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The Influence of Social Location on the

Experience of Early Dementia

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'…a life is inseparably the sum of the events of an individual existence seen as a history and the narrative of that history… life is like a path, a road, a track, with crossroads, pitfalls, even ambushes. Life can also be seen as a progression, that is, a way that one is clearing and has yet to clear, a trip, a trajectory, a unidirectional and linear move, consisting of a beginning, various stages, and an end, understood both as a termination and as a goal […] One can understand a trajectory […] only on condition of having previously constructed the successive states of the field through which the trajectory has progressed.

Pierre Bourdieu (1986) *The Biographical Illusion.* In DuGay P, Evans J and Redman P (eds) (2005) *Identity: A reader.* London. Sage. p299.

In memory of Vera and Jack

(i) Acknowledgements

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(ii) Abstract

This thesis investigates the intersections of social class and gender with the early dementia experience. 20 older people with a likely dementia diagnosis were recruited from memory clinic referrals. Unstructured interviews were conducted in the person's home in the liminal space between referral and formal diagnosis and were analysed using interpretative phenomenological traditions.

Drawing on Bourdieusian concepts of habitus and capital allowed a nuanced and complex understanding of meaning creation to be explored. Understandings and meanings of memory loss and dementia were conceptualised by participants in terms of biographical flow and expectations of ageing. Prior experience of dementia caring roles promoted earlier help seeking behaviour, whilst attitudes towards classifying dementia as a mental or physical illness, was a powerful instigator of uncertainty in meaning. The desire to reduce stigma prompted avoidance coping mechanisms in terms of physical withdrawal, and social and mental distancing from potentially challenging situations, and reinterpretation of cognitive limitations. These responses were simultaneously shaped and defended by a sense of a life lived and personal biography, whilst the level of challenge to biographical flow was directly related to the meaning attributed to memory loss.

These findings uphold the view that dementia is not universally understood as a wholly devastating illness by those experiencing memory loss, and that services need to take account of personal biography and the level of interruption to biographical flow in assessing the meaning making related to memory loss. 'One size' of memory service, does not 'fit all'.

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(iii) Introduction

This thesis explores the significance of social location and life experience in shaping the meaning and experience of early stage dementia. It addresses the research question:

What influences the differential nature of the experience and meaning of early stage dementia?

The individuality of people with dementia is given primacy through gathering subjective meanings and understandings from people experiencing memory loss and at an early stage of illness. This thesis explores the interplay of idiosyncrasy and particularity, set within the larger structural factors of social class and gender that shape everyday meanings. The subjectivity of individuals is foregrounded in this research but considered in socially located terms so as to uncover the influences on the formation of the meaning and understanding of dementia.

This study has shown that early dementia was experienced within the context of socially located, long lived lives. For example, driving was considered by working class men to be publicly orientated in terms of its representation of masculinity and independence, as car ownership and a driving licence were considered to represent ability and autonomy. The potential for driving cessation linked to memory loss was, therefore, considered a threat and occupied special meaning for this particular group. The interconnectedness of social class and gender, and the particularity of individual experiences, created a subjective understanding and meaning of memory loss, that is present but under-explored in previous studies.

Earlier work by Hulko (2009) brought differences in dementia experiences related to social location into research focus when she studied responses from contrasting groups of socially

marginalised and privileged people. She revealed a scale from 'not a big deal' to 'hellish' that corresponded with the importance that memory and intellectual standing held for individuals. Broadly, more marginalised people were able to accommodate their memory loss in a 'business as usual' approach, whilst more privileged people struggled to come to terms with it. Hulko's research therefore suggested that social class might have a defining role in shaping dementia experiences.

Gender differences in experiences of ill-health are familiar from the medical sociology literature (Lane and Cibula 2000, Charteris-Black and Seale 2010, Macintyre, Hunt and Sweeting 1996), and are prominent throughout sociological and psychological literature that examines lifespan experiences (World Health Organisation 2014, Cornal 2011, Emslie and Hunt 2008). However, how social difference may shape the experience of memory loss at the intersection of normal cognitive function is a relatively unexplored area that my research addresses directly.

To investigate the early dementia experience from varying social location perspectives, I needed to conceptualise social class and gender without relying on occupational status because I anticipated that most of my potential participants would be retired given that dementia is related to ageing (Graham and Warner 2009, Department of Health 2009). I wanted to capture individuality, and to frame this within the theoretical context of the intersection between health, illness, social class and gender. Therefore I chose the Bourdieusian (1986a) approach of forms of capital and habitus as a lens through which I could view the complexities of current social location and the legacy of a lifetime of socially located experiences, in the context of memory loss. These lifetime experiences would include the impact of medical encounters themselves shaped by social location as predicted by Bury and Gabe (2004). Life time experiences also determined individual responses in relation to, for example, the value placed upon memory.

Adoption of the personhood framework (Kitwood 1997) was important for this study as a tool for recognising the deeply individual nature of lifetime experiences within social locations. Personhood, with the intrinsic value it places upon individual human existence, has moved our understandings away from a homogenous, unitary view of the dementia experience, towards an appreciation of the heterogeneity of embedded personal understandings and meanings.

My research revealed that meanings of ageing and earlier lifetime experiences of caring for a person with dementia greatly influenced help seeking behaviour and coping strategies, and shaped attitudes towards medication and the role of the medical profession. Contrary to popular and 'common sense' thinking, those with strong emotional experiences of caring were more likely to seek help earlier for their own memory loss than those without caring experiences. Those with little or no previous experiences tended to adopt the lay view of the devastating character of dementia whilst denying that they may indeed be at the beginning of such a journey, and preferred to think of their memory loss as a symptom of growing older.

The potential for distress at forgetting was further complicated by the value placed upon the forgotten memories. Value was directly linked to socially located activities and meanings. In general, women were particularly fearful of forgetting to maintain the household diary and manage their housekeeping duties, whilst men were threatened by forgetting how to perform tasks that were perceived as symbols of social position among their peers, such as do-it-yourself and sports and social club memberships. The threats were often constructed in terms of stigma and included elements of hiding or avoiding social situations that would highlight the memory difficulties, demonstrating that memory loss per se was not stigmatising, but the meaning of losing valued abilities was key to self-stigmatisation.

My original contribution to research is that subjective experiences and meaning making by people with dementia is dynamic, complex and related to social location and lifetime caring experiences. This is important in the current policy climate that is addressing growing numbers of people affected by dementia as the population ages, and services are required to adopt person centred care planning strategies (Department of Health 2009, Adams 2008, Dewing 2007). My research has underlined that early dementia is not experienced equally by all those affected, and furthermore, the subjective meaning that memory loss holds is impacted by deep personal understandings based on lifetime experiences within social locations. Therefore the early diagnostic process should be mindful of the heterogeneity of individual understandings and meanings notwithstanding social location.

Estimates suggest that by 2015 850,000 people in the UK will have dementia (Alzheimer's Society 2014e), but this is set to rise to around 1 million by 2025 (Alzheimer's Society 2014f) and 1.7 million by 2051 (Alzheimer's Society 2013). Therefore a need exists for the production of sound research that examines the social experience of dementia that can better understand the complexities of living with the disease. This is especially important in the drive for early diagnosis spearheading the current Dementia Challenge (Department of Health 2012) aimed at raising the current diagnosis rate of approximately 46-48% (Department of Health 2014).

The policy drive for early diagnosis centred around the benefits of early drug interventions and more personal time for emotional adjustments and planning and decision making for the future, thus allowing the person with dementia to take an active role in their future care (Department of Health 2009, Alzheimer's Society 2013). This drive assumed a blanket benefit to all those affected, but this has been questioned more recently with lively debate ongoing within the British Medical journal sparked by Gordon and Gordon (2011) concerning the mental health effects of pushing people towards diagnosis when they may

not be ready, and highlighting that a diagnostic label is not value neutral. In addition, the International Longevity Centre- UK (2014) highlights the 'double jeopardy' (pg6) of aging and dementia that challenges the balance of empathy and empowerment with care and protection.

At the same time, there has been a general implementation throughout the National Health Service of person centred care that broadly acknowledges the differential nature of illness perspectives (Goodwin et al 2012, Care Quality Commission 2014, National Institute for Health and Care Excellence 2011, Clare et al 2011, NHS 2013). This is somewhat at odds with the uniform character of early diagnosis policy, and underpins the need to investigate the differential nature of the early dementia experience.

This thesis directly addresses the differential nature of the dementia experience from the perspective of those experiencing it. The knowledge generated by people with dementia is given primary focus and importance, and the position of dementia as an illness associated with ageing, places it within the context of long lived lives that are socially located in terms of gender and social class. Meanings and understandings that have been generated over a life time of experience and are now called to the fore as the person experiences memory loss. This is the essence of this study and forms the explanation of the differential nature of the experience and meaning of early stage dementia.

(iv) Thesis outline

This thesis opens with a review of the relevant literature pertaining to the intersection of social class and gender, health and illness, and policy development within the context of ageing. I have arranged this review in to four sections that directly address the early dementia experience.

In the first section I highlight the importance of seeing older people as a heterogeneous group in all senses other than chronological age. Here the concept of personhood, and the recognition that framework brings to the context and complexities of understanding and meaning creation, is foregrounded, followed by a review of the variety in experiences of ageing. I discuss how illness creates biographical disruption when the future is uncertain. In the final subsection I address stigma and stigmatising illnesses.

In the second section I explore the intersectional nature of social location and health and illness. I consider Bourdieu's forms of capital (1986) as a useful theoretical approach for locating social position within the complexities of retirement and ill health. I then examine intersectionality and its efficacy for exploring socially located meaning, before lastly focussing on gender roles and the importance of daily activities.

In the third section I investigate early experiences of illness and consider which factors prompt a person to seek help, before moving on to discuss the variety of coping styles when faced with illness. I explore the transition from health to illness in terms of the liminal period pre-diagnosis, before addressing how people may engage with the biomedical world. I conclude with a review of the challenges that medicine faces in adopting person centred

practice and the availability of dementia medication within a population that has growing expectations of care.

In the final section of the literature review I provide an overview of policy development in the area of dementia services. This includes the roll out of memory clinics and the extension of their remit to provide early diagnosis. I consider the symbolic meaning of dementia in terms of its position within psychiatry and the paradox of the inclusion of dementia as a mental illness albeit resulting from an organic problem.

In Chapter Two I explain my study design and methodological choices, and outline how I was able to access the field and satisfy political as well as research restrictions, whilst retaining my ontological perspective of valuing lived experiences, and my epistemological perspective of dementia as an illness that retains particular meanings.

In the five empirical chapters that follow I report my findings and explore the perspectives and important features as identified by the respondents and revealed in analysis. I start in Chapter Three with concepts of movement over time, from past lifetime experiences through to looking into the future with memory loss. Participants' sense of self was clearly rooted in their lifetime experiences and provided their identity in the present, and their biography for the future.

Throughout Chapter Four I concentrate on how memory loss was confronted, charting how and if it was acknowledged, and to what it could be attributed. Participants attributed their memory loss to a range of causes including a symptom of dementia, normal ageing and a

symptom of a different illness, and I note the emotional associations and impact of the different attributions.

Chapter Five considers the major theme of uncertainty. Rationalisation ebbed and flowed fluidly as my participants tried to make sense of memory loss and predict the future. The inevitability of ageing was used by all participants as a tool for grounding the uncertainty of memory loss in something predictable, especially when faced with the emotional responses of fear and loss associated with forgetting caused by dementia.

In Chapter Six I uncover tactics for the preservation of self, apparent in coping mechanisms, comparing self to others, and deliberate withdrawal from social encounters. Preservation of self through employing overt tactics was used by my participants as a defence against both societal stigma and self-constructed stigma.

Lastly Chapter Seven explains how boundaries of selfhood are re-evaluated and re-negotiated into convincers of continued competence, and things that could be considered as markers of decline in the future. I discuss how these boundaries of competence and decline are constantly re-evaluated as memory loss increases, and conclude that constant re-evaluation ensures convincers of competence are foregrounded whilst boundaries of decline are never met.

