner. Unlike the above literature, this thesis will use a social constructionist framework to explore selfhood.

2.5 Conclusion

The research question for the present study emerged as a result of gaps identified within the above literature, particularly in relation to the experiences of women and the role of self-esteem in qualitative research. This thesis will therefore explore the impact of dementia on the selfhood and identity of women, giving particular consideration to their self-esteem, and how they perceive themselves.

The literature review considered both the importance of individual and social forces in shaping the experience of chronic illness, and dementia specifically. In an individual context, illness can be conceptualised as a form of biographical disruption that poses a threat to selfhood and identity. Numerous studies, reflecting the dominance of the biomedical model, have purported that the nature of dementia means that selfhood is inevitably lost. Others, however, have challenged this view. Of particular relevance to this present thesis, is the literature that has focused specifically on the selfhood and identity of women.

All of the literature above will contribute something important to this thesis, which I will draw upon, expand and challenge. Section one of the review, which deals with lay understandings of illness, shows how people make sense of and interpret symptoms and the associated threats to identity. It purports that a diagnosis can threaten one's sense of self. This literature is relevant to this thesis because the nature of dementia means that people living with the disease are particularly vulnerable to a loss of self. Stigma, both felt and enacted, can impact the person's

decision to disclose their illness to others, which can in turn impact selfhood and self-esteem – one of the central concerns of this thesis.

Section two deals with selfhood and identity in the context of dementia, which is relevant because this thesis explores these concepts with regards to women. Thus, those theories that have challenged traditional assumptions of selfhood as being linked with memory are challenged. Self-esteem is an important component of the social constructionist model, and is relevant because I am particularly interested in the interplay between people's evaluative aspects of their self-knowledge, and their ability to construct a social identity.

The literature on the experiences of women with dementia is important, because, although small, this is the starting point for the present thesis. I will contribute to this body of work by developing concepts related to selfhood and identity further, and also by including a larger and more diverse sample than other studies. This will help to explore how women from differing social backgrounds, with different life experiences, are impacted by dementia. This should challenge the view, presented in the extant literature, that women are largely defined by the socially constructed, but restricted roles of carer and nurturer. Instead, this thesis hopes to show that women's roles in lives should be conceptualised far more broadly.

The following chapter draws on the above literature to set out the theoretical framework I will apply to this study.

Chapter 3: Theoretical Framework

3.1 Introduction

This chapter explores the theoretical framework of the thesis and argues the reasoning behind adopting a social constructionist approach to selfhood in dementia. The social constructionist approach is based on psychosocial models of dementia and adopts the principle that selfhood is expressed through discourse and the telling of stories (Sabat, 2001). This is the first way in which it is an ideal framework for the present study; all participants were willing and able to talk at length about their lives.

Secondly, the social constructionist framework takes into account how personal and social identity are impacted by the disease – both of which this thesis explores. The interview schedules explore personal identity through questions on how the participants perceived themselves, and how this had changed. They explore social identity through discussion of interpersonal relationships and social networks.

Thirdly, my interview schedules have given specific focus to the role of self-esteem, which this thesis also explores. Whilst not considered a core component of the social constructionist model itself, both Sabat (2001) and Harré (1998) have acknowledged its importance in the context of the Self 2 – or as an aspect of one's self-concept. They discuss how negative positioning can affect a person's self-esteem, which in turn impacts both the Self 2 and 3. This thesis will expand on the above theory, but will also consider self-esteem more broadly, rather than purely as a result of negative positioning by others.

Finally, and more broadly, there is now a wealth of evidence supporting the view that chronic illness should be considered within a wider context (e.g. Turner and Kelly, 2000). In other words, biomedical models of illness are limited in their capacity to account for how people respond to and cope with a diagnosis, and the impact on their psychological wellbeing. Relatedly, research into dementia has lagged behind in that it has only relatively recently begun to include first-person accounts, having hitherto either given primacy to caregiver accounts of living with the disease, or used these in place of first-hand experiences (Cotrell and Schulz, 1993). Thus, the social constructionist model fits with this study's fundamental philosophy, which is to contribute to the growing literature that puts the perspectives of the person with

dementia at the forefront of research (e.g. Lyman, 1989, Brooker, 2003), in allowing for selfhood to be expressed through the construction and co-construction of narratives.

The first section of this theoretical framework chapter begins by setting the scene for the social shift in dementia research, by considering the dominance of the biomedical model through the years. The following sections will signal the move away from this, beginning with a look back at the origins of the social self. This will discuss the work of G.H. Mead and Charles Cooley, before considering William Stern's Critical Personalism – upon which the social constructionist model of dementia is ultimately based. The chapter then moves onto the social constructionist model of dementia itself, describing in detail the individual and collective contributions of its two founders: Steven Sabat and Rom Harré. It finishes with a section on self-esteem – an integral concept, both to the above model and to this thesis.

3.2 Setting the scene: The dominance of the biomedical model in dementia research

Psychosocial models of dementia were developed in opposition to the predominance of the biomedical model that in many ways still continues to take precedence. This is supported by the DSM-V definition of dementia as a neurodegenerative condition, classified by a deterioration in one's cognitive capacities (American Psychiatric Association, 2013). The psychologist Steven Sabat, whose research was dedicated to evidencing that people with brain injuries retained social and cognitive abilities, referred to this as the 'Classical Science' approach (2001, p.9). He was a vocal critic of what he saw as a missed opportunity to view the person with dementia as defined by anything other than standardised test scores. It removed the person from real-world situations, from their social milieu. Moreover, it did not account for the fact that, whilst encountering difficulties in responding to cognitive testing, people with neurological impairments nonetheless depend more heavily on socially contextual information than people without such impairments (Sacks, 1985).

This echoes the critique of experimental psychology more broadly, particularly the dominance of statistical models. Kurt Danziger, who wrote widely about the history of psychology, decried what he saw as its methodology becoming 'institutionalised' (1985, p.3). In other words, the design of experiments being dictated by statistical techniques that also impacted on the way in which data was gathered. Such techniques were concerned with numerical data, which in turn required the imposition of a numerical system on the data source. According to Danziger, this meant that the numerical system was taken to 'represent the structure of the empirical system'

(p.4). The empirical system is therefore only knowable through the numerical system used for statistical inference. He concluded his critique by noting that the numerical system involves the structuring of the domain in question, into elements with particular properties. The elements must be independently identifiable – for example, specific responses on a cognitive test, such as the MMSE. This inevitably results in the psychological world in which one is interested, being narrowed down and structured according to clearly defined parameters (Danziger, 1985).

However, before moving on to the critique of the biomedical model of dementia, specifically, it is important to recognise the other side of the argument, namely that the biomedical model has been a force for good. Dementia is a pathological condition, distinct from normal ageing – although the exact biological determinants thereof are complex (Kenigsberg et al. 2016). This has arguably helped to lessen the stigma associated with dementia, because the patient is perceived as a victim of circumstance, with no responsibility for, or control over their illness (Wade and Halligan, 2004). Moreover, the biomedical model has helped to legitimise government policy and funding initiatives, with dementia now widely seen as a growing public health issue, that will place strain on the NHS and health and social care resources (Manthorpe and Iliffe, 2016).

As early as 1989, Karen Lyman offered a strong critique of what she saw as the ‘biomedicalisation of dementia’ (p.587). The model failed, Lyman argued, because it did not take into account the ‘quirks and eccentricities’ of individual lives, or how so-called deviant behaviours might be related to a person’s life history (Lyman, 1989, p.600). The work of Erving Goffman is also relevant to a critique of the first proponent of the biomedical model of dementia: a pathological condition. In discussing the proliferation of asylums, Goffman described the ‘moral career’ of the mental patient (1961, p.127). The labelling of someone as ‘abnormal’ – based on their receipt of a neurological diagnosis – triggers a similar set of circumstances and has far-reaching implications. These circumstances occur, not because of the illness, but in spite of it. The act of assigning ‘common fate and common character’ to those afflicted with the diagnosis, serves to distance oneself from the reality faced by others (p.129). By virtue of having been labelled, that person’s social opportunities are reduced, if not denied to them completely. Ultimately, Goffman argued, the effect of being *treated* as deviant was distinct from the pathological traits associated with a particular illness (1961). Such a view was supported by the substantial contribution to the literature of Anselm Strauss (1975), who discussed the social impact of chronic illness. Labelling causes the individual to be cast aside,

consigned to a category of persons assumed to be defective or inferior. This in turn results in excess disabilities (Brody et al. 1971) and learned helplessness (Seligman, 1972).

Lyman also rebutted the second claim of the biomedical model; the notion that dementia was characterised by progressive deterioration. Specifically, the assumption that brain deterioration corresponds with impairment throughout the course of the disease. This creates a stage theory of decline within the biomedical model, which in turn leads to expectations of a person's competence or incompetence. Yet evidence has shown there to be very little universality in the progression of dementia, with the rate of decline varying significantly from person to person (e.g. Ritchie et al. 2015). Hence, expectations that are built on acceptance of the model's stage theory may create a negative social environment for the person with dementia, where they are presumed – erroneously – to have a certain level of impairment (Lyman, 1989). Finally, Lyman turned her attention to the final claim of the biomedical model, namely that it is medical authorities who must provide care and treatment. There was, she argued, a pertinent issue here, to do with power and control, and how this was exerted over vulnerable adults. This stemmed mainly from the fact that dependency in care settings, was encouraged, with autonomy and independence quashed. Viewing dementia as a purely biomedical condition, therefore, individualises the disease, and depoliticises these power relationships between caregiver and care-receiver (Lyman, 1989).

In much the same way as G.H. Mead (1934) endeavoured to show that the mind and self were intrinsically linked with the social world, Lyman proposed that all human experience – including dementia – was rooted in socially structured environments, and that consideration of these was missing from research and the literature (Lyman, 1989). In the following decade, a shift from the biomedical to the psychosocial model of dementia, finally began to take hold. Steven Sabat and Tom Kitwood were two of the most prominent figures at the forefront of this movement, with their theories of selfhood (1992) and personhood (1997) embedded within the dementia experience respectively.

3.3 The origins of the social self

In order to understand the grounding of the social constructionist approach, it is necessary to go back through the work of influential early 20th century thinkers, such as Charles Cooley and G.H. Mead, both of whom advanced the theory that selfhood was social. In contrast to the psychology of cognitivists, where human action was considered the domain of individual

mental processes, the social constructivists asserted that human action was instead conceived of 'the joint intentional actions of minded creatures, whose minds are structured and stocked from a social and interpersonal reality' (Harré, 1983, p.8).

Mead, a social psychologist, wrote widely on a variety of interrelated topics that explored the complex, multi-faceted nature of selfhood. In the introduction to his first book: *Mind, Self and Society*, one of his former students, Charles W. Morris notes that Mead's aim was to transform the biologic individual into a social being, by illustrating the capacity possessed by that individual for self-consciousness, abstract reasoning and purposive behaviour (Mead, 1934). In contrast to the theory of biological determinism, Mead proposed that the self did not exist at birth, rather it was developed over time in social interaction and relations, enabled by language – to which he assigned primacy. This social self was regarded as 'an agent of interpretation, definition, and action within a social field' (Dunn, 1997, p.688).

Mead identified two stages in the development of the self: play and game. Firstly, in play, the child is able to assume the role and attitudes of one other person or animal. Secondly, in game, she assumes the roles and attitudes of all other members within a wider social group. In other words, she assumes the attitudes of what Mead called the 'generalised other' (Mead, 1934, p.154). Essentially, then, the generalised other refers to the attitudes possessed by different social groups. The self-conscious individual assumes these attitudes of the group to which he belongs. For example, identifying as a member of a political party involves adopting the wider attitudes of that party in response to particular situations.

These attitudes, specific and general, are assimilated into the facet of selfhood that Mead terms the 'Me'. The 'Me' is the attitudes of others. The second facet of selfhood is the 'I', which is the action and impulse principle, reacting to the 'Me'.

'The individual experiences himself from the particular standpoints of other individual members of the same social group, or from the generalised standpoint of the social group as a whole'. (Mead, 1934, p.138)

In other words, the actions of others reflect back on oneself. This leads to the individual becoming an object to himself, in the same way that other people are objects to him. The impulsive being, therefore, through exposure to society, becomes a rational man who acquires reflective thought and the capacity to choose one course of action over another on the basis of

the anticipated consequences. This in turn transforms society itself into a structure where the ‘roles of others are implicated in the common activity’ (Morris, 1934, p. xxvi).

Charles Cooley proposed the theory of the ‘looking glass self’ (1992, p.184). In other words (and aligning with Mead’s ‘Me’), one perceives oneself, in terms of appearance, character, personality etc. as though through the other. This interpretation acts as one’s social reference point – the way in which one imagines oneself is perceived in the mind of another. Perception of one’s character and subsequent evaluation of how that will be judged in a social context accordingly produces positive or negative feelings. Importantly, the assigned weight given to the other in question will have a significant impact as to the potency of these feelings. Accordingly, they will be more marked if facing the judgement of someone whose opinion we value. There is also an allusion, in Cooley’s theory, to Goffman’s theory of self-presentation, which will be discussed in more detail below. Cooley (1983) asserted that, depending on how one perceived the other and social context, and by implication, the anticipated judgements, one learns to be different things to different people.

Another important contributor to the social constructionist account of selfhood, was the German philosopher and psychologist William Stern. Sabat (2001) specifically acknowledged Stern’s influence, citing his theory of Critical Personalism (1938) as central to social constructionism. Stern stated that ‘research carried out in psychology over the past half-century has made apparent to us a huge variety of mental attributes that are or could be present in a given individual’ (Stern, 1917, p.113). Indeed, he was disdainful of what were at the time, mainstream scientific methods, contrasting his personalistic approach with the ‘*impersonalism*’ of these (Lamiell and Deutsch, 2000, p.719). This included criticism of his own most high-profile concept: the intelligence quotient or IQ, and the quantitative measurement of this. He was concerned that the flourishing of such experimental approaches would lead to what Lamiell and Deutsch (2000) describe as ‘mechanistic accounts of mental life and behaviour’ (p.718). As a result, Stern emphasised the weaknesses inherent in such tools, and their inability to capture the ‘enduring psychological characteristics’ of a person (Stern cited in Sabat, 2001, p.226).

Critical Personalism was Stern’s response, through which he believed he could understand more fully, the complex psychological depths of human beings and their behaviour (Sabat, 2001). He conceived of the person as an intentional agent and argued that we act out our intentions through the body. In other words, ‘goal-directed activity is manifested in breathing

and limb movements as well as in thinking and striving' (Stern, 1938, p.70). The body is also a vehicle through which a person's psychological experience of the external world is understood. It follows, as Sabat (2001) argues, that if a person's brain were to become damaged, this would impact on their ability to employ their body as a vehicle through which to experience the world around them. Furthermore, Stern's (1938) conception of the person as an active agent, 'striving toward goals' (p.70), chimes with Sabat's (2001) description of a 'meaning-driven subject' (p.231).

One important way in which meaning can be observed is through processes such as what Stern calls "assimilation" and "counteraction". Stern states that the person 'reacts against the world with the force of counteraction whenever his own being must be asserted in opposition to the process of assimilation' (1938, p.91). In describing assimilation, Stern refers to a person being made into a homogenous 'number among other numbers', and thereby losing their individual identity (Sabat, 2001, p.231). Healthy people may be able to oppose this by way of counteraction, through assertion of their individuality. However, for someone with dementia, it is more difficult. Thus, if this person is positioned in such a way that they are grouped into the category of 'Alzheimer's patient', there is a danger that more valued attributes and characteristics will be overlooked, and ultimately, that this person will become subsumed into a highly stereotyped category (Sabat, 2001, p.231). Furthermore, any attempt at counteraction by the person with dementia risks being misinterpreted by others as merely confirmatory evidence of this stereotyping.

This is akin to various theories of dehumanisation, particularly those put forward by Haslam (2006), who asserted that such behaviour occurred along two dimensions of humaneness. The first of these was human nature characteristics, including 'emotion, intuition, spontaneity, and soul or spirit' (p.254). These are what differentiate humans from robots, and they are seen as shared, fundamental features of people. The second dimension was human uniqueness, which included 'civility, refinement, moral sensibility, higher cognition and maturity' (p.257). These set humans apart from animals. Thus, denying a person human nature characteristics led to the perception of that person as cold and unfeeling. Denying a person human uniqueness led to the perception of that person as childlike, immature or immoral. Miron et al. (2017) found that people are more likely to apply the latter to people with dementia, assigning them lower status, condescension, disrespect and denying them their autonomy. Dehumanisation also leads to negative self-perceptions, which has been shown in research on dementia and stigma (e.g.

O'Sullivan et al. 2014). Empathy, it was concluded by Norman (1996) was key to the care of and interactions with people with dementia. This helped to focus on the 'person, not an illness' and for human connectedness to persevere over professional objectivity (p.315).

The above refers to relations between the person and the external world, however Stern also turned his attention to personal dimensions of psychological life. The two most important of these, for the purposes of this thesis, are the inward-outward dimension and personal present. In describing the former, Stern observed that 'the personal world has a natural centre from which and toward which everything pertaining to it extends' (1938, p.91). In other words, the inward-outward dimension can be compared to Rom Harré's Self 1; the continuous experience of an individual in the world (1983). One's thoughts and feelings are 'inside', and things and other people are 'outside' (Sabat, 2001, p.232). From this natural centre, people with dementia have been shown to evidence different social personae, as well as the ability to evaluate the significance of social situations (e.g. Sabat and Harré, 1992).

The personal present, described by Stern, refers to the here and now. Crucially, however, this is determined by personal perspective. In other words, being a doctor, nurse, daughter or mother can be part of someone's present even though they are aspects of that person's past. Sabat (2001) uses the example of a male participant with dementia, who, when introduced as having been a lawyer, offers the rebuke: 'I *am* a lawyer' (p.233). Thus, being a lawyer was part of his personal present, even though he had not practiced law for many years. By bringing these valued attributes to the fore, the participant may even be attempting to dissociate himself from merely being assigned to the category of 'dementia patient'. For Stern, the personal present was not dependent on the objective definition of temporality, rather 'upon the personal relevance of the factors contained in the life pattern and the situation' (1938, p.93).

Finally, a person's reality is impossible to understand without being able to relate this to goals. Sabat (2001) argues that we cannot understand the experience of the person with dementia without 'exploring the goals and intentions of the afflicted person, what fills his or her personal present, the ways in which he or she engages the world, and behaves with counteraction' (p.234). Stern identified two types of goal-directed behaviour: autotelic and heterotelic. The former relate to self-development, to individual growth. The latter extend beyond one's own interests and are reconciled with the goals of others (Lamiell and Deutsch, 2000). This illustrates how critical personalism is far from a theory of individual psychology. The process by which the heterotelic are taken into the autotelic signals 'the convergence of a person with

the world around him' (Lamiell and Deutsch, 2000, p.725). This includes convergence with other people, and ultimately marks critical personalism out as a social psychology; one that heavily influenced Sabat and Harré's subsequent constructionist account of selfhood, and hence the theoretical underpinning of this thesis.

3.4 Social constructionism and selfhood

The notion of dementia as socially constructed was put forward by Harding and Palfrey (1997), who argued that Western conceptualisations of dementia – as an illness of old age – fuelled a sense of fear in the ageing population. The medical profession, moreover, was considered key to this, with medicine defining what constituted normal and abnormal behaviour in society. The person with dementia, therefore, whose behaviour didn't conform to society's expectations, could find themselves treated in such a way that was rendered acceptable by the medical profession. The social construction of dementia as a disease entity furthermore dominated the discourse surrounding care regimes. The authors claimed that 'with ageing comes a retreat from the body, and with this retreat comes a loss of sense of self' (p.140). Thus, difficulty in observing the three aspects of self as will be outlined below by Harré, may be compounded by the difficulty the person with dementia has in recognising their ageing body and retreating to earlier memories of a healthier, youthful mind and body.

Harding and Palfrey (1997) drew on Foucault's conception of the body and gaze, and the notion of society as a body, made up of cells represented by human members. Thus, the elderly or those not in good health are presented as threatening the body – or society – as a whole. People with dementia, specifically, are believed to be unable to exert self-control and hence pose a threat to the social body, which reinforces the notion that they need to be controlled. Gilleard and Higgs (2000), similarly, claimed that 'a body which the mind has lost control of becomes instead the decivilized body' (p.168). The state is then conceived of as occupying a civilising role within society, with family members and others responsible for providing care, as regulating and controlling the person with dementia.

The social constructionist approach to selfhood was heavily influenced by the theories of Mead and Cooley outlined in the previous section, and was developed initially by Rom Harré, a British philosopher and psychologist. Harré would later collaborate with Steven Sabat in applying the social constructionist account of selfhood to dementia, specifically. Harré conceived of the Self, not as an entity, but as three distinct manifestations of personhood

(1998). Firstly, the Self 1, according to Harré's theory, involves one's point of view and the location from which one perceives and acts on the world. Self 2 denotes the sense of self in terms of one's attributes (e.g. undergraduate, doctor, mother, Alzheimer's patient), which, whilst fluid and changing, nonetheless remain constant in the realm of being unique to that individual. Finally, Self 3, referring to the impression of oneself through the eyes of others (Harré, 1998). With regards to the Self 3, Harré differentiated between two distinct aspects of this; the persona as one attempts to present it to other people, but crucially, the way in which this presentation is interpreted by others. The former is carried out through ways of acting and speaking, and the latter is manifested in the ways in which personality and character traits are attributed to a person.

Also central to the social constructionist model is the notion of 'positioning'. Positioning, according to Harré and colleagues, is concerned with 'revealing the implicit and explicit patterns of reasoning that are realised in the ways people act towards others' (2009, p.5). In other words, if someone with dementia is positioned as a 'patient' by their spouse, this will inform said spouse's behaviour towards that person. Implicit in this theory is the distribution of rights that takes place within social interaction. Positioning can also lead to the development of future expectations and interpretations of a person's behaviour. Using the example above, the positioning of someone as a 'patient' will be reinforced by the interpretation of future actions and behaviours accordingly because these fit the narrative already created (Sabat, 2001). There is an inherent power dynamic at play in situations such as this, in the sense that someone with dementia may not have the ability to resist being positioned in a negative manner, compared with someone with no cognitive impairment.

Within this thesis, positioning will be considered in the ways that people within the social worlds of the women with dementia behave towards them. However, it will also be considered in the ways in which the women position themselves to me, as the interviewer, and how I in turn participate in these positions – or indeed, may attempt to counter-position a participant. An example of this can be found when Stella realises she can't remember her granddaughter's name. My response was to play down the impact of such forgetfulness – to normalise it. Stella then agreed with my assessment, and avoided being positioned as someone with more serious memory problems. This is also consistent with the interpretative element of IPA; showing how meanings are constituted both within and in relation to the interview environment (Holstein and Gubrium, 1997).

Positioning theory has many similarities with other related theories, such as labelling. Labelling first came to prominence in the 1960's, in the work of a group of sociologists, among them Howard Becker and Edwin Lemert. Becker (1963), in his discussion on deviance, asserted that there was no such thing as deviance, rather it was a form of behaviour created by the social labels applied to others. Deviancy, therefore, refers to behaviour labelled by others as abnormal in some way. Once the label has been applied, the person is treated differently, and their self-perception may be altered, thus creating a self-fulfilling prophecy. Lemert (1964) drew a distinction between primary and secondary deviance. Primary deviance was the act of labelling by someone accepted as having the authority to do so. Secondary deviance was the effect of the labelling on the person themselves. Using the example of dementia, when a diagnosis has been received by someone in the medical profession, the label is legitimised. In terms of the effect on the person, being labelled as 'demented' or 'confused' can result in others treating them in a manner that is infantilising or demeaning (Bond and Corner, 2001, p.102). As a consequence of such treatment, the person with dementia may respond in such a way that reinforces application of the label.

Sabat and Harré (1992) describe selfhood as rooted in both personal and social identity. The former refers to one's point of view and agency, the latter to the self that one presents in public. The three dimensions of selfhood will now be discussed in more depth, as well as the relevance of each dimension to the present thesis.

The Self 1 is described by Sabat and Harré (1992) as the self of 'personal identity' (p.445), used to express one's point of view and evidenced linguistically through the use of personal pronouns, such as 'I', 'me' and 'my'. In other words, the Self 1 is the 'singular self', and reflects the fact that the above referenced point of view 'must be continuous relative to an encompassing material framework, including the world of other embodied beings' (Harré, 1998). The use of the personal pronoun 'I' serves as self-reference; allowing speech acts to be individually located and experience to be organised (Harré, 1983). The Self 1 signals ownership of what one is saying, and is 'a point in psychological space'; hence it is not dependent on the cooperation of others (Sabat and Harré 1992, p.446). Moreover, such above linguistic expression is intertwined with personal history, in the way that the speaker uses indexicals and pronouns to construct a narrative autobiographical account. Self 1 has been shown to be preserved in people with dementia; that is to say, even in the latter stages of the disease, people retain the ability to index their accounts and take ownership of experiences, no

matter how significant the decline in other cognitive and functional attributes (e.g. Sabat and Harré, 1992).

This evidence is important because it serves to nuance the accounts of the relationship between loss of selfhood and dementia. The participants in the present study will be encouraged to construct narratives around personal identity, whereby they can index ownership of experiences, thoughts and emotions. Given that those with severe dementia still evidenced an intact Self 1, it is reasonable to assume that people with early-stage dementia will be able to do so to an even greater extent. The Self 1 is also a necessary precondition for the existence of multiple selves (the Self 3). In other words, the ‘lived experience of diversity’ in one’s Self 3 is the ‘common form of personhood in everyday life and presupposes the singularity of each Self 1 in association with just one body’ (Harré, 1991, p.55).

The Self 2 is important for exploring selfhood in dementia. Self 2 describes one’s personal characteristics and attributes, both desirable and undesirable. These include one’s physical and psychological traits, and one’s perception of one’s abilities (Sabat and Collins, 1999). They can be stable and have long histories (e.g. being a graduate of physics), or they can be more recent (e.g. being diagnosed with a chronic illness). It also includes one’s beliefs – including beliefs about one’s attributes. Some of these beliefs would engender feelings of pride. Due to the changing nature of the characteristics and attributes that make up a person, one’s beliefs fall in line with this; for example, beliefs about oneself in terms of what one used to be, or may become in the future (Sabat, 2001).

A diagnosis of dementia brings with it a whole new set of undesirable characteristics. For example, one might have memory problems, or experience changes in personality or emotional makeup. Previously valued activities may become difficult to engage in as a result of functional decline in ability to carry out certain tasks. Cessation of activities leads to avoidance of them in the future, for fear that they will cause embarrassment – which in itself represents a newly acquired personal attribute as a result of dementia (Sabat, 2001). While the Self 1 is expressed in discourse through the use of personal pronouns, the Self 2, according to Harré, is expressed through reflexive devices, such as confessions, descriptions and autobiographical accounts (1998). These devices are considered evidence of the beliefs offered to oneself and others at a precise moment in time. Public displays of Self 2 – the expression of ‘what I am’ – overlaps with and occurs in the display of Self 3.

The Self 3 – the self of social personae – has its roots in Erving Goffman’s study: *The Presentation of Self in Everyday Life* (1959), which Harré references (1998). Goffman’s study argues that, ‘when an individual appears in the presence of others, there will usually be some reason for him to mobilise his activity so that it will convey an impression to others which it is in his interests to convey’ (1959, p.3). For example, the persona one presents at work would be quite different from the persona one presents as a parent to one’s children. Hence, unlike the Self 1 and 2, a retained Self 3 is dependent on others. Specifically, on the cooperation of at least one other person in the social world of the individual in question, because ‘it is in the dynamic interplay of mutual recognition of one’s own and another person’s position in the social situation that the particular Self 3 is constructed’ (Sabat, 2001, p.295). Taking the aforementioned example of the employee, this might include one’s co-worker in the first instance, and one’s child in the second. Failure to cooperate will result in the failure of successful identity construction. This is particularly relevant for people with chronic illness, and dementia specifically, in moving away from the ‘label’ of the disease and the associated connotations of disability (Kitwood, 1990, p.182). In other words, many people who are chronically ill do not wish to be seen as ‘sick’ or defined purely in terms of their disease-related limitations.

Relatedly, it is important to draw on Harré’s interpretation of Goffman’s work, because Harré (1998) drew on certain constructs and incorporated them into his conception of the Self 3, which would form part of the social constructionist account of selfhood in dementia. ‘Personality’, according to Harré was the way in which people had a private and public style of being. ‘Character’, referred to the views and opinions held by others in relation to a person, particularly in terms of that person’s likely propensity to act towards them in a certain way (1998, p.78). Harré praised the richness of Goffman’s account, noting how emphasis was given to the way in which one attempted to present oneself as one wished to be perceived by others. These concepts are central to this thesis, which deals with selfhood and identity, and how these can be shaped by presenting oneself in a certain light, as well as how the perceptions and behaviours of others can reflect back on oneself, potentially impacting one’s self esteem.

This leads neatly to a second work of Goffman’s: *Stigma: Notes on the Management of Spoiled Identity* (1968), which also exerted significant influence on the social constructionist account of selfhood. Here, Goffman conceived of the notion that people could engage in active management of identities that they may wish to hide, or, as Harré observed, to which they could

display a ‘plausible discursive alternative’ (1998, p.78). This is akin to passing, whereby a stigma that is not perceivable is concealed by the stigma-bearer (Garfinkel, 1967). A variety of examples of potentially stigmatic identities were put forward by Goffman (1968), including social class and certain bodily dispositions – the corporeal body and its deviation from what is ‘deemed necessary or appropriate by social conventions’ (Waskul and van der Riet, 2002, p.488). It is easy to see how dementia could also constitute such an identity, given that we live in a ‘hypercognitive’ society (Post, 2006, p.231). This term refers to the tendency to define people by their mind alone, which has the potential to alienate people with neurodegenerative conditions (Beard, 2004).

Finally, it is important, at this point, to draw upon the work of Tom Kitwood, whose work, like Goffman’s before him, also influenced the incorporation of the Self 3 into the social constructionist theory of selfhood, specifically in relation to dementia. Kitwood was an advocate of putting the person with dementia first, eventually embedding this philosophy into a theory of ‘personhood’ that came to dominate much of the discourse surrounding dementia care for years to come (Kitwood and Bredin, 1992, p.270). Kitwood acknowledged the role of neurological impairments in the course of the disease, and the limits that these imposed on a person’s capabilities. However, he also emphasised the social and interpersonal factors that were responsible for many of the behavioural and emotional symptoms associated with dementia – hitherto assumed by scientists and researchers to be the result of disease aetiology (Kitwood and Bredin, 1992). These social factors and the concept of a ‘malignant social psychology’ are discussed in more detail in my literature review (Kitwood, 1997, p.46).

The Self 2 and 3, as well as the process of positioning, are all interrelated. If the person with dementia were to focus disproportionately on their disease-related characteristics – for example, on their losses and decline – that person is unlikely to attempt construction of a valued social persona. Similarly, if they attempt to construct a valued persona, and others within their social world reject this attempt, by positioning them in a negative manner, it is reasonable to assume that the Self 2 will in turn be impacted by this. In other words, a close relative who only participates in the construction of the person with dementia as a person with dementia, will affect the importance that the person themselves ascribes to positive and previously valued attributes and characteristics. This can be exemplified in Sabat and Collins’ (1999) case study, where the authors carried out in-depth interviews with a woman who had been diagnosed with Alzheimer’s disease. This participant expressed both a recognition of her achievements as a

teacher, and regret and frustration at her disease-related characteristics, which indicated an intact Self 2. Her family participated in the construction of herself in terms of those attributes that were positive and valued. Moreover, when Sabat himself posed questions pertaining to her teaching experience, thereby himself participating in such a construction, the woman's sense of pride and importance was evident, 'assuming the role of "expert" and manifesting poise and knowledge' (Sabat and Collins, 1999, p.17).

This section has presented an overview of the social constructionist account of selfhood in dementia, considering how the theory was developed and then applied to the study of dementia, as a means of illustrating that selfhood can be preserved throughout the course of the disease (e.g. Sabat and Harré, 1992). The final section of this chapter will consider a specific element of the Self 2: self-esteem, which emerged as a consistent theme in many interviews.

3.4.1 Self-esteem

The Self 2 is all-encompassing, in that it represents all attributes a person possesses, as well as all those attributes he or she has had and will have over the course of a lifespan. This is the 'unrestricted Self 2' (Sabat et al. 1999, p.7). Self-esteem can be traced back to an aspect of the Self 2, namely the 'self-concept' (Harré 1998, p.129). This involves being self-aware; having a perception and set of beliefs about the quality and standard of one's personal attributes – which may also be inaccurate, at least to some extent. Self-concept, therefore, refers specifically to the beliefs one has about the quality and standard of one's attributes, and not the attributes themselves. This, then, can broadly be equated with what is known today as self-esteem. Traditional experimental methods for measuring self-esteem (e.g. the Berger Self-Acceptance Scale, Berger, 1952) were criticised by Harré, who claimed that this was usually expressed indirectly, in the favourable or unfavourable way one presented oneself – in narrative and discourse, for example. High self-esteem could be defined as having a 'positive personal identity' (1998, p.132).

If a person has positive beliefs about an attribute he or she possesses, they are said to have high self-esteem about that attribute (Sabat et al. 1999). As dementia begins to erode certain attributes, it may follow that self-esteem in these domains is simultaneously eroded, which could lead to the person avoiding situations that highlight the attributes that are in decline. Role changes occur as a result, which may impact on one's self-perception and damage self-esteem further. Consequently, for people with dementia, the focus then shifts to those dysfunctional,

disease-related characteristics, and it is these that stand out over other, more valued ones (Sabat, 2001). Those aspects of a person that transcend dementia are diminished. The person may begin to be seen by others on the basis of what they can't do, rather than what they can do, which can lead to feelings of becoming a burden.

It is important, at this stage, to discuss the work of Henri Tajfel, the social psychologist who developed social identity theory, and who saw self-esteem as an integral part of this. Social identity theory is a theory of the social self; the notion that 'a social category (e.g. nationality, political affiliation, sports team) into which one falls, and to which one feels one belongs, provides a definition of who one is in terms of the defining characteristics of the category – a self-definition that is part of the self-concept' (Hogg et al. 1995, p.259). Tajfel asserted that self-esteem can derive from one's 'membership of a social group, together with the value and emotional significance attached to that membership' (1978, p.63). The fear of being assigned a social identity as part of one's membership of a group labelled, for example, 'dementia patients' is powerful. There is still a considerable amount of stigma surrounding dementia, and people are acutely aware of this (Devlin et al. 2007). One of Sabat's participants, for example, likened having been diagnosed with Alzheimer's disease to having the 'Scarlett Letter' (2001, p.114). Whilst one's self-perception is not necessarily linked with negative positioning, the way in which one is treated by others has an undeniable impact on how one sees oneself and one's associated feelings of self-worth (Sabat, 2001).

People with dementia are concerned with 'being valued' for who they are (Steeman et al. 2013, p.224). To have an identity other than 'patient' – which results in them being treated as such. In this scenario, they are assumed to have cognitive defects, seen as someone to be managed, and portrayed as unable to take part in social situations (Cheston and Bender, 1997). Such treatment is justified on the basis that the normal rules of interaction and behaviour do not apply to someone identified as a patient (Sabat et al. 1999). But the person desires their other, more positive aspects of the Self 2 to be recognised, and there are indeed a range of personae available to them. Each, however, requires the cooperation of others and it is impossible to successfully construct an alternative persona without this (Sabat, 2001). It is within these attempts to construct a valued Self 3 that the maintenance of and damage to self-esteem occurs. Successful construction – including validation by at least one other person – results in positive feelings of pride.

Self-esteem can be affected by negative positioning and its resultant impact on the Self 2 and Self 3 personae in people with dementia (Sabat, 2001). This will be important for my third findings chapter, where the impact of negative positioning of the person with dementia by others will be discussed. Such a process of assault on self-esteem can be understood in terms of Lamiell and Durbeck's theory of dialectical reasoning, which purports that we make judgements about ourselves and others based on 'who I am not, but might otherwise be' (1987, p.225). In other words, the person with dementia is aware of the losses – psychological, social and cognitive – suffered as a result of the disease, and reflects on how different life might have been had they not received such a diagnosis.

Denial is often misinterpreted in people with dementia. Downplaying or denying the existence of the disease can be seen by relatives as a refusal to accept the inevitability of the situation. But it can also be a way of coping (Clark and Prescott, 2019). In other words, the person may be aware of those Self 2 attributes that remain, and use denial as a means of preserving these and deliberately discounting the disease-related characteristics. Rather than a sign of cognitive decline or impairment, therefore, denial can be reconstructed as a way in which the person with dementia attempts to preserve their self-worth (Sabat, 2001). This will be particularly important for my first findings chapter, where people's coping mechanisms – including denial – are explored. This chapter will consider the possibility that denial can serve as a defence mechanism, a way of dissociating oneself from damaging group membership (i.e. dementia patient) and preserving a more valued persona and accompanying attributes.

The impact of positioning on self-esteem has been shown in a study by Ryan et al. (2009) who studied the benefits of writing as a means of reclaiming lost identity in people with dementia. Self-esteem was significantly enhanced, as the person was positioned as storyteller and writer. Through writing, participants were able to embody a multitude of other personae and social roles, thereby painting themselves as valued members of society – something which they had thus far struggled to achieve in life. It gave these participants a sense of control, of being able to take ownership of their own narrative. Finally, the act of writing about one's past also had a positive impact; reminding people of their achievements, motivations and likes and dislikes. The diminished sense of self-worth that had been caused by the erosion of valued Self 2 attributes was restored (Ryan et al. 2009). This study is important in the context of the present thesis, because it shows how, through a valued activity, people can resist the impact of dementia on their self-esteem, and enhance their sense of identity and purpose in life.

To conclude this section, the extent to which self-esteem can be maintained in dementia is dependent on the interaction between a person's Self 2 attributes and beliefs about those attributes, and the quality of one's social interactions in the context of constructing a Self 3. Sabat et al. (1999) illustrate this neatly;

1. The person with dementia has attributes in his or her past that he or she takes pride in, and retains the ability to take pride in.
2. He or she has other attributes – negative ones – brought on by their diagnosis. These are a source of embarrassment and unease.
3. He or she favours those interactions with other people that give equal weight to both 1. and 2. instead of favouring 2.

This highlights the role played by other people in preserving self-esteem. The concept of self-esteem is integral to this thesis as an important component of the social constructionist model of selfhood. In the following chapters I will explore how it is affected in women with dementia, and the impact that social relationships can have on the Self 2.

3.5 Conclusion

I have discussed throughout my literature review and theoretical framework, evidence that contradicts the claim that people with dementia lose their sense of identity and selfhood. Rather, they are dependent – far more so than someone with no cognitive impairment – on others within their social world. The development of the social constructionist model of selfhood in dementia, by Steven Sabat and Rom Harré, has served to differentiate between three forms of self and to illustrate the ways in which these are vulnerable to damage. They have also shown that selfhood can be preserved, even in the latter stages of the disease (e.g. Sabat, 2002), but that this requires the cooperation and positive positioning of the person with dementia by significant others.

This thesis uses the social constructionist model as its framework because it is centred on how dementia impacts the identity and selfhood of women living with the disease. It explores both personal and social identity, considering how participants see themselves, but also how others see them, and how this being-seen reflects back on them. It also discusses the role that self-esteem plays, both in terms of showing the impact that negative positioning can have on selfhood, and as a facet of Self 2 distinct from positioning. The social constructionist model is

an ideal framework through which to study all of the above, given the emphasis that it places on the individuality of experience and the role of others.

The focus of this thesis is on women because women are underrepresented in the dementia literature, as shown in the previous chapter. This despite the fact that 61% of people living with dementia are women, and women making up the vast majority of formal and informal caregivers the world over (Alzheimer's Disease International, 2015). Moreover, the social constructionist account of selfhood in dementia has not been applied to the study of selfhood and identity of this particular group. Therefore, it is hoped that this framework, which has provided interesting insights over the years (e.g. Sabat and Collins, 1999, Sabat, 2002, Kontos, 2005), could contribute something novel and valuable to the exploration of women's experiences of dementia. Bartlett et al. (2018) criticise the existing literature for being 'gender blind' (p.15). They take aim at the work of Kitwood and Sabat specifically, for being influential in the field, yet failing to distinguish between men and women with dementia, instead referring to 'people with dementia' (p.15). There was, they argued, a compelling argument to be made for distinguishing between the two, since concepts related to identity and selfhood are naturally bound to gender.

The social constructionist model has the advantage that all three types of self can be explored through the medium of language; that is to say, through interviews with participants (Caddell and Clare, 2010). I also kept a field diary, recording detailed observational notes pertaining to each encounter, with attention given to the space before and after each interview, as well as the interview itself. These methods ensured that potentially valuable data was collected at all times. Thus, selfhood could be observed in the nuances of everyday life, for example in the way a husband interacted with his wife, or a participant with the unexpected arrival of guests.

When first conceptualised, the social constructionist model of dementia was arguably ahead of its time, and, along with Kitwood's work, stood out among a body of literature that was still largely wedded to a biomedical approach. Now, however, it is acknowledged that people with the disease are active agents, capable of contributing to society (Bosco et al. 2019). This is precisely what Sabat and Harré (1992) aimed to show; that a diagnosis of dementia should not preclude people from being able to participate fully in the world around them, from having autonomy and independence and retaining interpersonal relationships.

Chapter 4: Research Design and Methodology

4.1 Introduction

This chapter will describe the design and methodology of the thesis. The aim of the methodological approach is to be able to answer the study's primary research question: *how does early-stage dementia impact on the selfhood and identity of women?* The question will consider, in the context of the social constructionist account of selfhood in dementia, the ways in which participants attempt to preserve aspects of their Self 2, despite the threat posed by diagnosis of the disease. It will consider how this threat impacts on a person's self-esteem, as they face up to new losses and challenges. Finally, it will consider the role of social networks and interpersonal relationships in helping to sustain self-esteem, and also the ways in which negative positioning can damage self-esteem.

In accordance with much of the literature that has emerged in recent years, this thesis puts the person with dementia at the forefront of the study, by giving voice to their experiences (Hubbard et al. 2003). The importance of first-hand accounts has now been recognised, in exploring the ability of people to live well with the disease (Morgan, 2018). It also fits with the efforts of researchers to afford people with dementia citizenship (Bartlett, 2014). This involves ensuring that people with dementia are 'intrinsically valued and regarded as (potentially) effective citizens' (p. 1292). In other words, that they are enabled to participate fully in society – and in research such as this PhD (McCabe and Bradley, 2012).

My thesis adopted a sampling approach that purposely recruited women with early-stage dementia, since it was the perspectives of this group I was targeting. I decided to use an open form of interviewing to collect the primary data. The participants were already involved in the questionnaire phases of the IDEAL study and consented for me to visit them at home and conduct the interviews. These interviews were presented as being informal, as I wanted participants to feel comfortable and able to engage with the process fully. The interview guide was constructed around the notion of giving participants the freedom to talk about a range of topics relating to their sense of self. Therefore, instead of structured questions, it utilised a more fluid approach, with topic areas to guide rather than dictate the flow of the interview.

The first part of this chapter describes the sampling and recruitment strategy used in the study, as well as the process of obtaining ethical approval. It then discusses my approach to

interviewing, and the merits of a semi-structured technique. It then discusses my methodological approach, which used aspects of both grounded theory and interpretative phenomenological analysis (IPA). This includes its origins as a method within psychology and sociology and my justification for using it in this thesis, with a particular focus on other studies that have used IPA to explore selfhood within a personal and/or social context. Finally, I consider the importance of researcher reflexivity.

4.2 Sampling and recruitment

A purposive sampling strategy was used, which is non-random and involves selecting a group of people, on the basis that they are able to offer insight into a particular phenomenon (Robinson, 2014). In this case, I was looking for participants who could provide insight into the experience of living with dementia. Hence, I deliberately sought out people who had been diagnosed with the disease, as well as (where relevant) their family members. As Smith et al. (2009, p.49) observe, participants in an IPA study represent a ‘perspective’, rather than a ‘population’. They were deliberately targeted because of their expertise, and ability to therefore offer first-hand accounts of what it was like to live with dementia. In addition to knowledge and experience, participants were also selected according to their availability and desire to participate in the study (Etikan et al. 2016).

I recruited my participants from the main IDEAL cohort. It is perhaps worth noting at this stage that participants who have made the decision to participate in a large-scale research project, such as IDEAL, may not be a particularly representative sample. IDEAL is made up of 29 National Health Service memory clinics working in partnership with the research study team. These memory clinics are located across England, Scotland and Wales. In this PhD, I used two sites from England, and one from Wales. I obtained quantitative background data, made available through IDEAL, on the participants, including educational level, previous occupation, occupation of spouse etc. This would enable me to explore the experiences of women with dementia from a range of social backgrounds. Initially, the focus of my research question was on social location. When it became clear that this was evolving towards selfhood and identity, social background nonetheless remained relevant, as it allowed me to explore the selfhood and identity of women living with dementia, from different walks of life. Finally, women were recruited to the study, who had been diagnosed with Alzheimer’s disease or vascular dementia. I also recruited those who had an MMSE score of over 20, which excluded those with moderate or severe dementia (Department of Health, 2014).

Guidelines regarding sample size for an IPA study vary, but Smith et al. (2009) advise between three and 16 participants, with the higher end of this scale being more suited to a larger-scale, funded project. This was the basis on which I worked, given that the present study fulfilled those criteria. With the combination of people who did not wish to take part and my exclusion of those who did not have capacity to consent or participate in an interview, I had to draw on three separate IDEAL research sites: two large teaching hospitals in big cities (England) and one in Wales serving a large area of urban and rural communities. In total I interviewed 12 women who had been diagnosed with dementia. My sample also included seven family members – six husbands and one daughter – who were the primary informal caregivers for the person with dementia. These interviews contributed to the third chapter, devoted to exploring close interpersonal relationships and how they had been impacted (or not) by dementia.

4.3 Capacity and ethical implications

The first step in obtaining ethical approval involved the putting together of a suite of documents in order to secure a research passport. These were sent to the Research & Development division of the Royal Devon & Exeter NHS Foundation Trust (the site overseeing the ethics involved with the wider IDEAL study). Once the research passport had come through, I liaised with the IDEAL Project Manager, and completed a Notice of Amendment form (see appendix 1). The thesis would constitute a substantial amendment to the main IDEAL study, and as such, I was not required to submit a separate study protocol to the ethics committee. I returned the Notice of Amendment form together with the relevant supporting documentation, including information sheets and consent forms for participants. The information sheets (see appendix 2 and 3) contained a more detailed description of the study, and also attempted to address common concerns, such as what taking part would involve, assurances of confidentiality and data protection and the contact details of my supervisor, should the participant wish to raise any concerns or issues whilst taking part. I would hand the information sheet to each participant before their interview began. We would then go through the consent form. The consent forms (see appendix 4 and 5) consisted of eleven statements, requiring the initialling of each to confirm consent. These were necessarily extensive and covered every conceivable issue, for protection of both the participant and the researcher. The participant had to consent, for example, to being audio recorded, to recognise their freedom to withdraw at any time, and that, should anything be raised that caused concern for their safety, an appropriate professional (e.g. their GP) would be contacted.

The Research Ethics Committee (REC) panel reached a favourable decision (REC reference number: 13/WA/0405), and I was issued with a formal letter of approval (see appendix 6). As I had now been granted full NHS ethical approval for the PhD, it was not necessary to obtain additional approval from the Cardiff University School of Social Sciences REC. However, as detailed in the following section, I was required to request a Letter of Access from the research sites themselves, to enable me to reach out to those participants connected to the site in question.

4.3.1 Making contact with potential participants

I had to be pragmatic with regards to my choice of IDEAL sites through which to access my participants; places I could travel to or place where I had family living, and could hence spend a prolonged period of time. I requested Letters of Access from the individual sites. Once the letters had been received, I liaised with the IDEAL team in Exeter and requested participant details for these sites.

I then identified potential participants to be contacted. All men were immediately excluded, as, due to the reasons identified in previous chapters, my focus in this thesis was on women with dementia. Women were excluded who did not have one of the most common forms of dementia, i.e. Alzheimer's disease or vascular dementia. By widening the inclusion criteria to include women with rarer forms, it would potentially have resulted in participants taking part who had distinctive sets of symptoms, unique to a particular type of dementia. The women were additionally required to have a mini-mental state exam (MMSE) score of 20-26. The MMSE is a test administered as part of the questionnaires for IDEAL, to determine what level of cognitive impairment a person has. If they met these criteria, initial contact was made. I put together a short document, introducing the study in layperson's language and sent this to all prospective participants (see appendix 7), along with an invitation letter (see appendix 8). The letter stated that I would follow up with a phone call, which I did within two to three days. Here, I explained who I was, and the fact that I had sent a letter detailing the study I was conducting. Many participants had forgotten about the letter entirely, so I repeated everything contained within it, giving them the opportunity to ask any initial questions they may have. They were assured that, just because they were taking part in the IDEAL study, this did not compel them to take part in the present PhD.

The response to these telephone calls was generally very positive. Only three people whom I contacted via telephone declined to take part. One of these was a husband, whose wife had recently passed away. The other two, however, were relatives who declined to take part on behalf of the person with dementia. One woman with dementia I spoke to said she would like to take part, only for her daughter to take the phone from her and tell me that she wasn't interested. This was clearly a problem, especially since the whole point of my research was to give a voice to a cohort of people whose voices are often not heard or ignored. However, I was also in a difficult position, in that, where there were relatives involved in the care of the person with dementia, I was relying on the cooperation of those relatives. Not merely in the sense that they were participants in my research as well, but also in the sense that I was going to be conducting the interviews in their homes. Moreover, it must also be acknowledged that the family members are the ones who have most access to and interaction with, the person with dementia. They know them better than anyone else, and there may be good reason for the two family members in this case declining to take part on behalf of that person.

The introduction to the study sheet that was sent out initially, described the interviews in layperson's language and stated that they could take place wherever the participant felt most comfortable. In all cases, this was their own home. It also left open the number of times a person would be interviewed. Some people were just interviewed once, and this interview was deemed exhaustive and covered all topics on the pre-prepared interview guide extensively. Others were interviewed twice, on account of various factors. Most of the time this had to do with tiredness setting in during the first interview, which was reflected in the participant's body language and their answers becoming briefer and less clearly articulated. On another occasion, the participant's heightened emotional state necessitated the curtailing of the first interview. On several other occasions, logistical or practical factors required two interviews. This transpired when, for example, a visitor turned up, or when the participant was only free in the early evening, meaning that we agreed to conduct two separate interviews to enable me to travel home.

4.3.2 The problem of 'consent'

Until relatively recently, no clear guidance existed on the procedure to be adopted for adults potentially lacking the cognitive capacity to consent (Sherratt et al. 2007). The *Mental Capacity Act 2005* was introduced in England and Wales in 2007, with the aim of protecting populations such as these and clarifying the process. The Act states that:

“...a person lacks capacity if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or the brain” (Mental Capacity Act 2005, p.2).

Clearly the aetiology of the disease means that people with dementia could reasonably be said to be categorised as such. However, the Act also embodies certain principles that, crucially, promote autonomy and agency – concepts that have historically been strikingly absent from the literature on dementia. Thus, it must be taken into account that capacity for some people may be variable. A person should not be assumed to lack capacity, simply because the relevant information can only be understood if presented in a way suited to their needs. Nor should the fact that some people may only be able to retain information pertinent to their ability to make a decision, for a short period of time, exclude them from the presumption of capacity (Mental Capacity Act 2005). These points are especially relevant where a disease such as dementia is concerned. In fact, they serve to shed light on the entire process of obtaining informed consent with people with dementia. Furthermore, the Act emphasises that, when determining capacity, people must, first and foremost, be encouraged to participate and the onus is on the researcher to be accommodating and creative, in order to enable them to do so (Mental Capacity Act 2005).

These principles reflect the view held by Dewing (2007), in discussing the ethical issues surrounding people with dementia. She asserted that the assumption must be that people with dementia retained a sense of self, and thus, their ability to express preferences with regards to participation. Consent was a reflective process, with the onus falling on the researcher to: do background preparation in order to gain access, establish the basis for consent (e.g. completion of a consent form), gain initial consent, monitor ongoing consent and if required, to provide feedback and support to caregivers. Cotrell and Schulz (1993) also identified potentially helpful strategies, such as conducting the research in the participant’s own home and allowing the person with dementia to set the time (to enhance their sense of control over the process). They stressed that people with dementia may welcome the opportunity to take part in research. Finally, Clarke and Keady (2002) advised a collaborative and creative approach to data collection with people with dementia, which involved developing a ‘mutually trusting relationship’ (p.40), and the researcher being engaged with the person.

My approach to this project was adoptive of all of the above principles, and reflects my own intellectual commitment to the position that that no group of participants should necessarily be

excluded from any form of research on the basis that there is uncertainty surrounding their capacity to consent. One cannot explore the lives of people with dementia, solely by involving caregivers, health professionals and service providers – yet not the people themselves. Hence, when ascertaining capacity, I attempted to provide the optimal circumstances for this to occur. For example, it is recognised that decision-making capacity is not static and can fluctuate according to various factors, such as the time of day. When I spoke to the participants and family members over the phone, we discussed this, and they were given the choice over when the interviews took place. Capacity was never presumed on the basis that participants were participating in the IDEAL study – again, since this can fluctuate, and capacity may have changed in the time between their initial assessment as part of the wider study and the interview as part of this PhD. I took the time to talk to participants before the interview (having also previously spoken to them via telephone), and the process was never rushed. In going through the formal consent process, I was flexible and adaptive to the needs of the individual. Some participants were able, for example, to go through the consent form and initial each point as required. For others, a more time-consuming approach was needed, whereby they wished to discuss points multiple times. Once the interviews were underway, I adopted the principle of monitoring body language and non-verbal cues, advocated by Dewing (2007). This simply involved being aware of any signs of discomfort or distress. If the participant did exhibit any of these, then the option was given to take a break, or to postpone the interview to a later date, or for them to withdraw from the study entirely. Finally, the determination of whether a participant had capacity to give consent was judged on an individual basis.

Participants were excluded where there was doubt over their capacity to consent – which also tied in with an inability to understand or answer interview questions. In all cases, this came down to language. I did not initially anticipate any issue regarding capacity. However, in the datasets I requested from IDEAL – and because these datasets were so large – there was significant variation between the last recorded dates of MMSE scores. Thus, some participants' scores were recorded in 2016, which was only the year before I started my fieldwork. Others', however, dated back to 2014. I soon discovered that those participants who may have recorded a score of 21 or 22 in 2014, had deteriorated in the three years since, to the point that their language comprehension and production were severely impaired. They could not partake in an interview, in the traditional sense, because they were unable either to understand the vast majority of questions I put to them, or to give answers to said questions. In all three cases, the husbands of the women with dementia were necessarily present, with the result that the

interviews were conducted almost solely with them. There was also clear doubt as to whether the women knew what they were signing or consenting to. Furthermore, one of the most important ethical facets of research involving people is the right to withdraw at any time (Edwards, 2005). Given the level of verbal impairment in these participants, it was deemed highly unlikely that they would be able to express this desire. It was therefore decided that both the women with dementia, and their partners, would be excluded from the study.

It must be noted that this decision was taken with specific reference to the present study. People with dementia should not be uniformly excluded from research on the basis that the disease is in its latter stages and language ability has therefore been compromised. Studies have shown, for example, that there are other ways of obtaining and maintaining a person's consent to take part in research, that focus on body language and behaviour (e.g. Black et al. 2010). This study, however, was exploring the lived experiences of women with mild, or early-stage dementia. It also relied on the ability of the participants to give reflective answers that were rich in descriptive detail.

As a final point, participants' identities were protected, and all personal names, place names and any other identifiable data was anonymised in the transcription process. Participants and family members themselves, were assigned pseudonyms, which were chosen by me. Any service names, such as *Silver Linings* were also anonymised.

4.4 Interviewing

Semi-structured interviews were used as the primary method of data collection in the present study, with other options, such as structured interviews and ethnographic interviews, being considered and then discarded for the reasons I will outline below.

Structured interviewing involves all participants being asked the same questions, in the same order – even, according to some researchers, in the same tone of voice (Gray, 2018). As Corbetta (2003) explains, this form of interviewing is effectively 'a questionnaire with open questions' (p.8). The method was not considered suitable for people with dementia, since it is rigid and does not permit probing or flexibility. Thus, one person with dementia may understand a particular question, whereas another person may not. If a person says something of interest, this cannot be followed up on.

Ethnographic interviewing is generally part of the wider field of ethnographic exploration, which uses multiple methods, including observation, focus groups, interviews, conversations, videotaping and document analysis (Jackson, 2015). Interviews are not considered sufficient by themselves, and for some researchers, they may not even be distinguished as interviews in the traditional form, instead consisting of, for example, periods of observation with interspersed conversation (Walford, 2007). An ethnographic approach was not considered suitable for the present study, due to the number of participants, and the amount of time and resources required to be devoted to each. Although many ethnographies are now conducted over shorter time periods than previously, these have often been criticised for being inadequate or lacking in quality and depth (Jackson, 2015).

Thus, a flexible, but semi-structured approach to interviews was adopted. I have called my approach semi-structured as opposed to unstructured, because interview guides were used, which were broken down into different topic areas to be explored. However, the direction of the interview could at times be dictated by the participant themselves, and follow-up areas explored that were not part of the original guide. Moreover, in reality, the lines between semi-structured and unstructured interviewing are blurred, with the true distinction arising between these two and structured interviewing (Corbetta, 2003).

Clarke (2009) posits that the IPA interview should be ‘led by the participant but guided by the researcher’ (p.38), and I was consistently mindful of this when conducting interviews for the present study. It was my intention, from the outset, to afford participants the time and space to answer questions fully, and in as much detail as possible, whilst the pre-prepared guide served merely to inform the direction of the interview. Indeed, depending on how the interview unfolded, not every question was asked in the order it appeared on the guide. Sometimes a question would be posed earlier on, if deemed appropriate, or phrased in a slightly different manner (Smith and Osborn, 2015).

Smith and Eatough (2012) stress the need for the IPA interview to be ‘empathic, but also, where necessary, questioning’ (p.447). This means adopting a stance that is sensitive to and considerate of the person being interviewed, and their stories, whilst at the same time, attempting to delve deeper into that person’s world. Entirely novel avenues could be opened up in the course of the participant’s response, resulting in follow-on questions being posed, to explore such areas further (Osborn and Smith, 1998). This in turn allowed the participant to expand on these and provide richer descriptions. Smith and Eatough (2012) observe that it is

often the discussions that arise spontaneously that are the source of the most interesting and insightful data, on account of the fact that these have come about unprompted by the participant themselves. The present cohort of participants opened up and spoke with increasing frankness about a range of issues pertinent to them. Similarly, it was important that the interview stayed on track and that its content retained relevance to the overall aim of the project. Some participants, for example, had a tendency to fixate on certain things, or to tell long, involved stories from their past, and whilst, to a certain extent, these were considered an important facet of the data being generated, it was also necessary, on occasion, to gently steer these participants back to the question at hand.

4.4.1 Development of an interview guide

Integral to the success of IPA studies that rely on interviews as a method of data collection, is the development of a guide that allows the participant to address the research question in such a way that their personal experiences can come to the fore. The researcher goes in with an open mind, and the freedom to adapt the guide according to how the interview develops or what the participant says. The main advantage of constructing an interview guide has to do with the fact that the researcher can consider beforehand, the broad areas they aim to cover, and also, the potential difficulties that may arise from certain lines of questioning (Smith and Osborn, 2015). I was able to identify these, and plan in advance how I would respond.

The last two clusters of questions on my interview guide, in particular, were sensitive and personal in nature. They had the potential to trigger emotive reactions in the participants – something for which I was prepared. Several participants, for example, became visibly upset or agitated at certain times during the interview. It was necessary to proceed carefully in such situations, with participants being in need of time and space. I always ensured that, in the first instance, they were granted this, before continuing. I planned to remain attuned to the body language of the participant, and if their distress appeared to be prolonged, to offer them the chance to stop the interview and continue it at a later date. When I concluded each interview, I also referred participants back to the information sheets with which they had been provided, and which contained my contact details. I reminded them that they were welcome to contact me with any questions or queries that they may subsequently have.

Topic areas, while broad, were first selected on the basis that they would enable the participant to talk about dementia in terms of social location – since this was my initial focus. This first

draft of the interview schedule can be found in appendix 9. In the initial stages of analysis, it became clear that social location was not something that emerged from the data, however, and the guide evolved to consider aspects of selfhood, identity and self-esteem (see appendix 10). The interview guide was adapted and shortened slightly for the familial caregivers (see appendix 11). The main aim of these interviews was to shed more light on the relationship dynamics between the person with dementia and their family.

All questions were open-ended (Smith and Eatough, 2012). Occasionally, how the interview unfolded meant that a closed question was unavoidable, but I ensured that this was constructed in such a way that it did not restrict the response (Smith and Osborn, 2015). I also included prompts in the form of more specific questions. These prompts were only deployed where necessary – usually to encourage participants who found it difficult, particularly in the initial stages, to talk freely, or in rare cases, to understand the original question posed (Willig, 2008). Questions were phrased in such a way, as to be free from academic jargon and able to be understood by people whose capacity for language comprehension may be impaired. The guide was divided into sections, including: *Early Life and Upbringing*, *Social Ties and Relationships*, *Changing Identities* and *Coping*.

There was a rationale behind the ordering of the questions that was based both on temporality and sensitivity. Thus, initial questions focused on life history, the middle set of questions on the diagnosis and impact of dementia, and the final questions considered the future (Bramley and Eatough, 2005). The interview began with questions on the person's early life and upbringing. These were important to contextualise the person's present life, and they also served as useful 'ice-breakers', due to the fact that they were benign and un-threatening. Many participants took a while to warm up, either out of nerves or uncertainty for what the next hour or two held. I found that, when invited to talk about things like their childhood, parents, and previous occupation, most soon began to relax. In the first instance, this was also thought to be a way of understanding social location. These initial questions helped to build rapport and trust between myself and the participant.

The next cluster of questions focused on what the participants did on a daily basis – their routines, their membership of certain clubs or groups, how they got out and about, how often, and with whom. I was particularly interested in whether dementia had affected these patterns of activity. This set of questions too, could still be considered benign in nature. The questions then moved onto potentially more sensitive and emotionally-charged topics, including the

person's relationships with other people. If they were married, for example, this would include: *'Could you describe your relationship with your husband?'* I also asked about extended family and friends, again focusing on the concept of changing relationships as a result of dementia. The final questions in this section explored the participant's experience of health and social care professionals. The next set of questions focused on selfhood and identity; how the individual saw themselves, whether this had changed as a result of dementia, and if so, how. I was particularly interested in self-esteem and the ways in which this was preserved or had been impacted by dementia. Finally, I asked about the participant's psychological health and how they felt they were coping.

4.5 A grounded iterative approach and Interpretative Phenomenological Analysis (IPA)

4.5.1 The approach for this study

When deciding on the most appropriate methodology to apply to this study, consideration was initially given to both grounded theory and discourse analysis, as well as interpretative phenomenological analysis (IPA), as viable options. The three approaches are bound by similarities, but it is their differences and particularly, their origins, that mark each as distinct. Grounded theory (Glaser and Strauss, 1967), is rooted in sociological traditions and is concerned with the development of theory from the data itself. In other words, 'generating grounded theory is a way of arriving at theory suited to its supposed users' (p.3). Discourse analysis has its origins in linguistics, and is concerned with how people use language to construct social life (Potter and Wetherell, 1987). IPA is derived from phenomenology and hermeneutics and is concerned with lived experience – in other words, describing events from the perspective of those who have experienced them (Smith et al. 2009).

It was decided early on that discourse analysis would not fit with the aims of the present study, which did not give primacy to language use. A discourse analytic approach, for example, would have asked how people talked about, or constructed their experience of dementia. Moreover, the fact that the cohort was largely made up of people variably affected by deterioration in language production and grammatical complexity, as a result of the disease, meant that a discursive approach was not considered appropriate (Kemper et al. 2001). Finally, and crucially, discourse analysis is not concerned with talk and underlying cognitions – in other words, what a person thinks or believes about a particular phenomenon (Smith, 1996).

With regards to the other two approaches – grounded theory and IPA, I decided to use a combination of the principles embedded in each. One of the principal tenets of grounded theory, for example, with regards to sampling strategy, is that people are recruited, who have different experiences of the phenomenon in question (Starks and Trinidad, 2007). I wanted my sample to be as diverse as possible, and recruited participants from a range of social and educational backgrounds. In addition, they had differing present circumstances, with some living alone and others living with a spouse or partner. This meant that a range of perspectives were captured by people from different walks of life.

Grounded theory also applies theoretical sampling, whereby data collection, coding and analysis are conducted as a fluid process (Glaser, 1978). In other words, the emergent findings of the analysis that is carried out on a dataset can influence the direction of subsequent guides. Thus, the initial iteration of the interview guides for this study contained topic areas around social location. However, after analysing the first transcripts, it became clear that themes related to selfhood, identity and self-esteem were more prevalent. In other words, the accounts of participants in this study influenced the direction of the analytical and theoretical approach, and vice versa. This led to the amendment of subsequent guides, to fit with the developing research question.

An IPA approach was chosen as the most fitting for the analysis of the data, based on the fact that it is ‘committed to the examination of how people make sense of their major life experiences’ (Smith et al. 2009, p.1). In relation to this thesis, therefore: how women made sense of their experiences of early-stage dementia and the impact that the disease had on different facets of their identity and selfhood. The aim of this research was to put the views of the women with dementia at the forefront, meaning that the social and personal complexities of living with a neurological condition called for a method that could ‘do justice to the individual lifeworld in all its meaningfulness’ (Bramley and Eatough, 2005, p.225). It is worth making a distinction here, between IPA and thematic analysis. Thematic analysis can address a wide variety of research questions, and the content of themes is similarly broad. With IPA, the focus is solely on the experiential (Smith and Osborn, 2015).

4.5.2 The origins of IPA

On a methodological level, IPA involves a highly intensive and detailed analysis of the accounts’ in question, and there is considerable scope for variation in how the researcher

undertakes the analytic process (Larkin et al. 2006). Theoretically, however, IPA is based on three key areas: phenomenology, hermeneutics and idiography (Wagstaff et al. 2014). The philosopher, Edmund Husserl, is considered the father of phenomenology and his work formed the basis of IPA's commitment to reflection and the examination of experience. However, Husserl's focus on 'the essence of experience' (p.2) was considered too abstract, so IPA drew from another philosopher, Martin Heidegger, and his theory of existential phenomenology. Phenomenological research seeks 'to construct a possible interpretation of the nature of a certain human experience' (Van Manen, 1990, p.41).

Husserl's phenomenology is a descriptive one, focusing on the essence of experiences in the way that these are related to subjectivity (Schacht, 1972). He claims that no knowledge is to be accepted unless certain, and everything else must be bracketed. According to Husserl, therefore, the role of the researcher is to reveal a subject matter by first setting aside our own preconceptions. Heidegger, however, claims that such setting aside is impossible, rejecting this in favour of the interpretation of lived experiences (Tuffour, 2017). In this sense, IPA is also connected to the hermeneutic – or interpretative – tradition, in that it involves the researcher making sense of the participant making sense of their personal and social world (Smith, 2004). In the case of the present study, I, as a researcher, was not concerned with the nature of dementia, rather with the women's experiences and understandings of dementia.

The description of experience is a co-construction between participant and researcher (Larkin et al. 2006). Heidegger emphasises the 'person-in-context' (p.106). In other words, the notion that humans are part of a meaningful world and can only be understood as a part of this world. He used the term 'Dasein' (being there) to describe the interrelationships and interconnectedness of human experience (Tuffour 2017, p.3). According to Heidegger, the concern of existential phenomenologists is to investigate interrelationships and interconnectedness, and to study Dasein by immersing themselves in the world of the person (Tuffour, 2017). Thus, IPA is idiographic, in that it assumes an individual focus, exploring how an individual interprets his or her world at a given point (Wagstaff et al. 2014). It is committed to 'finely textured analysis', assuming that individuals can offer a unique perspective on a particular phenomenon (Shinebourne, 2011, p.22).

Most IPA studies cross boundaries, and can fit into a number of different categories (Smith, 2004). This study, for example, crosses the boundaries of social science and social and health psychology. Further, the suitability of IPA for a particular study should be assessed based on

what one is trying to achieve, and the underpinnings of IPA. In other words, IPA may be a good option for a study exploring participants' 'personal and lived experiences' and in pursuing a 'detailed, individual examination of each case' (p.48). In evaluating existing IPA studies, Smith (2004) notes that many are concerned with issues around health and illness. More than this, they look at 'significant existential issues' (p.48), or 'life threatening events' (p.49). This made IPA a suitable option for the analysis of the data in the present study, with the impact of dementia on selfhood and identity falling into the category of an existential threat.

4.5.3 Doing IPA

Once interviews had been conducted with all participants, and recorded using a Sony ICD-PX440 digital voice recorder, they were transcribed verbatim. Pauses and instances of non-verbal communication, such as laughter, sighing, or crying, were also included, as it was assumed that these could represent some significance. Through doing IPA, it is expected that the researcher immerses themselves in the data and becomes attuned to the participant's way of speaking (Pietkiewicz and Smith, 2012). The process of conducting the analysis itself, followed the guidance as set out in Smith et al. (2009), and as such, I began with what I considered to be the most interesting and insightful transcript. This was based on my own judgement and experience of the interview that contained particularly rich, in-depth extracts.

The initial stage requires the researcher to familiarise themselves intimately with the material at hand. This first transcript was read and re-read several times. Whilst doing this, I noted down in the margins of the text, anything that occurred to me; thoughts, ideas – even my emotional responses to aspects of the interview. For this, I also consulted my research diary, detailing my encounters with each participant, in conjunction with the relevant transcript. Larkin and Thompson (2012) describe this first step as 'free coding', and an important part of the continuous process of reflexivity that underpins an IPA project (p.106). I decided not to use software to conduct the subsequent coding, despite being familiar with packages such as NVivo. Rather, I took clean copies of each transcript, with deliberately wide margins, and coded the data manually, using different coloured highlighter pens and physically cutting and pasting sections of text. This approach allowed me to get closer to the data and immerse myself in it to a fuller extent than a computer programme would have allowed.

The second stage of IPA involves a deeper exploration of the content and language deployed in an interview. Here, I went through the clean transcript again. This time, I wrote a

commentary on the ways in which the participant spoke about the issues under discussion, which emerged from the topic guides and centred on issues of selfhood and identity. The interpretative-phenomenological aspects of the analysis start to become evident here. There is a phenomenological focus in the sense that my notes reflected the concerns or experiences the participant themselves described, and the meaning of these to that participant (Smith et al. 2009). The interpretative focus comes from ‘making sense’ of the aforementioned concerns, thereby shedding light on the deeper psychological processes and meaning at play (Reid et al. 2005, p.22). When writing these comments and observations, I found it useful to follow a specific recommendation of Smith et al. (2009). The authors describe how, for purposes of clarity, different kinds of commentary can be broken down into three distinct categories, according to their function. Descriptive comments are comments that use the researcher’s own words to interpret what the participant has said, and highlight the things that are perceived to be of importance. Linguistic comments focus on aspects of language and language use. Conceptual comments engage with the text at a deeper, interrogative level (pp.88-89). This final category signifies a shift from what the participant has said, to the researcher embarking on the wider interpretative journey.

The third stage of the analytic process involves the drawing out of themes from the data. This is done by focusing primarily on the notes and annotations, rather than the transcript itself (Smith et al. 2009). Once an entire transcript had been combed through and a detailed exploratory commentary completed, there was a significant amount of additional information to work with. I used the left-hand margin of the page to condense into ‘thematic labels’ what was represented in the text through said commentary (Willig, 2008, p.60). Whereas the data collection and exploratory comments were governed by what the participant said, and the language they used, the identification of themes signals a shift towards the interpretative role of the researcher (Smith et al. 2009). Indeed, Smith and Osborn describe the need for a balance to be struck, between the identification of concepts that are ‘high-level’, and can be applied across cases, yet at the same time, remain grounded in and can be traced back to a specific part of the text (2015, p.41). This ensures the participant’s voice is preserved. As I went through the transcript, some themes repeated themselves, whilst others appeared as standalone. Moreover, not every passage of text generated an accompanying theme, and some parts of the transcript were far richer than others (Smith and Osborn, 2015). An example of this commentary, applied to a transcript, can be found in appendix 12. The green pen represents

descriptive comments, the blue, linguistic comments, and the red, conceptual comments. In the left-hand margin, the black pen represents the emergence of themes and sub-themes.

Once I had identified all of the themes in the first transcript, I listed them chronologically, on a separate sheet of paper. In a traditional IPA study, which would typically use smaller sample sizes, the researcher would proceed to read through them several times, with an ‘analytical eye’, looking for connections between themes (Smith and Osborn, 2015, p.43). This would lead to ‘clustering’; physically cutting each theme out, laying them on a table, and moving them into groups according to said connections or patterns between them (p.43). Smith et al. (2009, p.96) describes this process of clustering as being akin to certain themes acting as a ‘magnet’ and pulling other, related themes towards them. In the present study, this process was still carried out, but only after all other transcripts had first been analysed and the themes for each listed. Because participants in an IPA sample typically have something in common – for example, in the present study, they were women with dementia – looking for patterns across cases should facilitate a more generalised understanding of the phenomenon under investigation (Willig, 2008). Hence, the initial steps described above were repeated for all remaining participants. It was then that connections were sought between themes. The reason for this had to do with the fact that my sample size of women living with dementia was 12, and it was considered more practical, in keeping with Smith et al.’s (2009) recommendation, to conduct the clustering on the themes that emerged from the whole group, rather than on each individual case. However, the philosophy of approaching each transcript on an individual basis, that underpins IPA, was nonetheless retained. Also, as Smith et al. (2009, p.100) note, it is important that any emergent themes from the first case are ‘bracketed’ off, in order that, insofar as is possible, one is not influenced by these when analysing subsequent cases.

Examples of the final groupings included themes relating to different forms of loss, and themes relating to the participant’s psychological wellbeing. Once this process was complete, themes that did not fit into a particular cluster were discarded. The final groups of themes were reviewed once more, and a label given to each. This label is termed the ‘superordinate theme’ (Smith et al. 2009, p.96). I ensured that all theme labels clearly articulated both the content contained within each cluster, as well as the meaning attached to this by each participant (Larkin and Thompson, 2012). These data – the different clusters of themes and their superordinate labels – were represented in the form of a table, that also ascribed to each theme, direct quotes from relevant participants and the location of these within the transcripts.

Construction of this table was a fluid and developing process and involved the constant relabelling and reorganisation of themes.

The interpretative element of IPA can often take the form of very detailed microanalysis, where small sample sizes are concerned, allowing for the homing in on specific words (Smith et al. 2009). This is because, when working with three transcripts, for example, the researcher can expend significantly more time and effort on this part of the process than if they were working with ten transcripts. The sample size for the present study meant that such an intricate level of depth was not conducive or appropriate. Hence, in keeping with the way in which I had carried out the analysis, this study gave more weight to exploring the themes across the group as a whole, whilst retaining the focus on the individual through the supporting of these with extracts from specific transcripts (Biggerstaff and Thompson 2008).

It is also important, when working with larger samples, to record the recurrence of themes. Smith et al. (2009) stress that a boundary must be set for a superordinate theme to be classified as recurrent. I decided that presence in over half the cases would define a superordinate theme as such for the present study, and I recorded their occurrence (or not) in each participant's transcript, then counted the total instances of these. However, I did not take this approach for sub-themes (and the sub-sections of these). So, whilst my superordinate themes of: *The Changing Self, Resistance and Repair* and *The Dynamics of Interpersonal Relationships* were identified as such because they were found throughout the accounts of almost all participants, the sub-themes within these did not need to fulfil that criteria. I included sub-themes in my thesis, even if they were reflected in the accounts of only a few participants. My rationale for this was that I didn't want to lose sight of the importance of the individual experiences of women with dementia.

I was conscious of the potential issue of the double hermeneutic within IPA, which essentially involves the researcher making sense of the participant making sense of their experiences. As Brocki and Weardon (2006) note, interpretations may therefore be constrained by the 'researcher's ability to reflect and analyse' (p.88). To address this, I held regular meetings with my supervisors, whereby they would be sent a transcript and my interpretations in advance, and we would discuss these during the session.

4.5.4 Writing up

The themes identified in the analysis were translated into a narrative account, which would allow them to be ‘explained, illustrated and nuanced’ (Smith and Osborn, 2015, p.48). I did this by organising my findings chapters around the final table of superordinate themes. Superordinate themes refer to groupings of emergent themes, with a hierarchical relationship between them (Biggerstaff and Thompson, 2008). So, each grouping of themes was given an overarching title, which was the superordinate theme. A chapter was then dedicated to each theme. I began the chapter by introducing the theme in question. As Willig notes, the aim of the findings section of an IPA study is to ‘provide a convincing account of the nature and quality of the participants’ experience of the phenomenon under investigation’ (2008, p.63). In this case, the narrative would centre on the experience of women living with dementia.

Here, I again used the recommendations as set out in Smith et al. (2009) as a guide, with regards to writing up IPA studies with larger sample sizes. Initially, I referred to my table of recurrent themes and supporting quotes from the various transcripts. If a theme was classed as recurrent, I could reasonably describe the way that, for example, ‘most’ or ‘the majority’ of participants spoke about it. Essentially, this group-level analysis of recurrent superordinate themes involved summarising the main themes contained herein. For each theme, I read the supporting extracts from participants’ transcripts. I then proceeded to write down my interpretation of the shared experience. This initial summary was generic and focused, for the time being, on the whole (Smith et al. 2009). I then moved onto the highlighting of individual extracts, on the basis that they were either representative of the general group, or particularly rich or powerful in terms of their content. It was important to strike a balance between group-level and individual analysis.

The writing up phase essentially represents an expansion of the analysis conducted during the eliciting of themes from the data (Smith and Osborn, 2015). Seeing extracts from the transcripts visually written down, along with the researcher’s accompanying narrative account, can stimulate deeper analysis. The analysis and writing up therefore took on a fluidity that meant it was constantly changing and evolving (Smith and Osborn, 2015). Once written up, the whole narrative must be coherent and accessible, flowing easily and moving effortlessly between group and individual-level analysis, in order that it can be easily understood. The hermeneutics of an IPA study are in evidence here, as the reader must make sense of the researcher making sense of what the participant has said. Thus, in order to gain an understanding of the perspective

of the participants in question, the reader must be able to successfully navigate the researcher's analysis (Smith et al. 2009).

Finally, it is important to reflect on the role of literature, including books and journal articles, in the writing up process. In particular, the theoretical framework deployed in this thesis informed my writing. There was also a wealth of other literature relevant to the writing up process. Some examples of this includes: self-imposed boundaries in chronic illness, the impact of driving cessation for people with dementia, and how people with dementia use coping strategies.

4.6 Reflection on my own positionality

Reflexivity involves self-appraisal, the 'turning of the researcher lens back onto oneself' (Berger, 2015, p.220). In other words, I needed to acknowledge that I was a social being with a personal history and that my position may affect the research outcomes of my thesis. Knowledge production is not independent of the researcher's position; the two are closely intertwined, which is why many theorists argue that knowledge can only ever be subjective (Berger, 2015). Personal biases, while inevitable, should be acknowledged at the outset of the project, allowing for these to be brought to the fore, which makes it easier to approach the topic honestly and openly, as well as sensitising the researcher to their potential pre-judgements (Speziale and Carpenter, 2010).

I had no personal experience of dementia prior to beginning the study, so my knowledge of it had been shaped by what I had read and seen in the news. Studying the unfamiliar has its advantages; it puts the respondent in the position of 'expert', which can be empowering for an oft marginalised group (Berger, 2015, p.227). Several of my own participants, for example, expressed a sense of pride and importance that their views were being sought out. But unfamiliarity can have disadvantages; arguably I was not in a position to fully comprehend the experiences of either the women themselves or their family members. I was perhaps insensitive to the type of language used and how the questions were phrased – even though this was something that had been carefully considered. It was possible that some people did not like the term 'dementia' and would ordinarily have avoided it. Moreover, my unfamiliarity may have been a barrier to my picking up on 'disguised and subtle expressions of themes' (Berger, 2015, p.228).

I developed strategies for maintaining reflexivity throughout this project, including meetings with my supervisory team, where each decision was discussed – for example, the development of an interview guide for women with dementia and their family members, the use of IPA as a methodology. I also kept a research diary to raise awareness of how my experiences of fieldwork might have affected my interpretations. Within this, I recorded everything pertaining to each interview extensively. I described the journey to the participant's house, the surrounding area, the interior of the house, the participant's body language, their general demeanour, their interaction with other people who were present at various times. I also described my personal reactions to the interview process and feelings towards the participants and their family.

It is important to note that at times, I was participating in the practices of self-presentation of the women in this study. In other words, I was involved in the positioning and counter-positioning of participants. When Stella could not remember the age of her granddaughter, I reassured her that it was 'easily done', playing down the impact of her cognitive impairment, in order to try and assuage any potential upset that might follow. On another occasion, when Wendy told me she was no longer intelligent, I countered this, by explaining that her diagnosis did not change the fact that she was an intelligent woman. Both women responded positively, by agreeing with my assessment. In both cases, however, my input inevitably shaped the nature of the data produced.

Consideration was also given to how I would be perceived based on factors such as age, gender, occupation etc. Although the participants were all in their seventies and eighties, I considered the fact that they were women meant that I would be able to build a rapport with them. I believed this went a long way in enabling them to feel comfortable in sharing personal detail about their lives with me. I had not considered, prior to the interview, that my biographical information and life history would be of any relevance. However, one of the participants – Marian – had come to England from Germany as a refugee whose family had fled the war. She had also studied for a postgraduate degree in French. Upon discovering that I had lived in France and Germany as a child, Marian was delighted, and it was the basis for many an animated story about her love of Europe, as well as similarly enthusiastic responses to interview questions. She told me that she had been shocked by how snobby she found the English, but exonerated me from this generalisation on the basis that I had grown up in Europe

and would therefore not have such views. In other words, my personal background appeared to allow us to foster a sense of openness and affinity in the interview process.

The only time any personal or background factors had what could be described as a negative impact – at least visibly – was when I interviewed Wendy and Kevin, a couple who were extremely religious. They did not generally associate with people who weren't church-going Christians, and their entire social circle was made up of people from church. Although I had not said either way, Kevin appeared to decide that I was not a Christian, and made several comments reflecting his disapproval – even at one point referencing 'heathens'. As I was about to leave, he presented me with four books: two were Gospels, one was about reconciling belief in God with scientific knowledge, and one was about converting to Christianity. He made me promise that I would read them and let him know whether they had succeeded in converting me.

Rigorous qualitative enquiry is not dependent on the researcher and subject sharing characteristics or on their ability to identify with one another. Rather, it is simply about the researcher reflecting on commonalities and differences and acknowledging how these perspectives can influence the meaning-making process (Lietz et al. 2006). This is an important part of reflexive research. Throughout this project, I recognised my own role in the methodological design, development of the interview guide and interviews with the participants. I believed that by entering the field as an 'outsider', I was at an advantage, because I had little if any preconceptions about dementia (Berger, 2015, p.225).

4.7 Participant biographies

Alice, 70-74:

Alice and her husband Patrick lived in a small town, a short bus ride from a city in the East Midlands. The town had good transport links, a corner shop, and various other local amenities. Their house was large, and minimally decorated, with just a couple of framed photographs of their granddaughter and one of a mountain landscape adorning the walls.

The couple had a daughter and granddaughter who lived close by, and a son in Canada. They were heavily involved with their granddaughter, and saw her every day. Alice had worked as an auxiliary nurse, which she was extremely proud of and talked at length about.

Betty, 70-74:

Betty lived alone, not far from the centre of a city in the East Midlands. The city was within walking distance, and there were good transport links. She lived in a cul-de-sac of other small bungalows.

Betty's husband had died a few years ago. She had a dog, whom she adored. She had a daughter, Rachel, who lived close by, and a son who lived in Cornwall, as well as three grandchildren. Although Betty saw Rachel regularly, she endeavoured to be independent and to have her own social circles. In this sense, she was extremely active, and a member of numerous groups and organisations. Betty had worked as a nursery nurse before retiring.

Bridget, 70-74:

Bridget lived with her husband, Carl, in an extremely rural part of the Midlands. The village had very little in the way of transport links or amenities, save for an infrequent local bus service and an old pub. There was also very limited mobile phone reception. The couple would later tell me that they preferred this isolation. Their house was large, set within an acre of wild countryside.

Bridget was an animal-lover and was devoted to two large excitable rescue dogs, whom she treated and spoke to as if they were her children. She had previously run her own kennels. Before that, Bridget had been a lorry driver and spoke passionately about her enjoyment of that particular career.

Catherine, 75-79:

Catherine lived alone in an extremely rural and remote part of the East Midlands, in a small village, with no local amenities within walking distance. Her house was in a secluded row of around five other properties – all with large grounds and expensive cars in the driveways. I later discovered that Catherine's husband had been marketing director for a well-known drug, which had made him a millionaire. Both house and garden were immaculately presented.

Catherine's husband was now in a care home and his health was poor. She had three sons, two of whom she saw regularly, one of whom she was estranged from. She had also kept horses her entire life and still went horse-riding most days. Catherine had worked as hairdresser.

Flora, 75-79:

Flora lived alone in a rural part of the East Midlands; a small village, surrounded by fields, with few amenities other than a local shop. There was an infrequent bus service to a larger nearby town. Flora's house was nestled in a quiet cul-de-sac. Inside it was full of ornaments, magazines and family photographs.

Flora's husband had died some years ago. Her daughter lived next door, and her son lived on the same street. She saw her children and grandchildren every day. Flora also had a group of friends whom she met up with for lunch on a weekly basis. Flora had worked in a variety of different roles, including as a bus conductress and post-lady.

Joan, 70-74:

Joan and Harry lived a short bus ride from a city in the East Midlands, in a quiet residential area. Their house was full of ornaments, which Harry collected, as well as numerous photos of their many children and grandchildren.

Family was central to Joan's life, and they were heavily involved with their children – all of whom lived close by. They saw all three at least several times a week, and they went on yearly holidays together. Joan also had a close friend who lived next door, and together, they walked to the shops each morning to get the paper. Joan had been a secretary for almost all of her working life.

Lynda, 65-69:

Lynda lived in Carmarthenshire with her partner, in a heavily built-up area close to the town's train station. Her partner, Joe, still worked. They lived in a small bungalow, in one of many streets of identical properties.