After considering the evidence presented in the empirical chapters, my final and concluding chapter discusses and explains my primary finding that prior experiences relating to dementia play a significant role in shaping the 'living with memory loss' experience in the present. Social class and gender determine the likelihood of lifetime experiences, and

intersect with the meaning of dementia in a powerful way. This intersection determined help

seeking behaviour, continued social and familial relationships, self-appraisal, self-esteem

and shaped thinking about the future. This finding is important not just for sociological

understanding of the social location/dementia intersection, but can also be usefully applied

in assisting the engagement of older people with memory loss services.

Chapter 1: Literature Review

1.1 Introduction

This literature review explores the concepts central to addressing the research question of the differential nature of the experience of dementia. This thesis explores the subjectivity of the dementia experience and the meanings that contribute to how dementia is understood by individuals. I begin by addressing literature that explores personhood and individuality, and the meaning of ageing; these are fundamental to explaining differences in experiences, and counteracts the traditional tendency to objectify dementia from the outside, thereby othering people with dementia.

As dementia is an age related illness the meaning of ageing is a dominant theme. The expectations of ageing and health are important in constructing the meaning of dementia and memory loss as part of 'normal ageing' or as a 'health catastrophe' (Hulko 2009). These meanings however, as I shall show, are located in expectations of social class and gender, and also relate to the particularity of experiences gathered over a lifetime, and contribute to individuality and personal biographies.

Expectations are embedded in personal biography and so how dementia disrupts the biographical flow is explored through literature examining biographical disruption and narrative reconstruction. The level of impact of memory loss is determined by the individual's understanding of it, and the meaning that it holds in terms of narrative construction. Undoubtedly, dementia is a stigmatising illness and so literature that explores stigma is also of central importance to meaning creation. After exploring these principle

themes of personhood, ageing, biographical construction and the impact of stigma, I

consider how social location can be theorised for such a multi-faceted phenomenon.

In the second section of this review, I investigate the usefulness of Bourdieu's (1986)

concepts of habitus and capital for theorising social class and gender. Theorising social

location at the intersection of health and illness for older people required a move away from

class boundaries reliant on occupation because the participants were likely to be retired.

However, I needed to be able to combine the legacy of classed and gendered lifetime

experiences present in occupational choices that are created from, and formed by, capital

and habitus. Bourdieu provided a functional theoretical lens through which I could view

lifetime experiences at the intersection of health and illness.

The sociology of health and illness literature was important for underpinning the

intersectionality of gender, class, health and illness. This body of work contributed

understanding of the construction of illness experiences, and by examining research relating

to comparative degenerative illnesses, I could establish a sense of the diversity of

experiences and notably the differences in gendered experiences. The challenge to gendered

roles when illness strikes was an important factor in shaping illness narratives and provided

support for investigating gender as a differentiating factor in dementia experiences.

In the third section of this literature review I explore topics relevant to early interactions

with illness. Help-seeking behaviour has a long established literature relating to gendered

differences in how people engage with illness and with the medical world. The concepts

within help-seeking relate very closely to coping styles and dealing with liminality and the

symbolism of medicine. All of these factors are of importance in teasing apart the meaning

and understanding of dementia and memory loss, because diversity is present within each of

these concepts and is tied tightly to personhood and biographical disruption. The importance

of these sub-theme bodies of literature was in constructing a thematic framework for

locating social class and gender experiences.

The literature reviewed so far relates to the subjective and individual experiences of

dementia, but this inevitably operates within the formal objective structure of the biomedical

model. This was important to review because I was making contact with participants

through memory clinics after their initial referral. Therefore reviewing policy development

in terms of the impact and influence of memory clinics on early diagnosis, diagnosis

disclosure and decision making was important for contextualising wider societal views of

dementia. I needed to understand the objectives and functions of the memory clinic that my

participants were engaged with, and their subjective experiences that were central to

meaning creation and their understanding of dementia and memory loss. By reviewing

literature relating to aspects of diagnosis I was able to gain insight into the homogenous

world of policy, and foreground my participants' experiences and subjective understandings

against this backdrop.

1.2 Heterogeneity in Illness Experiences

The foregrounding of the subjective experience of dementia necessitates the exploration of

heterogeneity in illness experiences more generally. This is important because diversity in

illness experiences and meanings can be applied to dementia. Dementia tends to occur in

later life so meanings and understandings of illness have a long period of time to develop

and embed in personal history. Sociological research has for some time demonstrated that

differences occur in illness experiences according to individuality and life history (Herzlich 1973, Keady et al 2007) as well as through social class and gender (Downs 2000, Swanwick et al 1999, Seale and Charteris-Black 2008). Individuality and life history are inextricably entwined, because individual life history is idiosyncratic with no two people experiencing the world in exactly the same way, and with exactly the same predispositions (Schutz 1972). It is the extent of the differential experience of dementia that is under scrutiny in this study in the light of the rather homogenous approach of services and unitary view of the illness. Sociological research has identified variations in responses to the medical realm that relate to social class and gender (Barry and Yuill 2011, Young 2004, Boulton et al 1986). These variations can be translated into the likelihood of caring for another with dementia. These differences taken together with individual life history, social location and life time experiences potentially govern the way that dementia is perceived, understood and experienced on an individual level.

To provide a coherent framework within which differential experiences can be examined, I start with exploring the concept of personhood, and the meaning that this has in terms of person centred care. Dementia is strongly associated with ageing; therefore, this section also reviews the literature related to the diversity of experiences of ageing from a social class and gendered standpoint, before moving on to examine the biographical disruption that illness can bring, and the creation and management of stigma associated with both ageing and dementia.

1.2.1   Personhood

Tom Kitwood (1997) in *Dementia Reconsidered: the person comes first*, defined personhood as '*… a standing or status that is bestowed upon one human being, by others, in*

the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood and the failure to do so, have consequences that are empirically testable.' (Kitwood 1997: 8). This standpoint is of vital importance to this present study because it not only recognises the individuality of each person in social relationships, but also introduces the notion that personhood is a phenomenon rooted in philosophical underpinnings, which can be explored empirically.

Sullivan (2003) built upon Kantian philosophy and defined personhood as '…something more than mere biological life' (p 11), implying rights and moral duties related to humanity. He argued that the concept of personhood challenges the biomedical world which, with moral trepidation, makes decisions that concern a person's 'worth', for example at the start and end of life in terms of abortion and euthanasia. Dementia tends to be seen by biomedical professions as a hopeless disease because of the lack of cure (Bond et al 2005), and lay person discourse surrounding the destruction of the person through dementia has become similarly ingrained in popular thinking (Kitwood 1993). As a result, dementia patients in the past have been classified as a homogenous and hopeless group, suffering irrevocable decline, who lack personhood as the disease progresses and perceptions become confused, eventually leading to death.

Kitwood was exploring personhood for only 10 years before his death in 1998, and as Baldwin and Capstick (2007) explain, many of his ideas were not fully formulated, however his promotion of person centredness in dementia care has prevailed in policy and is central to service provision. This is remarkable given that direct views of people with dementia are absent from his work although he wrote for a wide ranging audience of academics, professionals, and family carers in a wide variety of publications. However, for Kitwood

personhood existed at an intersection of being and intrinsic value, ethical treatment, and existing within relationship networks (Phinney et al 2007). This intersection is central to the understanding of personhood for this study as these elements relate directly to the sense of a life lived through experiences.

The concept of personhood also underlies the policy emphasis on person centred care. This encompasses a number of domains that includes personal preferences, and social and medical factors, and its application takes into consideration such factors as coping style, life history, thoughts and perceptions and medical situation, that proceed to view the person 'in the whole' (NICE-SCIE 2006). The adoption of the personhood framework has been influential in furthering research and has influenced policy relating to many illnesses and disabilities.

Tom Kitwood (1997) recognised the rather narrow medical view that emphasised the pathology of dementia, and so he applied the notion of personhood to dementia patients. This marked a radical shift in dementia care research by incorporating a 'human' model that recognised the importance of treating people with dementia not just according to their pathology, but also according to their values and daily life patterns, with thoughts, values and beliefs. Kitwood (1997) criticised the medical model for putting *'aspects of personal being into one pan, and aspects of pathology and impairment into the other'* (Kitwood 1997 pg 7), and successfully argued that the contemporary medical model dominates without any logical grounding for ignoring personal and social aspects of the person's situation. He argued for a change of emphasis and a promotion of the 'person' in the 'person with dementia'. Personhood therefore acknowledges heterogeneity within patient groups and renders the argument of dementia patients as a homogenous group unsustainable.

There is a popular lay understanding that people with dementia lack awareness of their symptoms (Department of Health 2009, Trigg et al 2007). This assumption encourages and perpetuates a homogenous stigmatising attitude towards people with dementia, even though it has been shown to be false, and especially in the early stages of the illness (Clare 2003). Although a lack of awareness is a recognised symptom of Alzheimer's disease, as Clare et al (2005) explained, it can easily be confused with the adoption of a 'do not want to know' coping approach, thus supporting the view that dementia can be experienced differently and hold different meanings for different individuals.

The concept of personhood has long since been recognised as an important part of person centred care for cancer patients. Little and Sayers (2004) explored personhood in relation to cancer sufferers and survivors, and direct comparisons can be made to dementia sufferers in discourses of normality and 'getting on with it', and the introspection of resolving life projects and being as comfortable as possible until death. In addition, Thorne et al (2005) acknowledged the pervasiveness of cancer patients' desire for human connection, and to 'be known' in a meaningful way. Personhood encompasses this collection of ideas and as Krishna and Alswaigh (2014) have argued, it can be recognised not just as a way of improving patient centred care, but also as a way of exploring and recognising the multi-faceted phenomenon of dynamic and context dependent ideas present in meaning making. Personhood therefore is an important conceptual root for exploring the dementia experience and the meaning of memory loss.

Interventions related to person centred care and personhood have been recognised as making a substantial contribution to positive outcomes, psychological health, and quality of

life for all categories of patients (Sanderson and Bailey 2013, Sanderson and Lewis 2012, NICE 2011). As early assessment of symptoms and early diagnosis is becoming more common place in dementia care, people are able to retain more ability to be involved with decision-making, and in future planning, for when they can no longer make 'good' decisions.

As the push for early diagnosis has gathered pace in research and policy terms with the aim of stimulating decision making from the person's perspective; the interactions with medical staff and the individual's view of their illness in a medical and, increasingly in a social sense, has become a more prominent feature of the experience of early dementia. The concept of personhood has been used particularly in relation to vulnerable people at the start and end of life, and as Ploeg (2010) argues, it has shifted emphasis on dementia and ageing from a medical and mechanical framework, towards a more humanistic one, and represents a change in the conceptualisation of dementia within the location of ageing.

1.2.2   The Meaning of Ageing

The meaning of ageing is important in understanding dementia experiences because the two are closely related and entwined. Three main reasons relate the meaning of ageing with the meaning of dementia. Primarily, dementia is an age related illness with most cases appearing in those over 65 years and numbers are particularly concentrated in those over 80 years old, with 1 in 6 people affected (Alzheimer's Society 2013). Secondly, ageism in the modern society is combined with perceptions of dementia which reinforces the negativity of the illness, creating stereotypes and stigmatisation (Braithwaite 2004); and thirdly, as Hulko (2009) demonstrated, dementia is understood by some people as part of normal ageing.

We begin to age and develop from the moment we are born until we die, but aging is not just a biological pathway driven by physical changes; it is also a combination of psychological and social factors, and these are interpreted according to culture and social experiences, perceptions and attitudes. The variety of levels of material wealth, and cultural and social exchange, shape the experience of ageing in relation to class and gender through normative expectations and identities (Westerhof and Tulle 2008), and everyday interactions (Goffman 1968). However, as Braithwaite (2004) explained, stereotyping and stigmatisation label the whole person and age ordered group inaccurately because homogeneity is assumed, and particularity is not considered in an ageist society.

Psychological, physical and social functioning hold different age identities that are distinguished by positive and negative aspects (Montepare and Zebrowitz 1998) and build towards schemas of age at various points in the lifespan. Others (Keller et al 1989, Hooker 1999, Westerhof et al 1998) have found that positive aspects of older age related most strongly to social and psychological factors such as fewer responsibilities, relationships with grandchildren, wisdom from life experience, and freedom; whilst negative aspects were more strongly associated with physicality including loss of vitality, mobility, and changes in appearance and strength, importantly, loss of social position and loss of independence also rate highly in negative aspects, and particularly so when they impact on social relationships. Since these aspects are located socially, and with diversity, through class and gender, it is logical that ageing and dementia should be considered through a social lens in addition to the biomedical approach.

Age is unlike other social categories because it is one which most of us will join in time unlike ethnicity or religion, but the stereotyping associated with ageing is largely

unchallenged although destructive (Cuddy and Fiske 2004). Butler (1980) noted that ageism can be institutionalised and stigmatised in the same way as racism or sexism, changing a natural process into something that can be approached by some with dread. The emphasis of ageing in relation to dementia is therefore somewhat challenged by expectations of ageing and ill health. Pasupathi and Lockenhoff (2004) explained that health and sensory functioning are more variable among older people than any other age group, and that age alone is a poorer indicator of health in later adulthood than at any other time in the lifespan. Yet, medical professionals *and* older adults regularly consider such ailments as falls, memory loss, and incontinence, as symptoms of ageing rather than ill health (Pasupathi and Lockenhoff 2004).

Dementia aligns with ageing in the sense that it also can be understood within biological, psychological and social domains. Biologically the brain is changing, and an organic problem is developing; psychologically, emotions associated with forgetting and reducing cognition have to be reconciled; and socially, the symptom of memory loss creates issues around social perceptions and in relationships with others (Barry and Yull 2011). Therefore, the stigma associated with dementia requires negotiation in addition to that associated with ageing. Moreover because dementia is most common in older age, it is often confounded with the negative stereotypes of ageing. The 'dualism' (Phillipson 1998 p 113) of the positives of retirement, with the negative association of non-contribution to society and ill health (Butler 2005), taken together with the variation attributed to social divisions, contribute to a diversity of dementia experiences; the extent of which is under examination in this study.

Dementia challenges the positive experiences of ageing through memory loss, because the perceptions of relationships and independence are reduced. Concurrently, negative aspects of ageing related to appearance and loss of vitality are reinforced as dementia advances, and the templates built over a lifetime related to social identity are subjectively eroded. Westerhof and Tulle (2008) concluded that the identities of older people are reflected in discourses of everyday social interactions, so that viewing ageing as a process of physical decline produces a self-fulfilling prophecy of more decline. However, they also highlight how agency can create the possibility of resistance to negative discourses by feeling younger than chronological age. They argue that this is especially so in cultures that devalue old age in which subjective well-being is associated with health status.

Popular televisual images frequently portray and stereotype older people negatively as infirm, rambling and requiring 'looking after' (De Mendonca-Lima et al 2003). This image has been reinforced repeatedly in policy by concern over 'bed blocking' by older people (Moore 2003, Kings Fund 2013) and in the current surge of apprehension regarding an ageing UK population, resulting in raised retirement ages and concerns over pension provision (Department for Work and Pensions 2013). The contrasting views represent a confused approach to ageing that relate directly to economic wealth. On one hand, discrimination through ageism suggests that older people have a reduced status within society, whilst concurrently older people are recognised as a specialist consumer market that defines 'ageing well' with an improved health care and a booming consumer market.

Butler (2005) noted that most private intergenerational transfers go from old to young, and that most healthy individuals will have accumulated more savings and assets by their old age, than those with ill health. In addition, Turner (2013) reported for Joseph Rowntree

Foundation, that social divisions within generations are substantial, and therefore the experience of growing old can be framed around meaning generated through social class, as well as biological changes. Furthermore, the hard boundary of retirement no longer provides a fixed point of ritual passage into defining old age, because the relaxation of compulsory retirement ages in the UK in October 2011 has created choice over when to retire (Department of Business Innovation and Skills 2011), and provides further evidence of material differences in ageing experiences.

Views of ageing and dementia are therefore inextricably interwoven and are edified by expectations of older age. These expectations form a blueprint for the future that is held as a personal biography within which, if dementia symptoms are expected and considered 'normal', then the presupposition is that memory loss will not be considered a catastrophe. However, if expectations do not include dementia, and it is regarded as an ill health matter, then biographical disruption should be expected when symptoms develop.

1.2.3   Biographical Disruption and Narrative Reconstruction

The concept of biographical disruption at the onset of a chronic illness is important in the context of ageing and memory loss. Work focussed around 'personhood' (Kitwood 1997) and person centred care (Sanderson and Bailey 2013, Sanderson and Lewis 2012) recognise the individual nature of coping with an illness, medically, socially and psychologically. This point is emphasised by the introduction of personhood as a major target in delivering the National Dementia Strategy (Department of Health 2009) and adds to the evidence supporting the differential nature of any illness experience, including dementia.

The introduction of personhood, and interest in the psycho-social benefits of early diagnosis, have recognised and demonstrated that there is indeed a differential nature in the way that dementia is experienced (Kitwood 1997, O'Connor, Phinney and Hulko 2010, Milne 2009). Research from Hulko (2004) found a connection between social location and the lived experience of dementia, with social factors such as ethnicity, gender and social class all contributing to the meaning attached to moderate-to-late dementia. Although the precise influence of these factors remains unclear (Steerman et al 2005) there is an underlying assumption that class and gendered life time experiences produce a 'map' of future expectations, however the concept of biographical disruption (Bury 1982) at illness onset may challenge these future expectations.

Bury (1982) drew upon interviews with rheumatoid arthritis patients to explain how embedded lifetime expectations can be disrupted through *'a biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging'* (p 171). In the context of early dementia and noticeable memory loss, the biography or narrative that a person has constructed is now brought into question, and the future needs to be re-mapped and renegotiated. This is a concept that has been explored in a number of other chronic and life limiting conditions, for example in stroke (Faircloth et al 2004), Motor Neurone Disease (Locock et al 2009) and diabetes and multiple sclerosis (Larsson and Grassman 2012) that explored a range of the level of biographical disruption according to the perceived mapping of the future explained as 'biographical flow'. This is important to consider in relation to memory loss because in lay person conceptualisations memory loss may be considered part of biographical flow and 'normal ageing', whilst for the medical establishment, it requires a diagnosis and treatment (Scodellero and Pin 2011).

The notion of different conceptualisations of normalisation have been explained by

Sanderson et al (2011) as a way of understanding diverse responses to chronic illness. They

identified six typologies of normality in patients with rheumatoid arthritis on an axis from

disrupted through to continuing normality. Simon Williams (2000) noted the importance of

'normal illnesses' and the importance of timing and context in biographical disruption. He

explained why people choose to foreground one explanation for their illness over another

equally plausible one, and argued that reconstruction of personal narrative into an

acceptable resolution is pivotal in finding the meaning of illness. This can explain the

differential nature of the experience from a class and gendered perspective as memory loss

is interpreted in different ways according to lifetime experience. Evidence from Clarke and

Bennett (2013) emphasised this point and showed that illnesses were normalised and social

comparisons were made in gendered ways in order to achieve biographical flow in older

people with multiple chronic conditions. They reported that men's stories were significant in

reflecting *'norms of control, invulnerability, physical prowess, self-reliance and toughness'*,

whilst the women responded to *'feminine norms of selflessness, sensitivity to others and

nurturance'* (2013: 342). This important point further underpins the exploration of early

dementia from a social class and gendered perspective and suggests that biographical

narrative can indeed be reconstructed, even in the face of a life limiting and chronic

condition.

The move towards examining the attitudes to dementia by those experiencing it along with

the body of research detailed above has challenged the bio-medical view of generalising

dementia as a constellation of symptoms, and suggests that early dementia may be

experienced in multiple ways. The biomedical trajectory of the disease is one of irrevocable

decline (O'Connor and Purves 2009). However, particularly in the early stages of illness,

the person remains essentially the same person that they have always been, albeit typically with memory lapses and other cognition difficulties; thereby strengthening the influence of individual conceptualisations of memory loss and possible perceptions of stigma associated with ageing and dementia. Biographical disruption can be understood in terms of the impact of the illness, and narrative reconstruction can mitigate the effects of dementia as a highly stigmatising illness. This is particularly pertinent to people who have a long biography to disrupt, and a lifetime over which they have embedded personal narratives.

1.2.4   Impact of Stigma

In the UK, dementia is a highly stigmatising illness (Department of Health 2009, Innes 2009). Theoretical debate concerning stigma and the forms it may take originated from Goffman's (1968) seminal work in which he defines stigma as referring to attributes that are deeply discrediting because the person is reduced from 'normal' to 'something wrong'. Accordingly, forgetting can only be stigmatising if the person experiencing it feels shame through the discredit associated with memory loss; therefore the act of forgetting is stigmatising because of the value that is attached to remembering. Personal history is the essence of a sense of identity (Goffman 1968), so shame at forgetting how to perform usual activities, and recall loved ones birthdays for example, is central to stigma creation.

Stigma undoubtedly influences the meaning that memory loss holds through its association with dementia. The popular view of a dementia sufferer, sitting in a nursing home, totally removed from society, is a popular image (McKillop 2005, Kissel and Carpenter 2007, Department of Health 2009, Department of Health 2013a), and is the target of the improving

awareness campaign (Department of Health 2012) arising from the National Dementia

Strategy (Department of Health 2009).

Understanding the assault on identity posed by memory loss can be explained in part by

Goffman (1968) in his discussion of the relationship between labelling and assuming a

'master status' associated with the label. In this case, the label of 'dementia' strips the

person of their old identity and implants a new identity in line with socially constructed

views of the illness. This powerful process is evident in many dementia experience accounts

and blogs and features in celebrity and third sector campaigns that challenge labelling

perceptions of dementia. One such example is the author Terry Pratchett, who has continued

to author books since his diagnosis and has been vocal in promoting understanding of early

stage dementia (Alzheimer's Research UK 2013) by campaigning to challenge negative

public ideology. He also regularly takes part in chat shows and media events to dispel the

stigmatising image of dementia. This illustrates that individual reaction to dementia type

symptoms, is in part at least, governed by societal views as well as personal experience.

There is a current drive to educate the public and professionals about the needs of dementia

patients and raise the standing of the disease in social consciousness as typified recently in

the G8 Dementia Summit (2013) hosted by the UK. The re-education of people concerning

the stigmatisation of dementia has also been a matter of concern for some time within

academic and policy realms. Bannerjee (2008) stressed this point *'Dementia is quite an*

unattractive illness. It's seen as something dirty that should not be talked about. But if we

shut our eyes, it will not go away. It will only get worse.' Bannerjee also compared the

stigma surrounding dementia to that surrounding cancer in the 1950s. *'There is a false view*

that little or nothing can be done to assist people with dementia, and this has resulted in an

unwillingness to report early symptoms to the GP' (Bannerjee and Chan 2008). Bannerjee's view of challenging public perceptions aimed to encourage more people to speak to their GP earlier than they had traditionally considered, thereby alerting the public that memory loss can be a sign of dementia, with the hope that this may eventually feed into the collective consciousness of the public at large.

With the medical world in discussion of the benefits of early diagnosis it is not surprising that lay person advice is also a matter of considerable debate. People can often recognise actions that others should take, and can advise others on attitudes to illness; but when events are happening to oneself, own opinions are often distinguished from the given advice in some way (Calnan 1994). The profound stigmatisation associated with dementia reflects the fact that cognitive abilities relating to competence and capacity are valued highly in modern society more than in any other epoch (Bowling and Gabriel 2007, Husband 1999, Katsuno 2005, Lindesay 2008, Moniz-Cook et al 2006, Husband 2000) and this could account for the disparity in accepting advice.

Kontos (2005, 2012, 2013) has consistently argued that the modern emphasis on, and value of, cognitive capacity has driven stigmatising practice and informed social attitudes (Kontos 2005, 2012,2013, Kontos and Naglie 2007, 2009). She has highlighted this perception through research revolving around embodiment and selfhood, and has questioned the long standing notion that selfhood resides in the brain and hence, cognition. Kontos has drawn heavily on Kitwood's substantial and pivotal contribution to dementia research throughout the 1980s and 1990s, and she has explained how infantilization, stigmatisation and banishment of people with dementia in a socio-psychological and socio-cultural context, has labelled people based on the neuropathological and biomedical approach. Kontos's

approach and emphasis on the hypercognitive aspects of modern society go some way towards explaining why dementia is perceived to be such a threat to the sense of self, and why it has a pivotal role in demoting people from their own lives.