Lynda was extremely close to her daughter, who had learning disabilities, but who lived independently and locally. She was the only person with whom Lynda, due to her extreme self-consciousness, described being able to spend time. Lynda had worked for a UK government department, in a role that had involved a great deal of driving up and down the country – which she had enjoyed, and now missed greatly.

Marian, 85+:

Marian was German and had fled her homeland as a child, along with her parents and brother. She now lived alone in central London, on a quiet, cobbled street of attractive terraced houses. Marian's home was full of books and the walls were adorned with paintings by local artists.

Marian had never married and believed that many women only did so because it was expected of them. Despite having no immediate family left, she had many social networks. Marian had a PhD from Cambridge and had worked in academia and as a psychologist. Former colleagues and students would pay her regular visits and she was heavily involved in the local community.

Martha, 80-84:

Martha and Eric lived in a market town, with good transport links to a city in the East Midlands. It was a picturesque place, with a local park and golf club, and its own supermarket, shops and other amenities. Their house was in a quiet cul-de-sac of four other properties; all were fairly large and detached.

The couple had two daughters, one of whom lived with her family in the Netherlands, the other an hour's drive away. They saw their family regularly; making trips to see the

They appeared to have a close relationship, and deliberately struck a balance between doing things together and separately. Both were heavily involved with local clubs, particularly different forms of singing and dancing. Martha derived great enjoyment from the social aspects of these. Martha had worked as a keyboard operator, a job she had found dull and uninspiring.

Sally, 70-74:

Sally lived alone in an independent living facility, in a court of other, identical accommodations. She lived in a large town, not far from a major city, but that had all of its own amenities, including shops and transport links.

Sally's partner, Bruce, lived next door. She had two sons from a previous marriage, whom she did not see particularly often, and a close-knit group of friends within the court. Sally had worked as a hairdresser, and took great care with all aspects of her appearance.

Stella, 70-74:

Stella and her husband Frank lived in an affluent part of the East Midlands that could be described as semi-rural. Their house was on one of many streets of similar, neat, detached houses. Inside, it was clear that each room was decorated and colour-coordinated to perfection. I later discovered that this was Stella's pride and passion since retiring.

The couple had one son and two grandchildren who lived a short walk away, and whom they saw regularly. They also had many friends with whom they socialised. However, they enjoyed spending time as a couple and went for daily coffee and breakfasts together. Stella had worked as a hairdresser, and her hair, clothes and makeup were all carefully styled.

Wendy, 70-74:

Wendy and Kevin lived in a small town in the East Midlands, with good transport links. Their house was in a quiet cul-de-sac of similar properties. It was large, and religious artefacts featured prominently, including framed quotes from the bible, a crucifix, and numerous books.

The couple were heavily involved with the church, which also formed the basis of their social networks. They had three children and ten grandchildren. One daughter lived in France, and they consequently did not see as much of her as they did their other two children, who both lived locally. Wendy had a degree in physics, and had taught the subject at A Level – as well as having been head of the department.

4.8 Conclusion

This chapter has described the study's research design and methodology. It began by setting out my approach to the sampling of participants, which was purposive. Women with dementia, who came from a range of different backgrounds and who had an MMSE score of more than 21 were recruited from the main IDEAL dataset, along with seven family members. Capacity issues were navigated, by using principles advocated in previous research, particularly that conducted by Jan Dewing. Capacity was assessed on a case by case basis, which is reflective of the fact that three participants were excluded because there was doubt over their capacity to give informed consent.

Semi-structured interviews were conducted with participants, and topic guides produced that explored factors related to changing identities, selfhood and self-esteem. The interviews were

semi-structured, because such an approach allows for a degree of flexibility in exploring issues raised by the participants and not specified on the guide, that I considered important to this study. To analyse the interviews, I adopted the principles of IPA set out by Jonathan Smith. This included the use of different kinds of commentary within the texts, and striking a balance between a focus on the collective and idiographic. In line with IPA, I also considered my own positionality within the research process, and the impact this may have had.

The next three chapters describe the three superordinate themes and sub-themes that emerged from the data.

Chapter 5: The Changing Self

5.1 Introduction

This chapter, which represents the overarching theme of the changing self, begins by exploring the process of receiving and adjusting to a diagnosis of early-stage dementia. Within this, the representations of what a diagnosis of dementia is and what it means are considered, together with expectations regarding the outcome of medical appointments. How dementia is differentially conceptualised was shown to have a bearing on the emotional responses of the women to the disease and their ability to make sense of what is happening. The varying experiences of the diagnostic process, and medical professionals, are also addressed.

The second part of the chapter discusses the emotional and psychological impact of dementia, and the losses that have taken place, both physically and mentally. These responses are extremely varied and range from expressions of annoyance and frustration to expressions of deep sadness and helplessness. Some accounts reflect a sense of loss of the person they were and the person they see themselves becoming (Charmaz, 1983). Negative comparisons with past selves are made, to highlight the change. The concerns span a range of social and functional areas, from dwindling social networks, to the change in the perception of oneself and one's personality, to the ability to undertake car journeys.

The third part of the chapter explores stigma and how the women in this study present themselves to others. Stigma poses a threat to selfhood, both in terms of the shame attached to oneself and the expected experiences of discrimination by others, and in terms of actual episodes of discrimination (Scambler, 2004). Linked to this are the strategies of disclosure or non-disclosure that the women engage in. Those who fall into the latter group also use active self-management strategies to conceal their diagnosis. Stigma can threaten a person's Self 3 – the women's attempts to construct a valued social identity – as well as the Self 2, by reflecting back on how one perceives oneself.

Finally, the chapter focuses on boundary maintenance – the conscious modification by the women of their behaviour, to adapt to the changes experienced. This explores how people reconstruct the mental and physical boundaries between safety and danger, as a result of being diagnosed with dementia and reappraising threats. Much of this is linked to confidence and participants no longer trusting in their own capabilities, for fear that something would happen.

However, this section also reflects the active efforts made by women with dementia to continue to do things that were previously important to them, and hence maintain those valued aspects of their Self 2.

This chapter illustrates the wide-ranging impact that dementia can have on aspects of a woman's selfhood and identity. Each woman in the present study had assumed a new Self 2 characteristic: that of the person with dementia. This has the potential to impact on self-esteem by taking over those Self 2 attributes that were previously valued, which can lead to sadness, anger, frustration and other negative reactions. In response to the acquisition of this characteristic, women can engage in considered modification of their behaviour, which serves to protect both further aspects of the Self 2 and the Self 3.

5.2 'Worst day of my life': Receiving and adjusting to a diagnosis of dementia

Receiving a diagnosis of dementia was a life event of varying significance for the women in this study, and as such, triggered a similar array of reactions and appraisals, both at the time of diagnosis itself and beyond. Although coping strategies were used, these were not evidenced until later, as a means of resisting the impact of dementia and preserving a sense of self going forward (Clare, 2003). Indeed, upon being told of their diagnosis, almost all participants accepted it. However, this took on different forms. Some were relieved, others were shocked, others confused about what it meant.

Two participants in the present study had known for a while that something was wrong and had battled for their voices to be heard. Their inner convictions contradicted the assertions of family and health professionals. Hence, being formally diagnosed did not come as a shock to these women – rather there was an overwhelming feeling of relief:

She's saying: 'No, you're just getting older, Mum'. And I'm saying: 'No, it's not that. This is different'. I don't want to be like this, and I want to know what it is. And that's why I was pleased when they actually gave me a diagnosis. (Betty)

Here, it was Betty's daughter, Rachel, who did not entertain the idea that her mother's behaviour was down to dementia, and insisted it was part of the normal process of ageing. The two went back and forth, until Betty was formally diagnosed. Betty actually used the word 'pleased' to describe her reaction to the news, indicating that she was convinced that it was coming, and merely needed this confirmation to prove to herself and others that she did indeed

have dementia. Betty also called her diagnosis ‘knowledge’, which in itself was revealing and in keeping with her general attitude towards the disease. She immediately began to educate herself on everything to do with dementia, joined the local Alzheimer’s association and became a vocal advocate for the rights of people with dementia. In this sense, Betty was one of the few participants whose acceptance of dementia as an illness did not have a negative impact on her wellbeing. Instead, it led to her gaining increased access to different forms of social support and equipped her with the motivation to find out more information in order to enhance her personal situation.

Lynda, like Betty, had faced resistance from her family, who had not believed that she had dementia either. For Lynda, the process of getting a formal diagnosis was a long and painful one:

I found out that it was three years it took me to be diagnosed. And...because I'd been complaining to doctors and everything about this before, and it took me three years. That...when she told me, it was the relief. You know, because nobody was believing me, and even Joe started to call me a hypochondriac, you know. And...so it was the relief. (Lynda)

The above extract suggests Lynda had to do battle with the medical profession in order to obtain validation for her symptoms. Throughout this process, she describes the ignominy of having her complaints dismissed. Both the health professionals that she initially came into contact with and her own family dismissed her assertion that there was something wrong. Consequently, Lynda was left to feel alone. For her, when she was finally diagnosed, there was no sense of pleasure, simply relief; justification that she had been right all along, despite no one else having taken her seriously. However, potentially due to the amount of damage to her Self 2 that she had suffered during this period – including her claims to being unwell being refuted and, as she describes, being labelled a ‘hypochondriac’ – Lynda described a difficult adjustment to the diagnosis going forward, and struggled in a number of ways. Moreover, her faith in the medical profession had been eradicated, which appeared to leave a lasting impression on her. This illustrates how people with dementia are sensitive to the manner of doctors and other health professionals, which can impact on their Self 3, and make them feel invalidated.

Like Betty and Lynda, the diagnosis did not come as a shock to Sally. However, in contrast to the other two, who displayed initial relief at being formally diagnosed, Sally was devastated.

Even though she had known there was something wrong, confirmation of the fact still had a significant psychological impact on her:

I knew I had problems. I knew it wasn't just...forgetting things...it was something more. And then they did a scan and they told me on Black Friday, would you believe? What a day. I'll never forget that. Worst day of my life. (Sally)

The impact of the diagnosis on Sally was catastrophic. Describing it as the 'worst day of [her] life' seemed significant in light of the fact that she had also experienced a number of close family losses. It served to lay bare the life-changing shift that came with being diagnosed with such an illness – the 'existential gravity' of it (Williams, 1984, p.197). The initial devastation experienced by Sally was still felt keenly today, and she described her sense of self – of the essence of who she was as a person – as having been permanently altered. One positive aspect of the dementia experience for Sally, however, had been the diagnostic process:

*I just thank goodness that...I was diagnosed early. I was very grateful that my doctor listened to me. I **knew** I had problems, and normally if you say: 'Well I'm forgetting this or that', but I knew it was something more. And, bless her, she listened to me and sent me to the memory clinic. (Sally)*

Sally's experience of the medical profession had been vastly different from Lynda's and she acknowledged that it was not necessarily the norm and that doctors could quite easily dismiss symptoms of forgetfulness. Many people with dementia who describe similarly positive experiences of initial visits to their doctor also put this down to the luck of the draw in terms of having someone who is both knowledgeable and listens (Sutcliffe et al. 2015). Sally, like the other participants whose representations of dementia aligned with illness or disease, desired, more than anything to know what was going on. For these participants, being convinced that something was wrong and not having an explanation for their problems was particularly hard.

Bridget described the process of being diagnosed and her reaction to it, in bleakly negative terms:

I didn't know which way was right, or whether it was up or down. I just, I just was being led by the nose, it's as simple as that. And I thought to myself, oh that's it, that's it, I'm signed to the bin. All sorts of things were going through my head. (Bridget)

Much like Sally, the diagnosis had devastated Bridget. She did not just associate dementia with an illness or disease, but with something akin to mental illness. These accounts highlight the acute threat that dementia poses to the reality of some of the women in this study, as images of morbidity, suffering and mortality were conjured up (Bury, 1982). Bridget was convinced that she would be committed to the ‘bin’, which conjures up outdated images of asylums for the insane.

Wendy had also come to expect a formal diagnosis, for the reason that she had cared for her mother whilst she had the disease, and recognised that there was a hereditary link (Wolters et al. 2017). Wendy viewed dementia as an illness, distinct from normal ageing:

My mum had it and when we were looking after her, we had to keep an eye on her. She'd go out and do the shopping and then she wouldn't come back because she'd forgotten, you see? So I diagnosed myself really, and then the doctors...proved it. (Wendy)

Having experienced dementia first-hand from a caregiver's perspective, Wendy recognised the symptoms in herself. She was insightful enough to concede that it was the wandering behaviour – which she herself was also prone to – that provoked this recognition. Unlike many participants who react with fear, having seen first-hand, the effects of dementia in a relative (Pratt and Wilkinson, 2001), Wendy was very pragmatic about her situation. A large part of this appeared to be due to her religious beliefs. It was also helped by her son being a doctor; meaning that she did not have to go through the lengthy process of obtaining a diagnosis that other participants had, and for her, it had been relatively quick and straightforward.

For others, being diagnosed with dementia was unexpected – their own perception of the problem lying at odds with this (Clare, 2003). In most cases, contrary to the above participants, it was family members who had convinced them to seek help. There was also confusion on the part of some of these participants, about dementia and what it actually meant:

Well the word 'dementia'. I don't really...perhaps I have come across it before, but not really knowingly. And I think it was a bit of a shock when it's got a name to it. I didn't feel that I came under that category. (Joan)

You don't really know what it is, you know, so it's a bit like: 'Oh dear, what do I think?' (Stella)

I was quite surprised, I thought no, they've got it wrong [laughs]. But I mean...dementia...I don't know what it means, to be honest with you. I suppose it's something that comes when you're between seventy and eighty. (Catherine)

The above quotes from Joan, Stella and Catherine displayed a similar reaction in the sense that all three women were unclear as to what dementia actually meant. This lack of understanding perhaps reflects the fact that, even in the realm of science, relatively little is known about the causes of dementia. Moreover, the symptoms and nature of progression of Alzheimer's and other forms of dementia are experienced variably. Therefore, the lack of clarity in the accounts of some participants about what dementia means, could be reflective of the uncertainty about what it will mean for their lives, both now and in the future. Despite not knowing what it entailed, neither Joan nor Catherine saw themselves as belonging to this group. Nonetheless, Joan admitted her shock at the news and the reality of having a clinical label attached to her symptoms. Catherine's representation of dementia was as part of the normal process of ageing.

Martha, too, had been taken by surprise at her diagnosis, having not realised that anything was wrong:

Oh yeah, dementia. You know, that part of me brain's... [places a hand over the back of her head] I was a bit upset at first, you know, 'cause I didn't realise I'd got it. But Eric noticed that I kept saying: 'Where's this, where's that?' So I went and I found at the hospital. And I was a bit upset, but then I went to the hospital, to all the classes, and I realised I was better than some of them, so it didn't bother me after. And that's it, it's just a memory problem, really, isn't it? (Martha)

Martha's construction of dementia was as an illness – as evidenced by her attempt at indicating that it concerned a problem with part of her brain. Her reaction did not convey a sense of shock or devastation, despite her admission that she had been 'a bit upset'. However, the one thing that helped Martha to come to terms with her diagnosis, and a running theme in her interview, was the fact that she attended a series of support groups at the hospital, where she had been surrounded by people in varying stages of the disease. As will be discussed in the second chapter, making downward social comparisons with these other people allowed Martha's sense of self to be boosted, because she was 'better than some of them'. This protective strategy perhaps enabled Martha to conclude by presenting her diagnosis as 'just a memory problem'.

Alice's account represented the way in which she perceived dementia:

Then me mum got involved, with all this going on, about losing things and forgetting things. I just try and get away from the actual word. I mean, I know what's going on. I feel I know what's going on, I know who's who. (Alice)

For Alice, there was a similar sense of confusion as expressed by other participants. She did not understand why she had been referred to a memory clinic, and was indignant at the idea of being grouped together with other people whom she considered older and more impaired than herself. Instead, she presented her symptoms in terms of normal forgetfulness. This helped Alice to preserve a sense of self and ward off the threat that accepting a diagnosis of dementia may have posed to her. She doubled down on this narrative by insisting that she was aware of what was happening in her social environment, as though she associated dementia with a lack of such insight. Therefore, Alice, like Martha, derived her explanation of dementia from her own lived experience, rather than from medical definitions – which she actively avoided (Belgrave, 2004). This helped her to resist being characterised as having an illness and to normalise her situation, thus protecting her self-concept.

In conclusion, this section has explored the ways in which people experience the diagnostic process and their initial responses to being told they have dementia. The responses could broadly be aligned with the work by Clare et al. (2016) on the illness representations of people with dementia. The authors concluded that some people conceptualised their diagnosis in terms of an illness, using diagnostic labels when interviewed by researchers and focusing on causes beyond the normal trajectory of ageing. Others viewed dementia as part of the normal ageing process, assigning causality to becoming older. Diagnostic labels were less evident in this group. The third group simply dismissed dementia, insisting that they had no problems, beyond minor ones associated with age, and displaying limited awareness of their own functionality (Clare et al. 2016). Those who accepted that dementia was an illness or disease displayed better cognition and greater awareness. But they were also more anxious, had lower mood, and greater concern for the implications that would follow. Whereas those who did not accept dementia for what it was, had better mood. As the authors noted, this lack of acceptance of dementia as an illness can serve a protective function for many participants, as it enables them to normalise it and to carry on as before. The account of Catherine, above, could be considered an example of this.

The findings of the present study support this notion. On the one hand, there were those representations of dementia that aligned with the illness/disease view, and this group was

adamant in the knowledge that their symptoms signified something pathological. They accepted their diagnosis unreservedly, having largely already prepared themselves for the eventuality, but they also struggled with negative emotions going forward. The accounts of others attributed dementia to the normal ageing process, whilst several expressed confusion and uncertainty about what dementia actually meant (Clare, 2003). However, these women appeared to display better emotional adjustment to the disease, which will be discussed in the next section of the chapter.

5.3 ‘It’s like being a child again’: The emotional and psychological impact of dementia

The struggle to adjust to a diagnosis of dementia, coupled with the recognition of losses and the effort of self-presentation for fear of stigma, can lead to a range of emotional responses. Many participants described feeling anxious, frustrated, depressed, or lonely. They often found it hard to reconcile their limitations, and had decreased self-esteem and confidence in their own abilities. This can be linked to the Self 2. The Self 2 consists of one’s attributes, and one’s beliefs about those attributes. A diagnosis of dementia can lead one to negatively compare one’s former attributes with one’s present attributes, which will be shown below, and which can have a significant toll on the emotional wellbeing of those concerned. Several participants thus experienced a crumbling away of their former self-images (Charmaz, 1983).

One of the most feared losses in dementia is the loss of identity (Aminzadeh et al. 2007). Often this is related to social stigma – as will be evidenced later – but other times, it is not. Sally, for example, had a close, supportive network of friends and family. Yet she frequently described no longer being the same person as she was:

It still bothers me. But I just don’t seem to have control sometimes. That’s my biggest...thing I’ve noticed – my personality. I’m not...I’m not the Sally I used to be. And he [Howard] definitely knows I’m not the Sally I used to be. Makes me wonder sometimes how on earth he puts up with me. I know I’m different. That does bother me. Particularly when I’m nasty to Howard. He’s so good to me. I think, why does he put up with it?! Like he says: ‘Well, I love you’. But I don’t know why he puts up with it. That’s the sad bit, I think. I’m not the person I was. And that...bothers me. But there’s nothing I can do about it. Really. (Sally)

Sally was one participant who talked explicitly about being a different person since her diagnosis, which mirrors how people with dementia are sometimes described by their family

members (e.g. Ward, 2015, Hughes, 2001). Dementia, according to Sally, had robbed her of the person she once was; the person who was happy, sociable and relaxed. She struggled to understand why exactly things had changed, but concluded that she was powerless to stop it. There was an air of resigned acceptance about Sally, as though she had no fight left in her.

Sally's account was notable for the fact that it explicitly referenced herself as being changed – in other words, she was a different person now.

Lynda was another participant who mourned the loss of her previous self, in terms of her role identity as a mother and homemaker:

I was always the one in charge. I was really strong. Strong-minded and...you know. I was the boss in the house. If anything needed doing, I was the one that'd do it. And because my daughter's got learning disabilities, I was the one that dealt with all the benefits and anything else that needed doing. If she'd got bills to pay, I used to help her. And now...well, she doesn't rely on me anymore. For anything. I'm the one that relies on everybody else. So compared to what I used to be like, I've changed ever such a lot. I just haven't got the confidence anymore. I can't rely on myself anymore, because my memory...you know. (Lynda)

Changes in the power dynamics of role-based relationships can threaten the identity of a person with dementia (Wadham et al. 2016). The above extract, for example, paints a stark contrast between how Lynda perceived her former and present self. Unlike Sally, who articulated the change in her sense of self with less specific examples, Lynda did provide these. She had been strong and capable; she had juggled a busy job with the running of the house and family affairs. Importantly, she had taken care of everything to do with her daughter, and had been the one on whom others relied. Losing the ability to perform such tasks that had been central to her familial – and gendered – role, as the 'one in charge' threatened Lynda's identity (Borley and Hardy, 2014). These roles were cherished, they made up her Self 2. Now, there had been a shift, as Lynda became the one who was reliant on everybody else – including her daughter. The beliefs about her former attributes in these domains had therefore changed, and her self-esteem – the evaluative component of self-knowledge – impacted as a result.

Lynda expanded on this distinction, by describing further the discrepancy between her past and present self-confidence:

I had bags of confidence before. Yeah, I was really confident. I didn't have problems talking to people or making decisions, you know. I was always the one in charge. So it's changed quite a lot. (Lynda)

Lynda made a comparison between her past Self 2 – as confident and outgoing – and her present self, as having to rely far more on other people because she did not trust herself. Restrictions imposed by dementia foster a sense of loss of Self 2 attributes, as expressed in the above extract. As a result of these losses, the person's overall self-esteem may become damaged over time, as a lack of trust in oneself and feelings of insecurity prevail (Olsson et al. 2013). Lynda, for example, now found social interaction extremely challenging, and avoided it where possible. She also struggled with decision-making:

I'm terrible at making decisions. If you give me three things, and say: 'right, choose which one' – I can't. I can't do that. So I need somebody to tell me which one. (Lynda)

Lynda linked her inability to make decisions to her lack of confidence and self-belief. She doubted everything she said and did, which served to make daily living mentally and physically exhausting. Hence, she readily relinquished control over most aspects of her life to others (Samsi and Manthorpe, 2013). An example that Lynda gave of her decision-making quandary involved her going into a room and sitting down on a chair. She would then become anxious and start to fret inwardly that she had chosen 'the wrong chair' and that another chair was 'better'. If she was alone, she would move to another chair. But if she was with other people – either members of her family or those she knew less well – she would not dare to move, for fear of revealing the issue. This would put paid to the hard work Lynda invested in 'passing', her careful attempts to conceal her diagnosis in every social situation (Goffman, 1968, p.42). She was therefore caught between reliance on others for support in decision-making and fear of revealing her insecurities and weaknesses. Instead, she turned the thought over and over in her mind, unable to concentrate on the conversation going on around her, and able to focus only on her choice of chair. This example was extreme, but it was indicative of Lynda's struggle. So uncertain was she of any kind of belief in her own capabilities, that she did not trust herself to pick the right chair to sit down in. Similarly, when it came to meals, Joe had to decide what they were having for dinner in advance, as otherwise, this would present another hurdle for her – one which she could not overcome.

Interestingly, Bridget veered between an animated demeanour, where she would often show fight and tenacity, and one that was resigned. This is reflected in the below extracts, as she switched between insisting that she has retained all her former capabilities and the concession that she could no longer do anything:

Because I know that I can do what anybody else can do, and I want to do it, and nobody will let me because I can't...the only thing is, is this damn thing. After everything else, the God Almighty decided to swipe me with this and I daren't...I just daren't go off piste, in case I turn left and I should've turned right. That's the only thing that bothers me, it's the only thing that gets me. If they could pick this up, take it out of me brain, I'd be normal and I could...everything would come back. I'd know where I am. (Bridget)

And you know, I just...I just feel worthless half the time, as if I can't do anything. I'm not being...it's like being a child again and nobody's teaching me, you know? That sort of thing. Does that make sense to you? (Bridget)

In the first extract, Bridget began by seemingly insisting that nothing had changed, that she could still do everything she had previously. She went on to imply that it was other people placing restrictions on her. In other words, she could not construct a valued Self 3 persona, because people did not cooperate in this construction, instead focusing on her disease-related limitations. In contrast, the second extract merely concedes global feelings of worthlessness – pointing to damaged self-esteem. It is possible that these perceived restrictions imposed by others had reflected back on Bridget's Self 2, changing how she saw herself, which was now as incapable of doing things she had previously.

There were a range of formerly enjoyed hobbies and activities that participants whose self-esteem had been affected by dementia no longer took part in. Others continued to take part, but made concessions that they saw as essential in order for them to do so. This will be discussed later in the chapter:

Howard does most of the cooking now, 'cause I've lost confidence. That confidence seems to have...poof! I'm all right with some things, but I just can't do it unless he's there with me. (Sally)

Sally referenced her confidence having deserted her on numerous occasions. It was, she explained, the thing that affected her the most, and something with which she struggled to come

to terms. It impacted on almost every part of her life and was strongly linked to what she described as her personality having changed. She observed that there was no obvious reason for such a sudden dearth in her perceived self-esteem – for Sally, there had been no single traumatic event that had triggered the spiral of anxiety and helplessness – rather it seemed to have simply vanished. In the above extract, Sally conceded that her partner, who lived next door, now did most of the cooking, and went on to elaborate on this:

I used to be quite happy cooking. Now I'm...very unsure. Which is stupid really, but...that has affected me. Very unsure. I've lost my confidence, put it that way. It's a confidence thing.
(Sally)

Having previously enjoyed cooking, which was a valued Self 2 attribute, Sally had given it up because of the change in her beliefs about this attribute. In other words, she no longer believed she was capable of it. It was one of many examples she gave, illustrating starkly how seemingly trivial day-to-day tasks and activities were no longer achievable. They had become something far bigger in her mind and presented an insurmountable hurdle. She dismissed this as 'stupid' and during our interview, would regularly attempt to brush off other issues as such, appearing annoyed at herself, but simultaneously unable to overcome them. Thus, Sally presented things like cooking, not as a loss brought about dementia, but as a loss brought about by an overall lack of confidence and belief in herself as a result of dementia.

A lack of self-confidence in one's ability to navigate the normal realms of life can lead to loneliness and isolation. People's lives can become constrained by 'defensive avoidance of social, recreational and vocational activities that might expose them to threats' (Bandura, 1997, p.319). To take the example of social anxiety, described by Bandura: people withdraw from social situations because they believe that they do not have the capacity to meet normal social standards. This, however, is down to a lack of perceived efficacy to successfully negotiate the situation, rather than the person actually having deficient social skills (Bandura, 1997). It can be aligned with the distinction between felt and enacted stigma; it is the perception on the part of the person with dementia that is often the crucial factor – a perception that is not necessarily reflective of reality. Consequently, low levels of confidence in domains such as social support lead to lowered perceptions of health-related quality of life and self-esteem (Fry, 2001).

Those participants in the present study, who had withdrawn from social situations because of a lack of confidence in their ability to cope with them, inevitably encountered loneliness and

isolation as a result. Loneliness occurs as a result of a ‘discrepancy between desired and available relationships’ (Walton et al. 1991, p.169). The ageing process, it is commonly accepted, makes one especially vulnerable to loneliness, as health declines, close relationships are lost and people experience age-related losses. There is also a relationship between loneliness and hopelessness. If someone feels hopeless, they are more likely to view problems as insurmountable (Walton et al. 1991). This ties in closely with self-esteem – the notion that people do not seek out social relationships or connections, because they feel inadequately equipped to do so.

Loneliness and isolation, in turn, were major contributing factors to the mood of the women with dementia in the present study, and appeared to be intrinsically linked to expressions of sadness:

It's lonely in the fact that I feel...I'd always worked before so, now I feel I haven't got that much conversation because I don't do that much. Erm...so that sort of, has made me feel isolated in a way because I haven't got anything to talk about and the other thing is, sort of, because I do try and act normal, but I don't feel that I am. (Lynda)

Evident in the above extract was how Lynda perceived herself, which was as diverging from socially acceptable norms. She was also struggling to cope with the fact that she no longer worked, which is one of the common age-related losses described above. Lynda had lost both the sense of importance and self-worth that came with having a job, and her social networks, since these had been forged through work. Also in evidence was the fact that Lynda's self-concept was damaged – she no longer felt ‘normal’ – and this conflicted with her self-presentation. Despite trying to put on a front in social situations, to engage in ‘passing’ in an attempt to become part of the ‘normal’ group (Goffman, 1968, p.42), she could not alleviate her own feelings of insecurity, and it led to her withdrawing from situations, for fear of being exposed:

You feel lonely and you feel isolated. Even though I've got Joe and I've got my daughter, who are close. You still feel isolated. You're not...you know. And it's hard to make...because you don't do...I don't do as much conversation. My conversation is pretty bad. I can't start a conversation, really. So that sort of isolates you even more. (Lynda)

Lynda kept referring to not having the conversational skills required to interact with people in a social situation. However, on the two occasions I met her, both during the interview and in

the informal space before and after, she seemed to have no trouble with these. Her answers to interview questions were broad and wide-ranging, and when the Dictaphone had stopped recording, she instigated conversations about my travel arrangements, the weather, and my upcoming plans for Christmas. This led me to the conclusion referred to by Weeks (1994), that people's subjective assessment of their social skills often did not correlate with actual deficits, and that it was a case of faulty self-attributions. It is also worth considering the social stigma Lynda had been subjected to on several occasions, by people claiming she did not 'look disabled', and by all of her numerous siblings abandoning contact since she had informed them of her diagnosis. Such experiences could easily reflect back on Lynda's Self 2 in a negative manner, influencing how she perceived herself.

Betty was an interesting paradox of someone who was incredibly active in the community and had a lot of networks, but seemed to shy away from forming close relationships. She admitted that all the people she knew were acquaintances, rather than friends. Below, she explained her reasoning for this:

I was always quite a positive person and now I think more about how other people perceive me than I would ever have done. Once I was brash, but I felt confident enough that, in what I was doing, that I was doing what was right for me. I still do think, what's right for me, but I question it more now, as to whether people will see the same thing of me as I see. (Betty)

Dementia had changed Betty's Self 2 – her evaluation of herself as a 'confident' person. Now she was more uncertain, experiencing self-doubt in social interactions. Previously, she admitted she would not have thought twice about the responses of others, whereas now she did. Significantly, close to the time she was diagnosed, Betty had also lost her husband. Living alone is a significant predictor of loneliness and psychological distress, particularly when one has been accustomed to a constant source of human contact (Fry and Debats, 2002):

Being on my own, living on your own is very hard. The feeling, still, of isolation that I close the curtains about half past four now and I won't talk to anybody till I dog walk the next morning. 'Cause when you go out at night, you keep your head down and you just do the dog walk and...and it's that talk, even if it's just a 'hello', it's that spark of a human being. That spark of intelligence that you want, just to keep you knowing that you're a useful piece of the environment, you know? (Betty)

Weeks (1994) identified a distinction between emotional and social loneliness, with the former referring to loss of a close and intimate relationship, often provided by a partner or spouse, and the latter, to meaningful friendships. Whilst most participants experienced social loneliness, emotional loneliness can give rise to feelings of emptiness, which was what Betty described in the above extract. An ability to mobilise social support from others is moderated by belief in one's ability to do so (Smith et al. 2000). Betty did not appear to believe she was capable of this; it is possible that, had she successfully been able to, some of her social loneliness may have been alleviated, which may in turn have acted as a buffer against the emotional loneliness.

Bridget was another participant who struggled to come to terms with feelings of loneliness:

I just feel lonely, I suppose – permanently. I feel as though I'm on my own and I'm fighting in my own corner, in my own way and hoping and praying that something is going to come out the bag. Erm...something that's concrete, if you like...touchable, that sort of thing. There's no point...I found out there's no point in sitting down and crying 'cause it's not going to go anywhere and all I'm going to do is make me eyes all red raw and one thing and another and I'm going to get a bloody headache, so... (Bridget)

Bridget described her marriage in rather bleak terms, painting a picture of her husband as being both controlling of aspects of her life, yet uninterested in spending any time with her. Similar sentiments were expressed in a study by de Jong Gierveld et al. (2009), who explored emotional loneliness among older married individuals. The authors found that 18% of women reported feeling emotionally lonely, which was a result of lack of perceived instrumental support from their spouse, and lack of spousal attentiveness. The above passage reflected on this situation. To use Weeks' (1994) terminology, Bridget experienced both emotional and social loneliness. Emotional in the sense that her relationship with her husband had – in her eyes – deteriorated. Social in the sense that she reported having no friendships, which appeared to be partly exacerbated by living in a rural part of the country. More importantly, however, like others, Bridget withdrew from social situations when they arose, for fear of people realising she was mentally unstable – or 'batty', as she put it:

I stand in here, I walk round the house and I'm thinking to myself, what the bloody hell am I doing here? I might as well kill myself here and now and have it over and done with, you know? It's not a good thought, that isn't...no. (Bridget)

The seriousness of some of the emotional reactions described by Bridget is reflected in the above extract. There were occasions, when she was feeling particularly low, when she would contemplate the futility of her own existence. She talked flippantly about ending it all, whilst simultaneously acknowledging that such thoughts were harmful.

Betty also described feelings of low mood that could be traced back to loneliness and isolation. These, however, were not as intense as Bridget's, and Betty appeared only occasionally susceptible to them:

90% of the time I'm happy, 5% of the time I can be really down, but I suffered from post-natal depression and that never leaves you. I still feel that sometimes I can go down so quickly and feel so miserable. Not that I want to end my life or anything like that, but it's very hard to find something to lift you because I always say, somewhere in your time...whatever you're doing, something small will lift you just that little bit. Enough to, you know, give you that oomph, to think, there is life and I can go on. (Betty)

One of the main reasons why Betty filled her days with social interaction, advocacy and activity was because she had struggled to adapt to her husband's death. In coping with spousal bereavement, the notion of keeping oneself busy and occupied is often stressed (e.g. Caserta and Lund, 2007). Thus, Betty's packed schedule served the dual function of helping her to maintain a positive self-concept and see herself in terms of her retained capabilities, and also providing 'human contact'. She was constantly striving to find things to 'lift' her mood. On those occasions where she couldn't, Betty was vulnerable to feeling depressed. This, she admitted, was particularly difficult in the winter months, when the days were shorter and the time spent in her flat, alone with her feelings, and without the distraction of other people around her, was intensified.

For several participants, there was a more general struggle with their mood, seemingly unconnected to loneliness, but potentially linked to the impact of dementia on one's self concept. This is consistent with research that has shown the psychological losses a person experiences as a result of the disease can give way to feelings of depression (Cheston and Bender, 1999). Lynda, for example, was on medication for depression and also suffered from panic attacks:

It's a strange kind of depression...because I don't have that many emotions. Sometimes I feel tearful, but I don't know why. I think that's the biggest thing I've noticed really, is my emotions.

I don't feel things like I used to. When people say: 'How d'you feel?' Well I don't know, I don't know how I feel. (Lynda)

In the above extract, Lynda described an emotional bluntness taking hold, whereby she could no longer 'feel things'. Drago et al. (2010) found that people with Alzheimer's disease had a decreased emotional experience. Lynda struggled to make sense of these changes taking place within her. She described an ongoing difficulty in articulating her feelings to other people, in response to well-meaning but frustrating questions. Such questions were an inevitable accompaniment to a diagnosis of dementia, yet they only served to highlight to Lynda, the fact that she could not conjure an answer, because she did not have the same capacity for interpreting or understanding her emotions and feelings as previously.

Wendy described how she had initially been susceptible to low mood, as a result of the difficulties she faced when navigating the public transport system:

I got very depressed to begin with...when they were doing the erm...tram. Because I used to go to things – not the Sunday things – but the other things, that happened in church, that I was part of. And in some of them, I was one of the workers, helping there. And it got so messy, because you could never find the bus waiting for you in the place where it waited for you the other day! So...that's pretty hard. (Wendy)

On the surface, the development of the city's tram network, and the disruption associated with this, may be considered a rather innocuous reason for using a word like 'depressed'. But when this extract is considered in the context of Wendy's life and identity, it is easy to see how the impact of it could be significant. Wendy, after all, was committed to her church. It gave her a sense of purpose, it afforded her social connections and it took up a large part of her life. In relation to her Self 3, this was where she constructed a valued identity as a 'worker' – someone who was central to the running of the various church groups – which then reflected positively on her Self 2 attributes. Whilst the construction of the tram network was ongoing, this threatened Wendy's sense of self, because it impeded her ability to carry out those valued roles. As has already been discussed, in the context of Lynda, losing those social roles and status is associated with feelings akin to grief.

Anxiety was also evidenced in many participants' accounts. Some, like Marian, played this down:

I just feel it like I feel I've stubbed a toe. You know, it's like a painful thing. Only sort of...erm...I'm sitting and I'm talking and I'm thinking about what you're saying, and so and so. And in the back of my mind, there's a sort of...ah, yeah, I'm worried about my bag, ah yeah... But OK, you stubbed your toe, your nose is bleeding, we'll have to go without those books I meant to buy. But it's all so factual. Whereas depression – I mean, it's so depressing.
(Marian)

Marian, perhaps revealing her clinical insight, compared anxiety to depression, claiming that she would rather have the former, because it was, in her words, more 'manageable'. Moreover, Marian's anxiety did not seem to have too great an impact on her life. She described it as more akin to a nagging worry in the back of her mind that sometimes meant she couldn't give due attention to what people were saying. This was evidenced in the space between one of our interviews, when Marian would get distracted by minor things, and seemed to fret over these. As we were walking through to her kitchen, for example, she noticed a pile of papers and magazines on the table in the hall. She stopped to inspect these and muttered to herself that someone must have let themselves into the house when she had been out, as she did not remember the pile of papers having been laid out in that way. She would also stop mid-flow, when answering a question, to check that she had poured the tea, or on the whereabouts of her cat.

Lynda described a more acute sense of anxiety, that appeared on the one hand to be related to her exposure to social situations, but could also strike in the form of panic attacks, at seemingly any time:

I'd been having some episodes where I'd been out...erm...I sort of lose my breath, can't get my breath back. And I get the shakes. I had a panic attack, sort of, walking up the hill there and every time I see a hill now, I think I'm going to have a panic attack. (Lynda)

Lynda had begun to suffer from frequent panic attacks whilst out and about. Because she had once had an attack when walking up the hill to her house, she had formed an association between hills and panic attacks. Walking up the hill had previously been a benign, neutral event for Lynda. Now, since having formed an association between hills and having a panic attack, she appraised all hills as threatening, and actively avoided them:

I have it with the crowds as well in the doctors, yeah. I was lucky when I went on my own 'cause I was the only one there. But when the reception is full, I can't tell which is the

receptionist's voice calling my name over the people talking, and with the noise, my head starts going. At the hospital, they know me now and they have me in straight away because I've started crying before because the noise...and my head starts going. (Lynda)

Lynda was also vulnerable to panic attacks in situations like the above, which were a major source of stress. The first example she gave – walking up the hill – could be considered relatively benign, and was perhaps indicative of how severe Lynda's anxiety was. But the notion of being in a crowded reception area at the doctor's surgery or hospital, and not being able to hear the receptionist over the noise, is one that many people could potentially relate to. Particularly given that the reason for Lynda being there in the first place had to do with the fact that she was either about to find out whether she could continue to drive, or to receive an update on the progression of the disease. It is not hard to imagine the level of distress that this would cause someone already prone to panic attacks and who had become fearful of having to do anything by herself of late.

Sally had talked about the benefit that attending her local Alzheimer's group would provide, but insisted her anxiety would always prevent her from attending. The only people with whom Sally interacted, were a trusted and close-knit group of friends. Even this sometimes posed a challenge for her, given that she had become extremely nervous in such situations. Indeed, Sally struggled to leave the house without her partner, Howard by her side:

There's a fear in me. I do find that. I haven't talked to Howard a lot about that, but...there is a fear in me when I'm out, even. If I can't see him near me. And I don't know why. I don't know why I've got that fear, or really what the fear is about. (Sally)

In the above extract, Sally expanded on her anxieties, admitting that she had not even discussed them with Howard. What she was describing appeared to be something innate; she acknowledged that dementia had changed her in many ways, and this was one of the fundamental ones. She was now gripped by a pervasive fear – the reasons for which she could not explain. It had a wide-ranging impact on all aspects of her life. She could not do anything without her partner, to the extent that she would begin to panic if she lost sight of him when they were out together.

Other emotional responses to dementia and its symptoms revolve around feelings of anger and frustration. Catherine, for example, directed her anger at herself:

I think, what an idiot I am sometimes. For god's sake, why can't you remember?! You know...where did you put this? Where is it? It was here a minute ago...you know. And I get irritated and...frustrated. (Catherine)

In the above extract, Catherine expressed exasperation with her memory – referring to herself as an ‘idiot’. Feelings of frustration and anger at memory blunders, leading to self-castigation, are common in people with dementia (e.g. Howarth and Saper, 2003, Clare, 2003). Catherine did not openly acknowledge or accept her diagnosis during the course of our interview, and never used the term explicitly. Instead, she referenced forgetfulness, which caused her immense frustration and led to a fear of her being embarrassed in a social context.

Accounts such as the above discuss the emotional and psychological impact of dementia on the women in this study. There was a wide range of these, with some participants expressing a global impact on selfhood and self-esteem, and others frustration with aspects of their cognitive impairments. The self-concept of several women in the present study had changed – in other words, they saw themselves as fundamentally different to before. The loss of certain past attributes was also expressed and with this, a valued aspect of the person’s identity. Several women experienced loneliness and isolation that sometimes appeared to be linked to their lack of self-esteem and withdrawal from social situations, and other times, appeared to be a contributory factor to feelings of low mood.

Evidence has suggested that people who have low self-esteem that has been sustained over time, will experience a greater decline in agentic capabilities with ageing; in other words, will withdraw from social interaction and experience an increased sense of loneliness (e.g. Fry, 2001, Smith et al. 2000). However, this did not hold true for the participants in the present study. Those who described feeling lonely, did so as a result of the threat posed to self-esteem by dementia, specifically comparing their present situation negatively with the past. Indeed, many women in the present study specifically asserted that they had previously been confident, outgoing people.

Bender and Cheston (1997) theorised that powerful emotional responses to dementia are indicative of the fact that it engenders such fear in people. Mieson (1993) claimed that the catastrophic losses suffered – in terms of status, roles, cognitive functioning and relationships – fuel a kind of grief and mourning process for ‘the decreased ability to experience oneself as a continuity’ (p.152). As was touched on in the previous section, the types of illness

representations that people with dementia have appears to impact on their ability to psychologically adjust. For example, people who accepted that dementia was an illness and did not attempt to minimise its impact were those who appeared to express the strongest emotional reaction.

5.4 ‘I have to try and act normal’: Self-presentation and stigma

Due to dementia being a non-visible condition – at least in the early stages – people can choose to manage awareness of their symptoms in a social context (Beard, 2004). Almost all participants in the present study engaged in some form of self-management in social situations, and actively considered whether to disclose their illness or not. Hence, they made conscious choices about self-presentation that served to lessen the perceived threat posed by social interaction (Clare, 2003). The reasons they gave for either choosing to hide or disclose their dementia were insightful, and often reflective of their experiences in the social world thus far. This relates directly to Tom Kitwood’s (1997) ‘malignant social psychology’, and the notion that people with dementia are affected by a wide range of (not necessarily malicious) behaviours on the part of family, friends and acquaintances that could have a detrimental impact upon their ability to be themselves around others.