The theme of stigma has been raised in many testimonies of people with dementia and their families), and has been expressed as one of the key areas of detrimental effects to quality of life (Husband 2000, Department of Health 2009, Alzheimer's Society 2013). The desire to be treated as 'normal' and 'ordinary people' is often reported (Chronister et al 2013, Beattie et al 2004, Alzheimer's Society's 'talking point' forum) by people with dementia as they do not assess themselves to be declining as rapidly as those around them would suggest. This view is additionally upheld in accounts from people with dementia using social media such as Kate Swaffer who has dementia and writes an online blog at kateswaffer.com, and Leah who writes a blog for healthcentral.com. Research supports the view that general quality of life can be as satisfying for dementia patients as for the wider population (Byrne-Davis, Bennett and Wilcock 2006) although perspectives and domains of quality of life may differ (Droes et al 2006). This discrepancy indicates a mismatch between the internal experience of dementia and the wider social world's perception that dementia is a 'taken for granted' wholly negative experience. Whilst people with dementia assess their general quality of life as satisfactory they often report that the reactions of others creates negative social experiences (Kitwood 1998), and it is these negative social interactions that can have a profound impact on psycho-social wellbeing and create stigma (Bowling and Gabriel 2007, Betts Adams and McClendon 2006, Clare et al 2008). It is the sense of wellbeing gained through social interactions that is meaningful and central to social life (Dittman-Kohli 2005), and as Blaxter (1998 p 102) explains *'…variables which are more 'social' or personal than socio-economic – social support, integration or isolation, social networks,*

social roles and activities – are closely associated with health.' Therefore a strong negative response from society to dementia would impact upon daily activities and the quality of life that exposure of cognitive difficulties would bring; causing the person to withdraw from social encounters or not seek help at an early stage (Husband 2000, Calnan 1994, Barry and Yuill 2011).

The mismatch of felt quality of life by dementia sufferers and the depiction by others of dementia as an entirely invalidating illness has created a 'malignant social psychology' (Kitwood 1998: 23) that undermines selfhood through a process of stigmatisation, rather than through neurological breakdown. This perspective taken together with a society wide assumption of incapacity to make simple decisions even in the early stages of the illness as evident in the National Dementia Strategy campaign's encouragement to report memory loss, have amalgamated to create a universal depiction of the person with dementia as one who cannot reasonably function to judge their own wellbeing. Even as people with early stage disease are now included in discussions with doctors about their own care (Department of Health 2009), often policy and practice relies on, and encourages relatives to speak on their behalf (Department of Health 2009, Luke et al 2008) further reinforcing stigma associated with memory loss and eroding personhood.

Social position including that of dementia patient status, is experienced in relation to others via shared morality, values and emotions that are located in social class and gender (Sayer 2011). For example shame, compassion, respect and pride are evaluative judgements that are often based on a 'mental heuristic or 'rule of thumb' that has been embedded and developed over time according to the life experiences and perceptions of the individual' (Nussbaum 2004). These emotions are reflections of how we think others perceive us and

how we perceive ourselves and result in fear of stigma that is often reported by dementia patients (Husband 2000, Barry and Yuill 2011, Department of Health 2009). This is particularly relevant in the early stage of the illness when the patient has awareness that others may see them as lacking something that society values (Nussbaum 2004), and ties with Hulko's (2009) research that places marginalisation and privilege as important factors in shaping the dementia experience. Mental heuristics are hard wired mental strategies to shorten the decision making process based on earlier experiences. Heuristics regarding dementia arise from classed and gendered lives and are both formed by, and further the social stigma that is held society wide (Bannerjee 2008, McKillop 2005). The heuristics relating to stigma will inevitably be internalised into the individual's psyche because they are a short cut strategy rather than a considered evaluative process (Herbert 2010). The extent to which stigma is felt, may vary with social location and embedded knowledge, as well as individual factors, and create a complex intersection of competing pressures.

Campbell, Converse and Rodgers (1976) discussing quality of life over 35 years ago recognised that a person can evaluate their quality of life through their own internal experience, and that we should not assume to exclude an experience as invalid, based on disability or impairment. The fact that people with dementia argue that they want to be treated as 'normal' (McColgan 2004) suggests that they are able to recognise that they are being stigmatised by those around them. LeBel (2008) in discussing the perceptions of, and responses to, stigma noted that stigma-related research bridges many disciplines including sociology, psychology, social psychology and public health, and that much can be gained by considering research about one stigmatised group and applying it to another.

There is a vast body of literature relating to mental health and stigma, and within this a smaller but significant literature surrounding stigma within old age psychiatry and specifically stigma attached to such ingrained and stereotypical views that they are masked behind shared cultural beliefs and practices (Hinshaw 2006, Werner et al 2004). This concept of 'hidden in plain view' has been explored in terms of language used in everyday conversations (Werner and Heinik 2008), with obvious examples in expressions such as 'she is out of her mind!', 'you're insane!' and 'going round the twist'. These types of phrases are often 'throw away' comments but they represent a cultural norm of stigmatizing mental illness (Hinshaw 2006). The same can be said of the language of dementia with phrases such as 'away with the fairies', 'going senile' and 'losing it'. Foucault (1969) made an important contribution to our understanding of language of this type when he discussed the meaning of seemingly insignificant comments. He explained:

> *However banal it may be, however unimportant its consequences may appear to be, however quickly it may be forgotten after its appearance, however little heard or however badly deciphered we may suppose it to be, a statement is always an event that neither the language nor the meaning can quite exhaust … first …it opens up to itself a residual existence in the field of memory … secondly … it is unique, yet subject to repetition, transformation, and reactivation… because it is linked not only to the situations that provoked it… but…to the statements that precede and follow it.* (Foucault 1969: 31).

Foucault's understanding of the use of language is particularly relevant in explaining contemporary statements regarding dementia and age associated stigma across Europe. Examples include Carlos et al's (2003) support for the World Health Organisation (WHO) and World Psychiatric Association's (WPA) (2002) technical statement in finding that

stigma and discrimination against older people with mental illness were present in both the health sector and the public at large across Europe in such a powerful way, that they described old age and mental health as a 'double jeopardy' (pg 681), with Godfrey et al (2005) describing this layered discrimination as a 'double whammy'.

Almost ten years after the WHO and WPA statement, this pervasive problem of ingrained stigma at a cultural level was still apparent across Europe as Aromaa et al (2011) found that stigma against mental disorders generally was particular high among men, older people and those unfamiliar with mental illness, whilst Depla et al (2005) found that stigmatisation affected quality of life more than reduced social participation. This indicates that older men are more likely to find dementia stigmatising, and especially so if they have no prior knowledge of the illness.

The importance of noting gender and age differences from the mental health literature in relation to stigma, is that it further underpins the need for knowledge about social location and its intersection with the dementia experience. Milne (2010) declared that *'stigma permeates every dimension of the lives of people with dementia'* (2010: 229) and stigma encourages people with dementia to withdraw from social contact (Milne and Peet 2008), but the levels of withdrawal and permeation of stigma may vary according to individual life experiences that are played out through classed and gendered lives.

1.3 Theorising Social Location

1.3.1 Introduction

This section explains the theoretical framework for this study and offers argument supporting approaching early stage dementia from an intersectional perspective. This is important for this study because multiple factors relating to social location are present in understanding dementia, through health and illness, stigma associated with dementia and ageing, and social class and gender. In addition, social class relating to occupation alone is not appropriate for this group because they are retired, and so theorising social location in a more nuanced approach that can accommodate the complexity of dementia and older age is necessary.

Medical sociologists have been concerned with gender, social class and health behaviour for a number of years and have often examined these factors as 'stand-alone' alignments with which to analyse health patterns (Williams 1995). More recently health behaviour has been viewed through an intersectional lens as the importance and the complexity of social location and inequality has been more widely recognised (Hulko 2009, Ridge et al 2011, Turner 2013). Social location is important for understanding the experience and meaning of the dementia experience because it filters throughout meaning making processes and societal reactions to memory loss. The inequalities and properties associated with various aspects of social location come together to form the dementia experience typically towards the end of a lifetime of embedded socially located thinking. Bourdieu's (1986) conceptual framework of fields, capital and habitus provide an intersectional perspective of illness, social class and gender through which dementia can be explored (Rhynas 2005, Smith 2009, Bowman 2010).

1.3.2 Bourdieu: Forms of Capital and Habitus

Under the influence of postmodernism, sociology has moved from its earlier focus on social class and other forms of social structure towards a greater engagement with the individual and with agency (Savage, Warde and Devine 2005). The intersection between agency and structure and the role of reflexivity and subjectivity (Archer 2003) have become major themes in sociological research. These developments are important for dementia research, as they affect how we understand personhood in dementia care. Bourdieu (1986) viewed the social world as an accumulation of personal and social history (Bartlett and O'Connor 2010) and his concepts of social, economic and cultural capital have been used to explore the nuances of intersecting social inequalities in a variety of areas of research within health and social care.

Capital is described by Bourdieu in *The Forms of Capital* (1986) as *'what makes the games of society - not least, the economic game - something other than simple games of chance offering at every moment the possibility of a miracle'* (Bourdieu 1986: p 241). His approach recognised the connotations, and predictable and perpetuating nature of opportunities afforded to social locations through economic, social and cultural capital.

As recognised globally at the recent G8 Dementia Summit, dementia is present across social divisions (Department of Health 2013), and so how this illness is experienced by individuals within differing social groups is relevant and important to contemporary knowledge. Bourdieu (1986) explains to us that cultural capital can come in the form of cultural goods such as books and fine art, or in more embodied forms such as knowing how to access services (Bartlett and O'Connor 2009). He also explains the importance of social capital in

terms of friendship groups, neighbourhoods and collegiality, and in terms of material resources such as gadgets and transport. As Bartlett and O'Connor (2009) state *'From Bourdieu's perspective, the important point is that there are many forms of capital, not just wealth'* (p115). This is significant when addressing dementia because it is an illness related to ageing, and most often presents after retirement when changes are usually occurring in social engagements and material wealth.

The forms of capital concept offers a wider explanation and framework for understanding more about life chances, lifestyle and experience than classic class theory. Bourdieu rejected the deterministic view of mechanical explanations of social life through ascribed status, and furthermore, did not accept conscious and deliberate intentions as a sufficient explanation of actions (Jenkins 2007). Rather he recognised that there are underlying factors rooted in the different forms of capital that influence how we think of ourselves and the world around us (Bourdieu 1986). This more faceted view of social location enables examination of changing patterns of thought across the life course as status is achieved and lost; it is this factor that is vitally important in understanding the experience of early dementia.

In addition to forms of capital, Bourdieu's concept of habitus has allowed dementia research to explore personhood and the embodied state (Kontos and Ngalie 2009, Kontos 2005, Kontos and Ngalie 2007, Millett 2011, Twigg and Buse 2013) by understanding cultural and social dispositions rooted in experiences that regulate human behaviour (Bourdieu 1990). Habitus focuses on our way of thinking, feeling and behaving, and creates our disposition. *'It generates perceptions, appreciations and practices.'* (Bourdieu 1990 p 53). Bourdieu (1990) explains that habitus is our own history that has shaped how we respond to our present circumstances and governs how we make choices; it is also active and on-going, and

constantly under revision. Habitus is structured by our present and past, and is systematically ordered and not random, and it draws on elements such as our family upbringing and education (Maton 2008). Through habitus, our personal history is shaped, and our reactions to present circumstances are influenced by the meanings that we attribute from individual and collective practices embedded in social class and gender (Jenkins 2007), that will undoubtedly contribute to meanings associated with memory loss.

Social differences therefore are not totally embedded in class, but are also based on individual factors, for example the nature of skills that the individual holds, the motivation to work and social factors such as ethnicity, age, sexuality, geographical location and household circumstances to name but a few. These factors contribute to a person's identity and inform habitus, and define meanings of experiences. Bourdieu (1986) provides the theoretical framework for uncovering the influence on meaning creation related to social location in all its guises of economic, social, cultural and symbolic values (Sayer 2005), and as we understand that differences exist in meanings across these social axis, they are of importance in understanding the memory loss experience.

People with dementia are gradually losing the ability to make conscious and deliberate decisions (Alzheimer's Society 2014a) but they retain a social life and continue to take part in a socially constructed environment. They may gradually become removed from what they know of the world and their place in it, but there will be an 'official' or normative understanding of dementia that is constructed around lifetime knowledge and a version of the 'sick role' (Shilling 2003), concurrently, forms of capital are important in self-positioning and characterise how we are perceived by others. Normative accounts could include expectations for treatment, progression of symptoms, plans for the future, and what

these things mean for the individual. Bourdieu sees capital as encoded in a sense of self-worth, and in attitudes and awareness of others (Savage 2000), and for the person with dementia these things are acutely felt as the disease progresses (Aggarwal et al 2003, Askham et al 2007, Clare 2003, Husband 1999).