In contrast to other studies (e.g. Beard, 2004), which found that most participants would rather be open about the fact they had dementia, the majority of participants in the present study attempted to hide their symptoms. Of those, Lynda was almost constantly concerned with how she came across and engaged in self-management with everyone, including family, acquaintances and strangers. With the latter two groups, Lynda actively concealed her symptoms in order to reduce the risk of being stigmatised. She believed she would be seen as ‘stupid’ otherwise, and feared being asked a question that she would be unable to articulate an acceptable answer to, and that would expose – or discredit – her. In other words, Lynda feared being perceived as a ‘social liability’, which promoted her defensive strategy of non-disclosure (Scambler, 1989, p.57). Moreover, she also felt the need to put on an act in front of her family, to convince them that she was not deteriorating:

I put on an act. I try and act as normal as I can! It’s real hard work and I get really tired because I find it’s real hard work but that’s what I’ll do most of the time...round my partner and round everybody really. I don’t want them to worry, or I don’t want to make things hard for them. (Lynda)

The above extract is another example of Goffman's notion of 'passing', whereby Lynda describes her attempts to act 'normal', and to conceal any symptoms of dementia (1968, p.42). Whilst most people will carefully manage symptoms in front of those to whom they have chosen not to disclose their illness, Lynda's passing extended to her partner and children, because she did not want to worry them with her behaviour, or become a burden. Previously, Lynda had also referenced the fact that her partner had taken the news about her dementia badly. She was concerned about his ability to cope with any signs of deterioration, and, apparently to the detriment of her own wellbeing, appeared to have put his needs before her own. Lynda was thus engaged in a continuous process of symptom management, as a result of which she felt drained and exhausted. She was so accustomed to it, however, that she even engaged in it when with her daughter, whom she was extremely close to, and whom she admitted saw straight through her act anyway.

Lynda's decision to hide her diagnosis from non-family members, on the other hand, can be linked to her experience of enacted stigma:

When I first heard, the neighbours...when they saw me drive the car after they found out I'd got dementia, they gave me this look as if to say: 'What are you doing driving?' That's another thing, disabled people are the worst people when it comes to...I get some really bad looks because I've got a blue badge. I've seen them taking down my number plate. I've had people come up to me and say: 'Can I see your blue badge?' (Lynda)

I've even had carers...we used to go and give talks, and they used to take me along. And it used to be quite funny, really. They'd say: 'Oh, you don't look like you've got Alzheimer's'. And I think, what are you supposed to look like?! (Lynda)

Lynda could not believe that formal carers, and members of voluntary organisations, who were supposed to be sensitive and sympathetic to the nature of the disease and the personhood of those it affected, would come out with something like this. She had initially done considerable voluntary work on behalf of charities and even spoken publicly about her dementia. However, experiences like the above had caused her to withdraw from all of this. She would also routinely encounter hostile and unpleasant reactions from strangers when out and about. For example, despite being a blue badge holder, she would be subject to queries about the legitimacy of this, because she did not 'look' disabled. It is possible that her age – she was the youngest of my participants – and appearance confounded people's expectations of disability. People with

dementia who *looked* elderly, for example, may not have been subjected to the same scrutiny. Yet people with dementia who dressed in jeans and t-shirts and wore makeup, perhaps did not fit the stereotype. Lynda therefore faced discrimination on the basis of both her illness and her age (Milne, 2010). The end result was that her experiences of enacted stigma had now translated into felt stigma, which had combined to have a significant impact on her sense of self. Lynda carefully avoided social situations, for fear of being exposed.

Another participant who had experienced enacted stigma that had in turn impacted on her disclosure practices, was Bridget:

In the beginning – maybe I shouldn't have done it – erm...in the beginning: 'Well, I'm sorry I can't do that because I've got dementia'. And they're: 'Uh, uh', like this... So I panicked. I thought people would understand in this day and age. (Bridget)

Whilst these experiences did not result in the same kind of overt discrimination as Lynda's had, they nonetheless took Bridget by surprise. She had expected that 'in this day and age' there would be more understanding. For her, it had been quite natural, in the beginning, to excuse herself from various situations on account of having dementia. But people reacted with unease and awkwardness, as evidenced in Bridget's imitation of them, together with her body language of drawing back sharply, as though to illustrate a fear on the part of that person that they might catch something. Interestingly, this accorded neatly with another extract of Bridget's, later on in the interview:

There's only one person: 'Ooh, don't go near her she's batty, you'll catch something'. That was a bloke saying to his wife: 'Don't you go near her'. (Bridget)

Bridget made frequent references to herself as 'batty' throughout our interview. It is possible that this kind of felt stigma was the result of her absorbing instances of enacted stigma like the above. Here, according to Bridget, she had witnessed a man warning his wife not to go near her. This reflects the fact that stigma in relation to dementia, is often aligned with mental illness. People believe they are dealing with someone who 'isn't all there' (O'Connor et al. 2018, p.47). Now, Bridget was engaged in self-management, ensuring that her illness was concealed rather than disclosed:

Nobody knows that I've got dementia. I don't...you know...if I meet somebody on the street o'and: 'Can you tell me how to get to so-and-so?' And so: 'Oh yeah, round the corner, turn left, go right, 20 yards up the road and you're there'. (Bridget)

According to Bridget, she was easily able to hide the fact that she had dementia. Moreover, because she was so isolated – both socially and geographically – her potential for social interaction was extremely limited. It was only on the rare occasion that she would come across someone else, whilst walking in the vicinity of her house and she was safe in the knowledge that if they needed directions, she would be able to provide them with these competently, so that her dementia would not be unmasked.

Catherine was the only participant who had not told anyone of her diagnosis. Unlike Lynda, she had been able to get away with this because her husband was in a care home:

My family don't know. It didn't occur to me to tell them, really. I've sort of kept it to myself. (Catherine)

Catherine had concealed it from her family, including her children, sister – to whom she was close – and friends. She did not see a problem with this, and on the surface, did not appear to be withholding it out of a fear of stigma and discrimination. Indeed, Catherine described valued interpersonal relationships and good social networks. She played down the impact of dementia to such an extent that she claimed it did not merit being discussed with her family. Hence, while Lynda would have withheld the diagnosis from her family due to a combination of felt and enacted stigma, Catherine did so because she considered it a matter of no significance. She also described how she approached non-disclosure with friends and acquaintances:

I don't say: 'Forgive me, I've got dementia', or something like that. No, I wouldn't say that...well I would think that would make them feel rather awkward. You know... yes probably sometimes I am bluffing my way through things. (Catherine)

Unlike Betty, who used precisely such a caveat in order to prepare people for potential memory lapses or other signs of impairment, Catherine considered the idea outlandish. The way in which she imitated herself conveyed a dry sarcasm, as though she was ridiculing the notion that she would ever do such a thing. Rather than referencing her own feelings, Catherine chose to focus on the impact that disclosure of dementia would have on other people. Throughout her interview, was an underlying sensitivity to bad social etiquette. It was not necessarily that

Catherine worried about the stigma of disclosing her diagnosis, rather than she worried about the stigma and social embarrassment of causing people to feel 'awkward'. Or the embarrassment of forgetfulness – which she considered the height of bad manners, and which led her to rely heavily on her diary as a means of saving face. Catherine had therefore chosen to engage in 'passing' – or 'bluffing', as she called it – with everyone, including close family members (Goffman, 1968, p.42). She was pretending to have, what she considered a less stigmatic identity, and had seemingly created a situation where she couldn't confide in people about her illness.

Stella experienced felt stigma and had thus only disclosed her diagnosis to her husband and children. She was ashamed of the disease and expected to be stigmatised by others. Stella therefore highlighted her retained capabilities in relation to hiding her dementia from people other than close family:

Yeah, I mean if I said to you: 'Ooh yes, I've got dementia', then it'd be like that [recoils], wouldn't it? And everyone...they don't seem to know any different. You know, I mean, if they came and wanted a cup of tea, I could come in here and make it and it wouldn't be any different.
(Stella)

Stella outlined her reason for not disclosing the fact that she had dementia in quite a vivid way. She physically recoiled to illustrate her belief in the horror of people's reactions. This highlights the issue of the perceived stigma surrounding the disease for many people. Stella's defensive non-disclosure strategy, therefore, was borne out of the expected rejection by others (Scambler, 1989). She was, however, confident in her ability to successfully conceal it, by reasoning that she was still able to make a cup of tea for anyone who came around to visit – just as she had always done. In other words, like Catherine, she was capable of 'bluffing'.

Martha also insisted that there was no need to tell people beyond her family about her diagnosis because it could be adequately concealed. Martha did not see herself as having dementia, and so did not experience felt stigma:

I mean, none of my friends know that I've got dementia, you know? I don't feel as though I've got it myself, to be quite honest with you. And I wouldn't say that I've got dementia...I don't tell people: 'Oh I've got dementia'. Cause I just live my life, like I've always lived it. Yeah...I never discuss it with anybody...don't tell anybody. (Martha)

Martha had told very few people about her diagnosis – in fact, apart from her immediate family, she was adamant that no one else knew. Her justification for this had to do with self-perception. Martha did not see herself as having dementia, and certainly did not identify with people who had dementia. She continued to do all the things that she had previously done, and from her point of view, therefore, nothing had changed. She associated dementia with incapacity, and because she retained her capabilities, she did not have dementia. Thus, according to Martha, she was not consciously hiding the disease from other people, rather the continuity between her past and present selves meant that she still saw herself as not having the disease.

Sally had been selective in whom she had told of her diagnosis. Only her family and a few close friends had been made aware – in other words, she too was ‘passing’, by carefully managing the nature of her illness disclosure (Goffman, 1968, p.42):

I've only told a chosen few. I haven't told everybody. I've told my close friends and they're fine. Nobody...I mean...it's only three in here that I've told. And obviously my family. (Sally)

Sally's self-concept appeared fragile and she was aware of the losses she had suffered as a result of dementia. Therefore, the protective strategy of telling a close inner circle had two functions. Firstly, it meant that she could conceal her diagnosis when socialising with other friends or acquaintances, to maintain her sense of self. Secondly, it allowed her to reap the social benefits of disclosure, in the form of support and empathy from her family and close friends.

Joan had a similar strategy for disclosure:

Well it just depends who they are really. I'm not a...I don't advertise the fact that I've got dementia. I'm hoping- I'm hoping it isn't sort of obvious! (Joan)

Having a large but close-knit family meant that the number of people who knew about Joan's diagnosis was many. Moreover, she had several close friends whom she had also told. Yet Joan was still careful and did not disclose beyond her inner circle.

In stark contrast to other participants in the study, who engaged in passing when around other people – to a greater, or lesser extent – Betty shunned this option. For Betty, it was important that, when meeting someone, she immediately disclosed her dementia in full. In the same way

that she wanted to know about the disease, and sought to accumulate knowledge from every available source, Betty placed equal value on telling (Hellström and Torres, 2013):

I want people to be aware that if I can't find a word, there's a reason why I can't find that word. Or if my memory slips...or I might jump to something else, unrelated, it's only that I've thought of it and had to open my mouth whilst I remember it. But anyway, I want people to be aware that it's happening more, and that people should be looking towards their later life because that's when it's going to impact more. (Betty)

Betty always primed people that she had dementia, before getting into conversations with them. This can be termed 'protective disclosure' (Charmaz, 1991, p.119), where the person positions themselves as in control. Betty did not want people to assume she was stupid, or incompetent. This, to her, was in fact a stigma in itself that she wanted to avoid. She would rather people know the truth, which was that there was a medical explanation for her behaviour. For some, therefore, the biomedical model and the labels it assigns, can be destigmatising. Nor did Betty want people to think that if she interrupted a conversation, she was rude – rather that she had to speak at that precise moment, otherwise she would forget what she wanted to say. Interestingly, she also alluded to a desire to be held up as a visible example of a person with dementia. In this regard, Betty's disclosure is a means of claiming active 'social citizenship' (O'Connor et al. 2018, p.46). By discussing dementia, she was able to contribute to the debate on increasing understanding of the disease and helping others to modify their behaviours. Betty often spoke of this; of the need to reduce the stigma associated with the disease and for people to be far more open about it. Hence, her own unwavering honesty. The same sentiment was reflected in Beard's (2004) participants, who thought it important that people be open about their dementia and not hide it.

This section has explored the nature of disclosure, stigma and discrimination in the face of dementia. It relates to change – the theme at the heart of this chapter – in the sense that many women with dementia had altered the ways in which they engaged with the world around them. Enacted stigma – experiences of discrimination – could lead to felt stigma, and to people choosing to conceal their symptoms in future interactions. This served to protect their Self 3, as it meant that others would have less opportunity to invalidate the attempt to construct a social identity or to give primacy to the identity of 'patient', whilst at the same time, it protected their Self 2 and self-esteem. Felt stigma was also present in the accounts of those who did not describe having experienced discrimination, and this group similarly concealed their dementia.

Finally, several women concealed it because they played down its significance, asserting that there was no need for other people to know, because it did not interfere with their lives. This could also be an attempt to preserve self-esteem, by downplaying its significance, and hence, its threat to their selfhood. For most women in the present study, who to tell is a carefully considered, 'strategic' decision that reflects active citizenship and control and insight into one's situation (O'Connor et al. 2018, p.50). It was clear that indiscriminate disclosure carried risks, associated with the perceived loss of opportunities for meaningful engagement, and subsequent threat to selfhood.

The experiences of those who attempted to conceal dementia symptoms from people close to them, was unusual. Langdon et al. (2007) found that, generally, people were quite willing to share a diagnosis of dementia with people within their 'inner circle', and more reticent to share it with those in their 'outer circle' (p.994). This was consistent with most of the other participants in the present study. Hence, immediate family and close friends would normally be told, whereas distant family and acquaintances would not. This stemmed from a fear, on the part of the person with dementia that they would be stereotyped or labelled, or that others would talk about them behind their backs in a negative manner, which relates to Goffman's (1968) notion of being discredited.

Stigma is important in the context of dementia because it threatens social citizenship – the inclusion of people with dementia in society as deserving of the same rights as everyone else (Phinney et al. 2016). Diagnostic disclosure, meanwhile, has been thoroughly researched, but from a one-dimensional perspective; disclosure of dementia from health professionals to the person and family members themselves (e.g. Bamford et al. 2004, Byszewski et al. 2007). This thesis has considered the disclosure practices of the person with dementia to others within their social world. Little attention has been paid to such practices, yet disclosure is heavily linked with stigma and the ability to live well (O'Connor, 2018). Hence, attendance to this issue has a significant part to play in contributing to the debate on dementia care.

5.5 'I wouldn't drive a long distance': Boundary maintenance

Many participants in the present study had mentally readjusted the boundaries between safety and danger. Normal, day-to-day activities that would not previously have been given a second thought, were suddenly re-evaluated for their potential to lead to problems. This appeared to be due to an awareness of the disease progression and of the changes taking place within them

as a result. Participants' confidence was affected, and they no longer trusted in their ability to carry on as before; to drive for long distances, to go out walking, to venture out alone. Instead, they had consciously redefined where the line of safety was, and they were careful not to cross it. Some participants were able to renegotiate boundaries successfully, with minimal damage to their sense of self. Others found the process harder – usually when the activity concerned had been particularly central to their past identity, and there was nothing to mitigate the narrowing of boundaries.

Such renegotiation of personal limitations, as described above, can be seen in the contrasting accounts of several participants in the present study: Catherine, Flora, Lynda and Bridget, in relation to driving habits. Bandura (1997, p.38) described driving self-efficacy as more than a simple matter of turning the ignition, going through the gears, and using the pedals. Instead, different traffic conditions presented different levels of challenge. People are required to navigate roads that might be narrow, alongside other drivers of varying levels of proficiency. This requires coordination, vigilance and an ability to make split-second decisions. Knowledge of the kinds of skills required, combined with an awareness of cognitive decline, impacted the driving efficacy of certain participants in the present study.

Driving was an activity that was inherently important to these women. Yet being diagnosed with dementia and an awareness of the accompanying cognitive deficits meant that previously taken-for-granted habits were reconsidered. The level of personal comfort felt by the individual plays a big part in this monitoring process, with people employing various strategies of self-regulation (Rudman et al. 2006). Now, Flora had stopped driving at night. Bridget only drove to her twice weekly *Silver Linings* sessions (a dementia support group for the local community). Lynda only drove for shorter journeys. Catherine continued to drive most frequently, which was in large part down to the fact that she was very geographically isolated and there were no amenities within walking distance of her house. Even she, however, had modified her driving habits to ensure that she didn't undertake long journeys. All four women had engaged in active consideration of the acceptable levels of risk involved, when setting renewed boundaries (Armstrong and Morris, 2010). Whilst Flora and Catherine had successfully renegotiated their personal boundaries with regards to driving, apparently without damage to their self-esteem, the other two had not.

Catherine had a sister on the south coast, whom she visited regularly. In years gone by, she would have made the long trip herself:

*I mean I used to drive – god, I can't think how I did it now. Mind you, the roads were better then. I did used to drive down there. But there's no way I'm going on that M1 anymore! Last time I went on, it was an **absolute** nightmare. I couldn't cope with it anymore. You just don't want the hassle with traffic, do you? So last year – and I think it's probably the same this year – my son's going to drive me down. (Catherine)*

Catherine was more than happy to relinquish the responsibility of driving down to her sister's, and instead to rely on her son. Whilst maintaining that she still drove in all other scenarios, she drew the line at this long, stressful journey on a busy motorway. Catherine brushed off the reasons for this as the mere aggravation and impatience with traffic conditions, as felt by the majority of motorists. Thus, like Flora below, Catherine's renegotiation of driving boundaries was achieved successfully and her self-esteem preserved:

I mean I still drive, and I feel quite happy driving. But I wouldn't drive a long distance. Erm...I would if someone was with me, I just wouldn't feel very happy if I drove between here and on me own...the back roads...if I broke down. But I still drive quite regularly to meet friends, every Sunday. At Crestford. (Flora)

Flora explained that she no longer drove for long distances, for fear of breaking down. Although her Self 2 had therefore changed – she had previously driven far more regularly, and for longer distances, quite comfortably, whereas now she perceived herself as unable to do so – the impact was lessened because she focused on her retained capabilities; namely the fact that she could still drive, and indeed, drove to Crestford every week to meet friends. Crucially, therefore, she maintained an element of control over the situation, and the mere preservation of the ability to drive was enough for her. Despite the boundaries of driving possibilities having been narrowed, which was reflected in the reduction in frequency and duration of car journeys, Flora had successfully renegotiated them, and was happy and accepting of her new role as a weekend driver.

Bridget, for whom driving had also been a central part of her identity, appeared to express more of a difficulty in coming to terms with the self-imposed restrictions in this area:

I want to drive, but then I'm beginning to think...under normal circumstances, wouldn't bat an eyelid. But with this, I've got to think about it. I've got to remember that I'm not normal and I can't just zoom off, you know, and go like that. Whereas I did before and never batted an eyelid. (Bridget)

It was clear that Bridget no longer had the same confidence behind the wheel as she had previously. Her beliefs about this Self 2 attribute – being an extremely competent, trusted driver had changed in line with being diagnosed with dementia. Bridget used the word ‘normal’, twice, to highlight the transition from pre-diagnosis, when she would not have thought anything of getting in her car and driving for hours, to the present, where she was constrained by her illness. This was another example of how Bridget perceived herself as a result of dementia, which was as someone who was often defined by her limitations. There was an evident conflict between her desire to drive, which was strong, and the part of her that rationalised the dangers of it. Unlike Flora, Bridget’s social relationships appeared to have been damaged by dementia, and she expressed feelings of isolation and hopelessness throughout the interview. It is therefore possible that Flora, who had a close network of family and friends, and, on the surface at least, a positive outlook, was able to successfully adjust her boundaries with regards to driving, because her networks mediated its importance to her sense of self. For Bridget, along with *Silver Linings*, driving was the only thing she had. Moreover, Flora was able to call on these social networks in order to get to where she wanted, and the alteration of her driving habits had not resulted in her missing out on anything. From a practical and logistical point of view, therefore, Bridget’s lack of social networks also served to highlight the importance of being able to continue to drive as she had before:

I’d love to be able to try it and do it now. Not Birmingham, but even just go round [city in the East Midlands]. Just somewhere where it’s all a bit more...hustle and bustle. Not London or anything, but locally, you know...just round somewhere local. (Bridget)

Whereas Flora was accepting of her newfound boundaries, and was almost relieved that she no longer had to worry about driving longer distances, Bridget found it much harder to come to terms with. She expressed regret over the situation, and it was clear that these restrictions represented to her, a form of loss of selfhood. What was also reinforced in the above extract, was the lack of available social networks to mediate this loss, as evidenced by her desire for ‘hustle and bustle’. Physically and socially, Bridget was extremely isolated and at times, appeared to lament the lack of interaction she had with other people. Reflecting on her past, as a lorry driver, she remembered driving ‘up and down the country’, and the freedom that this afforded her. She found it difficult to accept and readjust to a new way of life. Driving remained central to her identity, and the damage sustained to this as a result of having to alter her habits, was more significant compared with other participants.

Bridget had also changed her walking habits. She had previously been an avid walker, who made the most of the miles of surrounding countryside in which she lived:

In the early stages, it got quite hairy at times. I didn't dare go out. At all. Just in case. And then one day, I thought...you know...I'm not gonna sit in the house all day. I want to go out. I've got a life to live. And I went...I wanted to...just go round the block. I forgot to keep to turning left. So...but I stood. I can remember one of the roads, and I was roaring, absolutely roaring. And I thought...I couldn't stop it. It just had me. I was literally streaming, I was. Me nose was running. I got nothing with me, nobody was around. And I thought, my god, what the hell've I done? (Bridget)

Bridget had realised the impact that dementia was having on her day-to-day life, and the fact that it was preventing her from doing the kinds of simple things she had previously enjoyed. Thus, she made a conscious decision to address the situation and take control. Unfortunately, this event proved pivotal for the wrong reasons. The walk resulted in her getting lost, and ending up on a housing estate by the river, miles away from home. She described the rising sense of panic and being gripped by an almost paralysing fear. She went on to recount how she had finally managed to negotiate her way back, by forcing herself to stand still and calm down. She then retraced her steps until she arrived at a landmark she recognised. By the time she got home she was exhausted, and the experience quite obviously scarred her, because after that, Bridget no longer went for walks to the same extent as she had previously:

I can go through the gate and pick the paper up from the paper boy. See somebody, have a natter on the road and that – as long as I don't go out of the area where I feel safe. (Bridget)

Having previously been an avid walker, who loved the wild, rural landscape on her doorstep, and who would happily roam it for miles with her dogs, Bridget now stayed close to home. The single traumatic event described above represented a turning point for her, and she regularly came back to it in the course of our interview, to explain her reluctance to do things or to try anything new. She did not believe that her husband, Carl, supported her in attempting to negotiate such difficulties, or to regain her confidence. As a result, she was accepting of her world shrinking, and now ventured no further than an established boundary of safety. Despite this change, the effort that Bridget had made to continue to go out and do, albeit short walks, represented a positive attempt to maintain an important aspect of her selfhood. She loved the

outdoors and, whilst the earlier adverse experience had obviously made an impact on her, she had only modified her behaviour, rather than give up the valued activity of walking entirely.

Sally also displayed an implicit acknowledgement of newly formed boundaries, and had restricted her activities accordingly:

I don't feel right out there. I don't feel...I feel more vulnerable out there. Not happy with people around me at all. I feel like everybody's looking at me. And I know they're not, but that's just the way I feel. (Sally)

This reference to 'out there' hinted at the sinister and unknown. She was talking about the outside world, but in her mind, it had become something much bigger, something almost insurmountable. She was no longer able to venture into town, because she found it unbearably stressful and such situations made her feel horribly exposed. She had also had a bad experience whilst out shopping a few years ago, when she had fainted – which had only served to increase her anxiety of being out and about. In fact, Sally now lived in fear of any interaction with people whom she did not know, which prevented her from doing the normal day-to-day things that previously, she would not have thought twice about. She deliberately restricted her terrain to local, familiar territory – the assisted living community in which she lived – where she would not be exposed to the perceived threat of the gaze and questioning of strangers or acquaintances.

This final section illustrates the variety of ways in which women with dementia engage in the management of boundaries. Previously valued aspects of the Self 2 – such as driving and walking – had to be reconsidered. Several women had therefore changed how they carried these activities out. Driving was of central significance to a number of participants, due to its links with their past identities, and occupational or familial roles. This explains, why, in contrast to others, who relinquished their driver's licence because it was of no real importance or significance to them, this particular group held onto it. Even though they had modified the nature of present car journeys, it was the retention of the ability to drive, even if only for short journeys, or once a week, that served to enhance their selfhood and identity.

There has been a significant amount of research carried out on how people with chronic conditions negotiate boundaries. This has predominantly focused on the restrictive impact of physical pain (e.g. Mackichan et al. 2013), but such findings can also be applied to the experiences of living with dementia. Kralik et al. (2004) studied arthritis patients, and found

that the pain associated with this particular chronic condition created boundaries for people as they carried out daily activities. This served as a constant, physical reminder of limitations and dependencies. Patients, as a result, began to monitor themselves and the ways in which they responded to activities, as a way of becoming familiar with boundaries and recognising what was possible. This allowed them to explore personal limitations and achieve a sense of progress, which in turn prevented the damage to self-esteem that might otherwise have occurred, as a result of being unable to achieve something that had previously been taken for granted (Kralik et al. 2004).

5.6. Conclusion

This chapter has explored the notion of the changing self in dementia, and has shown that dementia has a wide-ranging impact on the psychological, social, emotional and physical domains of the lives of the women in the present study. The women had differing representations of dementia – with some equating it with a pathological condition, and others with normal ageing. Others were not entirely sure what it meant. There were differing experiences of the diagnostic process, with some describing more favourable interactions with the medical profession than others. The role of family within this should also be noted. Some family members were the ones who noticed the changes in the person and encouraged them to seek help. Other family members assured the person – who was convinced that there was something wrong – that they did not have dementia.

Those women who perceived dementia to be an illness appeared to experience a greater emotional or psychological impact as a result, in line with the findings of Clare et al. (2016). Whereas those who displayed either a lack of understanding or equated it with normal ageing, appeared to be generally happier and more content. The emotions expressed by participants included sadness and grief at the loss of aspects of their selfhood. For example, the comparing of the present to the past, and the reflection of what they had previously been able to do. Perception of those Self 2 attributes was now altered, with many seeing themselves in terms of the limitations imposed by dementia. Psychological reactions to the disease were also prevalent in many accounts, with women describing feeling anxious or depressed. Feelings of loneliness were expressed, which had the potential to impact further on emotional wellbeing.

Participants recognised the stigma attached to dementia, and either internalised it, in anticipation of experiencing negative reactions from others, or indeed had experienced such

reactions, which left them expecting these in the future. In order to protect their selfhood from the threat of stigma, participants engaged in considered self-management strategies. This included deciding under what circumstances and to whom to disclose their diagnosis, and for those who decided against disclosure, the ways in which efforts were made to conceal it in social situations.

Many of the women in the present study regularly engaged in boundary management. They altered their behaviour as a result of dementia, or perhaps due to the impact of dementia on their confidence in their ability to do the things in the same way as they had previously. However, this section is significant because it illustrates the active way in which women with dementia redefine the boundaries of what they are capable of, to ensure that valued activities that form part of their Self 2 can still be carried out. This helps to sustain selfhood, even though the activity may have been modified.

The sections within this chapter show that the selfhood and identity of women who receive a diagnosis of dementia are vulnerable. There are changes brought on by the disease that threaten aspects of selfhood. The Self 2, the self of personal attributes and characteristics, and beliefs about these, can be impacted by dementia. Sabat and Harré (1992) and Sabat (2001) suggest that the Self 3 (the self of social personae) is most vulnerable to damage, due to the actions and behaviours of others. The findings in this chapter show support for this notion, in the sense that stigma can prevent women with dementia from constructing valued social identities, and reflect back upon their Self 2 in a negative manner. The findings do also suggest, however, that the Self 2 in itself can be vulnerable to the threat of dementia. This is shown in the way that women talk of the losses experienced, and compare the present unfavourably with the past. It is further demonstrated in the range of emotional and psychological reactions to dementia and the associated losses. These suggest that dementia does not just target social identity, but personal identity too. Many women, despite describing largely supportive relational environments, nonetheless describe dementia as impacting on their self-concept, threatening their self-esteem and emotional wellbeing. The section on boundary maintenance shows how women try to adapt their behaviours in order to preserve those aspects of selfhood that are central. This will be taken further in the following chapter, which will explore how women attempt to resist the impact of dementia on their selfhood and identity.

Chapter 6: Resistance and Repair

6.1 Introduction

The concepts of resistance and repair represent the second theme to emerge from the study's findings. This chapter focuses on the resources, both internal and external, that a person can draw upon when faced with an adverse life event, such as dementia (Yates and Masten, 2004). The first section explores how women with dementia enrich their lives, by maintaining connections to past identities and aspects of their Self 2. It also explores how many women have taken up new activities, since being diagnosed with dementia, and how these activities have similarly taken on a valued aspect of their Self 2. These activities may seem trivial on the surface, but to the participants in this study, they are anything but, providing a way for the women to resist the impact of dementia by enabling them to engage in something that enhanced self-esteem and made them feel good about themselves.

The second section looks at how women resist the impact of dementia by being independent. This is expressed variably as a 'human right' and way of rejecting the narrative of decline and over-reliance on one's family members. Other women construct themselves as independent by taking ownership of decisions – for example, with regards to choosing to stop or reduce engagement in a previously valued activity. This is preferable to somebody else making the decision on their behalf. This section also explores the coping strategies that people use in order to enable them to live independent, self-sufficient lives, as well as considering those coping strategies that signify reliance on others.

The third section illustrates how maintaining a positive self-concept, often with the help of others within their social world, allows women with dementia to resist the impact of the disease on this. Some highlight their academic achievements, and continuing to see themselves as intelligent, others perceive themselves as capable and self-sufficient, presenting evidence and reasoning for this. The final section explores the strategies of minimising and normalising that women engage in, as well as the social comparisons they make. This includes downward comparisons with other people with dementia and the relationship to their own perceived health status. It also considers the problematic impact of downward social comparisons, as well as those women, who, far from normalising their symptoms, present themselves as somehow abnormal.

The overall aim of this thesis is to explore the ways in which the selfhood and identity of women is impacted by dementia, and crucially, how it is sustained in the face of such threats. Hence, this chapter considers the variety of ways in which women can resist the threat posed by dementia, and repair aspects of their selfhood that may have been damaged by the disease. Even those who describe their Self 2 as having changed significantly as a result of dementia, and of consequently experiencing a range of negative emotions and psychological effects, still find ways of preserving selfhood.

6.2 ‘I like to keep busy’: Enriching life

The first section discusses the various ways in which women with dementia enrich their lives, through continuing to live in the ‘best possible way’ (MacQuarrie, 2005, p.1031). Even those participants whose self-esteem had been impacted by dementia and who experienced pervasive feelings of sadness, loneliness or anxiety, still engaged in activities that were important in preserving a sense of self. This first sub-theme paves the way for the others; by engaging in activities that served to enrich one’s life, one’s independence was preserved, and consequently, a positive self-concept maintained.

6.2.1 Staying active

A large number of participants in the present study had made a conscious effort to keep physically active, filling their days with attendances at various groups, and having a set routine of things to do in a given week. Betty and Martha were two participants whose self-image was inexorably tied to leisure activities (Charmaz, 2006). For them, participation in such activities represented the very definition of living fulfilling lives:

I'm a striver, I want to see things happen, I want to do things and I don't want to sit around doing nothing, just...twiddling my thumbs, that does annoy me. I'd rather be doing something.
(Betty)

Here, Betty framed herself as a ‘striver’ – someone who made a concerted effort to keep active, and who disliked the idea of inertia. In this way, there was a continuity with Betty’s sense of self, and a rejection of the narrative of ageing or decline (Robertson, 2014). Betty constantly positioned herself as an active participant in many different realms of life, thus rejecting the idea that she was someone who collected her pension every week whilst failing (in her view) to contribute to society.

Betty's desire to be active, much like the retention of her independence, was something she went to great lengths to preserve. Thus, when describing her weekly routine, the only time she was not engaged in some kind of social or physical activity, was in the evenings, when she returned home from an event-filled day. Even then, there was dog-walking to do:

Monday is often a free day, but I usually find something to do. Tuesday, I go to a singing group in the afternoon. Erm...Wednesday morning I go swimming. Thursday, I can do all sorts of things – like I'm going to a memory cafe today, but I volunteer there, I'm not actually a member any more. Friday is another day when I do lots of things...it's not a typical week, because every week is different. And Saturday I swim, Sunday I go to church. So I keep myself very busy.
(Betty)

Although much of Betty's life was taken up with volunteering for various organisations, she still found time to swim, sing and go to her church alongside this. In fact, even on days where she did not have anything officially pencilled in, she would actively seek out things to do. Betty believed firmly in the notion that the more active a person was, both physically and mentally, the more chance they would have of staving off cognitive decline. Moreover, she expressed feelings of loneliness and isolation, which were thrown into stark relief when she was in her bungalow, on her own.

Martha was similar to Betty in many respects. She too framed herself as someone for whom actively seeking out things to do was an intrinsic facet of their personality, and drew a distinction between herself and others who did 'nothing':

I'm fine, because I do things. That's just me, it's the way I am. I couldn't just sit indoors and not do anything. I go singing, and I go to a ladies' group...I go dancing. Line-dancing. Tap dancing. Yeah, I do as much as I can do with my life. I couldn't live a life where I'm just at home all the time, not doing things. 'Cause I've always, always been in...activity, you know? I've always done it, so I'll continue to do it, as long as I live. (Martha)

The groups that Martha was a member of included a singing group and various dance groups. Some of these she attended with her husband, Eric, others, alone. She stressed that they had a healthy balance between doing things together and separately. Martha admitted that she tried to do as much as she possibly could with her life, and would continue to do so, because it was who she was – she identified as a woman who was physically active. There was a clear

continuity with her past; having always been active, it was important and only natural that she remained so, thus reinforcing this aspect of her biography (Hillman et al. 2018).

Marian, despite being the oldest of all the participants, was also one of the most physically active. In fact, she would walk around five miles each day:

I still walk, and I would advise it to anybody. I'm very lucky...I started walking with The Ramblers. Which I recommend if you want to walk. It's very nice. You can walk and you don't have to talk and...you can listen. And they're good people to listen. And if there are idiots amongst them, well then you do up your shoelaces! I used to go a couple of times a month. (Marian)

Marian maintained a continuity between her past identity as an avid walker, and the present. Despite the fact that she was no longer a member of *The Ramblers*, she nonetheless made use of her proximity to the River Thames:

If you walk in a park or something, I can be relied upon to take the wrong turn! So...I had problems with the river when I started. I several times walked right to the end of the...where it becomes a lake, I think. Right up to the end there. But erm...if it was always saying: 'Left to London', I knew I was always going the right way. (Marian)

Unlike Bridget, who had also been a keen walker prior to being diagnosed with dementia, Marian had not relinquished this much-enjoyed hobby. Whereas Bridget had attempted to carry on walking, but had been forever deterred after a frightening experience, where she had got lost, Marian, despite the same thing having happened to her – several times – had not. Instead, she had developed a coping strategy to enable her to navigate her way along the river. This involved paying careful attention to the signs, and the knowledge that as long as these were showing London to the left, she was on the right track.

Of course, it is possible that Marian's persistence was due to the fact that she lived in Central London. If something went wrong, there were always people around to help – so this may have been the safety net in the back of her mind. She was after all, extremely sociable with strangers and would strike up conversations with many people she encountered when we walked into town together. Bridget's surrounding area, on the other hand, was wild and rural to the extent that one could quite easily walk for hours without seeing another person. Moreover, there were clear differences in self-esteem between the two women; Bridget no longer trusted in her own

capabilities, and focused on the losses that had occurred since being diagnosed with dementia. Marian played down her illness, asserting that it did not stop her from doing anything. In other words, Marian's beliefs about her Self 2 attributes had largely remained intact, supported as they were, by the fact that she lived on her own and had a social network of people who cooperated in her construction of certain identities (which will be discussed further later on).

Catherine was another participant who continued to live an extremely active lifestyle. This was also linked to her past – she had been an avid rider and breeder of horses for show-jumping competitions:

I ride three times a week. I mean, I know people that ride, and I ride out with them. I play badminton on a Tuesday – there's usually about six of us, and we play doubles. That's really all the things week-by-week, that I do as a regular thing. Erm...you might ask me why...when do I get time to do any gardening! The rest of the time is gardening. And mowing lawns...in the summer, you know...and things like that. (Catherine)

These activities also served to preserve Catherine's identity. Horse-riding, for example was something that had always been important to her. She had owned several horses and had even competed in prestigious national events. There were proudly framed photographs of the animals all over her house – which far outnumbered those of her grandchildren. Now, Catherine owned one horse, whom she kept in a nearby field and whom she was devoted to and still rode regularly. She also played badminton for two hours each week, commenting that it was 'exhausting', but was something from which she derived enjoyment.

Although there was a social element to these activities, this was very much secondary in terms of importance to Catherine. Indeed, she actively denounced the notion that the people with whom she rode and played badminton were friends – instead, describing them as 'acquaintances'. This distinction that Catherine drew will be discussed further in the third chapter on interpersonal relationships.

6.2.2 Baking

Women with dementia also gave specific examples of hobbies or activities they took part in. Given that she struggled with low self-esteem and feelings of anxiety since being diagnosed with dementia, the importance of baking to the preservation of Sally's selfhood was clear:

I get very nasty and agitated. So I do baking – that’s my therapy! I keep everybody here in cakes...I find that helps calm me down, ’cause I’ve always liked baking. If I get down, I will go and bake something. Yeah, I do find that helps me. I used to bake years ago, when the kiddies were small. (Sally)

Thus, while dementia had, as described in the previous chapter, changed Sally’s personality, making her ‘nasty’ and ‘agitated’, in contrast to how she used to be, baking was a way of resisting this unwanted impact on her Self 2, and repairing the damage by helping her to ‘calm down’. Moreover, baking itself was an aspect of her Self 2 that had endured from her past, and preservation of this was important, as were her beliefs that she could continue to do so – given that much of her self-esteem had been impacted by dementia:

My friend that I see every other Friday, and talk to every Tuesday, she rang up last night – well, we were talking last night. And she said: ‘I’ve got a date for you!’ And I knew what was coming. ’Cause she...her grandson’s got a football do, end of August. Or middle of August. If I’d do some cakes. If she has coffee morning, or the church, or anything like that, I’ll...I’ll always do cakes. I said: ‘Well you’ll have to tell me before that’, ’cause it’s...20th August, something like that. But I’ve written it on my calendar! (Sally)

This underlines the significance of baking to Sally’s sense of self. Having become renowned as a source of excellent cakes, her products were in demand amongst her friends. Using her calendar as a ‘compensatory aid’ (Dröes et al. 2011, p.1772) mitigated the danger of forgetting important dates and enabled Sally to continue doing something she loved, even in the face of those other valued aspects of her selfhood that had been lost as a result of dementia. When anyone had a social event on the horizon, that required a cake to be baked, Sally positioned herself as being relied upon for this. Thus, her social Self 3 reinforced the Self 2. Sally’s friends cooperated in her attempts to construct an identity as a baker – an identity that had endured from her past – which reinforced and maintained continuity with this aspect of her Self 2. Thus, there was a sense of pride that came from feeling valued and useful. Again, this was of particular importance to Sally, because she was often wary about even venturing out of the house, and certainly refrained from doing much of the day-to-day activities that she had previously taken for granted. Baking, and the accompanying positive reactions of her friends, therefore, helped to improve Sally’s self-esteem.

6.2.3 Advocacy

One way in which people with dementia can enrich their lives is by joining groups and becoming involved in advocacy and volunteer work aimed at promoting their rights and needs. The reasons given for such involvement include a desire not to be excluded and to add structure and coherence to one's life, as well as the sense of unity that comes from sharing stories and experiences with people in similar situations. Finally, advocacy work keeps people with dementia from worrying about what they can't do and focuses on what they can (Knauss and Moyer, 2006). Hillman et al. (2018), who studied the narratives of people living with dementia who belonged to advocacy groups found that the sharing of stories was an important way in which these participants were able to live well with the disease. It also enabled them to contribute to a wider understanding – for example, at a societal level, among policy makers and researchers – of dementia. Advocacy fostered a sense of meaning and purpose that was central to challenging the narrative of loss and decline. The personal nature of advocacy narratives, together with their ability to shape wider perceptions, was evident in the account of Betty.

Betty took her advocacy role seriously, becoming a prominent voice in speaking out against the side-lining of people living with dementia and championing their rights and inclusion in normal realms of life. This was something that was of extreme importance to her:

I'm volunteering now. That's happened in the last year. Erm...I went to the Alzheimer's and said I wanted to do more, erm...so I went through the volunteer process. I didn't do all of it, because I found that the actual screen reading for the e-learning was phasing me out. I couldn't...I kept wanting to go back and back, and instead of being a four-hour exercise, it was turning into a ridiculous time, and it was annoying me. So I spoke to the volunteer supervisor there and she talked to her bosses, and they agreed that I could miss that part out and do all the other stuff and become a volunteer. So now I'm called a local representative. (Betty)

The above extract exemplified Betty's attitude towards life; having decided to become a volunteer, she had begun the induction process, only to find that she couldn't keep pace with the e-learning aspect of this. Instead of taking this as evidence of her diminishing cognitive capacities and her self-esteem being damaged as a result, Betty merely saw it as a hurdle to be overcome. She successfully negotiated this, and her pride in being called a 'local representative' was evident. Indeed, she went on to expand on what the role entailed,

deliberately distinguishing herself from a mere volunteer and highlighting the importance of the work she did. This work, she was again keen to emphasise, was not confined to her own local area:

I'm not just a volunteer, I've started doing talks. I've now done two. One to the local GP practices in the area – not just my area – the East Midlands area. And then, another guy and I, we went out to Marchfield to open the Citizen's Advice Bureau. And I'm also involved with the local GP practice...Patient Participation Group. I went there and did a walk through to see what problems I would foresee in their surgery. I've been down to London twice, with the Alzheimer's...once to look at a national committee, that I decided I wasn't ready for yet, and then once because I'm involved with the Dementia Champions group. And we meet at Marchfield once a month – and they asked for a few representatives to go down to London and do a talk down there. So we did, we went down and we met other people, 'cause I keep saying, I want to network. (Betty)

Betty spoke about this volunteering and advocacy work with enthusiasm. She talked of travelling to towns and cities across the UK, of her membership of various groups and committees, of her desire to build networks. Each extract that referenced her involvement, however, laid claim to her own personal role therein, emphasising it in terms of an impressive level of capability and indeed, responsibility. What Betty did, was presented not merely as token volunteer work, but as something that held the potential for genuine widespread impact. People with dementia who belong to advocacy groups have an enhanced sense of personal worth and a retained sense of self, through continued engagement in life (Clare et al. 2008). They take pride in both their own personal achievements and in those of the organisation in general. Crucially – and something that was also reflected strongly in Betty's account – it gives people a sense of purpose and empowers them with the knowledge that through such advocacy work, they can help others and act as pioneers:

One other thing...with being involved in the Alzheimer's erm...I went to a meeting – 'cause I like public meetings. It was an Alzheimer's...Dementia Friends workshop. And I was sitting there, listening to the meeting, and they were talking about what carers could do for their...the people they were working with. And I just put my hand up and said: 'What about me? I don't need a carer yet. You're not suggesting anything that you can offer me'. And this guy pricked his ears up, and afterwards, he said: 'I'm glad you said that'. He said: 'Everybody's nodded and agreed with you'. Because everybody's geared up to the carers, and how to support them.

But there are a lot of us that are post-diagnosed, that don't get the support. And he said: 'I've got a group that you might go to. It's called the Dementia Service Users United'. Yeah...so they've really given me a voice. (Betty)

With regards to the above meeting, described by Betty, her daughter, Rachel, recounted the same story, having also been present. Her reaction, however, was one of acute embarrassment at her mother's brazenness. Yet the response of a fellow dementia advocate was more revealing. He admitted that everyone had agreed with Betty's blunt assessment, but she was the only one who had actually spoken up. As a result of this encounter, she was invited to join a group set up for service users – another form of advocacy that similarly allowed for her voice to be heard, in an arena where, typically, it is the accounts of carers that have dominated (Kirkman, 2006).

The above discussion of Betty's advocacy work and involvement with different organisations is related to the literature on citizenship and dementia (Bartlett and O'Connor, 2007). Citizenship was influenced by Kitwood's theory of personhood (1997) to encompass a political dimension when talking about the rights of people with dementia. Thus, Betty campaigned tirelessly to reduce the stigma attached to the disease, to increase the effectiveness of support services and to educate herself and others on what could be done, on an individual level, to increase people's quality of life. These activities have an unmistakable political meaning attached to them; rather than merely seeking to maintain her own personhood, Betty was repositioning herself as an 'active citizen' (Bartlett and O'Connor, 2007, p.1120).

6.2.4 Driving

Maintaining the ability to drive, despite a diagnosis of dementia, was extremely important to a subset of participants in the present study. This was discussed in the previous chapter, in relation to the redefining of boundaries, but its importance is worth discussing here, in relation to its use as a strategy for resisting the impact of dementia on selfhood. Driving was central to the past identities of many women in the present study, and so maintaining continuity with this enabled them to see this valued attribute of their Self 2 and their beliefs about their ability to accomplish it, in a positive light, thus enhancing self-esteem and by implication, selfhood. Moreover, the ability to drive is seen as an indicator of health and wellbeing, cessation as an indicator of decline (Rudman et al. 2006). Despite the fact that almost all participants in this

section had modified their driving habits in some way, preservation of driving ability remained vital.

For both Lynda and Bridget, maintaining the ability to drive was extremely important to their sense of self. Neither had strong social support networks, and both described a struggle with the psychological impact of having dementia. Driving was one of the few things that they took pleasure in. Lynda had worked for the Home Office, and her job had required her to travel throughout the UK. She had taken great pride and enjoyment in the long hours and driving, and relished the responsibility that came with it. Lynda had continued to drive after being diagnosed with dementia, although she had been forced to modify her driving habits of late, as she suffered from chronic tiredness. The journeys that Lynda now undertook were fewer and shorter, yet the very act of being able to drive had assumed vital importance in the face of what she described as her declining capabilities and loss of interest in other aspects of her life. This reflects Metz' (2000) assertion that driving, for many older people, is simply about the 'potential to make trips that are not actually made' (p.150). This alone is enough to grant a sense of independence and control:

Driving...that's the last thing that I've got from my past, sort of thing. So, it's really important for me to hold on to that for as long as I can. I think once I give that up...my licence up, then that's it, you know? It's sort of, the only thing that I feel that I can do for myself. (Lynda)

The direct reference by Lynda to her 'past' exemplifies the findings put forward by Liddle et al. (2012), that driving is closely linked with occupational histories, and that the strength of this connection impacts on whether people with dementia are able to successfully adapt to driving cessation. In Lynda's case, driving had constituted an integral part of her job – a job that she had loved, and the above extract put into sharp focus the significance of driving to Lynda. Practically speaking, it would not cause her undue inconvenience if she did not drive. She lived in a built-up area with good public transport links, and both her partner and daughter, whom she saw regularly, drove. For Lynda, it had nothing to do with practicality, and everything to do with symbolism attached to those valued roles and identities. In other words, driving was about fulfilling affective needs, rather than utilitarian needs (Musselwhite and Haddad 2010). Lynda referred, on several occasions, to having a 'licence', as though this was a physical representation of freedom and independence.

Many people with dementia view driving cessation as a marker of decline (Sanford et al. 2019), and such a view was clearly evidenced by Lynda. Indeed, several participants in a study by Rudman et al. (2006) expressed the same fatalistic view as Lynda – the notion that if they no longer drove, there would be little left to live for. As Lynda herself explained, the relinquishing of her licence would represent a relinquishing of everything; a sense that that would be ‘it’, confirmation of a departure from normality and self-sufficiency into uncertainty or dependency. Driving had been integral to Lynda’s Self 2 identity, in her past occupational and familial roles.

Bridget was another participant who stressed the importance of driving continuity, which could be linked to a variety of factors:

I want to keep my driving, if I can. That’s extremely important. It’s top of the tree, as far as I’m concerned. Because I’ve driven from the day that I passed me test. I was always in a vehicle, always. (Bridget)

Bridget had been a lorry driver, and was used to spending days on the roads. In this sense, driving was related to her occupational history, like it was for Lynda. She had relished the responsibility, and the hours of travelling that took her to different parts of the UK. Bridget too, described with a sense of unmistakable pride, being the one whom her boss relied on, above all others, to undertake journeys on the weekends or that were considered particularly important. Like Lynda, driving was central to Bridget’s present identity, precisely because of the tangible link with her past. Driving was fulfilling an affective need because of its associations with previously valued role identities (Musselwhite and Haddad, 2010).

Furthermore, the two most important things in Bridget’s life: *Silver Linings* and the ability to drive were intimately connected. She had lost confidence behind the wheel and would only drive the relatively short distance to the dementia support group twice a week. Hence, each were depended on the other. She was determined to attend *Silver Linings*, because it was her sole opportunity for meaningful social interaction. Therefore, she had no choice but to drive herself there. Likewise, she loved driving, and the group gave her a reason to retain this capability:

Yeah, I’ve got hiccups, but I still drive. Erm...I get meself from point A to point B. I don’t go anywhere out of the realm of things, I go to Silver Linings and back for me brain training.

Keep me savvy and that. I drive there and I drive back, so far – touch wood. And that’s my little bit of driving. I like my driving. (Bridget)

It is interesting to note how Bridget referred to ‘my driving’ throughout the interview. Again, this served to highlight the connection to personal identity and the close relationship between driving and Bridget’s life history (Liddle et al. 2013). In describing her journeys to *Silver Linings*, she was emphasising the importance of driving as a utilitarian need – both in terms of the need to drive to appointments, but also, the need to drive in order to socialise (Musselwhite and Haddad, 2010). The fact that Bridget lived in an extremely rural part of the country, with no shopping amenities within walking distance was never touched upon, however. It certainly did not figure as an important factor in her continued ability to drive. For her, driving was all about the connections to be forged, both with her past identity and socially, with her friends at the memory clinic, the latter of which represented an escape from her present, unhappy situation at home.

The meaning of driving to Catherine did not have the same emotional ties to occupational histories or friendship groups as it did for the other participants. For Catherine, the continued ability to drive was simply a practical necessity, particularly as she lived alone in an extremely rural part of the country:

Well it’s important living here because there’s nothing else...I have to drive to go and get a pint of milk – well I could have a milkman I suppose, but I don’t. But you know, shopping...I have to get in the car and go...and...and shop. But I don’t find that a problem. (Catherine)

The village where Catherine lived did not have any amenities within walking distance. She had no other option but to retain her driving licence, else face the prospect of moving somewhere more urban – the possibility of which she emphatically denounced. Therefore, it was the utilitarian need for accessibility in order to complete daily tasks that necessitated Catherine’s driving continuity (Musselwhite and Haddad, 2010).

It is now worth contrasting the above accounts with that of Alice – who also had a significant personal driving history. She, like other participants, had been an avid driver all her life. Yet unlike the others, she had been forced to give up her licence by medical professionals. The loss had been felt keenly:

I'm not allowed to drive at all. My daughter says: 'Can she drive?' And they says: 'No, I don't think so'. I used to drive all over the place, over the years. Bringing the kids up. I used to go into town every Saturday morning and get shopping... (Alice)

As Alice recounted the doctors giving her the news that she could no longer drive, her voice broke and she began to cry. The emotional impact that driving cessation had had on her was plain to see. Alice had been the family's principal driver, and in describing her role as a mother and homemaker, she was emphasising the 'social responsibility' attached to driving (Siren and Hakamies-Blomqvist, 2005, p.219). Thus, having to give it up represented a loss of an important Self 2 attribute, and there was a discontinuity between past and present self as a result. Although Alice's husband, Patrick, drove, this failed to mitigate the impact of driving cessation on her sense of wellbeing and feelings of loss (Fonda et al. 2001), despite the fact that it enabled her to accomplish the same tasks. This suggests it is not the utilitarian aspect of driving that is important to Alice, rather the affective dimension – the sense of being independent and in control, particularly in the sense of her familial role (Musselwhite and Haddad, 2010).

Among the participants in the present study, only Alice had been forced to give up driving. She was experiencing a myriad of negative emotions as a result of this, including anger, frustration and sadness, and reflected the fact that for some older people, driving cessation was a deeply traumatic event (Whitehead et al. 2006). Other participants had given up voluntarily. This group did not experience such profound negative emotional effects as a result of driving cessation, largely because they appeared to have personality traits that helped to mitigate against the loss, or strong familial support networks that meant they were still able to participate in social activities (Sanford et al. 2019).

6.2.5 Spirituality

Religion was a big part of Wendy's life and a central aspect of her selfhood. Her faith was a great source of comfort, strength, and, crucially, a means of coping – particularly with regards to the future (Katsuno, 2003). Because of this faith in God, Wendy did not fear the future, and actively looked forward to the day she would die and ascend to heaven. It was something that Wendy and her husband, Kevin, talked about extensively, and even planned for. In this sense, because dementia was beyond her own control and in God's hands, she was relieved from worrying about the uncertainty (Katsuno, 2003). Furthermore, Wendy was part of a large

church-going community, all of whom had rallied round to support her. These spiritual resources were something from which Wendy drew strength in her self-management of the disease and which gave her life meaning and purpose (Schulman-Green et al. 2012).

The themes of religion and spirituality ran through Wendy's description of her life and of living with dementia, from recollections about how she had converted to Christianity at the age of five, to her dismay at one of her children marrying a man who was not a Christian, to her present reliance on the church-going community. It was an interesting connective thread, given that Wendy struggled with many other aspects of memory recall and often had difficulty in finding the right words. Yet, she could talk about the religious aspects of her life in great depth and detail. There was strong evidence of continuity, in her reliance on religious rituals, the spiritual community and the social connections she had forged through the church (Trevitt and MacKinlay, 2004). This continuity was important to preserve in the face of dementia, to enable Wendy to maintain a sense of identity, to which religion was evidently integral.

The extent to which Wendy's life revolved around her church was highlighted in the below extract:

Well, on Sunday we're in church morning and evening. Tuesday is Tuesday fellowship, which I've just been to. That's at church. Ladies' group is at church, where I'm going tomorrow. That's on a Wednesday. Oh, and on Wednesday, is this either home group or...a big meeting altogether in church. Thursday, nothing...at church to go to. But on Friday we have an early morning prayer meeting, and we get to church at six o'clock in the morning. So a lot of my identity's the church. (Wendy)

People with dementia, for whom religion is an important aspect of their lives, continue to maintain spiritual connections within their changed circumstances (Dalby et al. 2011). Wendy was a prime example of someone who, with support from the community, was enabled to sustain this central aspect of her own life, and with it, her sense of self. She also displayed strong and unwavering belief. Wendy prayed twice a day, spoke to God and attended church or church-related groups devotedly. Her religious beliefs, therefore, could be described as being the 'basis for a worldview' – meaning that they dictated how Wendy navigated her life, including her response to being diagnosed with dementia (Koenig, 2002, p.489). Such complete engagement in religion, such as attendance at church, can have important social benefits, and is associated with lower rates of depression and anxiety in the face of chronic illness (Koenig,

1998). Furthermore, it is possible that Wendy's devotion to prayer enabled her to focus on helping other people, and offered a distraction from her own situation (Koenig, 2002):

I have a prayer book here, okay? I've got my...little list, for in the morning. Those are my readings in the Bible. So this morning I was reading from this. And the other thing, that is here...is my prayer requests. And I also read some of Samuel in there. So...my prayer requests are people I've known, my family – Kevin and Sophie, and my grandchildren – ten of them. And I've got a very good friend, June Maddison and Al Maddison, and he's been very ill, so I pray for him. And...well I've written my funeral songs [laughs]. (Wendy)

Wendy described in detail, the contents of the notebooks. They were clearly of immense personal importance to her, and she always seemed to keep them close at hand, resting them on her knees, or on the sofa next to her, regularly instinctively touching them. At one point, after the interview had finished, Wendy picked up a pen and started writing, copying down a passage from the Bible laid out in front of her. She did not like to be distracted whilst doing this and it was clear that the task demanded all of her concentration. Wendy believed strongly in the power of prayer, and had a list of people in the parish congregation for whom she would pray at any given time, in addition to her family members and friends:

I talk to lots of people in church before the actual meeting starts. And ask them how they are. And then...they often say, something that's gone wrong. So I just say: 'Let me write down who that is, and I'll pray for them'. (Wendy)

Prayer as a form of spiritual expression is an important part of the lived experience of people with strong religious beliefs. It is also possible that it allowed Wendy to focus on others and to distract herself from her own pain (Koenig, 2002). Fortunately, she had friends on whom she could rely to do the same for her, although she never asked anything of them.

Spirituality allowed Wendy to resist the impact of dementia. In one of the prayer groups I accompanied her to, she described how, when she was first diagnosed with dementia, her faith wavered for the first time, as she questioned why God should have afflicted her with the disease. This intrinsic and thus far stable Self 2 attribute that Wendy possessed: being a devout Christian, was threatened by a diagnosis of dementia. After the initial period of confusion and doubt, however, Wendy remembered the song 'Count your Blessings'. The words, she explained, helped her to realise all that she had to be thankful to God for. Slowly, her faith was restored; this damaged facet of her identity repaired. Through embodying spiritual values that

were now sustained through the experience of dementia, and engagement with the spiritual community and practices, Wendy's faith continued to be a buffer against dementia and the threats it posed to her sense of self, enabling her to construct a valued personal and social identity.

The above accounts illustrated the myriad of ways in which women filled their lives with pursuits and activities that were important to them. These were related to the women's past identities, hence continuity reflected a means of preserving selfhood and minimising the disruption to their biographies (Bury, 1982). Even those women who had described experiencing losses in many domains of life, had things they could accomplish, that were of value to them. Such involvement could have a positive impact on self-esteem. Not only in the sense that they were retained attributes from the participants' pasts, but also in the sense that many activities enabled the construction of a social identity. For example, Sally, who baked for her friends, and Wendy who was a member of the church-going community.

6.3 'I decide what I want to do': Being independent

This section on independence explores how women with dementia resist the impact of the disease on their selfhood by asserting their retained capacity to do things for themselves. This includes making their own decisions – which many women saw as extremely important – and asserting the ways in which they did things without the help of family members and others. They were thus maintaining a sense of continuity with a previously valued Self 2 attribute. Even though dementia may have threatened other aspects of their selfhood, these women all resisted its impact through being independent.

This was encapsulated in a comment made by Marian, when she discussed her insistence on making her own decisions:

I mean, there are people who know things, that I can take advice on. But all of them know that, in the end, I decide what I want to do. And that seems to me a human right, you know? (Marian)

This simple statement outlined the fact that Marian considered the right to make one's own decisions a given for everyone, whether dementia was a factor or not. According to Marian, her illness should make no difference to this. Not being so stubborn as to be unable to take advice from people, she nonetheless stressed ownership of every decision. Much of this unrelenting desire to hold on to her autonomy appeared to stem from her career:

I don't want a mummy or a daddy. I spent time at university, slogging away at essays...and now I want my own way! (Marian)

Here, Marian equated the fact that she had gone to university and worked hard for a number of years – in the process, gaining a first-class degree and going on to do a Masters and PhD – with having earned the right to assert her self-sufficiency. She described working as a researcher at the University of Cambridge and being subject to sexist, misogynous jokes by male colleagues. Marian would always respond drily with the observation that she had ‘lost’ her sense of humour. She had been one of the only women in what was, at the time, a male-dominated environment, had never married, and lamented the fact that she believed many women felt obliged to marry, Marian had defied convention her entire life, unconcerned with what was considered the norm or expected of her. The result was that now, as a 92-year-old woman with dementia, she held her fiercely-valued independence dear and was not prepared to relinquish it for anyone.

Betty was another participant who expressed a strong desire to remain independent. She spoke extensively of her advocacy work, or the social groups she was a member of, or her insistence on living alone in her rented bungalow, rather than move in with her daughter, Rachel. Betty was keen to assert her ability to be her own person, rather than someone who deferred to other people to make decisions on her behalf. This was reinforced by witnessing how a fellow member of one of the social groups she attended, and his wife, interacted with people around them:

Mostly, I support myself. Because I feel that I'm still able to, and I want to. And the easier it is to slip into being supported...is where you lose your independence. One of the guys in the Singing for Fun group, if you ask him a question, he says: 'Ask me wife'. And that's really sad. 'Cause that's not using his brain. I mean it's more comfortable, isn't it – to get someone else to answer for you? (Betty)

Betty was firm in her desire to support herself, and was careful about the amount of time she spent with her daughter, admitting that when they were together, she would slip into the habit of deferring decisions to Rachel. Rachel herself had also found it difficult to accept Betty's steadfast desire to be independent at first, but was slowly coming to terms with it:

It's very important to make my own decisions and to be the one to make my decisions. And sometimes I'll do something and I don't always run it past my daughter till I've done it, and

then say: 'Oh, by the way, I've done so-and-so'. And she'll say: 'Fine'. Sometimes it would be nice to be with her, but then I feel I would defer to her if she...that it might not be my own decision, it would be her decision – are you with me? She might have her own ideas as to how it could be done differently, and it might not be the way that I want it. (Betty)

For Betty, having a sense of control over her life and maintaining her independence – even using deliberate strategies of avoiding spending time with her daughter to achieve this – were extremely important. She equated this independence with positive adjustment to the disease, and saw reliance on other people as evidence of not being one's own person, or what she called 'a supported person'. Betty's independence and insistence on doing everything for herself, therefore, was her way of resisting the impact of dementia on her selfhood. It was a valued aspect of her Self 2 – one which dependency would threaten. It also reinforced her Self 3 as a capable, self-sufficient person, rather than someone who relied on others for help. Betty's daughter did cooperate in this construction, even though Betty perceived her as sometimes not being entirely on board with it.

It is also important at this stage, to note that other participants relied on family members for help with many aspects of their lives. For these women, maintaining such a deliberately independent way of life was not so integral to their selfhood, and losing their independence did not hold such fear and connotations with decline as it did for Betty. Indeed, for these women, the very fact that they could rely on others for help and support, enabled them to maintain valued aspects of their Self 2, that otherwise, might have been vulnerable to loss. Like Sally, who could only bake when her partner, Howard was with her. Or Stella, who loved garden centres, but who could only go several times a week, because her husband, Frank drove her.

Alice, too, constructed herself as making her own decisions, when discussing the fact that she did not go out without her husband:

I don't go out unless Patrick's with me. I might...well, I don't go into town. He's got to be there to take me. I can get on a bus, there's a bus stop right on the corner. So I could go if I wanted, but why should I? And somebody might see me and say: 'I saw Alice in town'. I'd rather not go against him, he wouldn't like that. (Alice)

When I interviewed Patrick, he told me that Alice could no longer go out alone, because she would get lost. Alice insisted that she was perfectly capable of getting the bus into town if she wanted, but chose not to in order to keep Patrick happy. This illustrates the discrepancy that

often exists in relationships, between the perspective of the person with dementia and that of the caregiver (MacQuarrie, 2005). It also illustrates the dilemma for family members in balancing the wishes of the person with dementia and concerns over their safety (Hughes et al. 2002). For Alice, however, it is possible that by asserting it was her choice not to travel by bus, in order to placate her husband, she was resisting the impact of dementia on her selfhood. Alice had always enjoyed frequent bus journeys into town, and to meet up with her sister. If she perceived herself as no longer capable of undertaking these, this could threaten her self-esteem. By framing it as a choice, however, Alice's self-esteem is more likely to be preserved, and her beliefs about her ability to catch a bus into town, remained intact – as evidenced by the above extract.

Independence can also be embodied, for example, through appearance choices. Sally was someone whose independence had been severely affected by dementia, on account of the chronic lack of self-esteem from which she suffered. However, she was able to assert her identity through her appearance and dress. The importance of these to Sally was evident from the observational data I collected in the form of my research diary. Sally's hair was platinum blonde and cut to a fashionable bob. She wore makeup, including lipstick, highlighter and blusher. Her clothes were bright and perfectly colour-coordinated, accessorised with simple silver jewellery. Her nails also matched her outfit, and were immaculately manicured. The care she took over her appearance, which was further illustrated by an exchange during our interview:

Sally: *I like taking care of my nails, things like that. I do like to buy me different nail varnishes.*

Interviewer: *Yes, I noticed your nails look nice.*

Sally: *Oh yeah, I do enjoy that sort of thing. I do enjoy that sort of thing. Yeah, I've told my lad, and Howard, the day they see that I don't put makeup on and do my nails – be worried! 'Cause that would not be me.*

Interviewer: *You take pride in your appearance, then?*

Sally: *Mm. Yeah. If I didn't, I think everybody would be worried. There's something wrong.*

Sally explained that her appearance was important to her, and that she had always derived enjoyment from the practices involved with it. As Twigg (2010) argues, clothing and dress are part of performative identity, 'expressive of the self and its choices; acting back on that self and reinforcing identities by underwriting them at the level of bodily dispositions and appearances' (p.229). In the same vein, Sally's continuation in the realm of putting on makeup

and doing her nails represented the preservation of her identity and sense of self as a well-presented woman who took pride in her appearance. Thus, it was such an integral part of who she was, that she reasserted the need for her family to 'be worried' if she ceased to take care in her personal grooming. Sally was, through the embodied practice of dress, constructing 'normalcy' and 'ordinariness' (Buse and Twigg, 2018, p.21). Disruption of this would represent the opposite; abnormality and the implicit recognition of decline and decay.

Sally's specific reference to her daily application of makeup and carefully chosen nail polish represented what Ward et al. (2014, p.67) termed 'appearance signatures'. The authors used this term to describe the particular aesthetics favoured by individuals in relation to their physical appearance. These signatures, it was noted, were used to deliberately and knowingly uphold continuity, and preserve a sense of self in the face of dementia. Continuity was both subjective and emotional, and evidence of this can be seen in Sally's account, in her intimation that as long as she had makeup on and her nails were painted, she was the person she had always been. Dress practice and appearance work, therefore, can be described as one of the everyday acts of 'construction and reconstruction' that 'create a continuous sense of ontological security; meaning a desire for continuity of self-identity and reliability of social life over the life course' (Gregory, 2005, p.374).

6.3.1 Coping strategies

People with chronic illness deploy various practical coping strategies to help them maintain their independence, which for many women in the present study, was a valued Self 2 attribute. Practical coping strategies, such as memory aids are commonly used by people with dementia, to compensate for losses (Aggarwal et al. 2003). Such strategies were evidenced by several participants in the present study. These largely took the form of physical aids, such as diaries or brain training programmes. The use of external memory aids as a compensation strategy for memory loss is well-established, and has been shown to increase retrieval support (Smith et al. 2011).

Betty and Catherine relied heavily on their diaries. This was central in enabling them to continue to lead their own lives. Both lived alone, and neither wished to become reliant on family members. Hence, they had devised their own practical strategies for ensuring that appointments were adhered to and birthdays not missed. These two women, in particular, also had strong social networks and had a lot going on in any given week, meaning that a diary was

a necessity to keep on top of their busy schedules. Resources such as diaries and calendars have proven to be effective strategies for compensating against memory loss (Dröes et al. 2011). For Catherine, it was also extremely important that she did not miss an event, because of the social embarrassment it would cause – something that she was acutely aware of:

I have to write everything down in my diary, to be sure that I remember it. Which probably isn't very good, is it? If I tried to remember things without writing them down, it might exercise my brain a bit more. But I don't...I can't risk forgetting something. (Catherine)

Well it's a bit annoying and sometimes a bit embarrassing if you miss a date. Erm...because erm...you don't want to let people down, do you? It would be rather awkward. And it would be disappointing if I thought I'd missed somebody's birthday, as well. I'd be...quite upset if I forgot that. So all those dates are in there as well. (Catherine)

Forgetfulness poses a threat to the selfhood of many women in the present study, such as Catherine, making important dates liable to be missed. This could potentially then impact how the person is perceived by others – with symptoms of dementia taking precedence over more valued attributes and characteristics. Therefore, coping strategies that allow for symptoms of forgetfulness to be managed effectively have the function of protecting social identity.

Strategies such as list-making and relying on a diary were also central to Betty's ability to function as independently as she did:

I find myself making lists more, or notes all over the place. On the back of my phone I've got a piece of erm...post-it-note, for if I'm out and I think of something...I can write it down. And I carry a diary round with me. I don't always have to rely on that...I mean, I'm really pleased with me when I can carry a memory of something I want to do for most of the day. But sometimes, it's like anyone... (Betty)

Betty had a large number of social networks, through involvement in all kinds of voluntary organisations and activity groups. She was a strong advocate for the rights of people living with dementia and her voice was widely used in this respect. Thus, use of a diary for her was a necessity, given the tremendous amount of networking she did. She nonetheless stressed that she did not always have to rely on it, and was particularly pleased when she managed to avoid doing so. In the end, Betty concluded by normalising her use of a diary, likening it to the fact that everyone with a busy lifestyle had to write things down, else risk forgetting them.

Marian was another participant, whose asserted sense of independence was aided by the use of a diary and calendar:

I write down shopping lists. And providing I write down anything like 'this person will come at 11:30'. But if I forget to write it in the diary – you might just put that in – I realised it did look pompous to write things in your diary, but it was better...otherwise... But you feel like a right fool! 'See you next Tuesday at tea-time!' (Marian)

Marian, too, was someone who had a very busy life, despite the fact that – like Betty and Catherine – she lived alone. There were visits from former students, old friends, neighbours, as well as committee meetings and community events to diarise. Marian did not feel comfortable using a diary, which was something she associated with people of a certain class; people whom she would regularly refer to throughout our interview as 'pompous' or 'snooty'. She had been shocked by the class system in the UK having fled the Netherlands with her family when she was 13. Marian did anything and everything to distance herself from it. However, the use of a diary was a concession that she had been forced to make, albeit reluctantly, as she recognised that it was the only way in which she could successfully adapt to her memory problems. At one point during our interview, Marian took out her diary to make a note of something that had just occurred to her. It was full of long lines of small, neat handwriting. In order to mark the days that had already passed, the corners of these pages had been carefully folded down.

Computer-based brain training programmes were used by Lynda and Wendy. These served a slightly different function than diaries and lists; with the aim of keeping one's brain active, rather than as an immediate device to recall. Lynda's adherence to the programme was sporadic and she dismissed its usefulness. For Wendy, however, it was central to her wellbeing, and she derived both great enjoyment and great benefit from it:

I have a brain training programme on my computer, and that helps me to think. It comes up with things to do, and they're not all the same every day. Some are things like...you get maths questions, you know? 'If you spent this much, and this much, and this much, how much do you have to pay?' And also...I can't remember what it's called but you have to work out the truth of something that's said. Oh yes – and you can drive a car. The car's going, and then it pulls out, and you have to make sure you don't crash! It's worth the money, I think, 'cause you at least want to keep some of your brain working. (Wendy)

The importance of this computer-based brain-training programme to Wendy was quite evident. It was not merely a game to her, and she took it extremely seriously. When I came back to interview her for a second time, her husband showed me into the living room, where she was sat huddled over a computer, staring with great concentration at the screen. I made to go and greet her, but without turning around, Wendy asked us to ‘please be quiet’. Instead, her husband and I retreated to another room to allow her to finish her session for that day in peace. It was not something that she dipped in and out of, when she felt like it, rather it had become an inexorable part of her daily routine. When she talked about it, her enthusiasm and enjoyment shone through and she credited it with improving her memory and functioning.

Practical coping strategies are important to people with dementia, and were particularly vital to the participants in the present study who lived alone. It was no coincidence that Betty, Catherine and Marian were exceptionally independent, both in terms of making their own decisions and preserving the physical activities they took part in. The importance of keeping a diary in enabling them to live as such was self-evident, as without a partner or relative living with them to help them with recall, they were forced to use alternative strategies.

This section, therefore, has shown that independence was important for many women in the present study. Independence took different forms – for some women, it was expressed in the taking control over decision-making and other aspects of their lives, and rejection of reliance on family members. For others, such as Sally, who in fact relied heavily on her partner with regards to most aspects of her life, it was expressed through embodiment and dress practices, which were a way of asserting her identity. Moreover, those women who were more dependent on their family members for help, either through a lack of confidence or incapability to carry out tasks in the same way that they had previously, did not always experience a threat to selfhood. Indeed, this reliance could be a way of enabling them to preserve aspects of a previously valued self, that would otherwise have been lost. Finally, for those women living alone, practical coping strategies were central to them maintaining their independence.

6.4 ‘I really am clever’: Maintaining a positive self-concept

The continued ability to see oneself in a positive light seemed to go hand-in-hand with being content with life. Harris (2008) described such maintenance of a positive self-concept as an important asset that people with dementia have at their disposal. Some women did this by drawing on the continuity of past identities, such as Marian who asserted her intelligence.

Others sought to maintain their capabilities. Other women compared themselves and their symptoms positively to those of others. Maintaining a positive self-concept often requires the cooperation of other people within the person's social world, hence this section is connected to the final chapter, which will describe how support networks are mobilised.

One way in which Marian maintained a positive self-concept was through emphasising her intelligence. There was an unmistakable link with her past, as a prominent professional with a PhD, in this act of identity preservation. It chimes directly with one of Steven Sabat's vignettes, about a retired professor with dementia, living in a care home, whose pride in his academic achievements was such that he eschewed the traditional activities of the care home in favour of seeking out members of staff for intellectual stimulation. He showed a keen interest in Sabat's research project, which held value for him, as a scientist (Sabat, 2001). The same tendency to differentiate oneself from others on the basis of intelligence was found in Marian's account:

The most important thing, to me, is that I really am clever. And what happens is, you get ones who are angry and resentful, because I say: 'I think that was 1972, wasn't it?' And of course, it's stupid to say that to someone who's just said '73 – I'm contradicting them. (Marian)

The fact that Marian continued to see herself as a woman of standing and intelligence was vital to her wellbeing. In other words, there was no biographical disruption. Her identity and sense of self had not been tarnished by dementia. She read books and participated actively and enthusiastically in community issues. She was politically aware, and opinionated on a range of topics. Marian, like the subject of Sabat's vignette, also appeared to take an academically-motivated, increased interest in the present study, asking numerous questions and at one point, suggesting the premise for a follow-up project that would involve comparing the experiences of people living with dementia in different European countries. For the present discussion, it is worth noting how Marian's account of her self-concept contrasted with that of Wendy's, evidenced in the following chapter. They were the only two participants who had attended university, so the contrast is particularly interesting. Whilst Marian continued to see herself as intelligent, Wendy explained that she had once been, but was no longer.

It is important to explore the reasons for Marian's continued positive self-concept, which appeared not to have been affected by dementia. This can be explored in relation to Sabat's theory of multiple selves, and particularly, with reference to the one most subject to damage –

the Self 3. Self 3 refers to the personae one constructs in different social situations, and thus is dependent on the cooperation of others (Sabat, 2001). Marian lived alone and had no family in England. In this regard, there was perhaps less opportunity for her to sustain damage to the Self 3 in quite the same way as Wendy. Her social networks consisted of longstanding friends and acquaintances – many of whom were fellow academics – as well as neighbours in the local community. Former students whose PhD's she had supervised, also dropped by. Importantly, Marian had two formal caregivers, who came around every day, to assist her with household tasks and chores such as shopping. I was able to observe these dynamics first-hand, as the carers were present when I arrived for both interviews, and on the second occasion, I was invited to accompany Marian and one of her carers to the local supermarket and for lunch at a restaurant before we began the interview.

It soon became clear that the carers were treated as friends. Marian did not construct herself as dependent on anyone – on the contrary, she valued what she saw as her independence and autonomy. Crucially, however, both carers cooperated in this construction. They treated Marian as a perfectly capable, independent woman, who made her own decisions. These decisions may have seemed trivial on the surface; whether or not she wanted to wear a coat for the walk to the supermarket, what items she wanted to buy when there, what combination of items she wanted from the buffet bar at the restaurant. But each time, she made the decision. The carers assumed a backseat role, and appeared to primarily assist with the physical side of things, such as helping Marian to load the shopping into bags and in carrying it back to the house. Perhaps the most significant role the carers played, however, in relation to Sabat's notion of the Self 3, was in cooperating in Marian's construction of herself as an intelligent, sharp academic. One carer, in particular, eulogised about Marian's success and spoke at length about the books she had written. Marian, seemingly both bashful, yet brimming with pride, hurried off to fetch the books, and when she returned, a discussion about the contents of each ensued. The carer picked up one and informed us that this was her favourite – although she had read all of them. She told me that the books continued to sell, especially in America, which Marian seemed pleased about. Marian, therefore, was able to successfully maintain a positive self-concept and retain her identity as an intelligent, capable woman, largely thanks to a network of people who actively participated in her construction as such.

Flora also maintained a positive self-concept through insisting that dementia had not impacted on her intelligence:

It is nice. 'Cause the carers are nice, and the people, I mean...we've just got a problem, all of us. But we're not...daft! (Flora)

In describing the dementia support group she attended, Flora admitted that she had initially been extremely reluctant to go. However, now, it had become an important part of her life. She asserted that neither she, nor her fellow group members were 'daft' – a word that has connotations with stupidity or ignorance. Instead, she normalised dementia, presenting it as a problem, just like many other illnesses or conditions are problems. This protected her beliefs about how she perceived herself, in terms of those Self 2 attributes, such as intelligence and normality. Moreover, it could evidence recognition on Flora's behalf, of the stigma that often surrounds dementia, and the above extract may have been an attempt to refute this. In other words, it is an 'effort to assert [her] own normality' in face of the fear and uncertainty of those whose reactions are guided by outdated dementia stereotypes (Devlin et al. 2007, p.52).

Also important to the selfhood of many women in the present study, was the positioning of oneself as capable. When talking about the impact of the disease on their lives, people with dementia who position themselves as such can assert and maintain their identity (Robertson, 2014). This helps to construct a narrative of independence, and serves as a way of proving to themselves and others that they are still capable of doing the things they had previously (Fetherstonhaugh et al. 2013):

*But she knows I'm **capable** of seeing to myself. I mean, I do all me own cleaning. I don't get no housework done for me. I cook, wash, clean, garden for myself. (Flora)*

The word 'capable' was emphasised in the above extract, as Flora went on to substantiate this with evidence. Thus, by listing all of the things she could still do, she was asserting the ways in which she was resisting the threat to selfhood posed by dementia. Self 2 consists of one's attributes and characteristics; Flora emphasised these in relation to her role as a homemaker. The positive perception of those attributes she possessed could also serve to enhance Flora's self-esteem – the evaluative component of self-concept.

Another way in which Flora stressed her independence, was in acknowledging that she spent a lot of time with her son and daughter, both of whom lived on the same street. Her daughter Helen, moreover, lived next-door to her mother. Flora was eager to clarify the specifics of this arrangement:

I didn't move next to Helen, she moved next door. I was here first! So...that's her choice...just to...not go far away. She chose to move in next door. And I mean, I'm not always knocking on her door or anything! (Flora)

Here, Flora again distanced herself from the notion of someone who was dependent on her family. She asserted – as she did throughout the interview – that Helen had moved next door to her, not the other way round. This was an important detail for Flora, lest people view the situation as having demanded that her daughter be there to keep an eye on her. Instead, Helen had actively desired to be close to home, and Flora spent a lot of time with her, because she was invited to do so. Hence, Flora noted, it would be rude to decline the regular invitations to come round for dinner, or to accompany the family on excursions. Importantly, however, this was a choice on her part, rather than a sign of dependency.

Stella's house was spotless and it was clear that she took immense pride in her housework, as she always had done:

I'm always cleaning. Yeah...because at one time, Frank did say to me: 'Why don't you get a lady to come once a week?' And I said to him: 'I don't want anybody in, I can do it myself!' 'Cause I mean, it's there, you know...come and have a look at my lounge, you'd be surprised at it...this was the lounge, but now it's the dining room... (Stella)

The idea that the couple would hire a professional to come in and do the cleaning, now that she had been diagnosed with dementia, was absurd and faintly offensive to Stella. To her, it was an attempt by Frank to frame her as incapable, which was problematic to Stella's sense of self as someone who was resolutely house-proud (Robertson, 2014). Hence, she emphatically rejected the label, and, as if to prove her point, insisted on showing me around the adjoining rooms:

Interviewer: *Oh my gosh, it's all immaculate.*

Stella: *And this...is the lounge.*

Interviewer: *Wow...*

Stella: *It's lovely isn't it?*

Interviewer: *It's beautiful! It's spotless.*

Stella: *It is, isn't it?*

Interviewer: *Gosh, it looks like something out of a magazine.*

Stella: *I feel quite proud you said that [laughs].*

Interviewer: *Yeah, it's beautiful!*

Stella: *Yeah...well one or two people said to me: 'Yeah you've got right good taste'. Every time I walk in here...I sort of have to 'ooh' like this, yeah... 'cause it's- it's so nice that it sort of...y-you want to look at it for a while, don't you?*

Home design has become a way for people, particularly women, to develop and express their identity (Gram-Hanssen and Bech-Danielson, 2004). This was undoubtedly true of Stella. The above exchange took place as she showed me around her newly decorated lounge, which was indeed spotless and had the appearance of a showroom. She clearly took tremendous pride in this, and seemed genuinely delighted with my approval. The positive comments of other people also boosted her self-esteem and served as a rebuke to Frank's suggestion that they could get someone in who could maintain the same exacting standards of cleanliness and perfection. The rooms in the house had Stella's stamp on them; they were an extension of her identity, a reflection of her choices and autonomy.

Whilst Lynda did not have a particularly positive view of herself in general, and tended to focus on the losses suffered as a result of dementia, a recent trip to the doctors that she had been forced to undertake alone, had served to enhance her self-esteem:

I actually took myself to the doctors – that's the first time I've been on my own and that was because of the pleurisy I had. I woke up with a lot of pain and didn't want to bother Joe with it, you know...else he'd have been leaving work. And my daughter, I knew that she had a delivery so she couldn't come with me. So, I phoned the doctors and took myself off to the doctors. So, I did that and I was quite pleased with myself when I did it. (Lynda)

Lynda was not often prepared to venture out by herself, particularly to medical appointments. She had had a string of bad experiences with doctors' surgeries and hospitals and actively avoided them where at all possible. For this reason, and because of the fact that her self-efficacy in general had been severely impacted by dementia, the above anecdote was significant. This recent successful excursion proved to Lynda that she could indeed accomplish things. Such successes, however small, are the most influential source of efficacy information that a person draws upon in future. A resilient sense of efficacy is built upon accomplishments – the fact that Lynda had experienced several previous setbacks, and almost expected to fail, making this particular success all the more satisfying (Bandura, 1997). Despite her negative past experiences and resultant conviction that she could not achieve anything unless someone was

with her, there was the sense that this latest excursion could perhaps tentatively serve as base for Lynda going forward.

In a similar vein, Alice also positioned herself as capable of doing things, and instead as choosing to let others help her:

Thursdays, my daughter comes up and does the cleaning for me. She does all the main bits, and the washing and that. I can do it myself – I know what I'm doing, and I usually do it. But she said: 'I think you need some help'. So I thought, fine. So she comes up once a week. (Alice)

Here, Alice explained that her daughter came around once a week to help with the cleaning and housework. Interestingly, this was true of several participants; Lynda and Wendy had daughters who did the same. In the above extract, Alice constructed herself as perfectly able to maintain a high standard of housework – insisting that she usually did it anyway. The reason why she allowed her daughter to come and help once a week, appeared to be that, much like Flora and Stella, she was accommodating the wishes of a family member. Therefore, independence in these accounts is slightly ambiguous; by accepting the need for help, the women are essentially conceding that they are not able to do labour-intensive tasks, such as housework, to the same extent as they had previously. This concession, particularly if it had been important to their role identity as homemaker, could potentially threaten their Self 2. However, by choosing who comes to help with these tasks – i.e. their daughters – they retain some control over the situation, and face potentially less of threat to self-esteem as a result.

6.4.1 Minimising and normalising

Strategies, such as minimising and normalising were used by many participants as a way of maintaining a positive self-concept. MacQuarrie (2005) describes minimising as an attempt by the person to downplay the significance and severity of dementia symptoms. Normalising involves attributing symptoms to the ageing process, rather than something clinical. An important aspect to the process of minimising for the women in the present study, appeared to be the ways in which they compared themselves to other people with dementia. People are particularly prone to self-evaluation in times of stress or uncertainty – for example, after having been diagnosed with a chronic illness – because it has the potential to enhance self-esteem (Dibb and Yardley, 2006).

When making downward social comparisons, people compare themselves to others who are in their view in a less favourable situation (Peterson and Ritz, 2010). In a chronic illness context, this will usually centre on the severity of symptoms. This is also intrinsically linked with a person's affective evaluation of their illness. Making downward social comparisons has been shown to reduce emotional distress and can have an impact on a person's ability to self-manage (Peterson and Ritz, 2010). The person may feel lucky that their own situation is not as bad, and experience positive feelings as a result, which in turn produces positive coping strategies. Conversely, the comparison may result in anxiety and fear that one day, they themselves may be in this situation (Dibb and Yardley, 2006).

Martha was one such participant, who was adamant that dementia had no effect on her life, due to the comparisons she made with other people:

To me, I haven't got dementia...when I seen them other people. I know I forget and I don't remember everything, but when I've seen them other people and I realise how...what state they're in, it is awful. It is awful to see it. (Martha)

This offered an interesting insight into Martha's thought processes and coping mechanisms, because she was quite accepting of the fact that she had been diagnosed with dementia, and did not shy away from using the term 'dementia' or 'Alzheimer's'. However, Martha's eagerness to minimise her own symptoms throughout our interview, and to present herself as not having the disease, stemmed from her experience of an Alzheimer's group set up by the hospital, which she attended for six months after being diagnosed. Here, she came into contact with people who were in the mid-late stages of the disease, and whose symptoms were clearly far more advanced than her own. Thus, Martha made a downward comparison between herself and this group, asserting that there were people worse off than her, which served to preserve her own dignity and self-esteem (Gillies and Johnston, 2004). She did not deny she had memory problems, but she drew a distinction between this and having dementia – which she believed manifested itself in extreme behavioural and emotional states. Martha did not consider that it was a progressive illness and that she may become more impaired in the future. Instead, she placed herself in a category distinct from these other people. She saw them in a sympathetic, pitiful light, describing one session, where a man was sat in the circle, dribbling, without realising it. Martha took a tissue out of his pocket and wiped his mouth for him – almost as if she was his mother and he was a small child.