Any reduction in social capital value, such as the loss or reduction of cognitive powers in a society which prizes such things, will lead to a reduction of status and could account for stigma creation (Goffman 1968). In the early stages of dementia, sufferers may be aware of social mistakes and/or know what the disease trajectory is likely to be, and choose to withdraw from areas of the social world where their reduced capital is likely to be felt most acutely, thereby reducing stigma and preserving selfhood.

Bourdieu's (1986) model of capital explained as resources within a given social domain, is a concrete concept but it is flexible enough to identify social differences in more than one dimension, thereby allowing for meaning to be created by the subjective experience and the 'sense' of class and gender, even if it is not able to be identified directly by the individual (Skeggs 2002, Savage 2000). Bourdieu's view of social class is implicit in capital, but he does not set class boundaries or offer distinct typologies of classes (Crossley 2008). This explains class in a more social sense than can be achieved by examining material wealth or power alone. This is important for the people taking part in this study who are retired and therefore fall outside of classic class theory conceptions of categories of occupation, but whose sense of class and gender has been embedded across a lifetime.

Bourdieu was concerned with social practice and what individuals do in their everyday lives. He did not accept that individual decision making or social structures determine

everything about social practice (Bourdieu 2010). Bourdieu considered disposition or habitus to be a midway position between social structures and individual agency, in other words it is a habitual conditioning of social relations (Jenkins 2007). Habitus is in the minds of social actors and it contains generative schemas of the body, and it is the way that we make sense of the world through sensory experience (Shilling 1993). It is also present in our social interactions, so it is not abstract or idealist, or only manifested in behaviour; but it is an integral part of it (Jenkins 2007). Therefore, habitus is the mediating link between experiences and meanings. Habitus generated from class and gender based socialisation can influence the meanings that are attached to early dementia symptoms, and it is present in the conclusions drawn by Hulko (2004) that suggest that marginalisation and privilege play a role in the theorisation of dementia for each individual; and also in Bartlett and O'Connor's (2009) argument that personhood and citizenship are shaped by, and in turn, shape habitus.

Bartlett and O'Connor (2010) support a broadening awareness of heterogeneity in the experiences of people with dementia. They argue, the focus has for too long been upon the biomedical approach, or the psychosocial approach that is focussed on constructs such as 'coping', 'awareness' and 'identity'; they introduced the broadening of the debate to contrast personhood and habitus with citizenship, and pointed out the lack of literature that refers directly to examples that support socio-political positioning such as *'younger men with Lewy Body dementia, or to find analysis of the situation facing single older women with dementia on a low income'* (2000 p 6). Hulko's (2009) study provides an example of incorporating social position into the dementia experience discussion by documenting a range of interpretations from marginalised and privileged people with dementia. Wendy Hulko's study is rare in highlighting this important aspect that people with dementia can be living fulfilled and active lives, and that social position can influence the day to day

experience. Bartlett and O'Connor (2010) furthered this point by including the stage of life in which dementia occurs as influential in the personhood and citizenship debate, arguing that the notion of citizenship is tied to collective notions of being a 'good citizen' in old age (2010: 29), whilst personhood relates to the individual and the *'uniqueness of human experience'* (2010: 38).

Reaction to the onset of any illness will by necessity draw upon individual life history and habitus to create meanings and order to the present situation (Radley 2004). Social difference is also embedded in our past and shapes our socially constructed ideas about the world (Giddens 2006). Jenkins (2007) reflected on this point and argued that habitus can also be changed by shifting circumstances as it constantly re-writes personal history, and so the perception of memory loss rooted in habitus could influence the meaning that it holds, and change as new experiences become assimilated into understanding.

New experiences such as attending a memory clinic for the first time, together with input from class and gender, could contribute to an explanation of changed behaviour in the face of illness and feelings of loss of status. Bourdieu (1990) explained that 'Fields' are areas of social activity that contain a subjective sense of direction and outcome for those who commit to its presuppositions, and objective sense is applied in terms of social 'rules', rationality, and practices (Bourdieu 1990). From this explanation, it is clear that dementia and memory clinics achieve meaning through the ideas associated with them by implicit representations of those 'types' of people that attend them. The meaning that the memory clinic holds therefore, rests upon the understanding that the individual has of memory clinics and how and if clinics represent dementia.

Coping strategies would necessarily result from interactions between habitus and the immediate social field. However as each field has its own associated logic, (Bourdieu 1984), the explanation of how an individual may cope with the social field of dementia will be reliant upon their habitus or embedded life knowledge. Social fields can act as a producer of habitus by promoting specific behaviours, and in turn also be a product of habitus by reinforcement of the field's validity through the behaviours of its social actors (Jenkins 2007). This could explain the perpetuation of belief that dementia is stigmatising because, as a society, we value good health and good cognition, and have been guilty of measuring a person's worth by their function. A person's functionality as a measure of value has been a contested point for rights for disabled people for many years (Swain et al 2008), and is an on-going debate, but one that is beyond the scope of this study.

Bourdieu (1984) recognised formal occupation as an important factor in social identity but one that does not address the subjectivity of habitus. Two people may share very similar formal occupational status and have differing habitus due to their life experiences; and therefore a different ontological position of memory loss. Habitus is acquired as part of a personal journey through life and is instilled in culture, class and other fields (Bourdieu 1984), but a conflict could occur when a new field such as the medical world is encountered. This could form at least part of the reported emotional turmoil of memory loss (Husband 1999).

Class identity invites people to situate themselves socially. This has been shown to be problematic, as often class can be discussed in relation to others but is more difficult to recognise or define for oneself (Savage 2000, Skeggs 2001). This could impact upon the way that illness is experienced from a class perspective, and by the meaning that symptoms

hold for the individual, resulting in a range of medical and social experiences. This underlines the importance of examining memory loss from an intersectional perspective that can accommodate illness, class, gender and ageing. Bourdieu's ideas concerning the nature of habitus and the concept of capital fulfil this requirement for this study.

1.3.4 Gendered Lives

Gender is significant for this study because it is a structuring principle in responses arising from a life lived through socially located experiences and habitus. Social class and gender are inextricably entwined in this sense, because one cannot be actively considered without reference to the other (Crompton 2009, Skeggs 2002, Jenkins 2008). This argument is embedded in discussions of identity and its fundamental attributes. Bourdieu in *The Biographical Illusion* (1986b) refers to identity as a set of properties such as sex, gender, age, and social class, through which social identity is created. He explains that the personal life history goes beyond the official presentation of oneself, and is the sum of biographical events that are investments in social activities. Bourdieu's explanation of identity is important and explanatory for this study in understanding the personal, subjective and idiosyncratic nature of social classed and gendered experiences, and furthermore, foregrounds the individuality and particularity within the structural forces of social location.

Gender is important in understanding socially located responses because carrying out social activities becomes especially challenging as dementia progresses (Alzheimer's Society 2014). Research from care givers perspectives suggests that as dementia progresses, changes in gendered perspectives are particularly challenging both for the person with dementia and their relatives. Challenges may include the re-allocation of household duties in heterosexual and homosexual partnerships, and the reversal of caring roles (Roelands et al 2008,

Alzheimer's Society 2014b), along with social values arising from the home and the workplace (Skeggs 2002, Rakovski and Price-Glynn 2010), and gendered interpretations of coping (Dijkhuizen et al 2006). As dementia progresses and cognitive capacity reduces, individual social standing also becomes challenged (Sayer 2005, Goffman 1968). The perception and level of devaluing associated with these challenges could vary across social classes and account for a further stigma and impact on the understanding and meaning of memory loss.

Expressions of illness and pain and emotional displays are gendered to produce normative and socially acceptable behaviour (Radley 2004, McCall 1992). The topics of childbirth, self-worth and moral boundaries, as they intersect with gender and social class have been a focus for health and illness sociology in the postmodern era, and have illuminated the socially constructed nature of understandings (Bury and Gabe 2004, Radley 2004, Davey, Gray and Seale 2001, Acker 1973). Examples of the small body of literature concerning social location in association with early stage dementia have also identified gendered differences in the meaning of friendships whilst living with the disease (Dijkuitzen et al 2006, Harris 2011). These studies particularly highlight the feminine trait of a need for connectedness with others, which is based in lifetime experience (Barrett, Pai and Redmond 2012), and offers further support of the importance of habitus and social location in the dementia experience.

The majority of participants in this present study inhabit a particular era of societal changes in the shape of families and trends in marriage and divorce (Finch and Mason 2001, Skeggs 2001, Crompton 2009, Bottero 2012, Hartmann 1976), whilst concurrently being part of the generation that adopted traditional household roles (Rakovski and Price-Glynn 2010).

Consequently as one partner is diagnosed with dementia, the other may be forced to adopt a

new household role that they view as gendered, supporting the appropriateness of an

intersectional approach to dementia research that is present in this study.

1.3.3 Intersectionality

How different people broach, understand, and give meaning to the social field of dementia

is at the heart of this study, accordingly approaching social location combined with health

and illness, and ageing, requires a multi-faceted pathway.

Intersectionality is a term first used by Crenshaw (1989) to describe the socially located

factors of ethnicity and gender, and has a strong history of enquiry in feminist literature

(Plump and Geist-Martin 2013, Hulko 2009). The term can be used to explain the

interlocking influences of complex and multiple identity inequalities, such as ethnicity,

social class, gender, age, sexuality, faith and so on, and how together these each inform the

other to shape a person's life chances and view of the world (Giddens and Sutton 2013).

Hill-Collins (1995) quoted in Dressel, Minkler and Yen (1997) defined intersectionality as

'micro level processes – namely, how each individual and group occupies a social position

with interlocking structures of oppression' (1997: 583-584). Hill-Collins made a crucial

distinction between the micro level of individuality and the macro level of structures of

oppression such as gender, class, race and age. This intersectional approach combined with

Bourdieu's concepts of habitus and forms of capital, can be used to bridge the theoretical

traditions that have concentrated upon either macro levels of structure, or micro levels of

agency (Baur 2014, Archer 2003b).

Intersectionality recognises that identity categories are multi-faceted and are experienced simultaneously (Rakovski and Price-Glynn 2010). The focus on the person, and emphasis on the socio-cultural context of dementia has been progressing in recent times through research focussed on person centred care (Downs 2000, Kitwood 1997, Sanderson and Bailey 2013), citizenship rights for people with dementia (Innes 2002), and research examining the intersection of social location with dementia (Hulko 2002, 2004, 2009).

Person centred care has also recognised the differential nature to aspects of living with dementia *'...that living with dementia can be more or less stressful at different stages and in different people at different times...'* (Lipinska 2009. p 37). This illustrates the complex nature of experiences and upholds the need to investigate the differential nature of the experience of dementia from a sociological, as well as a biomedical perspective. Since stress is conceived diversely by different people at different times (Lipinska 2009), evidently, something other than biomedical illness is contributing to the meaning of forgetting, and could explain differences in engagement patterns with services, as well as psycho-social wellbeing and perceived quality of life (Milne and Peet 2008).

Debate concerning quality of life and psycho-social wellbeing illustrates the calls for a sociology of diagnosis (Jutel 2009) that reflects the culturally specific nature of a diagnosis, and also supplies the definition for dysfunction, and the label for what should be treated. In the undiagnosed phase of dementia, the individual relies upon the cultural meaning of their symptom to classify its identity rather than the biomedical definition (Jutel 2009), therefore meaning making is constructed from knowledge gathered through a lifetime of classed and gendered life experiences.

Furthermore, Heller et al (2008) argued that class differences were apparent in the recognition and treatment of mental disorders, and suggested that services should be tailored according to social class. They argued that social class defined the cultural importance and meaning of 'disordered behaviours', and shaped engagement patterns with services. Heller et al (2008) distinguished cultural meaning from clinical diagnosis, and this distinction can be applied to meanings of memory loss.