Interestingly, it was not just other people with dementia with whom Martha made downward comparisons. She also compared herself to her sister, stressing their inherent differences on numerous occasions throughout our interview:

*I've got an older sister...and she does nothing. **Nothing.** Whereas me, I'm not like that, never have been. Probably that's helped me. Maybe if I didn't do the things I did, I might be...worse than I am. But it's being active. Yeah...I'm so different to her, it's unreal. She never had the life that I did. Never went singing, never went to a ladies' group. You see, me, I do all them things. And that's the way to do it. You've got to keep doing things. (Martha)*

It was quite striking, just how emphatically Martha distanced herself from her sister. She also equated her high levels of activity with her wellbeing, speculating that she would be 'worse' if she was not so physically active. Her sister was portrayed as someone who had a negative attitude towards life – indeed, this had led to them having fallen out recently – which in Martha's account she could not understand. It is possible that these comparisons, made with people like her sister, who did not have dementia, reinforced Martha's sense of self. To Martha, her life was more fulfilling than her sister's, her attitude was better than her sister's, despite her sister not having a dementia diagnosis.

Stella, like Martha, distanced herself from people with dementia, with more severe behavioural symptoms. In discussing her husband's ability to cope with dementia, she reasoned that she was easy to live with and reflected on the fact that she herself would not be able to put up with someone who did exhibit such symptoms:

I mean, I don't start throwing myself around [laughs]. Oh dear, yes. I couldn't stand it, that would drive me mad. (Stella)

In a similar vein, Alice described the moment she was diagnosed, at a memory clinic, surrounded by other people her own age. She too, did not identify with this group, and was eager to distance herself from them:

I couldn't understand why these other...they were about 70, 80 years old, you know – the ones that can't get around and that. What the heck am I doing here?! I still don't know. To this day I don't know. (Alice)

Her indignation at being associated with people whom she considered much older than herself (Alice was 70), was plain to see. She saw these people as incapacitated, and throughout the interview, reinforced the ways in which she retained all her own capabilities. She questioned what she was doing there, and despite having received the diagnosis, continued to reject it – even now. Alice avoided reference to the word ‘dementia’ and also normalised her symptoms.

For Sally, however, such downward social comparisons had the opposite effect. She was adamant that she would not attend dementia support groups or have anything to do with other people who had dementia in order to protect her sense of self:

It's the fear of seeing people in later stages of dementia, that's my biggest thing. I don't want to see anybody. You think, oh how long is it gonna be before I'm like that? (Sally)

The above extract reflects the downward social comparisons made by people with dementia, with those who have more severe symptoms. Rather than such comparisons enhancing self-esteem, as they did for Martha, they instead serve to threaten it (Lockwood, 2002). This is due to the alarm and fear triggered in the person, as they consider the prospect that the ‘worse-off other’ provides a relevant source of information for what will happen to them in the future (p.343). Sally’s self-esteem had been impacted by dementia; her Self 2 attributes and beliefs about those attributes damaged. The idea of coming into contact with people in the later stages of dementia, therefore engendered fear in Sally, and a desire to protect her sense of self. By contrast, Martha had a positive self-concept, boosted by high self-esteem and the perception of herself as capable and constantly active – as she had always been, in fact. Thus, there was a continuity between her past and present self. For Martha, seeing others worse off than herself merely highlighted the distance between her and them. Much of whether social comparisons are seen as a threat or a boost to self-esteem comes down to the perceived ease with which one can imagine a self like the other. If the person sees themselves as particularly vulnerable to becoming like the other, they are likely to perceive a negative outcome. Sally knew that dementia was a progressive condition, characterised by degeneration over time. She also knew there was no cure. It is possible that people in the latter stages of dementia reflected Sally’s ‘feared selves’ – an integral part of one’s self-concept (Markus and Nurius, 1986, p.957).

Another participant who minimised her symptoms and the effect they had on her life was Flora, who, like Martha, accepted her diagnosis for what it was, but who insisted that she was unaffected by it:

I'm still the same. Well...I say I forget. I forget and I don't forget. I might forget some things I ought to remember, but I mean...I always know me way home. (Flora)

This statement began with a categorical assertion of her retained identity. The very same quote can be found in a study by Caddell and Clare (2011), illustrating how participants maintained some concept of themselves and used examples to justify this. Flora alternated between asserting that dementia had not impacted on her life at all, and conceding that she was somewhat forgetful. The one thing that cropped up throughout her interview, however, was the fact that she would always be able to find her way home if she was out and about. This, she clung to, coming full circle to once again prove that her impairment was minimal – and engaging in the same kind of justification that Cadell and Clare (2011) found.

Other participants tended to normalise their memory loss, evidence of which can be found in the literature (e.g. Gillies and Johnston, 2004). Sometimes this took the form of light-heartedly dismissing memory problems encountered during the course of the interview:

Oh, my memory! (Marian)

Oh yes, I do forget things! (Joan)

I can't remember the dates now, to be honest. They'll come back to me when I'm not thinking about them! (Alice)

These statements served as acknowledgement of memory problems, but in a way that trivialised them and set them apart from dementia. They are the type of off-the-cuff remark, for example, that anyone without dementia might come out with if they struggled to remember a particular event.

When I asked Stella a question about her granddaughter, the following exchange ensued:

Stella: *I think she's...I don't know if it's 18 or 19...I can't think of her name...*

Interviewer: *That's OK, don't worry about it. It's easily done.*

Stella: *It is, isn't it?*

Stella struggled with the realisation that she could not remember the name of her own granddaughter. My immediate reaction was to reassure her that this was normal, and I reasoned that there was no point in allowing her to continue to brood over it, as she seemed like she

might become upset. Stella seemed grateful for this response, and quickly agreed that indeed, it was easily done.

Normalising also took the form of more specific attributions of memory problems to age. This is supported by previous studies that found similar coping responses:

It's something that comes when you're between 70 and 80 sort of thing, I suppose. (Catherine)

Catherine had no prior knowledge of what dementia was, and even once diagnosed, did not appear to understand what it entailed – or possibly chose not to associate the label of dementia with her own experience. She was extremely relaxed, and – on the surface at least – relatively unbothered by it. Hence, this statement, where she put it down to part of the normal process of ageing. MacQuarrie (2005) found similar efforts to normalise dementia, and describes them as a form of ‘recontextualised knowing’ (p.436). In other words, participants used attribution strategies to assert that dementia was something to be expected once one reached a certain age in life.

Of course, as discussed in the previous chapter, there are counter examples of participants who, far from normalising the disease, presented it as something *abnormal* and a source of fear:

I've changed so much. I just don't seem to have control sometimes. My confidence, my personality, my security...it's all just... (Sally)

Sally had noticed that dementia had severely impacted her personality, causing her to have mood swings and to become aggressive. This frightened her because it was in stark contrast to how she had perceived herself prior to her diagnosis. Relatedly, it was hard to reconcile the person she was describing with my own impression of Sally in the interview. She came across as mild-mannered and kind. Her acute awareness of these changes also produced a heightened emotional response. Even in describing them to me, Sally became extremely upset, asserting that she no longer recognised herself. She described feelings of intense anxiety and fear that impacted on most aspects of her life.

Bridget was another participant who found it hard to adjust to her diagnosis, struggling to find a positive outlook on life:

I didn't want to live with what I'd got, and you know...I'm supposed to be batty. (Bridget)

The word ‘batty’ was used on numerous occasions throughout Bridget’s account. She believed her husband was embarrassed about having a ‘batty wife’, and she referred to the people at the memory clinic as ‘the batty people’. This chimes with findings from other studies that suggest people with dementia commonly experience feelings of ‘going mad’, and as a result, try and avoid situations where this feeling may be intensified – such as support groups (Cheston, 2013, p.86). Yet Bridget did not distance herself from people with dementia, as many of the other participants did, in order to maintain a positive self-concept or engage in downward social comparisons. Rather, Bridget saw herself as a member of this group; one of ‘the batty people’. Her self-esteem suffered as a result. Bridget appeared to see herself in an almost exclusively negative light. If she had not been accepted into *Silver Linings*, which was her lifeline, she told me she would not have survived, because without it, she was ‘ready for the bin’.

Lynda, like Sally, was aware of the signs of decline:

I find it, as time goes on, a little bit harder. Because I am getting worse. So there’s...you know, I do feel the effects of that as, as time goes on. And I have to try and act normal in front of the family, which is really tiring. (Lynda)

Balancing an awareness of the disease progression and the daunting knowledge that she was ‘getting worse’ with the constant effort of trying to act ‘normal’ in front of her family was mentally and physically draining for Lynda. She longed for a break and was actively looking into a care home close by, where she could go for a day a week, simply to unwind from the pressures of everyday life. Unlike those participants who normalised dementia by dismissing symptoms or attributing them to age, Lynda saw herself deteriorating. Her personality was changing, she was forgetful and she had to rely on other people, having previously been extremely self-reliant. The result was that Lynda’s self-concept was severely damaged and she perceived herself largely in terms of what she could no longer do.

The above accounts illustrate the variety of ways in which women living with dementia strive to maintain a positive self-concept. This involved presenting themselves in such a way that positive attributes were highlighted. For example, Marian had been an academic, and she continued to see herself as intelligent. Stella was a keen homemaker and took pride in having an eye for interior design. These perceived attributes – which, importantly, were reinforced by others – contributed to enhanced self-esteem. Many women also maintained a positive view of themselves by minimising or normalising their symptoms. Comparing oneself favourably to

other people with dementia served to enhance self-esteem, as did the presentation of dementia as being akin to normal ageing.

6.5. Conclusion

This chapter has explored how women with dementia resist the threat posed by the disease, to selfhood and identity, as well as how they repair aspects of selfhood or identity that may have been damaged. Almost all women described engaging in activities that enriched their lives and were central to wellbeing. Some described themselves as an active person, as though this was central to their personality, whilst other referred to specific things like baking, driving and spirituality.

The second section showed the ways in which women with dementia maintained their independence. This involved both physical independence, as well as making one's own decisions. Decision-making was extremely important to some women, as to them it signified control and a positive response to dementia. Others specifically outlined the ways in which they were more dependent on others, which also offers a means of preserving selfhood, in the form of family members supporting them to maintain valued Self 2 attributes, and consequently, self-esteem, that might otherwise have been lost as a result of dementia.

The final section explored how women with dementia maintained a positive self-concept. This involved maintaining continuity with one's past, for example, by asserting that they still did the things they used to do. It also applies to the more general perception of oneself as intelligent or capable. Many women also engaged in minimising the impact of dementia to preserve a positive self-concept. This included downplaying their symptoms and hence presenting it as less of a threat to selfhood. One way in which this was achieved was through downward comparisons with others, particularly those with more severe and visible symptoms of dementia. When the women in this study compared themselves to these other people, their self-concept was boosted because they evaluated their symptoms and overall situation as being quite different.

This chapter provides a detailed account of the practices, strategies and wider environment required to enable women to resist the threats posed to their selfhood and identity as a result of living with dementia. The Self 2 (the self of personal attributes, characteristics, and beliefs about these) is vulnerable to damage, as shown in the previous chapter. However, resistance

enables people to draw upon both internal and external resources and preserve selfhood. The chapter shows that aspects of people's lifestyle and activities can enable them to maintain a positive self-concept, as can self-presentation practices that seek to normalise or minimise the symptoms of dementia. All participants in the present study, even those who described negative emotions and low self-esteem, identified ways in which this preservation of selfhood could be achieved. These findings provide significant support for existing research that identifies engagement in leisure activities as helping people to resist the stereotypes associated with dementia and ageing, by showing them to be active, independent individuals (Genoe, 2010). The findings also serve to develop new insight into the role that these activities play in reinforcing social identity: for example, Betty in her role as advocate, Sally in her role as baker. This in turn can reflect back on personal identity, reinforcing self-esteem and beliefs about one's capabilities. The importance of constructing a valued social identity, and interpersonal relationships more generally, are clearly important in the responses of women to the threat of dementia. These will now be discussed in the next chapter.

Chapter 7: The Dynamics of Interpersonal Relationships

7.1 Introduction

The first two findings chapters have explored how people experience a changing sense of self as a result of dementia, and how they are able to resist the threat to selfhood by retaining valued activities, adapting these or developing new ones. This final findings chapter explores how, throughout the illness experience, selfhood is supported and impacted by the dynamics of various relationships in the person's social world. It includes interviews with family members, to supplement the primary data from first-hand accounts. The chapter considers the integral role played by other people, and specifically, their cooperation or non-cooperation in attempts by the person with dementia to construct valued Self 3 personae (Sabat and Harré, 1992).

This chapter considers both the intimate and peripheral networks of people with dementia. The first section explores the benefits derived from attending support groups, and how these foster a shared sense of identity and belonging. The groups provide much needed relief from the stresses of everyday life, allowing participants to let their guard down and seek solace in the company of friends. The second section addresses how participants are positioned by people within their social networks, particularly by those closest to them. Positioning theory is concerned with revealing the explicit and implicit patterns of reasoning that are realised in the ways that people behave towards others' (Harré et al. 2009, p.5). This can be explored through language; the accounts of participants in the present study. The present chapter explores the subtle ways in which positioning occurs, and how people with dementia are positioned in a variety of different ways by others within their social world.

Finally, the dynamics of interpersonal relationships are explored with reference to changes in role and participants' expectations of the future. These themes connect back to the previous two findings chapters in terms of how people negotiate changing identities and resist threats to their selfhood posed by the challenges of living with dementia. Changes in role are discussed in relation to negotiating gendered identities, and the varying importance assigned to these by different couples. This final section also discusses the ways in which couples navigate changing relationship dynamics and how these are considered in relation to their perceptions of the future; how people perceive the future, drawing strength, or expressing fear and dread, and the relationships that facilitate these differing outlooks.

This chapter illustrates the role of interpersonal relationships in supporting or impacting on the selfhood and identity of women living with dementia. It considers both intimate and peripheral networks, and the ways in which these can preserve social identity – particularly with reference to the sense of collective identity fostered within dementia support groups. It considers how positioning – the relationships that make up the Self 3 – impact on selfhood, particularly, how they have the power to reflect back on and impact self-concept. Changes in roles and responsibilities can also lead to a diminished sense of self, although these are related to familial relationships and how women with dementia are positioned – in a way that can potentially enhance gendered identity. The chapter’s final section, on expectations for the future, is concerned with how the hopes and fears of women with dementia reflect the preservation of, or threat posed to, selfhood. In terms of the wider aims of the thesis, therefore, this chapter explores how the dynamics of interpersonal relationships can impact on selfhood and identity, through helping to sustain these in the face of the threat posed by dementia.

7.2 ‘You can say how you feel’: Support groups

Support groups are described by Goldsilver and Gruneir (2001) as a necessary antidote to the focus on disability and decline in the face of dementia, and something that people derive immense satisfaction from taking part in. Beard and Fox (2008) went further than this, asserting that support groups foster a ‘collective identity’ among members, and help to navigate the significant transitions encountered by people with dementia (p.1518). This collective identity involves the reconstructing of a new sense of self, with differing expectations and roles. Assuming the role of support group member allows people with dementia to successfully ‘re-story’ their lives (Holst and Hallberg 2003, p.364).

Some women in the present study actively resisted engaging in such support groups, however, for others, the groups were of vital importance – although for differing reasons. Some people attended support groups because being around others in a similar situation helped to alleviate feelings of loneliness (e.g. Willis et al. 2018). Several participants cited more simple, enjoyable – but no less important benefits. What these accounts had in common was the fact that the relationships with fellow group members could be described as ‘peripheral’, rather than close, in terms of proximity and intimacy (Bruggencate et al. 2018, p.1747). Yet in some cases, these peripheral relationships were described as far more central to the maintenance of selfhood than closer ones, by the very fact that they were removed from the sphere of intimate relationships – which could foster tension and disagreement.

Bridget and Lynda were two participants who spoke of their local support groups in terms of a range of social and emotional benefits:

I don't go very far...I'll go to Silver Linings. And that's brilliant. That's been my saviour, because I thought I was really for the bin. (Bridget)

Bridget described how, had it not been for *Silver Linings*, she would have been consigned to what she referred to as the 'bin'. In terms of selfhood, Bridget had perceived herself in terms of negative, disease-related attributes – a disease which carried the same connotations as mental illness for her – to the detriment of many positive and valued attributes. It was not difficult, therefore, to understand Bridget's deep attachment to *Silver Linings*, which offered her a more positive appraisal of her self-concept, and well as the opportunity to connect with other people:

I go to Silver Linings and that lifts me up if I'm in the doldrums. And if anybody speaks to me there then I'm on a roller. That's the only bit of interaction that I ever get. Yeah...I love it. If I could go every day, I would. It lightens me up. (Bridget)

For Bridget, the group provided her with her only opportunity for genuine social contact, and she described its effects in transformative terms. The simple act of someone speaking to her in a kindly manner had a monumental impact on her, and she rode on the psychological high for the rest of the day. Bridget described being prone to very low moods at times, and *Silver Linings* as her saviour that helped her to get through such periods. This accords with the findings of other studies that suggest support groups for people with dementia can indeed play a significant role in alleviating depressive symptoms. Participants in these studies describe the groups as being 'survival' and the one thing they look forward to (Yeh et al. 2001, p.45), a direct reflection of Bridget's extracts. Logsdon et al. (2010) found similar cathartic effects in relation to dementia support groups, noting the improvement in quality of life and decrease in depressive symptoms experienced by people who attended.

The importance of such groups was also stressed by Lynda, who derived immense benefit from the opportunities they provided for support and honest reflection:

And you can say how you feel – how you really feel. 'Cause you're amongst people who know first-hand what it's like. And you can say: 'Oh I'm having a bad day today'. And the others just say: 'Well it's the best place to be then'. And erm...you can say what you want, you haven't

got to worry. With your family, you can't say how you feel. You can't be straight with them. So this group is the only place that you can be yourself. (Lynda)

This account of a dementia group is reflective of the vital role they can play in enhancing people's wellbeing and providing relief from the pressures of the everyday. Because of the shared 'commonality of experience', members can empathise and bond with another, which allows for the development of reciprocally supportive relationships (Keyes et al. 2016, p.562). Given that she was unable to talk to her family about how she was feeling, it was particularly important that Lynda received this support from the dementia group. This allowed her to construct a valued Self 3 persona, not as a dementia patient, but as a member of the support group, who could share personal insights and experiences, and listen to those of other members. The constant preoccupation with performance and self-management with which Lynda was otherwise engaged, took its toll on her self-concept, and she described the support group as providing some much-needed relief from this.

Betty reiterated this need for the empowerment of people with dementia in her own account of the benefits of support groups:

Some have vascular dementia...we've all got different types of dementia. We meet in Mansfield, so I travel up to Mansfield once a month – on the Friday. And erm...really, really enjoy the...toing and froing. Because although...there's only one gentleman that takes his carer with him, because she's also the secretary of the group – the rest of us are all single people, and we all talk to each other. But...it's all relevant for me. Erm...there's not many of them that can't hold a really constructive conversation. And that's what I'm pushing with the Alzheimer's Society, that they need to do more post-diagnosis. You know, get friendly groups – that sort of thing. We can support ourselves, once they give us the opportunity to meet. 'Cause everything is so...closeted and secreted. We aren't getting the support we can give each other. (Betty)

If given the means to enable them to put together support groups, Betty believed this would allow people with dementia to become more independent. She cited her own experience, noting that this was a group made of people with different kinds of dementia, who all came together to meet once a month without their caregivers. They were capable of holding conversations and, beyond specific topics, it was the 'interpersonal communication dynamics' that allowed for 'affirming, engaged discourse' that ultimately led to a sense of validation and preserved selfhood (Snyder, 2006, p.262).

Wendy also derived personal benefits from her dementia support group, which were similarly important in contributing to an increased quality of life:

The Alzheimer's clinic is lovely, I have a lot of fun there. There was a man singing on the last one, and suddenly he remembered that I liked dancing. So he went and said: 'Can we do some dancing?' And nobody got up, and I thought, oh dear, I can't get up [laughs]. So he came and he got me, and suddenly my energy came back and we were twisting around [laughs]. And we got a big clap! (Wendy)

This extract is significant, because, on the surface, Wendy appeared to be an anxious and nervous woman. Yet her entire demeanour changed when talking about the Alzheimer's group. She recalled the last session, describing how a fellow group member 'remembered that [she] liked dancing'. It was an apparently insignificant remark, yet it spoke to the notion of a successful Self 3 – or social persona. Namely that another person within Wendy's social world enabled her to construct a persona beyond that of a dementia patient. He pulled her to her feet, despite her initial doubt that she was even capable of taking part, with the result that those previous Self 2 attributes – Wendy had always enjoyed dancing – were enhanced. Her self-esteem was further boosted by the clap they received from the rest of the group.

Dementia support groups came in many different forms, as evidenced by the below excerpt from Alice's interview. There was an emphasis on acceptance, on feeling part of a wider family, and of everyone simply having fun together:

It's mostly family, and the ones from the group, that we meet up with. We was out last week...was it Friday night last week? We went to one of the Christmas parties there. And then we're going to somebody else, just outside the town. So we're going to see them. So we're having more friends now. And erm...there's a sports hall, just out of town. And it's what they call Boccia. It's more or less like bowls. But erm...it's a case of...we just get out there, join them. Now we know all the ones that go to that club, they've accepted us, so... (Alice)

Alice derived enormous benefit – such as 'having more friends' – from taking part in the activities provided by her support group. In a similar vein, Phinney et al. (2016) describe a walking club for people with dementia as providing 'social citizenship' (p.381). Within this group, like Alice's, there was space for exercising, enhancing one's mood and generally fostering a sense of shared belonging, without the need to reference dementia. Such social groups do not necessarily involve coming together and discussing one's feelings. Whilst this

type of support was exactly what some people needed – Lynda being a prime example – because she wanted to be able to talk about dementia with people who knew first-hand what it was like to have the disease, it was not what others needed. Alice distanced herself from the notion that she even had dementia, insisting that there was nothing wrong with her and that she was fine. Hence the type of support group that held regular social events for members to engage in, and did not focus on the illness itself, was far more beneficial to someone like Alice. Each event was described as a gathering of friends – just as one would do if one did not have dementia.

This section has explored the importance of dementia support groups, in fostering and maintaining a positive sense of self. The benefits these groups offered were many and varied. Some people described them as a kind of safe place, where they were free from the effort of having to manage their behaviours. In these accounts, there was a sense of emotional support that came from everyone being in the same boat, that allowed for honest discussion of how participants were feeling, without fear of judgement. For others, the social aspect of groups was important. These accounts described the fun and enjoyment that people derived from attending. For those that attended them, dementia support groups were central to preserving selfhood. They allowed people to construct valued social identities which served to enhance self-esteem and feelings of positivity.

Wiersma et al. (2016) found that segregation between people with dementia and caregivers to be vital in allowing for support groups to serve their function. They further claimed that those who attended such groups did not feel they could talk openly and honestly in front of their family members. Often, as expressed by Lynda in the present study, this is for fear of causing them worry. The groups therefore become ‘safe spaces’, where people with dementia can gain the trust in one another to share personal experiences, without having to moderate or filter these experiences (Wiersma et al. 2016, p.419). This segregation breeds solidarity among group members; ‘a sense of being a unique and similarly-aligned community’ (p.424). Such solidarity can empower people, and create examples of social citizenship, as members step up to help others in times of crisis, as described in the above accounts. Support groups were therefore extremely important to many women in the present study. The relationships within them may be peripheral, rather than intimate, but they offered opportunities for preserving aspects of selfhood and identity that more intimate relationships often could not fulfil. Not only could the women construct a valued Self 3 persona within such settings, as a result of being a recognised

and valued member of a group, but this then had the potential to enhance their own Self 2 attributes, and self-concept.

7.3 ‘She’s not an equal companion’: The power of positioning

This section will explore the dynamics of positioning, as described through the accounts of women with dementia and family members, as well as observational field-notes. As already discussed, positioning is important to the social constructionist account of selfhood in dementia, because it is concerned with how one is portrayed by others, which in turn feeds into the view one has of oneself (Sabat, 2001). Hence this section looks at the impact that positioning can have on a person’s self-esteem and subsequent evaluation of their capabilities.

Positioning theory was introduced by van Langenhove and Harré (1994) to describe the processes by which people are ‘located’ within conversation (p.362). The theory includes the notion of the rights and obligations that speakers have, with reference to the social force of storylines. It takes into consideration the power relations at play in discursive acts, as well as relations of competence and trustworthiness, among others. Positioning is a way to explain both the behaviour of others and one’s own behaviour. Interactive positioning involves the positioning of a person by another, whereas reflexive positioning involves a person positioning him or herself in a certain way (Sabat et al. 2004). Daily life consists of a constant cycle of accepting and rejecting positions, as well as counter-positioning. This, however, is harder for people with dementia to engage in, as their social identities are threatened by the disease, and the resultant power discrepancies.

It is important to note that there has been much discussion and debate around positioning, particularly Sabat’s (2003) notion of ‘malignant positioning’, which involves positioning that can have negative effects on how a person with dementia is treated by others (p.85). This is related to Kitwood’s (1997) notion of malignant social psychology, which suggests that much of the behaviour displayed by people with dementia is not a symptom of the disease itself, but a reflection of how they are treated. Yet the thrust of these theories arguably risks apportioning much of the blame for the struggle of people with dementia to construct a valued social persona, to caregivers (Tolhurst et al. 2017). Nonetheless, positioning is an important component of the social constructionist model of selfhood in dementia. The focus of this chapter, and the thesis more generally, is to draw out the voice of the person with dementia, however this is evidently just one particular reading in terms of interpreting the dynamics of relationships – just as

qualitative research more broadly involves a subjective reading and interpreting of accounts of experiences.

Marian and Wendy were the only two women in the study who had attended university and achieved a degree. Both had held high-status positions – particularly given their gender and the time period in which they had their careers. Marian had been a clinical psychologist and PhD supervisor. Wendy had been Head of science at a sixth form college, and had also taught maths and engineering. Whilst both spoke of their advanced education and careers with pride, there were differences in the extent to which each woman's sense of her own intelligence contributed to her present-day self-esteem. Marian (as discussed in the previous chapter) maintained an extremely positive self-concept, supported largely by her beliefs about her academic attributes – a key facet of Self 2.

It is now worth turning to Wendy, who was much quieter than Marian, and appeared to be far less sure of herself, often commenting on her own sense of her defects and shortcomings. During one brief, and seemingly innocuous exchange, she described how she had helped her husband with his biology thesis:

Wendy: *And I helped Kevin with his PhD. He was terrible with the maths...so I helped him. And I said: 'You'd better tell them that I helped you!'*

Interviewer: *That's very impressive. You're clearly a very intelligent woman.*

Wendy: *I was, but I'm not now.*

Interviewer: *Just because you've got Alzheimer's, that doesn't change. You had that wonderful career, you went to university, when it was very rare for women to go...*

Wendy: *And as I say, I-I went early.*

Interviewer: *Exactly.*

Wendy: *Was a miracle, and I'd also been to two other places and got offers, and somehow or other, Manchester seemed to stick in my head.*

The above extract illustrates how Wendy's selfhood and identity had been affected by dementia. She talked about her career with great enthusiasm and vivacity, and her intelligence and capabilities as an academic person had clearly formed an integral aspect of her Self 2. However, it was also evident that this was no longer the case, and that Wendy's present beliefs about those attributes were that they had ceased to exist – they were in the past. Instead, the newfound experience of being a person with dementia appeared to dominate her self-concept

to the detriment of more positive appraisals. Despite Wendy's presentation of herself as a woman who was no longer intelligent, I suggested that perhaps the situation was more complex than she allowed. In this co-construction, what could then be observed, was a tentative attempt by Wendy to re-position herself – to focus on her achievements – rather than to continue to put herself down. She told me that not only had she attended university, but that she had gone there early, and as well as Manchester, she had received offers from a further two institutions. This appeared to be justification that maybe she was intelligent after all, and that these intellectual achievements could not simply be wiped out by a diagnosis of dementia.

It is important to consider, in the context of this study's theoretical framework, the potential reasons for Wendy's unwillingness or inability to construct a valued Self 3 persona as an academic, or explore why Marian presented herself to me as an intellectual, and Wendy, the opposite. Wendy's husband, Kevin, was a similarly highly educated biologist. It was evident that they were an intellectual family, with emphasis placed on education and attainment. Their son was a surgeon, their grandson – according to Kevin – a violin prodigy. When I interviewed Kevin, it was clear that he found it difficult to come to terms with his wife's diagnosis. He expressed irritation with Wendy, presenting her as someone who caused problems. Moreover, he lamented the fact that conversations now had to be simple and uncomplicated:

If you have a conversation with her about something, the following day she'll say: 'Oh but you said so-and-so'. And she'll make up something different...so you can't trust anything that erm...you can't trust a conversation with her. So I don't bother. I keep things very simple and non-controversial and...to erm...a routine...a routine that she can understand, which basically means simplifying life down to its lowest common denominator. (Kevin)

Kevin positioned Wendy as someone who was unpredictable and unreliable, who could not be trusted to hold a complex conversation. As a result, he responded by simplifying things, removing the complexity and the nuances. He also described having to respond to points of conflict and Wendy's questioning and contradicting of what he had said. However, his assertion that he now kept things 'non-controversial' and didn't engage Wendy in complicated conversations, could mean that Wendy had no opportunity to construct a valued Self 3 persona as a woman of continued intelligence, because Kevin positioned her as somehow lacking in this domain, and treated her accordingly. As Sabat (2001) notes, it is harder for someone with dementia to counter-position themselves than most, because of the power imbalance that is

already at play. Moreover, the anger and frustration that Kevin claimed Wendy displayed could be a response to how she was positioned.

Kevin also supported Wendy's claims that he found it difficult to adapt to his new responsibilities, and did not attempt to minimise the efforts involved in caregiving. At one point, when Wendy came into the kitchen to get a glass of water, the following exchange ensued:

Kevin: *Well, I do the cooking and most of the ironing. I have to change the bed, and things like that.*

Wendy: *I do the washing up bit, don't I?*

Kevin: *Wendy does **some** of the washing up.*

Wendy: *Almost all of it.*

Kevin: *Hmm. So anyway...I'm quite domesticated!*

The above exchange also reflects the ambiguities at play in relationships. On the one hand, this could be considered an example of second order positioning (Bourbonnais and Ducharme, 2015). Despite Wendy's presence in the room, Kevin positioned her as lacking in the ability to carry out domestic chores – which had once been entirely her domain. Wendy, in response, questioned the way she had been positioned, and attempted to counter-position herself. Thus, her intervening in the conversation can be construed as a means of not passively accepting her place, and of challenging the first-order position assigned to her (Bourbonnais and Ducharme, 2015). This, in turn, could enhance her beliefs about her Self 2 attributes as a homemaker, or at least about some of these attributes being persevered.

Kevin's positioning of Wendy could perhaps be explained by the way in which he now perceived their marriage:

I'm more and more on my own...she's not an equal companion. (Kevin)

This is an example of what Kaplan (2001, p.90) refers to as 'unmarried marrieds'. In other words, the collective identity that traditionally characterises a marriage was replaced by an individual identity. Kevin no longer considered himself part of a couple dynamic. Instead he described himself as feeling 'trapped', and unable to escape. He positioned himself as taking on the bulk of the work around the house, and Wendy as being unable to contribute to either

housework or conversation, which had led Kevin to the conclusion that he was ‘working alone’ (Keady and Nolan, 2003, p.15).

Bridget was another participant who experienced being positioned as somehow impaired in one domain or another. It has already been established that driving was extremely important for Bridget, and no exaggeration to claim that it was perhaps her most valued Self 2 attribute. Bridget now saw herself in terms of the limitations imposed by dementia, and driving was the one constant thing that had endured from her pre-diagnosis self; she described it as the ‘top of the tree’. However, there had been tension around her driving habits for some time:

I don't really want her driving. She hasn't been dangerous but she's very slow, which is not good, it makes other people dangerous. I managed to get her out of the car for the winter. Whether that's permanent or not, I don't know 'cause she's determined to keep driving. I say, hopefully, come the spring we can just carry on as normal and try and keep her off the road.
(Carl)

Carl, perhaps mindful of the fact that, in his role as husband, he felt responsible for Bridget's safety, became implicated in negative forms of positioning. In other words, the fraught interactions that had ensued between the couple over the issue of her driving had resulted in Bridget being positioned as less than capable, and consequently, her sense of self was affected:

She's driving a lot slower now, but...she can still judge distances, and where she is. She drives a lot better than a lot of people. I drive a lot of miles, and the idiots I see...[laughs]. (Carl)

Despite Carl wanting Bridget to relinquish her licence, he acknowledged that she herself was a safe driver. The issue, according to him, was that her slowness could make other people dangerous. Thus, Carl's behaviour could simply be borne of a desire to protect his wife. But the emotional price for this seemed to be a high one, given both the practical and symbolic importance of driving to Bridget. Carl still worked full-time, and it was unclear how Bridget would be able to attend her much-valued *Silver Linings* sessions, without the ability to drive. Moreover, Carl himself admitted that driving was Bridget's ‘link to her past’, something that Bridget routinely confirmed by stating how her love of driving was connected to her occupational history.

Bridget, for her part, was in no doubt that Carl's actions were a slight against her, and she evidenced an awareness that removal of the ability to drive would threaten an enduring aspect of her selfhood:

I'm worried that me car's now been taken away because of this winter basically, so he's nailed... 'cause he was barking over me having the car. I wasn't safe, and yet I was. I was a darned sight safer than him and perfectly all right, and this sort of thing...no problems, and he says: 'I think you ought to just pack it up for the winter'. So the winter started in August, beginning of August, and I haven't driven a car since! (Bridget)

It was clear to see that Bridget was both angry and upset by what had happened. As Carl positioned her as someone who wasn't safe on the roads, she counter-positioned herself as someone who was a perfectly competent and safe driver – safer than Carl himself, who she insisted would often drive around at speed in a makeshift old self-built car. As Bridget told it, there had been no issues with her driving, she had never caused any problems. Hence, her indignation and struggle to come to terms with his insistence that she give it up. Bridget described the impact that the whole situation had had on her:

It annoys me because it makes me feel inadequate. It makes me feel as though I'm incapable of doing what I want to do and what I have done and he's treating me a little bit like a child, I think. (Bridget)

The importance of driving to Bridget's identity has been discussed in the previous findings chapter. Indeed, she explicitly spelled out that her husband, in forcibly removing her licence, was treating her 'like a child'. If driving had not been such a central part of Bridget's identity, Carl encouraging her to give up her licence may not have caused any issues. She might have relinquished it willingly, and the subsequent heated debates and tension may never have arisen. Carl would not have been implicated in positioning Bridget as incapable, and Bridget would not have suffered such an assault on her sense of self. As it was, the issue appeared to have caused an irreconcilable rift in their relationship, at least from Bridget's point of view.

Another example of Bridget attempting to create and sustain a valued Self 3 persona was in regard to shopping. This was something had always been her domain, but since being diagnosed with dementia, it was Carl who did it:

I've never done the shopping for years. I tried it once, came out with three items that I'd paid for and everything. I thought ooh, I was ever so proud of myself 'cause I'd got three items and I thought, well next week I can get six, you know – build it up. Got home and Carl says: 'What you got?' I says: 'Well I've been and tried a bit of shopping at Asda'. He says: 'Well we don't eat dog food'. You know...so it's...and to me I'd done it all right, so...yeah. (Bridget)

This extract was interesting, because, by going to the supermarket and returning with three items, Bridget genuinely believed that she had achieved something significant. To her, it represented progress – from having given up shopping and become fearful of supermarkets, to having attempted to overcome this by forcing herself to do the shopping one day. Moreover, in her mind, the trip was successful; she had returned with three items. As she saw it, this was the stepping stone to buying six items next time. Perhaps to eventually graduating to a full weekly shop. It was a seemingly small, yet to her monumental achievement. However, according to Bridget, Carl's throwaway remark put paid to this, erasing in a second the tentative self-esteem that had been built up. In terms of the social constructionist view of selfhood, it was significant because as Bridget attempted to construct a valued Self 3 persona in keeping with an aspect of her life that she had always taken charge of, Carl's failure to cooperate in this construction had a lasting impact in terms of what Bridget would do in the future. Thus, she had never attempted to go shopping since; a single, seemingly minor incident was enough to put paid to any further attempts at this.

Another example of positioning can be found in the accounts of Harry, who considered it imperative that someone be with his wife, Joan, at all times, to keep an eye on her. Whilst this behaviour could be interpreted as the positioning of Joan as dependent, in other ways, the opposite was evident. Below, Harry recounted a visit from someone associated with the memory clinic:

He asked her one question and I was really proud of her answer – and I was dying to say the answer 'cause of course I knew it! He said to her: 'How long have you been married?' And she said: 'I can't remember', and I thought, oh dear, it's a big number, she can't remember. But then she said: 'But we got married when we were 21, and I'm now 81'. She says: 'So we've been married 60 years'. And as he was writing this down I said to him: 'Can I interrupt?' 'Cause I'd been very quiet up to then. I said: 'I think that's a brilliant answer. Because she's demonstrated she can remember how old she was, how old she is, deducted one from the other,

and got the right answer'. And he says: 'It's alright, I've already put that down!' So I- I was quite pleased about that. (Harry)

Harry displayed evident pride in this recollection, praising Joan for having successfully worked out the answer to the clinician's question. It would have been easy for her to resign herself to the fact that she simply did not know how long they had been married, but instead, she took the time to work it out. From his point of view, Harry could merely have contented himself with thinking she had done well. However, he verbalised his acclaim, setting out to both Joan and the clinician why it was such a 'brilliant answer'. He positioned Joan as clever; someone who had the awareness to work out how old she was and is, in order to be able to answer the question at hand. It is possible that such positive positioning would have an important knock-on effect on someone's self-esteem and reinforce Joan's perception of herself as able, thereby enhancing her Self 2.

Harry described another incident, involving cooking. It was important, he insisted, that Joan continued to cook, since she had always done it and always enjoyed it:

The other day, she said: 'Oh, I don't know what to do for dinner'. She says: 'What do you fancy?' I said: 'I fancy a rhubarb crumble this week'. So she says: 'I can't remember how to do a rhubarb crumble'. So, I just said to her: 'You've got a recipe book. To do it. Do you want me to find it for you, or do you want me to look at it?' 'Oh no, no', she says, 'I'll do that'. Anyway, doesn't say anything. Couple of hours later, at mealtime, she says: 'I've done the rhubarb crumble!' (Harry)

This apparently insignificant incident involved Harry resolutely positioning Joan as capable. She would often claim that she couldn't remember how to do things, and he, where possible, would counter that claim. In this instance, Joan maintained that she could not remember how to make a rhubarb crumble. There would have been a range of responses available for Harry to deploy to this remark, including simply acquiescing and accepting his wife's claim. However, instead he directed her towards her recipe book – where of course, instructions on how to make a crumble could be found. Moreover, he offered to help her find the correct page and go through the recipe with her, but this was not necessary. Joan, once reminded of the presence of the recipe book, had gone away and baked the crumble – proudly proclaiming this accomplishment over dinner. Thus, Harry's simple response could have contributed towards Joan having the belief in her ability to accomplish this task

From the extracts above, it can be seen how, according to positioning theory, people present themselves and others in certain ways. Likewise, the literature on dementia (e.g. Sabat, 1994) suggests that this is not necessarily intentional. Often, for example, caregivers and family members may simply be expressing a desire to protect the person with dementia. However, regardless of intentionality, it can have a significant impact on a person's selfhood, which is where the ability to counter-position oneself or engage in second order positioning comes in. This involves a rejection of being positioned in a certain way, a desire to be seen as competent and able.

7.4 'I'm running the house': Role changes

Many of the spousal relationships in the present study reflected a division of labour according to typically gendered norms. That is to say, the women had been responsible for housework, including cooking, cleaning and washing. Whereas their male partners had taken on the responsibility for more physical and manual tasks – or indeed, anything that required a computer, such as financial commitments. A diagnosis of dementia, however, threatened these norms, resulting in the men having to take up roles that were in some cases, entirely unfamiliar to them. In other words, they had to 'cross gender boundaries' (Calasanti and Bowen, 2006, p.253). There was also a link with positioning, in the sense that some men actively tried to keep their wives involved in household tasks, on the basis that it was beneficial to their sense of self to be positioned as capable and still competent in these areas. Others did not, preferring simply to assume these roles for themselves in order to ensure they were completed adequately.

There had been a transition in Wendy and Kevin's relationship, whereby one half of the couple was now taking on more work, and the other half was stepping back (Evans and Lee, 2014). This was challenging for both husband and wife to come to terms with:

I can't do as much for him as I could, 'cause I get very tired. And I think he's finding it hard looking after me...he has to do the cooking now, whereas I used to do it. (Wendy)

Wendy expressed regret that she could no longer do the things that she had previously done, in terms of looking after Kevin, as though this represented a form of failure. Previously, Wendy had worked full-time, raised their three children and taken care of all the housework and cooking. Such norms were fully ingrained in their lives. Once diagnosed with dementia, after initially having tried to persevere with the cooking – which represented the greatest challenge

in terms of role reversal, given that Kevin had never cooked before in his life – she admitted defeat. This came after she burnt her hand on the stove and the couple's daughter took charge, telling Wendy that she would no longer be allowed to cook, and that Kevin would have to take this on:

I'd have to do everything. Before, she would do the cooking, the cleaning, the washing, the ironing...I would do the car and the garden and...mending things and...yeah, but now I do it all. It's doubly hard because I can't be sort of creative or inventive, I've got to keep everything very simple. Food-wise that is, she's very picky. (Kevin)

Kevin appeared, not unreasonably, to feel a degree of burden with regards to the number of tasks for which he was now responsible. Cooking had represented a challenge for him, particularly at the outset, because he had never cooked before and had to learn from scratch – which posed a source of tension and stress (Calasanti and Bowen, 2006). However, he had now moved on to consider himself 'creative' in this department and appeared to enjoy cooking. Kevin's frustration stemmed, no longer from having to assume this role, but from what he described as having to live with a 'lack of appreciation for what I do'. Kevin still tried to include Wendy in the supermarket shop, explaining that he 'had to give her an outing now and then'. He would try to encourage her to select high-quality, exciting ingredients, but she would often fall back on rather basic, what Kevin considered uninspiring choices. When he cooked these for her, she had no interest in eating the meal, and it would be thrown in the bin, causing him further frustration. This characteristic is common in people with dementia, with the disease causing a change in eating patterns and enjoyment of food (Cullen et al. 1997). Although cooking was an added responsibility that Kevin had assumed, he could not derive the enjoyment and satisfaction in learning a new skill that he had hoped, due to Wendy's eating habits.