The arguments presented emphasise the need to consider the situation of people with dementia from a broader conceptual position than that offered by either a biomedical framework or a purely psychosocial one, and that can take account of social purpose and participation connected to social location. Bourdieu (1986a) conceptualised forms of capital and habitus as being involved in the reproduction of class and gender, and therefore can aid explanation of the hierarchical nature of social relations and conventions of behaviour that underpin arguments such as those posited by Heller et al (2008) in relation to mental illness, and those of personhood and citizenship raised by Bartlett and O'Connor (2010).

1.4 Early Interactions with Illness

1.4.1 Introduction

The participants in this study were recruited following their first contact and referral to memory services by their GP, therefore how early stage illness is given meaning, and the behaviours and beliefs that are associated with early illness interactions are important to review. Recognising class and gender as an important factor in shaping responses to illness,

implied that they will also impact helpseeking, coping behaviours, liminality, and medical

engagement, therefore these are salient topics for consideration in this study.

1.4.2 Help-Seeking Behaviour

The term 'help-seeking' has been used routinely within the medical realm for over 50 years

(Cornally and McCarthy 2011). Although the meaning of the term was regarded as self-

evident (Rickwood, Thomas and Bradford 2012), attempts to define it have derived largely

from mental health and nursing literature with common characteristics revolving around

'coping responses and a search for assistance from external sources' (Rickwood, Thomas

and Bradford 2012) related to health beliefs, and this is used for this present study.

Research accounts of living with the symptoms of dementia highlight societal reaction, and

the individuals understanding of their illness (Keady et al 2007, McKillop 2005, O'Connor

and Purves 2009, Hulko 2009), whilst first-hand accounts that are unmediated by

researchers are also accessible through biographies and autobiographies of people affected

by dementia (Bryden 2005, Stokes 2009, Conradi 2010, Talbot 2011). These accounts give

powerful and insightful narratives of the living with dementia experience. What is striking

about research and published narrative and biographical accounts are the interactions with

doctors that shape help seeking patterns.

Many studies have shown that there are differences in the reported rates of ill health

between men and women (Macintyre, Hunt and Sweeting 1996, Blaxter 1998) with women

consistently reporting higher levels of ill health than men. However Macintyre, Hunt and

Sweeting (1996) argue that this is more complex because most of the excess in female

engagement is related to *'psychological manifestations of distress'* (p 623), with most

occurring during childbearing years and a concentration of activity around the time of the

menopause. Once this is taken into account, there is little or no gender difference in

reporting physical conditions to a doctor. However, within the mental health literature there

is a notable difference in the way that men and women engage with doctors. MIND (2009)

highlight in their report *'Men and Mental Health'* that men are far more likely to watch

television or engage in physical activity to relieve their distress than see a doctor, whereas

women prefer to discuss with friends and family before engaging with professional help

(Dijkuitzen et al 2006). Ridge et al (2011) noted that very little is known about the

subjective meanings men give to distress, coping strategies, or for help seeking, and this

may be reflected in the engagement patterns of men with dementia.

What is known is that gendered help seeking behaviour is apparent over the life course, with

women far more likely to be experienced in help seeking than men, and are far more likely

to be able to discuss psychological distress with their GP. Evidence also indicates that men

find it particularly hard to engage with a doctor to discuss mental illness for fear of being

regarded as unmanly (Barry and Yuill 2008).

Busfield (1996) explained the importance of class and gendered constructions of mental

illness by highlighting that different illness perceptions exist in constructions, but not in

definitions of certain illnesses. She highlights anorexia nervosa as a typical example of this

because for a variety of social reasons, it is more frequently diagnosed in middle class

young women and girls, although men and boys can also experience it. Similarly, dementia

is age ordered, and Bamford (2011) noted a minority view in research that dementia is age

related, but not necessarily age dependent, thus highlighting the debate of demographic

prevalence measures, although the Office for National Statistics (2013) show that dementia is a leading cause of death for older women.

The gendered differences in mortality rates (ONS 2013) and earlier male in-patient discharge from hospitals, has led to a socially constructed view that older women are more often affected than men. In addition, Busfield (1996) highlighted the importance of marital status on perceptions of mental health, and found evidence that married people make less use of services, but among the married, female rates are higher; leading to the suggestion that as married people are numerically greater, the higher female rate is the noticeable statistic because it is more reliably reported. Additionally, Bamford (2011) highlighted the complexity of the intersection of gender, age and dementia in drawing attention to the disproportionate number of women to men among the oldest old (over 85years). Whilst the Alzheimer's Society (2014e) state that two thirds of people with dementia are women, therefore, a combination of these factors could explain the lay perception that dementia is predominantly an 'older female' illness.

McClearly et al (2012) found that people would often attribute early signs of dementia to ageing or personality, and that spouses and partners would modify the environment to take account of the changing behaviour for up to four years prior to seeking help. It was often the onset of another illness that highlighted cognitive difficulties to doctors, or when the involvement of other family members' living outside of the home encouraged contact with medical help, because they noticed deterioration in the time lapses between visits. Knowing when to seek help for memory loss can be difficult because it can be attributed to causes other than dementia. West (2003) stressed that *'the events and changes in the life of a person with early stage dementia who has yet to be diagnosed are generally only*

recognised as significant in retrospect.' (2003: 16). She argued that medical help was only

sought when a second or third incident occurred, or when somebody commented on

behaviour or mood.

Reasons for not seeking help as soon as symptoms become noticeable to the individual are

varied. Fear of diagnosis appears to be a major factor, particularly fear of Alzheimer's

disease and the associated stigma that is attached (Milne 2010). This may be because

Alzheimer's disease is more deeply ingrained in the public psyche than any other type of

dementia (Katsuno 2005). Previous studies have revealed that the associated fear of

devaluation, social exclusion, and social stigma, and the fear that nothing can be done are all

given as reasons not to seek help (Katsuno 2005, Clare 2003) and could contribute to

attributing memory loss to another cause.

Prior engagement with the medical world seems to underpin the intention to screen for

Alzheimer's disease. People who pursue, for example, dental checks and cancer screening

are more likely to seek help when they are worried about their cognitive function, with

cancer screening being the most powerful indicator (Galvin et al 2007). The intention to

screen could be interpreted as a willingness to discuss cognitive problems and encourage

discussion about diagnosis, and implies that the person wants to know what is wrong with

them. Health education and general awareness of dementia fuel the 'need to know'

mentality, and point towards an early disclosure of diagnosis being beneficial (Department

of Health 2009, Turner et al 2004). As a result, these individuals are more likely to engage

in help-seeking behaviour sooner in the disease trajectory, and this is also closely associated

with social class because middle class people are far more likely to engage in screening

programs (Galvin et al 2007).

Partaking in screening suggests the desire and/or ability to know the diagnosis, and social constructs such as social class and gender impact on the process, therefore, awareness of dementia can be considered to be multi-dimensional, multi-contextual, and resulting from the complex interaction of many factors, including cognitive function, individual psychological responses to reduced cognition, and importantly the social context (Woods and Pratt 2005).

The interaction between the social construction of dementia and the individual experience therefore requires negotiation and is pivotal in examining help-seeking, and coping with entering the liminal phase pre diagnosis, and moreover, is central to personhood.

1.4.3 Coping Styles

Bury (1991) defined 'coping' for the discipline of sociology to mean *'the cognitive processes whereby the individual learns <u>how</u> to tolerate or <u>put up</u> with the effects of illness'* (1991: 460 emphasis in original text), and this ability will vary from person to person because it is heavily influenced by past experiences and personality, interacting with the awareness of symptoms (Clare et al 2005). Through personal history and experiences, a person will develop a preferred way of dealing with difficult situations. Some people adopt a 'head on' approach to coping, whilst others attempt to minimize the threats to self and try to explain away or normalise their difficulties (Clare 2003, Clare et al 2005, Department of Health 2009, Chrisp et al 2012). People sometimes wait many months or years before seeking medical advice for memory loss (Department of Health 2009, Basic et al 2009, Caltagirone et al 2001), however they will often consult with family and close friends in the interim in an effort to secure reassurance (Stokes 2009, Steerman et al 2005). However,

supporters will sometimes overlook the importance of symptoms and explain them as normal behaviour by attributing them to a range of other possible explanations such as tiredness, stress reaction, depression, or old age (Graham and Warner 2009, Hamilton-West et al 2010). This illustrates the importance of the meaning that is attached to dementia symptoms for individuals, and supports Hulko's (2009) evidence that plausible reasoning of symptoms is influenced by habitus.

Lack of awareness can be a cognitive symptom of dementia, but it can also be confused with the adoption of a 'self-maintaining' coping style (Clare 2003). This style is broadly a 'business as usual' approach. The person adopting this style will theorise symptoms as normal ageing as Hulko (2004) and McCleary et al (2012) found in more marginalised groups. This contrasts with a 'self-adjusting' style in which the person will react to symptoms and seek advice from friends and family and eventually seek medical help (Clare 2003, Roelands et al 2008) and broadly corresponds to more privileged people. This apparent contrast in response to coping with memory loss goes some way to accounting for differences in help-seeking behaviour.

Hulko (2004) suggested that multiply privileged people are more likely to theorise their symptoms as an organic brain disease and seek help, whilst multiply marginalised people are more likely to make use of normal ageing theory to explain their symptoms. Although her sample was small and also included divisions of ethnicity, the interaction of meaning making and its associated coping style, together with social class and gender based in habitus, may explain why some people wait before seeking help from their GP until the later stages of the illness, and importantly influence the nature and meaning of the phase prior to diagnosis.

1.4.4 Liminality

The transitional phase of the diagnostic pathway provides the location of resolving the situational transfer from health to illness, therefore creating a liminal period. The concept of liminality has its roots in anthropology and the work of van Gennep (1960) who developed ideas around 'rites of passage' to describe people moving from one social status to another. This idea was furthered by Turner (1969) when he described this state as 'betwixt and between' (1969: 95), or being removed from an old status but not yet fully incorporated into the new status. This description is relevant for this study for helping to describe the in-between phase from 'healthy' to 'dementia patient' and exploring the early stage of dementia when cognition is becoming uncertain and the future is unpredictable.

The impact of the resulting 'state of imbalance' (Nicholson et al 2012) or liminal phase (Babcock 2001) can be linked to the acknowledgement that the individual has of their memory loss. Clearly if the individual feels that no loss is present, then they will not experience the in-between, unbalanced phase of waiting for a diagnosis. If the individual suspects dementia as a diagnosis, then the impact of the period of waiting throws them into an undefined status of being neither cognitively ill nor well (Murphy et al 1988).

Liminality as defined by van Gennep (1960) is characterised by separation or stripping away of the old identity, liminality as a mediating phase, before lastly, reincorporation back into society with a new identity. Anthropologists have used this model to note that those in a liminal phase are often powerless, suffer a complete lack of autonomy and are classed as a homogenous group (Whalley-Hammell 2006). Parallels can be drawn from this conceptualisation to the traditional view of dementia patients as a wholly homogenous group that lack autonomous thought. Although anthropologists use liminality to describe the

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rites of passage from a subordinate state to a superior one, Murphy et al (1988) equated

liminality to disability and explained that being in neither of two states could be useful for

theorising health, illness and disability. The 'no man's land' between referral and diagnosis

and the perceived powerlessness of those in a liminal state raises issues relating to the stress

of waiting for a diagnosis.

The stress that a person feels whilst waiting for a medical assessment and diagnosis will

vary according to the interaction between the individual and their environment (Bury and

Gabe 2004). The variance in the early dementia experience will be influenced by the

pathology of the stage of disease, and will also undoubtedly be influenced by individual

psychological experiences and life history. Psychological studies based on the general

population have shown that individual differences are apparent in how we deal with

stressful situations (Adame and Hornstein 2006). 'Stress inoculation' (Meichenbaum 2008)

or 'psychological resilience' through dispositional optimism and subjective well-being, may

influence the ability to cope with adverse situations (Kobasa 1979, He et al 2013). This

could partially explain why people with dementia express different emotional cultures or

'feeling rules' (Stets 2010) when memory losses occur, that are based in habitus and are the

emotional legacy of previous experiences of the medical world. Therefore as the person

experiences stress, uncertainty, and possibly fear at noticing memory loss, they can draw

upon their past to provide explanations for their situation (Clare 2003, Keady et al 2007).

The literature surrounding the sociology of health has for some time recognised that

uncertainty surrounding the meaning of symptoms can create considerable distress and

anxiety. As Blaxter (1998) explained *'you don't think about health until you're ill'*

(1998:148). For people experiencing memory loss, uncertainty surrounds not just the

meaning of forgetting, but also uncertainty regarding one's own ability to know when one

has forgotten (Mental Health Foundation 2008). The often protracted period of time from

first noticing symptoms, to visiting the GP and subsequent referral to the memory clinic and

diagnosis, realises a lengthy time frame that can create high levels of anxiety (Department

of Health 2009). This anxiety is often compounded by unhelpful comments from health

professionals and family and friends alike, who dismiss memory loss as part of normal

ageing (Mental Health Foundation 2008).

Anxiety created by uncertainty in the specific context of dementia is under researched but is

evident in the literature of other disabling conditions that also have a protracted diagnostic

process and are under diagnosed in the early stages of illness, such as irritable bowel

syndrome, fibromyalgia and chronic fatigue syndrome (Wessley and White 2004). The

distress caused by the delay in being given a diagnosis is pivotal in increasing anxiety as the

uncertainty persists (Moss-Morris and Wrapson 2008) and this is comparable to dementia.

Alaszewski et al (2006) examined how stroke victims adopted various measures to manage

the liminal and uncertain route to recovery. Managing uncertainty for stroke victims became

important as it increased anxiety and undermined security in activities of daily living

(Charmaz 1994). These are also features of dementia as memory loss increases and the

person becomes more reliant on others. Stroke can create an awareness of new dangers,

such as activities outside of the home and damage to social standing (Anderson and

Whitfield 2013) which is comparative to that reported in dementia biographies. Stroke

victims may adopt various measures to manage this uncertainty such as shortening time

horizons, abandoning long term plans and concentrating on the present (Alaszewski et al

2006). These measures have also been recognised in policy as a primary target of the

National Dementia Strategy (Department of Health 2009) through shortening the diagnostic process, and thereby creating more time for people to think about the future whilst living in the present.

Whilst many comparisons can be drawn, important differences are apparent. Stroke survivors may move on to setting new goals and measure recovery in terms of a return to valued activities (Alaszewski et al 2006); however dementia patients experience the reverse. As time passes, dementia patients will suffer further decline and this means that measurement is through the loss of goals and valued activities, rather than marks of recovery. However, even faced with this situation, dementia patients still generally report a sense of the diagnosis allowing things to make sense and a re-gaining of balance in daily life through the assurance that the symptoms were due to an organic brain disease, and not as a result of 'going mad' (Milne and Peet 2008). Keady et al 2007 explained that after the dementia diagnosis is disclosed, thoughts of 'taking each day as it comes' and 'making the most' of the lucid times ahead are often expressed, and these tactics can go some way towards managing and coping with uncertainty in conjunction with predisposition, constitution, temperament, and resilience associated with social class and gender (Herzlich 1973).

Continued participation in the social world is a key factor for all categories of patients and is widely recognised in the medical literature as aiding recovery, coping abilities, and managing uncertainty (Radley A 2004). This important point is evident in stroke survivors for whom the re-engagement in their social world, rather than regaining physical function is crucial. It is '...*an intensely personal experience, involving rebuilding and restructuring of an individual's world...the social context of recovery...was enabling participation in the*

social world through adaptation and development of coping skills, rather than improvement

in discrete physical function alone.' (Burton (2000) p 307).

Similarly for people with dementia, the continuation of social activity is often cited as a key determinant of quality of life (Gabriel and Bowling 2004, Wilhelmson et al 2005, Bowling and Gabriel 2007). Enhancing quality of life is emphasised as a key domain within the National Institute for Health and Care Excellence (2013) quality standards, with positive experiences of care and support a specific target for improvement. The uncertainty surrounding how long a person will be able to engage with their current social world is damaging to positive experiences and is potentially driven by the stigma and fear popularly associated with dementia, but also by individual understanding and meaning of memory loss. The structure of the individual's social world and their conceptualisation of it, will vary according to the intersection of many social factors (Hulko 2004), and how these factors inform the meaning of forgetting is relevant to engaging with, and the symbolism of, medicine.

1.4.5 The Symbolism of Medicine

The symbolism and meaning of medicine is important to address because it would inevitably shape the responses given to my inquiry. This literature emerged as significant because my interactions with participants were taking place at the point in time in which they were in first contact with the memory clinic. Understanding how and why participants engaged with medicine at this particular point in time would reveal itself later to revolve around the meaning of dementia as a psychiatric illness, or as an organic problem, and the symbolism of medicine for dealing with memory loss.

Traditionally doctors were considered superior by the general public and their position of power and scientific knowledge was rarely challenged (Nettleton 1998, Illich 1977). This view was embedded in dementia research as great focus was placed upon pathology and 'caretaking' patients, and indeed the recent G8 dementia summit (2013) still focussed heavily upon this paternal medical approach. At the same time we have seen a major increase and encouragement of 'emotional talk' between patients and professionals that resulted in person centred care (Brownlie 2011). Professionals are now expected to engage with the biomedical view of the body, and also with the emotional health and stability of patients. The emotional engagement of the memory loss patient with the professional, could therefore become challenged if the patient has decided to 'not go there' in emotional terms (Brownlie 2011), or indeed if the professional does not ascribe to personhood and adopts a more biomedical view of memory loss.

Accompanying the potentially uneasy fit of emotional engagement with medicine may be a fear of disclosing memory slips to the GP, especially if these are perceived as mental health issues. Dew et al (2007) explained that patients may be motivated by fear of the underlying representation of services. This is an important point for this current study because if memory loss is regarded as a mental illness, then the associated stigma could explain why some people choose not to confide in their GP, whilst concurrently engaging successfully for other health problems. This point corresponds with the notion of personhood in Kitwood's (1997) sense of the context of the relationship between patient and doctor and also re-visits Foucault's (1969) assertions discussed earlier in this chapter, of the power of language and its association with knowledge creation. The assertion is that the language of the bio-medical world creates a sense of power over patients that results in the adoption of

Goffman's (1968) 'master status', thus removing everyday responsibilities from the person with memory loss.

Removal of respect for decision making for people with dementia has been discussed by Manthorpe and Moriarty (2010) in relation to risk. They explain that a lack of research literature, except that in medical terms relating to risk of developing dementia, has led to a situation in which *'there is probably more user, practitioner, and organisational knowledge about risk than there is research'* (2010:16), highlighting the importance of knowledge gained from those most involved in daily experiences with dementia to inform policy and practice. Moriaty and Manthorpe (2012) pointed out that this kind of knowledge presents a 'research – practice gap' resulting in a lag between daily practice and research evidence that is hard to access. Yet it is precisely this kind of lived experience knowledge and subjectivity that forms the core of person centred care, and is pivotal in understanding meaning making for early stage dementia.

The notion of personhood and person centred care in dementia care has gathered momentum, and there has been a corresponding growth in social research adopting this approach (Kitwood 1997). Research in the past relied on the view of carers and relatives, making the assumption that the person with dementia would not be able to provide reliable data. This view has, however, been increasingly challenged in recent times (Kurz et al 2008), and there has been a marked growth in work that focuses directly on the views of people with dementia in research and policy making. This more inclusive approach has gathered momentum and has been supported by a variety of sources including large charities such as the Alzheimer's Society (2014c), health and social care research in a number of empirical studies (Wilkinson 2002), political ideology (G8 Summit), lay person beliefs

represented in popular magazines, books and news articles, and by arguably more informed

public views such as those embodied in the Alzheimer's Society's talking point online

forum.

Bury and Gabe (2004) argued that this marked shift in conceptual thinking coincides with

the growth in public willingness to challenge doctors' decisions, and is linked to a growing

lay assumption that the medical profession should be expected to address all illnesses and

conditions. This view is evidenced by the growing numbers of legal cases and challenges

about the use of dementia medicines (Alzheimer's Society 2007a, Patient Plus 2012,

Harding and Peel 2013). The availability under the NHS of certain dementia drugs has been

questioned in recent times and has raised the profile of dementia patients in the medical and

lay consciousness as a patient group who have a voice, rights and entitlements (Dyer 2008).

This shift in the public perception of new medicines and the medical profession, has

potentially altered the symbolism of medicine for memory loss. With the promise of

medication that might mitigate the symptoms of dementia, comes a perception of

entitlement to treatment that is tied to personhood and person centred care that is evidenced

in memory clinics.

1.4.6 Policy Development

The UK Government launched its first ever National Dementia Strategy in February 2009.

This set specific aims of improving public and professional awareness, a commitment to

early diagnosis, and improving the quality of care for patients whilst saving costs and

resources. This Strategy was the first explicit prioritisation of services for older people's

mental health and flows from the National Services Framework for Older People

(Department of Health 2001) and the publication of the Dementia UK (Alzheimer's Society

2007a) report into the state of dementia prevalence and services (Banerjee and Chan 2008).

Whilst it is clear that services and provision have been reorganised in recent years, the

question of the social impact of memory services is somewhat unexplored. As part of the

National Dementia Strategy (Department of Health 2009), there was a promotion of the role

of memory clinics from being a provider of caring services and information, towards a

direct role in diagnosis. They now offer a single point of GP referral to a range of

professionals (Walker and Butler 2001) with the current average waiting time for

assessment being approximately 5-6 weeks and provide a recognised diagnostic route from

initial assessment at the clinic of around 8 weeks (Royal College of Psychiatrists 2013), as

well as treatment and advice (Department of Health 2009, Kelly 2007).

GPs often adopt a 'watchful waiting' policy before referral to services because they are

reluctant to tell the person what they are looking for, due to the stigma and fear that

surrounds dementia (Department of Health 2009, Fisk et al 2007, Basic et al 2009, L.Clare

2003, J.Clare 2007). Through this liminal stage of watchful waiting, memory loss has

typically developed, and so the person experiencing this symptom will have been coping

with increasing cognitive difficulties for some time before the official diagnostic pathway

commences, and the person may have been surmising during this time about the potential

causes. The GP process of watchful waiting has consequently created a catalyst for the

experience of memory loss to be questioned and analysed by the individual experiencing the

symptoms.

The meaning of a referral to the memory clinic in the context of this study, is simply as a backdrop to accessing potential participants, and I emphasise that the service that they provide is not under scrutiny. However, through being referred to a memory clinic and the prospect of a diagnosis in the near future, it would be reasonable to assume that making sense of memory loss would be in the forefront of thinking for many people that are referred.

The role of the memory clinic in lay understanding raises an important issue, primarily it questions what dementia *is*. Dementia's placement within Mental Health Services for Older People (KMPT 2014) adds to public confusion of dementia being regarded as a mental illness or an organic one. In addition, the NHS advises patients that their GP referral is:

> *'to a specialist such as a neurologist (an expert in treating conditions that affect*
>
> *the brain and nervous system), an elderly care physician, or a psychiatrist with*
>
> *experience of treating dementia. The specialist may be based in a memory clinic*
>
> *alongside other professionals who are experts in diagnosing, caring for and*
>
> *advising people with dementia and their families.'* (NHS Choices 2013).

This is an important factor in establishing the meaning of memory loss at the point of referral, and precisely the time at which participants are engaged with this study.

Traditionally dementia has lagged behind other illnesses in social status, and in doctors' attitudes to diagnosis and disclosure (Turner et al 2004, Loppenen et al 2003, Bannerjee 2010). A direct comparison can be drawn between cancer patients' experiences of diagnosis disclosure over fifty years ago in which relatives were often told first and asked to make decision in the interest of the patient (Taylor 1988), and the current disclosure of dementia Until recently, doctors still often did not disclose a dementia diagnosis to the patient

(Karnieli-Miller et al 2007, Kissel and Carpenter 2007), and preferred to either withhold the diagnosis, or disclose to relatives of the patient for fear that it would be too upsetting. However, patients are now largely satisfied that doctors can be trusted to disclose and will actively seek experimental treatments and new drugs if they are perceived to be of benefit (Calnan and Sandford 2004).

The 'common sense model of illness representations' (Leventhal et al 1980) suggests that healthy people will often perceive the diagnosis of a major medical threat like dementia as wholly negative. However, evidence suggests that the patients themselves often hold a much more realistic and positive perception of their condition (Weinman and Petrie 1997). This appears to be the case for people with dementia although this area is under researched. Carpenter et al (2009) argued that most people do not appear to suffer emotional catastrophe on diagnosis, but report relief that the extended liminal period of living with undiagnosed symptoms had come to an end, and that a treatment plan can now be developed.