Carl also described a long list of things he now did, that Bridget had previously been responsible for:

I have taken over the feeding of the dogs because she was getting a bit...heavy handed, shall we say, with the food. So, I've taken that on. I do the shopping, I organise everything that she needs – she's going to the dentist next month, so...I get all her tablets for her, make sure she has those. So yeah, I suppose in a way, I'm sort of running the house. (Carl)

Carl had adopted a task-oriented approach to care (Hong and Coogle, 2016). He described himself as being in charge of most household tasks and chores, persuading Bridget to relinquish the feeding of the dogs and the shopping. He reasoned that the dogs were becoming overweight as a result of being overfed, hence presented the issue as concerning their wellbeing, although he freely admitted that the animals had always been his wife's domain. Hence, Carl's role had expanded, as he had assumed all of the caregiving and decision-making responsibilities (Evans and Lee, 2014). Unlike Wendy, however, Bridget attempted to resist this transition:

When Carl clears off, I do anything and everything. Cleaning, washing...I'm quite handy at being a scrubber, and tidying up. And gardening, I like doing. (Bridget)

Bridget's assertion that she did 'anything and everything' emphatically rejected any portrayal of herself as incapable. Carl may not have actively cooperated in her efforts to maintain a gendered Self 3 persona of homemaker (a role she had apparently always assumed), but this did not reflect back on Bridget's self-esteem. Instead, those Self 2 attributes that centred on her ability to maintain a tidy home and garden remained, according to Bridget, intact, and her belief in these attributes, unaffected by dementia or by Carl taking on the roles. She positioned herself as capable, and in fact, as Carl being the only obstacle to her successfully accomplishing such tasks, and thus to the preservation of an important sense of role identity.

Carl himself had uncomplainingly taken on additional roles – perhaps to the extent that he tried to limit his wife's involvement. When met with resistance to this, it caused friction and unrest between him and Bridget:

It's no problem. I don't know why people moan about it, to be honest. It's erm...I say not being house-proud, I don't have to worry about everything being pristine, you know, I've got to do this and that and the other. If I feel like doing it, I'll do it, if I don't, well it doesn't get done. Plus, I suppose it gives me something to do, you know, whereas if I had more time to myself, I might dwell a bit more on it, on the situation. But you know, I can get on and do things and hopefully keep the mind off it a bit. (Carl)

Carl liked to be busy, and had turned his domestic situation into a positive, by insisting that it gave him 'something to do'. If he were not occupied with things around the house, he feared slipping into what he called 'a depressed state'. Hence, his attempts to take more on and to discourage his wife's involvement, were perhaps borne of a need for self-preservation, or to 'keep the mind off it'. Carl regularly noted that once he finished working, he would be at

somewhat of a loose end and he was wary of the ease with which people could become despondent – particularly given that were rather an insular couple, who by their own admission, did not have friends or family that they socialised with. His view was similar to Harry's, though the latter's affiliation with role changes was borne of self-professed enjoyment of these:

You might not know this, but I do the dusting and the hoovering, and the tidying up because I love...I love tidying. One of the things I love best is when the family comes, they leave it...it's like a tip, and I love that. I love that, I just...I love the tidying up, I love hoovering, and I love...I don't like taking all these things off here to dust, but I do like dusting. (Harry)

Since retiring, Harry had thrown himself into gardening and DIY. Once Joan was diagnosed with dementia and became unable to do household chores, he took these on himself. Reasoning that his wife had always helped him out with the gardening, he did not see why he shouldn't return the favour now. Moreover, to Harry, they were not 'chores' in the traditional sense of the word, and he derived enormous enjoyment from them. It could even be said that he had attained a new set of Self 2 attributes and an enhanced self-concept in light of the extra roles he took on. For Harry, it was the pride in showing off successful care work – the social visibility of a newly-tidied room (Calasanti and King, 2007). However, as much as he had taken over most household tasks, he also believed it important that Joan continued to do those tasks of which she was still capable, and thus supported her to preserve a gendered sense of identity:

Joan'll still make the bed – she chunters a bit about it, but she'll still make the bed. Occasionally she'll say to me: 'The washer's not started' or she'll say: 'I think there's something wrong with the washer'. She does this nearly every time because it's a long while before it gets on to spin, and I said to her, I said: 'I'm sorry darling, but you say this every time and it's still all right!' And so occasionally, I will do the washing, you see, but it's only...once in four times or something like that. But I'm just there in case, 'cause most of the time she'll remember, but for some unknown reason, there'll be an occasion where she can't remember. (Harry)

Keen as he was to position Joan as capable, and not as defined by her dementia-related characteristics, Harry encouraged her to retain her independence and supported her in holding onto many of those housework roles that had been her domain (Evans and Lee, 2014). Thus, he was careful to try and refrain from taking over – admitting that he had become adept at making this a constant consideration, in order that Joan could benefit from actually

accomplishing things herself. Therefore, rather than take over the washing permanently, which perhaps would have been an easy solution, and one that by default, a lot of people may have fallen back on, Harry allowed Joan to inform him every time that ‘something was wrong’, in the hope that she would simply figure it out for herself. More often than not, she did. This was reinforced when I asked Joan about the household tasks, and she responded by saying: ‘I think I can cope with all that’, before conceding: ‘Well, Harry’ll tell you’. Joan’s beliefs about these Self 2 attributes, were therefore preserved, perhaps by Harry’s efforts to preserve them.

Three of the participants in the study had daughters who came and helped out with the housework. This could be a way for the husbands to mitigate the crossing of gendered boundaries – by having their daughters available to relieve some of the strain associated with housework (Calasanti and Bowen, 2006). It could also represent, on the part of the women themselves, a means of retaining self-esteem in this domain, since housework was based on reciprocity, and likely did not pose the same threat to self that, for example, paying someone external to come in and do this might (Adams, 2006):

Thursdays, she comes up and does the cleaning for me, so erm...she does all the main bits, and the washing and that. I can do it myself. But she says: ‘No, I think you need some help’. So that’s fine by me. We get to know each other’s...what we’re doing and who with. She comes up once a week, just to make sure I’ve got everything sorted. (Alice)

In the above extract, it was clear that her daughter, Ruth’s, involvement in the housework was an arrangement that worked well for Alice, who by nature, was extremely defensive about such things. She reinforced her retained capabilities, insisting that she could still ‘do it [herself]’. Ruth similarly, had appeared to present the scenario as Alice merely needing ‘some help’, rather than as her mother being unable to carry out such chores. Hence, from Alice’s point of view, those valued Self 2 attributes that made up her self-concept were unthreatened, and her daughter cooperated in the construction of the Self 3 persona she presented to her; the persona of a competent ‘mother’ who was able to maintain and run a clean and tidy house. This was reinforced by the last sentence, where Alice played down Ruth’s involvement, emphasising that she only came over once a week, ‘just to make sure’ that everything was under control. Alice also did a lot of babysitting for Ruth, helping her out with her own daughter in order that Ruth could continue to work full-time. A similar sentiment was expressed by Wendy:

Well Sue comes round and does some cleaning for us, my daughter. She'll come and vac things up. (Wendy)

Wendy presented herself as still being capable of carrying out such household tasks, but of being constrained by tiredness. Hence, Sue came and alleviated some of the burden associated with this, taking on the more physical aspects of housekeeping, such as vacuuming, that were a challenge to Wendy, who herself was rather frail. Moreover, they had a mutually beneficial arrangement; Kevin and Wendy had allowed Sue to live with them for a period of time after fleeing an abusive husband and had also helped her out financially. Therefore, Wendy presented the situation as her daughter repaying her parents' kindness.

This was not unlike Lynda, whose own daughter had learning difficulties, and whom she had always helped – sorting out her bills, liaising with her support worker, doing her shopping. It was a source of upset to Lynda that she could no longer fulfil such roles, and instead, conversely, had to rely on her daughter:

My daughter and her boyfriend, I give them money now to do my cleaning because although I know what needs cleaning, I...I'm really...I've gone OCD with the worktops. Continuously cleaning the worktops. But I can see what else needs doing, but it just doesn't seem to register properly. So I give them money to do the cleaning for me. Once a week. Once a week. Erm...he's got OCD so it works out quite good! [Laughs]. (Lynda)

Unlike Alice and Wendy, Lynda did not assert any retained capabilities in this domain, and instead, emphasised those disease-related Self 2 characteristics. In other words, she focused on her inability to compute an understanding of what needed cleaning, into action. This was something that Lynda struggled with, in general, since being diagnosed with dementia, and she often commented on the apparent disconnect between mind and body. Being “OCD” about cleanliness, yet unable to accomplish the tasks she set out to do, Lynda had come to an arrangement with her daughter and her boyfriend, whereby she paid them to do the cleaning for her. Whilst she found this reliance on other people alien and frustrating, Lynda nonetheless saw the humour in the situation, commenting that the arrangement worked well because her daughter's boyfriend had OCD too, meaning that her own high standards were inevitably met.

Role change was therefore significant, in that it had affected most participants. This was inexorably tied to gender, both in the sense that men assumed roles that had typically been the domain of their wives, and in that they tried to preserve their wives' gendered sense of self.

Some men became fond of their new roles – like Kevin had of cooking – and in this sense, it could be said that Kevin himself had attained a new set of Self 2 attributes around this. Although Wendy’s perceived indifference to his food often prevented him from constructing a valued Self 3 persona in this domain. It is possible that the importance of role identities, such as that of homemaker, were not always considered central to the selfhood of women, by the husbands in this study, which could account for why it may sometimes be easier to take on the task oneself, rather than try and find a way of accommodating their wife’s continued involvement, if they were seen as no longer capable in that domain. The importance of having daughters who helped with household chores was expressed by several women. This could serve to relieve some of the pressure on the husbands of the women, whilst also posing less of a threat to the identity and selfhood of the women themselves.

7.5 ‘I dread the consequences’: Expectations of the future

To date, little research has specifically explored the understandings held by people with dementia and their family members with regards to the future (Hellström and Torres, 2016), although several studies have included participants’ views of the future in the context of exploring wider issues (e.g. Moniz-Cook et al. 2006). This study, therefore, aims to consider ‘individuals’ ideas of what they might become, what they would like to become, and what they are afraid of becoming’ (Markus and Nurius, 1986, p.954), and specifically asked participants to think about how they perceived the future.

Kevin and Wendy were the only couple who agreed on what the future held, with a shared belief that God would take care of things. This was in keeping with their religious beliefs, which provided a sense of comfort and calm:

I do think about the future. I think I’m one day nearer death. And eventually it’s going to happen. (Wendy)

She’s waiting to be, erm...called home to die and yes, that would be a relief for both of us. (Kevin)

Wendy’s faith was so strong that she looked forward to being reconciled with God. Death, to her, was not something to be feared, rather embraced. There had, however, been a journey involved in this reconciliation, which was in evidence when I was invited by Wendy to accompany her to her ladies’ group at church, before our second interview. At one point during

this session, there was a period of quiet contemplation and reflection, during which people were invited to talk spontaneously about anything they felt the need. Wendy spoke up, detailing how, initially, she had found it hard to come to terms with being diagnosed with Alzheimer's and had even questioned her faith in God. She related how she had been scared and could not understand why such an event had befallen her. Then – as she narrated it – God had spoken to her, granting her the courage to carry on and to accept her diagnosis with dignity. Wendy had now come to terms with her illness, and her close relationship with God allowed her to approach life with a newfound sense of calm and tranquillity, and a positive perspective on the end of life (Dalby et al. 2011).

Many other couples in the present study, however, disagreed in their understanding of what the future held. Hellström and Torres (2016) found that, in the accounts of husbands and wives, only those diagnosed with dementia had a tendency to view the future in positive terms, and this study largely supports that assumption. It is possible that the uncertainty of the disease trajectory produced these differing accounts. In other words, the uncertainty of the trajectory convinced women living with dementia that life could continue as normal – similar to the findings of Locoock et al. (2009), who explored expectations of the future with regards to motor neurone disease. Whilst for men, the uncertainty of the trajectory led them to be fearful of what the future held, and the possibilities for the extent of decline:

I wouldn't like to be on my own down here, I must admit that, but I do things. I-I wouldn't stay in here I'd be out doing things like I do now. I think...life is what you make it, you know? I've always been that way and I don't think I'll ever be any other way, I couldn't just sit in here every day and not do anything, drive me mad. (Martha)

Well, I don't look forward to the future. I mean normally when you're getting old, you're looking forward to spending your retirement time together, but...if Martha gets as bad as some other people, there's not going to be very...she's not going to know about it, but I'm gonna be there. That's not a thing to really enjoy. (Eric)

Martha was positive about the future, in the sense that she believed she would continue to do all the things she did now, just as, since being diagnosed with dementia, she asserted her ability to continue to do all the things she had pre-diagnosis. A strong sense of 'biographical continuity' (Harnett and Jönson, 2017, p.1) could therefore be said to characterise Martha's account. She would maintain her established interests, and the very fact that she was someone

who led a busy life protected her sense of self, and would do so in the future. Eric, for his part, was conscious of the uncertainty and the varying disease progression. He worried whether Martha would deteriorate to the extent that he had witnessed other people do, and how he would cope if she did. A similar sentiment was echoed in the accounts of other family members:

The only thing I think about is, will Frank go before me...and then, [chuckling] if he does, the son and daughter-in-law's down 'cross the field, I'd go down to them. (Stella)

I just sometimes think well you know, it's-it's a shame this has happened now, we could've been doing this or could've been doing that and...I just wonder how bad it's going to get, if I'm going to be around for her, you know. If anything happened to me first...I mean she...it'd kill her to drag her out of this house, she couldn't...I don't think...she couldn't live here on her own. I-I just...dread the consequences really. (Frank)

Stella insisted the only thing she worried about was what would happen if her husband were to die first, but appeared to be perfectly content with the resolution to this – namely that she would move in with her son. On the other hand, Frank expressed far more anxiety and the situation caused him terrible worry. Like Eric, the uncertainty left him unable to make plans for the future, coupled with the distress felt at the loss of a ‘preferred future’ (Daley et al. 2018, p.83). Unlike Stella, he did not foresee a smooth transition if he were to die first, nor did he mention her moving in with their son’s family. Frank knew how much Stella adored their house and recognised that it would ‘kill’ her to move, but reasoned that she could not possibly stay there alone. Like Eric, he was aware of the illness trajectory, knowing that it would get worse, but knowing ‘how bad’:

I suppose if I thought it was going to get worse, I'd worry about it, but as things are at the moment with health and family and friends, I-I'm alright. (Joan)

It's just the worry for the future, that's the one thing. It's an untouchable thing, it's the uncertainty. And it's also things like...what do we do if erm, one of us has to go into a home? Because it could quite likely be me, just the same as Joan, you know. I'm sure the kids would turn up trumps, and erm...they know where everything is and what to do, that sort of thing. But I don't like the idea of us being separated at all. I can't...I can't bear the thought of that. (Harry)

Joan expressed a relaxed attitude towards the future, believing in her ability to continue to do the things she did. Harry, like other spouses, had a different view to his wife, and he too worried about the uncertainty of the future. He was troubled by the notion that either he or his wife would have to move into a home. This would threaten Joan's selfhood, and his ability to sustain her selfhood, as he maintained he did in a variety of ways. His account reflects the view held by caregivers in other studies, of care homes not being places conducive to sustaining selfhood (Moniz-Cook et al. 2016).

For Bridget and Carl, their understanding of the future, like those of the above couples, differed from one another. However, it was Bridget who held a negative view and Carl who was more sanguine:

All my independence will be taken away, lock, stock and barrel. I won't be able to go anywhere at all without him and I doubt very much if I'll go anything with him. (Bridget)

I don't dwell on it, I just think, oh well ok, it's going to happen. I can't plan for the future cos I don't know how it's going to happen. I'm quite...what's the best way to put it? Happy's not quite right – well, I'll say happy 'cause it's the easiest way to describe it – happy with my own company. I don't need people's company, I'll you know, quite happily stay in here all day and every day and not meet anybody, it wouldn't bother me. I'd always find things to do. So, once Bridget's gone, I don't worry about that. (Carl)

Bridget, in line with her account of her relationship with Carl, expressed a fatalistic view of the future. She was the only person with dementia who did not see any cause for hope, nor any way of preserving her selfhood in the future. Her independence, which she valued, and which had (until recently) allowed her to undertake her car journeys to her support group, was perceived as being under threat. Bridget expressed particular anger that, whilst apparently uninterested in spending time with her himself, Carl was nonetheless exerting control over what she could and couldn't do. The loss of freedom and independence that the ability to drive represented, would snowball, Bridget believed, into further dependency. She was therefore operating under the assumption that her future had 'shrunk' (Hellström and Torres, 2016). This posed a threat to her present sense of self, leaving her feeling angry and helpless. Carl, like other husbands, recognised the uncertainty that would follow, but this did not seem to cause him the same level of worry. He accepted that he could not change it, and was prepared.

Carl frequently described himself as not having or needing social networks, which he believed would help him come to terms with losing Bridget.

Those women who lived alone expressed a largely positive view of the future, such as Marian, who displayed the same outlook she appeared to have on most things:

If I'm very lucky, the future will continue exactly as it is. I've got a pension, it isn't going to change, thank goodness. I like the house. I don't propose to be bed-ridden for very long. But I haven't been bed-ridden yet, so I may be all right. If it's too upsetting for me, I'll see if I can find a way out, but if it's just sort of being nice to people and reading books which I haven't read yet, I think I can last out a bit longer. (Marian)

Marian had hope for the future, that things would continue as they were and not deteriorate (de Boer et al. 2012). Illustrative of the importance to her sense of self, of autonomy and independence, Marian considered that she would not be 'bed-ridden' for any length of time, intimating that she would take control over her fate if this were to become the case. Being bed-ridden, after all, implied dependence on others for aspects of basic human functioning and went entirely against Marian's positive self-concept and ability to construct a valued Self 3 persona as a capable intellectual, important member of the community and someone who was absolutely not dependent on anyone for anything. The Self 2 attributes she possessed, as well as the beliefs about those attributes would also be threatened, hence Marian's solution, should such an eventuality transpire, was to 'find a way out'.

This section has shown that dementia impacts how women think about their future selves, although the accounts of husbands and wives differed. Most women were optimistic about the future, expressing hope that they would not deteriorate further and that life would continue as it normal. To have such an outlook may serve a protective function for selfhood. Acknowledging and confronting the uncertainty of the dementia trajectory, as their husbands did, could leave the women vulnerable to losses in self-concept and self-esteem. It would involve them considering the possibility that future losses and decline could take place. Having a positive outlook and focusing on their current capabilities potentially helped to stave off this notion. These findings contradict those of previous research, which has found that people with dementia have high levels of uncertainty and anxiety about the future (e.g. Harman and Clare, 2006, Read et al. 2017). In this study, such emotions were largely present in the accounts of family members. For many husbands, there was significant concern about what would happen

to their wives if anything happened to them, the extent to which their wives could deteriorate, and a sense of loss of the opportunities that retirement could have presented if things had been different.

7.6 Conclusion

This chapter has explored how social networks and relationships play a crucial role in the experience of dementia. These can strengthen social identity by enabling the construction of valued personae and roles, whilst also reflecting back on the self-concept of the person with dementia. Support groups enabled people to foster a collective identity, and were vital to the maintenance of selfhood for many women. This took different forms; the maintenance of selfhood through emotional support, and the ability to talk to others who could understand first-hand what it was like to live with the disease. Such interaction had the potential to have a transformative effect on people's mental health. The maintenance of selfhood through the opportunity afforded for connection and networking, which allowed one to construct an identity beyond that of a dementia patient. Finally, the maintenance of selfhood, through the social aspects of the groups that reinforced aspects of one's Self 2 and enhanced self-esteem.

Within familial support networks, there was the issue of positioning. In other words, how the selfhood and crucially, self-esteem, of women, were impacted by the behaviour of those around them. Positioning was often nuanced, and could arise as a result of the tension and stress of a marriage whose dynamics were in the process of changing, due to one person having been diagnosed with dementia (O'Shaughnessy et al. 2010). However, what is important for this thesis, is the impact that being positioned as such, can have on the selfhood and identity of women with dementia.

The findings from this study, in relation to role change and the assumption of new responsibilities by male caregivers, do not necessarily accord with previous research that suggests men find this to be challenging. For example, Calasanti and Bowen (2006) found that husbands who become caregivers for their wives report greater challenges in taking on responsibility for daily household tasks, than vice versa. Most men in the present study appeared to accept the changes and did not express a particular sense of difficulty in carrying them out. Even Kevin, who did struggle with many of the domesticated roles, had actually grown to enjoy cooking. His frustration with this stemmed from Wendy's lack of interest in food, not the task itself. Indeed, Kevin looked forward to having people from church over, so

he could play host to ‘dinner parties’ and show off his newfound skills to those who would appreciate them.

The possible reasons for these differences can be found in a study by Kirsi et al. (2004). According to the authors, there are two kinds of activities involved in caregiving: those carried out on behalf of a spouse (such as household chores), and those performed for a spouse. The latter refer to more personal, hands-on caregiving, performed when the person with dementia is unable to carry out such basic functions for themselves. None of the women in the present study were at this stage, and it is possible that merely assuming a more prominent role in the carrying out of household chores, as opposed to having to concern oneself with tasks related to self-care, did not present such a challenge to the family members in the present study.

With regards to their outlook on the future, participants did not tend to dwell on this, with most expressing gratitude for the present and hope that they would not succumb to the disease any further. Participants’ husbands or partners appeared to express the more negative expectations of the future, in terms of fear and trepidation of what this might hold. A common thread in these accounts was the anxiety over what would happen if they were to die first, which reflected an awareness that their wives were dependent on them, not only for support, but in enabling them both to make the most of life and by implication, preserve selfhood and independence.

This chapter has explored the dynamics of interpersonal and familial relationships in different contexts, and considered how these impact on the selfhood and identity of women with dementia. Relationships play a vital role in sustaining Self 3, and by implication, reflect back on the Self 2. Women were enabled to construct a valued Self 3 persona according to a range of different roles: being a member of a dementia support group, being a homemaker, being a wife and/or mother. This led to a reinforcement of self-esteem. Some accounts of family members could be interpreted as positioning the person with dementia in such a way that prevented the construction of a successful Self 3 persona, which similarly had the potential to damage self-esteem and impact the person’s beliefs about Self 2 attributes. Selfhood was also related to the differing ways in which both women with dementia and their family members perceived the future. Avoidance of thinking about the future, or focusing on the here and now in the hope that things would not deteriorate, could protect selfhood. However, fear and worry was also expressed, which were linked to the uncertainty of what could happen. This uncertainty could threaten the selfhood of women with dementia, by creating a situation in which both Self 2 attributes and Self 3 persona could not be sustained.

Chapter 8: Discussion

8.1 Introduction

This study explored the impact of early-stage dementia on the selfhood and identity of women living with the disease. It gave primacy to the personal experiences of people with dementia, and in doing so, challenged aspects of the biomedical model. According to the biomedical model, dementia is a disease that should be defined and treated within the realm of the medical profession (Lyman, 1989). Pathologically speaking, it is a neurodegenerative disease with no cure, hence the surrounding discourse having historically reflected a 'social death' (Sweeting and Gilhooly, 1997, p.93).

However, over time, other theories emerged, in an attempt to resituate dementia within social and psychological factors, as opposed to purely biomedical ones. Research in this domain asserted that people living with dementia could retain a sense of selfhood and identity throughout the course of the disease. Scholars such as Kitwood (1997) and Sabat and Harré (1992) also claimed that much of the pervasive negative stereotyping associated with dementia arose from a failure to consider people's subjective experiences and to position the individual in such a way that denied them personhood.

The social constructionist approach to selfhood in dementia (Sabat and Harré, 1992) was used as the framework for the present study, which in turn was supported by key bodies of literatures, such as personhood (Kitwood, 1997) and stigma (Goffman 1968). Thus, this study adopted the view that there were three forms of Self. Self 1, of personal identity. Self 2 of personal attributes and beliefs about those attributes. Self 3 of social personae. According to Sabat and Harré (1992), it is the latter which is most vulnerable to damage when a person is diagnosed with dementia. This is because it is dependent upon other people within one's social world. However, this study also assigned importance to the Self 2. Specifically, to the threat posed by dementia to the self-concept and self-esteem of women.

This study also assigned importance to feminist research and methodology. Scholars have observed that research has tended to reflect the social values and concerns of dominant groups, meaning that these become imposed on a particular field, and consequently, the voices of more marginalised groups are diminished, together with their potential to yield new insight. (Campbell and Wasco, 2000). Feminist approaches to research, are defined by their

commitment to capturing ‘women’s lived experiences in a respectful manner that legitimates women’s voices as sources of knowledge’ (p.784). This can include familiar methods, such as interviews and focus groups, but it is the research process that is important in ensuring feminist values are upheld.

In interviewing, for example, there is often a power imbalance between researcher and participant, which is amplified when the participant is a woman with dementia (Proctor, 2001). It is suggested that, in order to alter this dynamic, ‘feminist researchers invest their personal experiences and emotions in the research process as a means of connecting with their respondents’ (Campbell and Wasco, 2000, p.786). I was mindful of this when conducting interviews, and willingly disclosed aspects of my own personal identity, in order to foster collaboration and trust, and to offset the traditional researcher-participant boundaries. IPA, as an approach, also fits with feminist ideology, in that it emphasises the co-construction of narratives and the visibility of the researcher, as well as giving primacy to lived experience.

Proctor’s (2001) research into women’s experiences of a day hospital found feminist themes present, including the belief expressed by women that they had no right to complain, and that their feelings weren’t important. Within this thesis, similarly, there were themes related to feminism, and to the subjugation of women. Lynda, for example, described her initial insurances that she had dementia as being dismissed, and of not being listened to, by her family or medical professionals. Bridget presented her husband as controlling aspects of her life, and of being powerless to resist. Wendy described herself as being unable to do as much for her husband as she had previously, which perhaps reflects the gendered presumption of that women are expected to care for others, not the other way round.

The three central themes that emerged from the data have been presented in three substantive chapters. These are: The Changing Self, Resistance and Repair, and The Dynamics of Interpersonal Relationships. This concluding chapter pulls together the work of these findings chapters and assesses how they answer the original research question: how is the selfhood of women impacted by early-stage dementia, and how is it preserved? In doing so, the chapter considers how dementia threatens the self-concept of women, and results in losses in various domains of life. It then explores how women are able to resist the threat to selfhood posed by dementia. Finally, it looks at the role of peripheral and intimate relationships, and the role that these can play in sustaining selfhood. Firstly, however, an overview of the study’s themes and sub-themes will be presented and summarised.

8.2 Heuristic of themes and sub-themes

Theme	Sub-theme
1. The Changing Self	1.1 Receiving and adjusting to a diagnosis of dementia 1.2 The emotional and psychological impact of dementia 1.3 Self-presentation and stigma 1.4 Boundary maintenance
2. Resistance and Repair	2.1 Enriching life 2.1.1 Staying active 2.1.2 Baking 2.1.3 Advocacy 2.1.4 Driving 2.1.5 Spirituality 2.2 Being independent 2.2.1 Coping strategies 2.3 Maintaining a positive self-concept 2.3.1 Minimising and normalising
3. The Dynamics of Interpersonal Relationships	3.1 Support groups 3.2 The power of positioning 3.3 Role changes 3.4 Expectations of the future

Fig. 1

The Changing Self: This theme represents the fact that dementia was shown to impact the personal identity of the women in this study. In receiving and adjusting to news of their diagnosis, participants described equating dementia differentially as part of the normal process of ageing, or as a pathological condition. Many women experienced an emotional or psychological reaction to dementia, and this was particularly evident in the accounts of those who presented dementia as an illness. These reactions included grief at the losses experienced, which was heightened by comparisons that women made with their pasts, and reinforced the notion of certain Self 2 attributes having altered. Self-presentation strategies were also prevalent in the accounts of participants, in the ways in which women described using Goffman's strategies, including passing, to conceal their illness. Sometimes this was related to having experienced stigma or discrimination, other times, it was related to the expectation of such stigma or discrimination occurring. The final sub-theme in this section is boundary maintenance, which refers to adaptations made by participants to the carrying out of previously

enjoyed activities and hobbies, such as driving or walking, to ensure these could nonetheless still be accomplished and hence contribute to preserving selfhood.

Resistance and Repair: This theme refers to the ways in which all women were able to resist the threat of dementia to aspects of their selfhood, and repair aspects of their selfhood that had been damaged by dementia. The first sub-theme within this was enriching life, which highlights the wide variety of activities that women engaged in, that brought them happiness and a sense of purpose, and in certain cases – like Sally and her baking, and Betty and her advocacy – these activities were linked to the ability of participants to construct a valued social identity. Maintaining their independence was also important to many women, which was expressed by a desire to have control over decisions and aspects of their life. This was achieved through coping strategies – the use of diaries and calendars, for example, were particularly important to those women living alone. Finally, the sub-theme of maintaining a positive self-concept was central to the overall theme of resistance. This allowed people to perceive themselves in a positive light, reinforcing capabilities and thereby protecting self-esteem. A key way in which this was achieved was through specific strategies such as minimising and normalising the impact of dementia. Women made downward comparisons with others who had dementia, which allowed them to preserve their own self-image on the basis that they were not as impaired as some of these people.

The Dynamics of Interpersonal Relationships: The final theme in the thesis represents the importance of different kinds of relationships. Firstly, support groups enabled women to construct a valued social identity – a collective identity – and consequently provided a range of social, emotional and psychological benefits. In terms of more intimate relationships, the second sub-theme discusses the power of positioning, and how being positioned in a certain way can have a positive or negative impact on the person with dementia. Similarly, role changes also take place within intimate relationships. Male spouses had acquired new Self 2 attributes associated with added responsibilities, whilst some also worked to maintain gendered aspects of their wives' identities'. The final sub-theme reflects the expectations held by women and their family members of the future. These accounts were marked by the uncertainty of the disease trajectory. Women were hopeful that deterioration was not an inevitability and that they could continue as they were. Family members, on the other hand, believed that uncertainty was a reason to be fearful of the future, and the inability to know 'how bad' dementia would get.

8.3 Dementia can have an impact on self-concept

This key finding showed that women experienced significant changes to their overall self-concept, and to their self-esteem. As such, it stands in contrast to numerous previous studies utilising the social constructionist approach to selfhood in dementia, which have found the Self 2 – one’s attributes and beliefs about those attributes (including one’s overall self-concept) – to be largely intact, and instead, vulnerable to damage only insofar as other people prevented the construction of a valued Self 3. In Sabat and Harré’s (1992) original study, loss of self was caused by the way in which the person with dementia was treated by others. They argued that loss of self could only be prevented, therefore, if caregivers and family members refrained from negative positioning. Sabat (2002) found that, even though people with dementia had assumed new Self 2 characteristics associated with the disease, their previous Self 2 attributes remained intact and preservation of selfhood relied on significant others to honour those existing positive attributes.

Sabat et al. (1999) argued that it was the interaction between the Self 3 and the Self 2 that led to loss of selfhood. The authors explored this notion with direct reference to the maintenance of and assaults on self-esteem. It was important that people with dementia were not treated as a sufferer or patient, which resulted in them being interacted with accordingly. Instead, the attempts to construct a valued social persona (Self 3) must be recognised, which was linked to the validation of the person’s Self 2 attributes. Thus, it was the quality of interactions with others that allowed or curtailed expressions of the Self 3, which in turn affected the Self 2, including, importantly, the person’s beliefs about his or her attributes – their self-esteem. In a study by Kelly (2010), care workers did not cooperate in the attempts by people with dementia to construct a valued social persona, which led to the person becoming disempowered and their selfhood damaged.

In other studies, damage to the Self 2 focused on specific disease-related symptoms. Caddell and Clare (2011) found that people with dementia described loss of Self 2 in relation to memory problems, rather than to themselves as a person – in other words, their overall self-concept. Similarly, people with dementia in a study by Hedman et al. (2012) described no major changes to their Self 2, feeling they were mainly the same person as they were before. Some even described positive changes they had experienced as a result of dementia. Changes were instead described in relation to memory skills and ability to multi-task. MacRae et al. (2010) also found

that people with dementia were not concerned that the disease had changed them, emphasising continuity with their pre-diagnosis selves.

In many ways, this thesis suggests that the preservation of Self 2 is related to the Self 3; in other words, that other people can have an impact on the ability of the person with dementia to maintain a sense of self. This was indeed found to be true for several women in the present study, whose attempts to construct a valued social persona often depended on the cooperation of others. This then reflected back on their self-esteem and overall self-concept and allowed them to be perceived in terms of more positive and valued attributes, as opposed to solely in terms of negative, disease-related ones. Some participants also described memory loss or forgetfulness as an acquired aspect of their Self 2, but played down the impact of dementia on themselves as a person, asserting that they were still the same. Martha, for example, readily acknowledged her dementia symptoms, but insisted they had no impact on her, and that she had not changed at all.

However, this PhD also shows that, for many women living with dementia, there is a more significant impact on their Self 2. A number of women described feeling that they were a different person, reporting more fundamental changes to their sense of self, their personality, who they were now compared to who they had been, pre-diagnosis. There was no clear relationship with social identity in these cases; indeed, these same women were still able, in certain situations, to construct a valued Self 3 persona, with the cooperation of others. This did not prevent them from perceiving themselves as having fundamentally changed. The present study, therefore, appears to contradict previous research that suggests people retain a positive self-concept, despite threats to other aspects of selfhood and identity as a result of dementia (e.g. Hedman et al. 2012).

This PhD was also concerned with exploring self-esteem, the evaluative component of the Self 2. Much of the previous research into self-esteem and dementia has involved quantitative measures, such as the State Self-Esteem Scale (e.g. Cotter et al. 2018) or the Rosenberg Self-Esteem Scale (e.g. Lamont et al. 2019). Other research has focused on the self-esteem of informal caregivers, rather than the person living with dementia themselves (e.g. Jütten et al. 2020). Those qualitative studies that have explored self-esteem and self-worth have suggested that it is threatened by the losses experienced in cognitive domains, and decline in the ability to manage aspects of one's life (Holst and Hallberg, 2003). People with dementia used specific coping strategies to deal with the effects of the disease, such as making note of important dates

– the purpose of which was to preserve feelings of self-worth and identity by enabling them to maintain an outward appearance of normality (Keady and Nolan, 2003).

Sabat et al. (1999) stressed the importance of such qualitative research, arguing that methods that explored self-esteem through narrative-based beliefs, rather than standardised tools – which may well be unsuited to people with dementia anyway – could enable a more complete understanding of self-esteem. Accounts of people living with dementia could facilitate an exploration with the interviewer of *why* a person had low self-esteem, as opposed to merely whether they had it or not. Thus, another of the key findings of this thesis is that many women experienced low self-esteem and decreased confidence in their abilities. They often made comparisons with their former attributes, highlighting their belief that they could no longer accomplish things in the same way. To protect their sense of self-worth, the women in this study avoided situations where they felt that this was under threat, for example, in social situations. Experiences of stigma had the potential to reflect back on participants' Self 2, and by implication, self-esteem.

In terms of the overall research question of how dementia impacts on the selfhood and identity of women, this key finding showed that women experienced significant changes to their overall self-concept, and to their self-esteem. Moreover, that selfhood could be affected by aspects of the disease and associated losses, not solely by the failure of others to help the person with dementia construct a valued Self 3 persona.

8.4 All women found ways to resist the effect of dementia on selfhood

Despite the impact of dementia on their sense of self, all women in the present study were able to find ways to resist its impact. This extends to those women who described their self-concept as permanently altered, and to those women who described feelings of low self-esteem. Much of the resistance stemmed from the ability of women to find ways to enrich their lives with activities and pursuits, which was often linked to maintaining a sense of independence. Within this, driving was central to the identities of several women in this study. Therefore, another key finding is that driving, and the threat of cessation is not, as has been suggested by previous research, more significant for men than women.

The accounts of women in the present study suggest that many had redefined the boundaries of what was possible as a result of dementia, but they nonetheless continued to take part in

valued activities that enhanced their self-concept and formed part of their Self 2. Several women, who spoke in terms of a desire to keep themselves generally busy, did so because they perceived this as being akin to fighting the disease effectively and stalling decline. Research into leisure activities has found that people with dementia can counter the changes experienced as a result of the disease by proactive engagement in such activities. This holds true, even though the nature of engagement may be different now – for example, due to diminished strength or capacity to take part (Genoe and Dupuis, 2014). A focus on those retained abilities and their possibility for enriching life was important for individuals to be able to negotiate the challenges of living with the disease (Beard et al. 2009). The meaning of leisure activities to people with dementia was found to be varied, with people deriving enjoyment and pleasure from their participation, as well as a sense of belonging, personal autonomy and identity (Phinney et al. 2007). People with dementia are also shown to be aware of the limitations the disease poses, and cease participation in less valued pursuits, in order to leave room for those that are most important to them (Öhman and Nygård, 2005).

This study particularly sheds light on the resistance strategies of those women who lived alone, and did not have family immediately available to structure a routine that enabled them to stay engaged. These women worked especially hard to maintain their involvement with the outside world, with all having routines and things they did on a daily or weekly basis, which included playing sport, meeting with friends, and active membership of community groups. For these women, staying occupied could help stave off isolation as well as enhancing their sense of self (Van Dijkhuizen et al. 2006). Betty, a prime example of this, kept a full diary of meet-ups with friends, swimming classes and volunteering. With her husband having passed away some years previously, such an active social life and involvement in different activities helped her to cope with the feelings of loneliness she was prone to.

The effects of taking part in valued activities, such as experiencing freedom, success and autonomy, could also serve to filter through into other aspects of the lives of women living with dementia (Genoe, 2010). This may be particularly important for those who described themselves as having changed as a person, and whose self-concept was fundamentally impacted by dementia. By continuing to engage in activities, it is possible that their self-esteem might be enhanced, leading them to perceive themselves in a more positive light. Cheston et al. (2015) argued that people living with dementia could increase self-esteem by investing in those things that were important to them, that gave them a sense of purpose. As part of this, the

connections to one's past were important. For example, although Sally described only being able to bake when her partner was with her, she continued to provide her friends with cakes for the required special occasions, as she always had done. This allowed for Sally's social identity to be preserved, and the praise she received, to reflect back on her Self 2, even though this was fragile and had been damaged by dementia.

Driving featured prominently in this thesis. This study suggests that driving was an activity central to the lives and identities of several women living with dementia, particularly considering that, within this cohort of participants, there were also women who had never driven, and so to whom driving was not relevant. Three women described having voluntarily given up driving, and this being of little consequence to them. One woman – Alice – had been forced by the medical profession to give up driving, and this had been central to her identity too, as she had been the family's main driver all her life. Consequently, she struggled to come to terms with it, becoming visibly upset when talking about no longer being allowed to drive. For those women who still drove, driving was a means of preserving selfhood and resisting the impact of dementia. It was a link to their past, in the form of either occupational or familial responsibilities, and, in contrast to the below studies, these women did have an emotion-centred relationship with driving. As a result, they used a range of strategies and adaptations to their driving habits (Adler, 2010), in line with their perceived changing capabilities, to ensure they were still able to preserve this valued aspect of their selfhood.

By contrast, previous research that has explored driving in relation to dementia suggests that the cessation process is most likely to affect women in their role as caregivers of male relatives living with the disease (Taylor and Tripodes, 2001). In other words, women who are caregivers often need to be able to drive to fulfil such duties. Baines et al. (2018) found that women with dementia were more than twice as likely to cease driving as men, and emphasised the need for gender-focused driving cessation support. Similarly, Musselwhite and Shergold (2013) found that women were far more proactive when it came to giving up driving in later life, as they were less likely to have a more emotion-centred relationship with driving, and more likely to see it as a practicality.

Resistance to dementia can also be accomplished through maintaining a positive self-concept – continuing to highlight one's capabilities and attributes. Related to this are the strategies of self-maintaining and self-adjusting responses to dementia (Clare et al. 2003). The former involves attempting to normalise the situation and minimise difficulties. Research has shown

that minimising and comparing oneself favourably to others can enhance self-esteem (Robinson et al. 2005). This thesis suggests that such strategies are particularly evident in the accounts of women living with dementia, with those who engaged in self-maintaining strategies displaying higher self-esteem than those who engaged in self-adjusting strategies. Self-maintaining responses, therefore, could potentially be more protective of selfhood than self-adjusting strategies. It is also worth noting that all of the women who lived alone used self-maintaining strategies and described a continuity with their past. Some even asserted that they did more, since being diagnosed with dementia.

This thesis has shown that all women were able to engage in activities or pursuits that contributed to resisting the threat of dementia on their selfhood and identity. It provides support for much of the extant literature that attaches value to the continued engagement in these activities, which can support a sense of self – particularly when women are faced with other areas of loss and decline. This study appears to contradict previous research into driving and dementia, which suggests that driving, and the threat of cessation is more significant for men. Instead, many women described driving as a central part of their identity, often linked to their past; for some, it was the single most important thing in their lives.

8.5 Relationships can support selfhood

The significance of relationships was evident throughout the accounts of women living with dementia in the present study. These relationships supported the construction of social identity, and also, as previously discussed, reflected back on how people perceived themselves. They consisted of relationships with family members, friends, and fellow members of support groups.

The existing literature has explored the relationship between couples, when one person is diagnosed with dementia. The disruptive experience of dementia challenges the tendency for people living with dementia and their spouses to position themselves as part of a couple, as opposed to separately (Hydén and Nilsson, 2015). Keady and Nolan (2003) found that, in order to successfully work together, both parties had to be willing to engage in open and honest discussion about the challenges and difficulties involved. Relationships where couples worked separately were characterised by a loss of shared activities and understanding, as well as negative comparisons with the past (O'Shaughnessy et al. 2010).

Clare and Shakespeare (2004) demonstrated the complexities involved in relationships, particularly marital relationships. The study highlighted the fact that family members were also required to adjust to living with dementia, in addition to the person with dementia themselves. Spouses emphasised that it was they who had to deal with much of the resulting difficulties, and presented themselves as collaboratively trying to find ways to overcome such difficulties. However, they resisted cooperating in attempts made by the person with dementia to minimise or normalise the situation. This could cause tension in the relationship, as one party played down the impact of dementia and the other did not.

This thesis supports the above literature on couples positioning themselves as working both together and separately. Some women and their partners described their 'us identity' (Davies, 2011, p.218) as being intact, with dementia perceived as something to be confronted together. Others described feeling separate from one another, and their relationship as characterised by losses and tension. Bridget and Carl were an example of this – with both describing how their relationship had changed, and each blaming the source of arguments and strain on the other. That is not to say that only those women who were part of marital relationships that worked together should have their Self 2 attributes preserved. For example, Bridget, despite being part of a relationship where her and her husband now did things separately, described her selfhood as being reinforced when she was apart from Carl. Doing things alone, such as driving to her support group, and interacting with people there, was vital to Bridget's self-esteem. In contrast, she described her self-esteem as being impacted by being around her husband.

Within the dementia literature, emphasis has largely focused on enabling people to maintain their independence (e.g. Yates et al. 2019). Resisting dependency on others and striving towards autonomy has been shown to reflect the positive adaptation of people living with dementia (e.g. Öhman and Nygård, 2005). This thesis, however, suggests that dependency is not universally a negative trait. It was important for the participants in the present study to ask for and receive help, when this was needed, and to know their limitations (Keady et al. 2007). Many women described how they had become far more reliant on their spouse or children for support. This had two positive impacts: first, by relying on family members for certain things, this left the women free to devote their efforts to those aspects of their lives that were of particular importance or value to them. For example, some women had relinquished driving responsibilities to their husbands, because they were not particularly attached to the notion of retaining their driver's licence, and there were other things they would rather focus on instead.

Martha had willingly given up driving, because it was not important to her, and she now left this to her husband. This allowed her to devote time and energy to her singing, dancing and socialising. Second, by relying on people for help in accomplishing a task, this could support the maintenance of selfhood of women in that domain. Joan, for example, liked to walk to and from her local shop, as she had done every day. She had become nervous about doing this on her own, so her husband now made sure that someone was with her, thus supporting her ability to continue to do her daily walk.

Support, moreover, was also reciprocal. This study highlights the importance of this – of women with dementia not merely being positioned as passive recipients of support. They were also capable of providing support of their own, giving back to their families and the wider community. Women looked after grandchildren, volunteered for various organisations, and participated in local neighbourhood schemes. Thus, Alice, whose daughter regularly helped with the housework and domestic chores, was not just a person in need of help. Alice was also able reciprocate this support, and did so by picking her granddaughter up from school nearly every day, feeding her, and taking her to her gymnastics lessons, to enable her daughter to work later. Alice was therefore contributing to the ‘social context’ of her family (Öhman and Nygård, 2005, p.92). Alice, and the other women who were relied upon to look after grandchildren, described particularly close relationships with both their children and grandchildren, perhaps evidencing the benefits of such reciprocity.

The literature on support groups for people with dementia has found that they have the potential to improve depressive symptoms and quality of life and increase self-esteem (Leung et al. 2015). They provide opportunities for participants to showcase their retained capabilities and to express their fears and emotions in a supportive environment (Goldsilver and Gruneir, 2001). Similarly, Mason et al. (2005) found that support groups offered the opportunity to construct social ties with others, and provide a forum for disclosure and meaningful social contact. In a systematic review of support groups, Toms et al. (2015) found that groups were rated positively, and even though there was considerable range in the format of the groups, just the fact of talking and discussing their situation with other people in a similar situation could be beneficial. The review, however, found that the majority of support group members were educated and male. This thesis, therefore, can expand on the literature and shed light on the experiences of women, from a variety of social backgrounds. The accounts of those women who attended support groups in the present study provide support for the existing literature that

suggests that such groups are beneficial. Indeed, all women spoke of the wide-ranging impacts of the various support groups they attended, that were on a continuum of the social, emotional and psychological. In some cases, they provided the women with one of their few sources of meaningful social contact. Some women described feeling unable to talk to those close to them, either because they didn't want to burden their family, or because they felt these relationships had deteriorated. Support groups therefore took on a heightened significance, providing a space where women could construct a social identity, where other people cooperated in its construction. This then had the potential to sustain selfhood, reflecting back on a person's self-concept. It is possible, therefore, to conclude that women derive particularly significant benefits from support groups. Moreover, out of those who were group members, only one was university-educated, suggesting that, in contrast to the review by Toms et al. (2015), support groups appeal to women from a variety of social backgrounds.

Relationships play an important role in sustaining selfhood and identity in women living with dementia. They enable women to construct a social identity, as well as reinforcing aspects of their self-concept. Relationships can be intimate or peripheral, with the latter having as much potential to positively impact the lives of people living with dementia as the former.

8.6 Implications of the study

8.6.1 For people living with dementia

This PhD has several implications for the lives, relationships and wellbeing of people living with dementia.

Firstly, it highlights the need to take account of personal biographies, throughout the diagnostic and intervention process. A person's biography could potentially shape responses to such processes, with some people perhaps more resistant and others more likely to take advice. Moreover, women in the early stages of dementia are able to provide rich, detailed accounts of their life history, their hopes, fears and experiences. It is at this stage that services should begin to engage with people living with dementia, in order to build up a picture of them as a person and make collaborative decisions about what would be best for them, both now and in the future. For example, unlike previous studies (e.g. Boyle, 2017) that have found men living with dementia to be tied to independence and their occupational personas, and women's concerns to centre on domestic competencies and relational aspects of their lives, this study found that

independence and occupational histories were important to most women. Many specifically highlighted how important it was that they were involved in decisions, because it was central to their identity as an independent, autonomous person. Engaging directly with people living with dementia also supports selfhood, by enabling the co-construction of a social persona as someone capable of contributing to discussion and decision-making, rather than simply positioning them as a patient.

The accounts of family members in this study suggest that a relationship-centred approach to care should be adopted. In other words, dementia affects not just the person themselves, but spouses, children and other relatives. This moves beyond seeing such family members only as carers, and to acknowledging the impact on the selfhood and identities of people as couples or families. More broadly, the importance of taking part in community or other forms of activity groups was emphasised in this study. Enabling and encouraging participation in such groups could enhance selfhood and by implication, wellbeing. This connects to the wider issue of decreasing the stigma of dementia, to the point that people living with the disease do not attempt to engage in the tiring process of modifying or hiding their symptoms, for fear of societal rejection.

Finally, the value and importance of support groups has been highlighted in this study. These had wide-ranging positive impacts that were discussed by numerous participants. Yet cuts to health and social care services across the UK mean that such groups are under threat (Humphries et al. 2016). One participant even spoke of her local group facing closure, and was extremely anxious and worried about what this would mean. Essentially, she would have to travel a significantly further distance, to attend a different group, and she had resigned herself to being unable to do so. Sometimes, free travel is provided by the groups themselves, but this only applies to people living locally. This study suggests that support groups need to be protected, and their numbers, far from being threatened, should in fact be increased. They are central to sustaining valued relationships and enhancing wellbeing, and provide particular benefit for people who may be struggling with low self-esteem, or other emotional issues as a result of dementia. Moreover, support groups have an advocacy role to play within society, speaking on behalf of their members, whose voices may otherwise be silenced (Walton et al. 2015).

8.6.2 For research

- The study highlights the importance of considering how different groups experience dementia. Within this, further research could explore how dementia impacts on the lives of different sub-groups of women – for example, those living alone, or those women diagnosed with early onset dementia. It could be expected, perhaps that this latter group may experience a particular threat to their selfhood and identity, as a result of potentially still being in employment at the time of diagnosis. This study has already shown that occupational identities are important for women living with dementia, hence such an area would be worthy of further exploration.
- Similarly, further research could explore the importance of driving to women living with dementia, which would broaden the literature that currently focuses on the significance of this to men. This could be explored in relation to occupational identities, and the way in which women confront the threat of driving cessation when driving has formed an important part of their past.

8.6.3 For policy

- People living with dementia should be empowered to participate in the development of policy and practices that affect their lives. In other words, decisions in these areas should not simply be made about the person with dementia. Since policy will have a direct impact on their lives, this should enable active engagement and inclusion.
- Policy focus should move beyond health and social care, and should consider dementia as a rights and equality-based issue. This includes the consideration of gender within policy discourse. Since this study, together with previous work, including that of Hulko (2009), has shown that specific groups can experience dementia differentially, the term ‘people with dementia’ could be deemed too generic and arguably should be replaced with terms such as ‘women with dementia’, as suggested by Bartlett et al. (2018).

8.6.4 For practice

- Dementia-friendly communities can provide people with dementia an opportunity to enhance wellbeing. But these should also take into account gendered interests. For example, support groups, and the opportunity to socialise with other people living with dementia are important to women. These should be integrated into care and offered to

people at the point of diagnosis, as their potential to increase psychological wellbeing and self-esteem has been evidenced.

8.6.5 For education

- This study highlights the need to meet the challenges of an ageing population by countering the common age-related biases and misunderstandings that are still shown to be prevalent, even among health professionals. This can result in discriminatory practices, which may be amplified among women.
- This study also emphasises the need for greater understanding of the emotional and psychological dimensions of dementia. There has historically been confusion associated with these, whereby they have been assumed to be a symptom of dementia, or where dementia has been misdiagnosed as depression (Scott et al. 2019). Instead, they should be acknowledged as a reaction to being diagnosed with the disease. Similarly, self-presentation strategies that suggest a lack of awareness on the part of the person with dementia could be construed as reactions to the person's social environment and to instances of felt or enacted stigma.

8.7 Study limitations

A drawback of this study relates to the sample size, which ended up being slightly smaller than I had hoped. I had to exclude those participants who I deemed unable to consent. Moreover, I would have liked to recruit from a wider geographical spread of IDEAL sites. As it happened, in order to maximise my time with those participants I had recruited, it was necessary to choose sites where I could spend a prolonged amount of time. A small sample size in an IPA study, however, is often considered a positive rather than a negative. IPA deliberately assigns an individualistic focus to accounts of a phenomena, and thus, considers a smaller sample size all the better for achieving this (Vasileiou et al. 2018).

Although my sample was diverse, in the sense that the women came from different social backgrounds, it must be noted that they were a self-selected sample, recruited from the IDEAL project, which could in itself, make them less than representative. People who take part in such large-scale research projects, for example, could have particular characteristics and be active and involved in a way that most people are not. This group could also be relatively comfortable with using terms such as 'dementia' in describing their situation. Several participants or family

members informed me that they deliberately took part in research-related activity in the hope that it would yield benefits for those people living with dementia in the future. Relatedly, the sample lacked ethnic diversity, with all participants being white British. The nature of the sample, therefore, could mean that the ways in which the women spoke of loss and difference, have an element of personal or social resilience that other groups of people living with dementia do not have available to them.

Another limitation relates to the drawbacks of doing a literature review, as opposed to a systematic review. Literature reviews examine the recent and current literature on a topic (or range of topics), but they don't have a standardised method of ensuring all literature is considered. As Grant and Booth (2009) explain, they 'lack an explicit intent to maximise scope or analyse data collected' (p.97). Relatedly, therefore, literature reviews are open to inadvertent bias on the part of the researcher, regarding the inclusion or omission of studies from significant sections of the literature. Systematic reviews search for, appraise, and synthesise, literature and research evidence, and therefore, aim to include all knowledge on a topic. They also use quality appraisal tools to assess the rigour of included studies. The establishment of the Campbell Collaboration and the Cochrane Qualitative Methods Group have represented a shift towards the inclusion of a wider range of study designs in systematic reviews, including quantitative, qualitative, and mixed methods studies (Grant and Booth, 2009).

The data collected took the form of one-off interviews for most participants. Whilst it was felt that these interviews went well, it is possible that the extent to which a relationship could be developed with such participants could be called into question. Particularly when compared to those participants with whom I spent a prolonged period of time – conducting multiple interviews, or accompanying them in going about aspects of their daily lives. The invitation letters were framed in an informal way, and gave participants control and choice about the nature of their involvement, in the hope of maximising inclusion. Whilst most women only wanted to have a one-off interview; others invited me to spend more time with them. It is perhaps inevitable that the latter scenario would foster closer, more trusting relationships.

Moreover, whilst all participants would choose to conduct the interviews in their own homes, three of them had family members present during the interview. These participants were able to consent, and to talk freely, answering questions without any issues. On two occasions, it was the family member who wanted to be present, possibly out of a protective inclination towards the person with dementia. On one occasion, the person with dementia wanted the family

member to be present because she explained that she was nervous talking to people she didn't know. It may have had the result, however, that participants were not able to talk entirely uninhibited, and potentially amended answers as a result of the family member's presence (Spencer et al. 2013). I attempted to mitigate this by encouraging the family members not to interfere, and by emphasising that the purpose of the interview was to understand the perspective of the person with dementia (Karlsson et al. 2014). However, I recognised the importance of developing a good relationship with both the women with dementia and their family members, since it was often the latter who acted as gatekeepers, or with whom I had initial contact. The interviews were therefore conducted in a manner that suited the preferences of both the person with dementia and the family member (Steeman et al. 2007). If a family member wished to be present during the interview, I believed it would be counter-productive to developing a good relationship to insist that they were not. It could also potentially have led to the family members withdrawing their relative from the study.

8.8 Conclusion

This study explored the impact of early-stage dementia on 12 women living with the disease. Some of these women lived alone, others with their spouse. They lived in three different areas of the UK and came from different social backgrounds. Different aspects of selfhood were conceptualised according to Sabat and Harré's (1992) social constructionist account. This framework states that there are three forms of selfhood and that these can endure in people with dementia, despite evidence suggesting that a loss of self occurred (Cotrell and Schulz, 1993).

My central research question was as follows: *how does early-stage dementia impact on the selfhood and identity of women?* I have answered it by showing that dementia affected the selfhood of all participants in the study, in many different ways. It impacted both personal and social aspects of selfhood, and was often associated with losses and a range of negative emotions. However, selfhood can also be preserved, through acts of resistance, maintaining continuity with the past and with the support of both intimate and peripheral relationships.

The central contribution of this thesis has been to show that dementia can have a wide-ranging impact on the selfhood of women living with the disease, that is not confined to the Self 3 – the ability to construct a social identity. Dementia can also have a significant impact on the Self 2 – the self of personal attributes and beliefs about these attributes. Moreover, all women, no matter what their living situation, or the perceived loss of Self 2 attributes and associated

loss of self-esteem, found ways of resisting the impact of dementia on their selfhood and repairing aspects of their selfhood that had been damaged by dementia. The findings also support the notion that selfhood can be impacted by the ability to construct a social identity, and that this relies on the cooperation of others within the social world of the person with dementia.

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Appendix 1 – Notice of Amendment form

Notice of Amendment

IRAS Version 5.3.2

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Enhancing active life and living well: the IDEAL study

1. Is your project research?

Yes No

2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

If your work does not fit any of these categories, select the option below:

Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? Yes No
- b) Will you be taking new human tissue samples (or other human biological samples)? Yes No
- c) Will you be using existing human tissue samples (or other human biological samples)? Yes No

3. In which countries of the UK will the research sites be located?(Tick all that apply)

- England
- Scotland

- Wales
 Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- England
 Scotland
 Wales
 Northern Ireland
 This study does not involve the NHS

4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

- IRAS Form
 NHS/HSC Research and Development offices
 Social Care Research Ethics Committee
 Research Ethics Committee
 Confidentiality Advisory Group (CAG)
 National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

5. Will any research sites in this study be NHS organisations?

- Yes No

5c. You have indicated that your study has sites located in England. For the research sites located in England, do you wish for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details

- Yes No

6. Do you plan to include any participants who are children?

- Yes No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- Yes No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory

Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

Yes No

9. Is the study or any part of it being undertaken as an educational project?

Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

Yes No

NOTICE OF SUBSTANTIAL AMENDMENT
 Please use this form to notify the main REC of substantial amendments to all research other than clinical trials of investigational medicinal products (CTIMPs).
 The form should be completed by the Chief Investigator using language comprehensible to a lay person.

Details of Chief Investigator:

	Title	Forename/Initials	Surname
Work Address	[REDACTED]	[REDACTED]	[REDACTED]
PostCode	[REDACTED]		
Email	[REDACTED]		
Telephone	[REDACTED]		
Fax			

For guidance on this section of the form refer to the guidance

Full title of study:	Improving the experience of dementia and enhancing active life: the IDEAL study
Lead sponsor:	University of Exeter
Name of REC:	North Wales REC - West
REC reference number:	13/WA/0405

Additional reference number(s):

Ref.Number	Description	Reference Number
	UKCRN reference number	16593

Name of lead R&D office:	Betsi Cadwaladr University Health Board
Date study commenced:	01/01/2014
Protocol reference (if applicable), current version and date:	IDEAL study protocol v4 010515
Amendment number and date:	12 12/10/16

Type of amendment

(a) Amendment to information previously given in IRAS

Yes No

If yes, please refer to relevant sections of IRAS in the "summary of changes" below.

(b) Amendment to the protocol

Yes No

If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

Yes No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified and not approved?

Yes No

Summary of changes

*Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.
If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.
If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.*

ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY
PhD Project: Social class, ageing and forms of identity among women living with dementia

We wish to submit the relevant documentation relating to the linked IDEAL PhD studentship to be undertaken by Hannah Scott, School of Social Sciences – Cardiff University. The planned work is an add-on to the IDEAL main study and constitutes an additional set of interviews on a related and relevant theme. People taking part in IDEAL will be approached to be interviewed, and the supporting information sheets, consent forms and invitation letter are enclosed for approval.

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.

List of enclosed documents

Document	Version	Date
IDEAL Cardiff PhD Information Sheet for participant v1 121016	1	12/10/2016
IDEAL Cardiff PhD Introduction to the study for participant and family friends v1 121016	1	12/10/2016
IDEAL Cardiff PhD Information Sheet for family member or friend v1 121016	1	12/10/2016
IDEAL Cardiff PhD Invitation letter and reply slip v1 121016	1	12/10/2016
IDEAL Cardiff PhD Consent form for participant v1 121016	1	12/10/2016
IDEAL Cardiff PhD Consent form for family member or friend v1 121016	1	12/10/2016

Declaration by Chief Investigator

1. *I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.*
2. *I consider that it would be reasonable for the proposed amendment to be implemented.*

This section was signed electronically by [REDACTED] on 14/10/2016 15:57.

Job Title/Post:

Organisation:

Email:

Declaration by the sponsor's representative

I confirm the sponsor's support for this substantial amendment.

This section was signed electronically by [REDACTED] on 21/10/2016 09:06.

Job Title/Post:

Organisation:

Email:

Appendix 2 – Person with Dementia Information Sheet

ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY

PhD Project: Social class, ageing and forms of identity among women living with dementia (information sheet for participant)

I am approaching you to ask if you would be willing to participate in a PhD project. It is an extension of the IDEAL study, and will look at the experiences of women with dementia from different backgrounds. IDEAL aims to provide advice and guidance on what can be done to make it easier for people with dementia to live well.

I will investigate if and how people's sense of who they are changes as a result of dementia, by spending time and talking with them, and also to family members or friends. This information sheet explains what taking part would involve in more detail. Please read it carefully and feel free to discuss it with others if you wish. If anything is unclear, or if you have any questions/concerns, please don't hesitate to ask. You can take as long as you want to decide whether to take part. Thank you.

Why have I been invited?

You have participated in the IDEAL study. As part of this, I am inviting you to join an associated PhD project looking specifically at the experiences of women with dementia from different backgrounds.

Can I choose whether or not to take part?

It is up to you to decide whether or not you want to take part. If you do, I will give you this information sheet to keep and ask you to sign a consent form. If you change your mind after agreeing to take part, you can withdraw at any time and you do not have to say why. If you decide not to take part, or to withdraw, this will not make any difference to your healthcare and it will not affect your rights in any way.

What will happen if I decide to take part?

If you agree to take part, I will arrange to visit you at home. In the first of these visits I will check that you are happy to proceed with the study, get you to sign a consent form and go over anything that is unclear. I would then like to get to know you and find out more about your life. This might involve having a chat over a cup of tea or a walk together to your local shops. This could be a one-off meeting, or a number of meetings over the course of a few months. How much you would like to do will be entirely up to you and we can decide on this together when we first meet. You will also be able to change your mind or withdraw from the study altogether at any time, without having to give a reason.

The interviews will be audio-recorded and transcribed by me. Once transcribed onto a secure, password-protected computer, the files will be deleted from the recording device. If you do not wish to be audio-recorded and would rather I made notes instead, that is also fine. If you agree to take part, personal details will be anonymized in the transcription. This means that people's names, place names etc. will be changed so that no one will be able to identify you from the information you provide.

What are the possible disadvantages or risks of taking part?

I do not anticipate that your taking part will involve any disadvantages or any specific risks to you or that it could cause you any harm. In the very unlikely event that you were harmed by taking part in the study, there are no special compensation arrangements. If you were harmed due to someone's negligence, then you might have grounds for a legal action, but you might have to pay your own legal costs.

What are the possible benefits of taking part?

This study is part of IDEAL, which aims to provide advice and guidance on what can be done to enable people with dementia to live well. The eventual aim is that care for those living with dementia will be improved. I also hope you will find it useful to talk to someone outside of the medical profession.

Will I be paid for taking part in the study?

You will not be paid for taking part, but your taking part is very much recognised and appreciated.

What if something goes wrong?

If you are unhappy or dissatisfied with any aspects of your participation, please in the first instance, raise these concerns with me. I will try to resolve them as swiftly as possible. My contact details are: Hannah Scott, School of Social Sciences – Cardiff University, 1-3 Museum Place, Cardiff, CF10 3BD. Tel: 07837102453. Email: ScottH1@cardiff.ac.uk. You also have the option to talk to my supervisor: Professor Ian Rees Jones, WISERD, Cardiff University, 46 Park Place, Cardiff, CF10 3BB. Tel: 02920 876662. Email: JonesIR4@cardiff.ac.uk.

How is the study organised?

The PhD is led by Cardiff University and is part of the IDEAL study co-ordinated by the University of Exeter. I will be responsible for running the project, including conducting interviews, transcribing the interviews, and analysing the information collected.

Will my taking part be kept confidential?

Yes, your taking part will be kept confidential. The only people who will have access to your personal details (e.g. name, address) are those involved in the IDEAL study. You have previously consented to take part in IDEAL and shared your contact detail with the co-ordinating centre at the University of Exeter.

All data collected will be stored securely on a password-protected computer and in locked fireproof cabinets. All interview transcripts will be anonymized. No one will be able to identify you from anything said during the interviews. The only exception to this would arise in the event of something being said during the interview, or observed, that caused concern for your health or wellbeing. In this case, I would have to inform a health professional, for example a GP or social worker. I would explain to you why I needed to do this if such a situation arose.

What will happen if I change my mind about taking part?

You are free to withdraw from the study at any time, without giving a reason. This will not affect your healthcare, or that of your family member/friend. Any information collected before your withdrawal will not be used.

What will happen to the results of the study?

The results will contribute to the findings of the wider IDEAL study. These will be published in journals, at conferences and to the wider health community. I will gladly provide you with information about the findings, should you wish to be briefed on these.

Who is organising and funding the research?

The PhD is an Economic and Social Research Council (ESRC) funded studentship based at Cardiff University. I report to my supervisors: Professor Ian Rees Jones and Dr Alexandra Hillman. The IDEAL study is led by Professor Linda Clare at the University of Exeter and this is also funded by the ESRC.

Who has reviewed the study?

All research undertaken with NHS patients is reviewed by the NHS Ethics Committee. The Committee has reviewed this study, along with Cardiff University School of Social Sciences Research Ethics Committee.

Who can I contact for further information?

Professor Ian Rees Jones, WISERD, Cardiff University, 46 Park Place, Cardiff, CF10 3BB.

Tel: 02920 876662

E-mail: JonesIR4@cardiff.ac.uk

Appendix 3 – Family Member Information Sheet

ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY

PhD Project: Social class, ageing and forms of identity among women living with dementia (information sheet for family member or friend)

I am approaching you to ask if you would be willing to participate in a PhD project. It is an extension of the IDEAL study, and will look at the experiences of women with dementia from different backgrounds. IDEAL aims to provide advice and guidance on what can be done to make it easier for people with dementia to live well.

I will investigate if and how people's sense of who they are changes as a result of dementia, by spending time and talking with them, and also to family members or friends. This information sheet explains what taking part would involve in more detail. Please read it carefully and feel free to discuss it with others if you wish. If anything is unclear, or if you have any questions/concerns, please don't hesitate to ask. You can take as long as you want to decide whether to take part. Thank you.

Why have I been invited?

You have participated in the IDEAL study. As part of this, I am inviting you to join an associated PhD project looking specifically at the experiences of women with dementia from different backgrounds.

Can I choose whether or not to take part?

It is up to you to decide whether or not you want to take part. If you do, I will give you this information sheet to keep and ask you to sign a consent form. If you change your mind after agreeing to take part, you can withdraw at any time and you do not have to say why. If you decide not to take part, or to withdraw, this will not make any difference to your healthcare and it will not affect your rights in any way.

What will happen if I decide to take part?

If you agree to take part, I will arrange to visit you at home. In the first of these visits I will check that you are happy to proceed with the study, get you to sign a consent form and go over anything that is unclear. I would then like to get to know you and find out more about your life. This might involve having a chat over a cup of tea or a walk together to your local shops. This could be a one-off meeting, or a number of meetings over the course of a few months. How much you would like to do will be entirely up to you and we can decide on this together when we first meet. You will also be able to change your mind or withdraw from the study altogether at any time, without having to give a reason.

The interviews will be audio-recorded and transcribed by me. Once transcribed onto a secure, password-protected computer, the files will be deleted from the recording device. If you do not wish to be audio-recorded and would rather I made notes instead, that is also fine. If you agree to take part, personal details will be anonymized in the transcription. This means that people's names, place names etc. will be changed so that no one can identify you from the information you provide.

What are the possible disadvantages or risks of taking part?

I do not anticipate that your taking part will involve any disadvantages or any specific risks to you or that it could cause you any harm. In the very unlikely event that you were harmed by taking part in the study, there are no special compensation arrangements. If you were harmed due to someone's negligence, then you might have grounds for a legal action, but you might have to pay your own legal costs.

What are the possible benefits of taking part?

This study is part of IDEAL, which aims to provide advice and guidance on what can be done to enable people with dementia to live well. The eventual aim is that care for those living with dementia will be improved. I also hope you will find it useful to talk to someone outside of the medical profession.

Will I be paid for taking part in the study?

You will not be paid for taking part, but your taking part is very much recognised and appreciated.

What if something goes wrong?

If you are unhappy or dissatisfied with any aspects of your participation, please in the first instance, raise these concerns with me. I will try to resolve them as swiftly as possible. My contact details are: Hannah Scott, School of Social Sciences – Cardiff University, 1-3 Museum Place, Cardiff, CF10 3BD. Tel: 07837102453. Email: ScottH1@cardiff.ac.uk. You also have the option to talk to my supervisor: Professor Ian Rees Jones, WISERD, Cardiff University, 46 Park Place, Cardiff, CF10 3BB. Tel: 02920 876662. Email: JonesIR4@cardiff.ac.uk.

How is the study organised?

The PhD is led by Cardiff University and is part of the IDEAL study co-ordinated by the University of Exeter. I will be responsible for running the project, including conducting interviews, transcribing the interviews, and analysing the information collected.

Will my taking part be kept confidential?

Yes, your taking part will be kept confidential. The only people who will have access to your personal details (e.g. name, address) are those involved in the IDEAL study. You have previously consented to take part in IDEAL and shared your contact detail with the co-ordinating centre at the University of Exeter.

All data collected will be stored securely on a password-protected computer and in locked fireproof cabinets. All interview transcripts will be anonymized. No one will be able to identify you from anything said during the interviews. The only exception to this would arise in the event of something being said during the interview, or observed, that caused concern for your health or wellbeing. In this case, I would have to inform a health professional, for example a GP or social worker. I would explain to you why I needed to do this if such a situation arose.

What will happen if I change my mind about taking part?

You are free to withdraw from the study at any time, without giving a reason. This will not affect your healthcare, or that of your family member/friend. Any information collected before your withdrawal will not be used.

What will happen to the results of the study?

The results will contribute to the findings of the wider IDEAL study. These will be published in journals, at conferences and to the wider health community. I will gladly provide you with information about the findings, should you wish to be briefed on these.

Who is organising and funding the research?

The PhD is an Economic and Social Research Council (ESRC) funded studentship based at Cardiff University. I report to my supervisors: Professor Ian Rees Jones and Dr Alexandra Hillman. The IDEAL study is led by Professor Linda Clare at the University of Exeter and this is also funded by the ESRC.

Who has reviewed the study?

All research undertaken with NHS patients is reviewed by the NHS Ethics Committee. The Committee has reviewed this study, along with Cardiff University School of Social Sciences Research Ethics Committee.

Who can I contact for further information?

Professor Ian Rees Jones, WISERD, Cardiff University, 46 Park Place, Cardiff, CF10 3BB.

Tel: 02920 876662

E-mail: JonesIR4@cardiff.ac.uk

Appendix 4 – Person with Dementia Consent Form

ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY

PhD Project: Social class, ageing and forms of identity among women living with dementia (consent form for participant)

Participant identification number:

Initial here if in agreement:

1	I have read and understand the information sheet IDEAL Cardiff PhD Information Sheet for participant v1 121016.	
2	I have spoken to the researcher and understand that my participation will involve being interviewed at a time and place to suit me. I have had the opportunity to ask questions about this process.	
3	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect my health care or my legal rights in any way.	
4	I understand that the information I give to the researcher will only be used for the purposes of research, and that personal details will be treated in the strictest confidence.	
5	I understand that if the researcher hears or observes anything that causes serious concern about my health, safety or well-being, s/he has a duty to inform my GP or another appropriate professional.	
6	I agree to the interview being audio recorded.	
7	I understand that all data will be stored securely and is covered by the data protection act.	
8	I understand that any data or information used in any publications which arise from this study will be anonymised and that no-one will be able to identify me personally in any way.	
9	I agree to the use of anonymised direct quotes in publications and reports.	
10	I agree that my anonymised interview data can be deposited in a data archive (ESDS Qualidata) which is available to researchers and the public for scholarly and educational purposes.	
11	I agree to take part in the interview.	

When all necessary boxes have been initialled please sign below:

Name of Participant

Date

Signature

Researcher taking consent

Date

Signature

Appendix 5 – Family Member Consent Form

ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY

PhD Project: Social class, ageing and forms of identity among women living with dementia (consent form for family member or friend)

Participant identification number:

Initial here if in agreement:

1	I have read and understand the information sheet IDEAL Cardiff PhD Information sheet for family member or friend v1 121016.	
2	I have spoken to the researcher and understand that my participation will involve being interviewed at a time and place to suit me. I have had the opportunity to ask questions about this process.	
3	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect my health care or my legal rights in any way.	
4	I understand that the information I give to the researcher will only be used for the purposes of research, and that personal details will be treated in the strictest confidence.	
5	I understand that if the researcher hears or observes anything that causes serious concern about my health, safety or well-being, s/he has a duty to inform my GP or another appropriate professional.	
6	I agree to the interview being audio recorded.	
7	I understand that all data will be stored securely and is covered by the data protection act.	
8	I understand that any data or information used in any publications which arise from this study will be anonymised and that no-one will be able to identify me personally in any way.	
9	I agree to the use of anonymised direct quotes in publications and reports.	
10	I agree that my anonymised interview data can be deposited in a data archive (ESDS Qualidata) which is available to researchers and the public for scholarly and educational purposes.	
11	I agree to take part in the interview.	

When all necessary boxes have been initialled please sign below:

Name of Participant

Date

Signature

Researcher taking consent

Date

Signature

Appendix 6 – REC Letter of Approval



Gwasanaeth Moeseg Ymchwil
Research Ethics Service



Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor

Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd
LL57 2PW
Telephone/ Facsimile: [REDACTED]
Email: [REDACTED]

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

06 November 2016

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

c/c: [REDACTED]

Dear [REDACTED]

Study title: Improving the experience of dementia and enhancing active life: the IDEAL study
REC reference: 13/WA/0405
Amendment number: 12
Amendment date: 12 October 2016
IRAS project ID: 141805

The above amendment was reviewed at the meeting of the Sub-Committee held on 03 November 2016

Ethical opinion

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

The Sub-Committee noted that amendment relates the linking in of a PhD study with the main study, consisting of an additional set of interviews on a related and relevant theme. New patient facing documentation has been developed.

On the basis of the submitted documentation the Sub-Committee decided that this amendment raises no ethical issues - this amendment does not significantly alter the initial research design or methodology nor impose additional significant burden on participants.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	12	12 October 2016
Letters of invitation to participant [IDEAL Cardiff PhD Introduction to the study for participant and family friends]	1	12 October 2016
Letters of invitation to participant [IDEAL Cardiff PhD Invitation letter and reply slip]	1	12 October 2016
Participant consent form [IDEAL Cardiff PhD Consent form for family member or friend]	1	12 October 2016
Participant consent form [IDEAL Cardiff PhD Consent form for participant]	1	12 October 2016
Participant information sheet (PIS) [IDEAL Cardiff PhD Information Sheet for participant]	1	12 October 2016
Participant information sheet (PIS) [IDEAL Cardiff PhD Information Sheet for family member or friend]	1	12 October 2016

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet
No declarations of interest were made in relation to this application.

Working with NHS Care Organisations

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

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.

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

13/WA/0405:

Please quote this number on all correspondence

Yours sincerely

[Redacted signature]

[Redacted name]

Chair

E-mail: [Redacted email address]

Enclosures:

List of names and professions of members who took part in the review

Copy:

Sponsor:

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

R&D Office:

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Wales Research Ethics Committee 5

Attendance at Sub-Committee meeting on 03 November 2016

Committee Members

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>	<i>Present</i>
[REDACTED]	General Practitioner (Chairman)	Expert	Yes
[REDACTED]	Consultant Anaesthetist (Vice-Chairman)	Expert	Yes
[REDACTED]	Student	Lay +	Yes

In attendance

<i>Name</i>	<i>Position (or reason for attending)</i>
[REDACTED]	Clinical Governance Officer / RES Manager

Appendix 7 – Introduction to the Study sheet

ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY

PhD Project: Social class, ageing and forms of identity among women living with dementia

What is the study about?

This PhD is part of a much larger project: IDEAL (Improving the Experience of Dementia and Enhancing Active Life). IDEAL aims to explore what factors contribute to or hinder a person's ability to live well with dementia.

It has commonly been thought that dementia can impact on our sense of who we are. More recently, however, evidence has suggested that the people around you and the support you receive can help you in your day-to-day life. I would like to talk and spend time with people with dementia from different backgrounds, to explore whether their sense of who they are has changed or been affected by dementia.

What does the research hope to achieve?

This PhD hopes to find out more about the experiences of women with dementia, from different backgrounds.

How is the study funded?

The PhD is funded by the ESRC (reference ES/L001853/2).

Who is carrying out the study?

I (Hannah Scott) will be carrying out the research under the supervision of Professor Ian Rees Jones and Dr Alex Hillman, who are involved with the wider IDEAL study. My PhD will also have the support of the external IDEAL research team based at the University of Exeter.

Who will take part?

We hope to involve a small number of participants from the IDEAL study in data collection over a period of several weeks.

What does taking part involve?

If you agree to take part, I (Hannah Scott) will visit you at home and ask you to complete a consent form and to provide some background information. I would then like to get to know you and find out more about your life. This might involve having a chat over a cup of tea or a walk together to your local shops. It could be a one-off meeting, or a number of meetings over the course of a few months. How much you would like to do will be entirely up to you and we can decide on this together when we first meet. You will also be able to change your mind or withdraw from the study altogether at any time, without having to give a reason

Your participation in this study is very much appreciated and will provide valuable insight into the worlds of both people living with dementia and their carers.

Appendix 8 – Invitation Letter

[Date]

[Participant name]

[Participant address]

Dear [Participant name],

Invitation to participate in a PhD project

I am writing to you, because you have participated in the IDEAL study (Improving the Experience of Dementia and Enhancing Active Life), which is being led by researchers at the University of Exeter.

As part of the IDEAL study, I am undertaking a PhD which will involve spending time with, and talking to people with dementia from different backgrounds. I have enclosed a summary sheet which provides more detail on the project.

I will follow this letter up with a phone call to go through any questions or queries you may have, and to arrange a meeting if you are willing to proceed. If you have a family member or friend who you think would also like to take part, please feel free to share this letter and enclosed summary sheet with them.

You are under no obligation to participate, and your decision will not affect your NHS care in any way.

Many thanks for considering this invitation.

Yours sincerely

Hannah Scott

Appendix 9 – First Draft Interview Schedule (PWD)

1. Neighbourhood and belonging
 - i. How long have you lived in this house?
 - ii. Do you like the area? (What is the best/worst thing about living here?)
 - iii. How would you feel about moving?
 - iv. Is there a sense of ‘community’?

2. Participation
 - i. Could you describe a typical week?
 - ii. Do you belong to any formal clubs/associations? (for example, church groups, political parties, sports clubs)
 - iii. Have your interests changed since being diagnosed with dementia? If so, how?

3. Social ties
 - i. Could you describe your relationship with your family? (How often do you see them?)
 - ii. Has your relationship with your family changed since being diagnosed with dementia?
 - iii. What about friends? Have these relationships changed?
 - iv. Who would you confide in if you had a problem?

4. Life stories/narrative history
 - i. Could you tell me about your life story? (No right way to do this/prompt could include to start from childhood etc.)

5. Identities
 - i. How would you describe yourself?
 - ii. Would you say you have changed as a person since the diagnosis? (If so, how? Has dementia impacted upon your identity/sense of self?)
 - iii. Are there things that you are happier with since the diagnosis? (Positive changes)
 - iv. What about things you are less happy with? (Negative changes)

- v. Do you think of yourself as belonging to a particular social class? (If so, which one and why?)
- vi. Is this also the class to which you belonged growing up?
- vii. What was your previous occupation? (Do you think this has shaped your sense of who you are?)
- viii. Have you found yourself needing to delegate roles and responsibilities to other people in order to adjust to dementia?
- ix. How important is your gender to your sense of identity/who you are?

Appendix 10 – Finalised Interview Schedule (PWD)

1. Early life and upbringing
 - i. Where were you brought up?
 - ii. What did your parents do for a living?
 - iii. What was your previous occupation?
 - iv. How long have you lived in this house?

2. Social ties and relationships
 - i. Could you describe a typical week?
 - ii. Do you belong to any formal clubs/associations? (E.g. church groups, political parties, sports clubs)
 - iii. Have your interests changed since being diagnosed with dementia? If so, how?
 - iv. Could you describe your relationship with your husband?
 - v. Could you describe your relationship with your wider family? (How often do you see them?)
 - vi. Could you describe your relationship with your friends?
 - vii. Do you think people treat you differently?
 - viii. How do you feel that health professionals have treated you? (E.g. GP, memory clinic staff, etc.)
 - ix. Who would you confide in if you had a problem?

3. Changing identities
 - i. What are the most important things that shape your sense of who you are?
 - ii. Do you think dementia has impacted on how you see yourself? If so, could you describe these changes?
 - iii. Are there things that you are happier with since the diagnosis? (Positive changes)
 - iv. What about things you are less happy with? (Negative changes)

4. Coping
 - i. How do you feel you are coping, in general?

- ii. Is there anything that is particularly challenging (hard) about living with dementia?
- iii. Have you found yourself needing to delegate roles and responsibilities to other people in order to adjust to dementia?
- iv. Do you think about the future? If so, what do you think about?

Appendix 11 – Interview Schedule (Family Member)

1. Early life and upbringing
 - i. Where were you brought up?
 - ii. What did your parents do for a living?
 - iii. What was your previous occupation?
 - iv. How long have you lived in this house?

2. Social ties and relationships
 - i. Could you describe a typical week?
 - ii. Do you belong to any formal clubs/associations? (E.g. church groups, political parties, sports clubs)
 - iii. Have your interests as a couple changed since your wife/family member was diagnosed with dementia? If so, how?
 - iv. Could you describe your relationship with your wife/family member?
 - v. Do you think people treat you differently (as a couple)?

3. Changing identities
 - i. What are the most important things that shape your sense of who you are?
 - ii. Are there things that you are happier with since the diagnosis? (Positive changes)
 - iii. What about things you are less happy with? (Negative changes)

4. Coping
 - i. How do you feel you are coping, in general?
 - ii. How do you feel that your wife/family member is coping?
 - iii. Is there anything that is particularly challenging (hard) about living with dementia?
 - iv. Do you think about the future? If so, what do you think about?

Appendix 12 – Commentary on Transcript

RELATIONSHIPS
/ POSITIONING

I: Could you describe your relationship with Carl?

BR: I think I'm a millstone round his neck, erm and I think that it's a lot of it is, he's got a batty wife. He doesn't want that to be known, you know... about, so he goes out and I go to Silver Linings, and that sort of thing and have a good time, he pays for it, yes but I don't think that he's happy about having somebody that's a little bit, isn't quite clued in, let's put it that way, um...

I: You think that bothers him?

BR: Yeah, I would think so. He won't admit to it but there's something wrong. I can't put a foot right at the moment. Erm, we've had arguments, I will still have an argument with him if I have to but it upsets me, now. It takes me a couple of days to calm down and settle down, not good for me at all. One minute he's turning round and saying we'll have to go out more and this sort of thing, never bloody well done anything about it at all. We've not been anywhere and he says, 'I know you won't want to go shopping' erm, I've not done shopping for year, for some years, I wouldn't even know where to start now.

I: Is that out of choice, or...?

BR: Erm no, well no, no... it was the dementia that stopped it. I've never done the shopping for years. I tried it once, came out with three items that I'd paid for and everything. I thought ooh, I was ever so proud of myself 'cause I'd got three items and I thought, well next week I can get six, you know – build it up. Got home and Carl says: 'What you got?' I says: 'Well I've been and tried a bit of shopping at Asda'. He says: 'Well we don't eat dog food'. You know... so it's... and to me I'd done it all right, so... yeah.

I: How did you feel about that?

BR: I feel very inadequate to say the least, inadequate and stupid I'd put it down as, that's why I don't, I don't go anywhere, I don't, I daren't, erm, I get erm, sometimes I get in the car, right, he's barred me from having the car over the winter months and I know what that's going to, you're looking at 5 months, right and I would think that if I get anywhere near that car or get in it, I don't think I'll know what to do with it.

I: Right.

BR: I'm worried that me car's now been taken away because of this winter basically, so he's nailed... 'cause he was barking over me having the car. I wasn't safe, and yet I was. I was a

strong wording to quite emphatic in its revelation of how she perceives relationship frequent use of this word

Bridget positions Carl as burden perceiving of her as a burden

Carl is being difficult to live with than she can do anything right. still fights over

Previously alluded to such arguments causing her extreme distress. Carl speaking for her

Carl as having lost Jordan informs to her

Initially claims it was down to the dementia confidence impacted

Impact on Self 3 - gendered identity etc. Carl's refusal to cooperate in this construction reflects back on how Bridget perceives herself. Self esteem is eroded.

The emotional impact of being positioned in a certain way impacts to carry ability to carry out future tasks

again, chronic of words - suggests control over aspects of her life

Not a case of having a discussion about it - pretty black + white

Clear disagreement about this positioning herself as safe driver,

RELATIONSHIPS
/

POSITIONING

*Belives he is in driver
fact a worse driver - the he
than her - she he
drives too fast etc.*

darned sight safer than him and perfectly all right, and this sort of thing... no problems, and he says: 'I think you ought to just pack it up for the winter'. So the winter started in August, beginning of August, and I haven't driven a car since!

*Intense fear linked
to ~~possessed~~ Carl
stopping her from
driving*

I: Since August?

paranoid

*No justification
for the decision - came out of the blue -
linked to her sense of outrage + upset*

BR: Winter starts early. So now what I want to do, he's taken the car keys away, I can't find them anywhere. I've tried, erm... I haven't said anything to him yet but that's going to be another argument. I now want to pick the car up and take it round the block. If I can get round the block, such like, just, you know, get the feel of it again.

*In prepared to hit him for it
Doesn't want to
lose driving*

I: Yeah.

*again, repetition
of this word*

BR: But I've lost the car keys, so I haven't got any car keys for the car. So he's nailed that as well, he's determined I'm not going to drive, I'm not going to do this that and the other and I think, basically, he wants me in here 24/7.

*Carl becomes
implicated in
positioning Bridget as
someone who is
incapable of driving,
become driving is
central to her
identity*

(interruption)

*Again - sense of feeling controlled,
of being having her freedom
severely restricted.*

I: So have your interests changed as a result of being diagnosed with dementia?

BR: Yes, yeah, I like to interact and one thing and another.

I: With people?

BR: More so now than before really cos erm I just wanted to know about this and that and the other, whereas before I wasn't very interested: 'oh it doesn't matter...'

*Interests
changed as a result
of dementia
Positive change?*

I: So you're more interested in socialising now, as opposed to before you had dementia?

BR: Yes.

*Quite definitive
that she is more
sociable now*

I: That's interesting.

BR: Yeah, yeah. I love going to Silver Linings. I can't get there fast enough in a morning. I go twice and erm, in the week, yeah something like that - twice in the month, sorry. I have to think about these things now and again.

*Repeats this on
numerous occasions -
clear impact of
SL on selfhood - social
aspect of it, being
around other people
than Carl, with whom
she derives a different
relationship.*

RELATIONSHIPS
/

SUPPORT
GROUPS