Concerns about adverse psychological reaction to diagnosis are usually raised by family members and care givers (Milne and Peet 2008). Their collaboration with clinicians in deciding which information to disclose and which to withhold (Fahy et al 2013, Kissel and Carpenter 2007 Karnieli-Miller et al 2007, Fisk et al 2007) demonstrates the lack of decision making that is often afforded to the person with dementia. However, with the introduction of the National Dementia Strategy (2009), this position is changing towards more shared or informed decision making (Royal College of Nursing 2014). This has also been reflected in research in which participants with dementia can speak with their own 'voice', and are no longer hidden or guarded by doctors and relatives (Wilkinson 2002). Moreover, they are

also best placed to assist with research such as this to provide insight into the differential nature of the early dementia experience.

1.5 Conclusion

The discussion presented considered social class and gender as fundamentally important for examining memory loss and the early dementia experience. In this context, the subjectivity of the individual is the primary focus in understanding the meaning of memory loss. Bourdieu's theoretical perspective of forms of capital and the formation of habitus provide an excellent tool for conceptualising changing social patterns associated with ageing, retirement, ill health, social class and gender, whilst allowing for a lifetime of experiences through habitus to be assimilated into current thinking about the memory loss experience.

The current policy position is to achieve diagnosis within an eight week diagnostic pathway (Royal College of Psychiatrists 2013). The importance of this point is that the participants would already have been referred by their GP, engaged with the pre-diagnostic nurse and discussed their memory difficulties, and possibly be at a point of undergoing physical examinations prior to commencing participation in this study. All of this activity would undoubtedly have primed the participants in thinking about their memory loss. Typically at this stage, patients are living at home and subject to all their usual social influences that shape class and gendered patterns of thought along with lifetime experiences. The resulting meanings can be explored from an individualistic perspective accessed through the single point of the memory clinic.

Social identity conceived and understood through social location and individual biography, are important for forming expectations of the future. Therefore, when dementia presents, it

is important to understand how it is given meaning and understood by those experiencing it. In examining social class and gender as axis of social identity, it is possible to conceptualise the meaning of dementia from the subjective viewpoint of those at this particular intersection of health and illness.

In the next chapter I address my methodology for teasing apart the meaning of dementia and its relationship to explaining the diversity of experiences of early stage dementia.

Chapter 2: Design and Methods

2.1 Introduction

This chapter will discuss the design of this study and the methodological approach undertaken to understand how early stage dementia was given meaning at the intersection of social class and gender. It is worth re-iterating at this point the main research question:

❖ *What influences the differential nature of the experience and meaning of dementia?*

This question was aimed at investigating the social aspects of living with the early dementia symptom of memory loss before dementia had been formally diagnosed, and whilst the person was in an early stage of medical investigations for their memory problems. The meaning making of memory loss and its connection with dementia was predicted to shape the experience of this transitional phase in conjunction with the social location of the participants. As Mason and Dale (2011) explained, the methods of investigation that are chosen influence the quality and scope of the knowledge generated; therefore my methods needed to be rigorous to produce reliable findings, and sensitive to capture the meaning that memory loss held at this particular point in time.

My approach is distinguished from earlier approaches to dementia research as it addressed the experience of probable early dementia by privileging the person experiencing indicators as central to the understanding and meaning of memory loss (Downs 1997). Rather than constructing accounts of patients' experiences and symptoms based on the diluted and 'second hand' accounts of well-meaning others; I sought to establish concentrated first-hand accounts of the experience of memory loss, and how the early symptoms were rationalised by a range of socially diverse individuals. My epistemological position was therefore very clear, that people experiencing memory loss were perceptive and insightful of their

experience, and were best placed to create knowledge of the subjective meaning and understanding of memory loss from their familiarity and knowledge of it. My role as a researcher was to scrutinise these experiences through the intersectional lens with a focus on social class and gender in an effort to construct a wider societal perception of the memory loss experience.

I was not aiming to seek a universal truth or generality about early stage dementia that equally applied to all people, but I was targeting the understanding of a range of social location perspectives of the experience. I therefore drew a sample that purposely represented gender and a range of social backgrounds within the limitations of the memory clinic cohort during the data collection phase, in order to achieve a fuller understanding of the social experience of memory loss, and by association, early stage dementia.

My approach was to engage my participants in unstructured qualitative interviews that explored the social aspects of living with memory loss. The fieldwork phase targeted people with recent GP referrals to the memory clinic, who agreed that I could visit them at home and ask them about their experiences. I used a narrative approach both as a methodological tool and as my interpretative focus to understand how the meaning of dementia was created and expressed within differing social locations through the phenomenon of memory loss.

The first two sections of this chapter are a critical analysis of the methodological approach of interpretative phenomenology and explain the relationship between this approach and the research question. Through an explanation of the strengths and limitations of this approach, I demonstrate the appropriateness of adopting an interpretavistic stance in understanding the issues at stake; namely the experience and meaning of early dementia. The epistemological status of dementia within this study, and its presentation as an entity that can hold particular meaning, is also debated.

The next sections discuss the elements that are included as data for this study and how this data assisted in answering the research question. This includes an appraisal of the narrative approach and the importance of gathering contextual information such as observations and field notes for this study. The selection of topics for inclusion in the narratives and how they map to the theory of Bourdieu and forms of capital that are underpinning this study are detailed.

I then move to describe how I gained access to the field of memory loss and its association with early dementia; and how participants were recruited to the study. I discuss gaining informed consent from people experiencing cognitive difficulties and the legal and ethical implications associated with interviewing people with memory loss sensitively and within institutionally imposed restrictions. The design of the unstructured interviews is then rationalised and includes how I was able to operationalize gender and social class in this context.

The last sections address the theoretical rationale and pragmatic issues concerning sample size and sampling strategy, data handling, and a detailed explanation of how the data was analysed. I explain how adopting a broad interpretavistic and phenomenological approach explained how themes were developed from the data that could then be reconstructed into coherent patterns of social class and gendered responses. Finally, I discuss researcher reflexivity and my place in data generation.

2.2 The Interpretative Phenomenological Approach

Interpretative methodology is focussed upon the subjective meaning and social reality of social actions (Bryman 2004, Morrison 2006). This was an important aspect for this study

and related directly to exploration of the meaning and understanding associated with memory loss and dementia. Schutz (1970) argued that people attribute meaning to the world around them from personal reality perspectives. When applied to memory loss it allows a focus on personal interpretations, rather than a hard science view of memory loss as an organic and medical problem.

Whilst the pathological nature of dementia diseases is one of never ending decline and ever reducing mental capacity, the journey with dementia must start from a healthy mind position (Age UK 2011). Therefore especially in the early stage of illness, memory loss needs to be understood and negotiated in the context of the individual's social world. Indicators from the dementia literature (Wilkinson 2002) and specifically that of Wendy Hulko (2009) demonstrate that not only do dementia sufferers retain insight and are capable of constructing meanings of memory loss, but also that meanings are likely to be shaped significantly by social class and gender. There is no doubt that dementia is indeed a collection of physical and organic diseases of the brain that in medical terms relate to atrophy and degeneration of temporal structures (Nelson 2007), but the meanings associated with dementia for a person experiencing it are socially constructed and vary according to social location.

The heterogeneity of patient responses to illness generally is a well-documented phenomenon in many other areas of medical research (Bury and Gabe 2004, Radley 2004, Nettleton 1998). Therefore although dementia has a relatively stable disease trajectory and pathology that mainly affects the older population (Alzheimer's Society 2012), and at present with limited treatments available will lead to decline and death; I suspected that it was a mistake to presume that all patients would experience the phenomenon of memory loss in the same way, or attribute the same meaning to forgetting.

Although a grounded theory approach in line with Glaser and Strauss (1967) and Charmaz (1994) at first seemed a logical choice of methodology for this study in terms of allowing meaning creation to emerge wholly from the data, I chose to reject this as I intended to apply a lens of gender and social class through which to view the meaning making that was taking place. As grounded theory clearly rejects a priori codes, and these inevitably would need to be applied because of the gender and social class focus, I chose to explore alternative methodologies that would allow exploration of the data through pre-set 'top-down' codes as well as 'bottom-up' codes derived from the data. The Interpretative Phenomenological Approach (IPA) fulfilled this demand and provided a sound and robust methodological tradition with which to explore the data set.

IPA is based in the philosophical traditions of hermeneutics derived from Husserl 1859-1938 and Schutz 1899-1959. Although there is some debate within the social sciences as to what exactly constitutes phenomenology, there is broad recognition that interpretations can be gained from recognising social reality and the meanings of social actions based in social phenomenon for individuals (Bryman 2004). This is the pivotal argument for adopting an IPA methodology for this study. It is the phenomenon of memory loss and the social reality and meanings that are linked with it that are under scrutiny and require interpreting from the participant's point of view.

2.3 Epistemological and Ontological Context

This study investigated how participants experienced and created meanings relating to their memory loss. Through speaking to people early in their connection with memory services I was able to gather understandings before they were influenced by medical intervention and dementia had been diagnosed. This important factor shaped knowledge creation through

reflecting on why they had been referred, and allowed participants to continue constructing the reality of their memory loss from their socially constructed ideas (Bannerjee et al 2009, Giddens 2006). Although memory loss had been recognised, reported and acknowledged by a medical professional in order for access from the memory clinic to be gained, the reality for participants was that they were entering a liminal patient status phase, pre-diagnosis, that required interpretation and a 'making sense' process.

There has been a marked shift in recent years in the perception of dementia in policy terms as it has attempted to address the ageing demographic of the UK (Office of National Statistics 2012) and adapted somewhat to try and accommodate differing individual needs through person centred care (Department of Health 2009, Allan 2002). The organic degeneration created by dementia and the subsequent devastation to the sense of self is often regarded by the medical profession and layperson audience as being the only meaningful way of assessing the impact of the disease. Public literature is littered with depictions of the person with dementia being vacant in their own life and requiring careful nursing support and management (Wearing 2005, Bayley 2002, Miller 2004, Grant 1999). These depictions have inevitably filtered into popular concepts of dementia and shaped, how knowledge of memory loss is socially constructed.

In addition to this popular epistemology of dementia is individual experiential knowledge created through previous dementia experiences. These experiences and the knowledge gained from them is a feature of the ontological components of the social world for an individual. Mason (2009) supports the view that through narrative and observation of the phenomenon at hand, namely memory loss, knowledge, explanation, and impact can be understood in relation to social ontology. Moreover, previous dementia experiences are incorporated into habitus and moulded through forms of capital to shape personal ontology.

I theorised social class as represented in forms of capital in Bourdieusian terms (1986) to identify the social locations that my participants were operating in, and then by exploring further their habitus in relation to dementia, I could interpret the meanings that were generated. In Bourdieu's view (1989) there is a clear correspondence between social structures such as social location, and mental structures such as distinctiveness and value, or in other terms, structure and agency (Archer 2003) that create meaning and understanding. It is the dominance and attention paid to these elements that brings significance to social actions.

Bourdieu (1969) argued that cognitive structures are at least partly produced by formal schooling and that social divisions such as class and gender roles are created by homogeneous reproduction. In other words, that we reproduce our parents' views and our society's views through teaching. Bourdieu and Wacquant (2007) proposed that habitus is the embodied version of these objective social structures and that socially constructed schemas are both natural and necessary. This illustrates how the perpetuation of negative language and popular discourse about dementia is embedded at a society wide level, and also regenerated through the telling at a local level to form personal ideas about what dementia means.

Bourdieu (1977) explained habitus operating as a 'structuring mechanism that enables agents to cope with unforeseen and ever-changing situations … integrating past experiences, functions…as a matrix of perceptions, appreciations and actions.' (Bourdieu 1977:214). By adopting an IPA and methodology I could explore dimensions of the social world that related to everyday life and the meanings and understandings that those hold for people with early dementia symptoms. The aim was not to produce an 'average' account of the dementia experience, but by accepting the existence of a range of social experiences that are related to social class and gender I could anticipate that meanings and understandings would be

complex and multi-dimensional, both for each individual and across the social spectrum as represented in their narratives.

2.4 Narratives

The study of narratives has become more popular in recent years as a method of data collection for the social sciences, although emphasis has shifted from producing 'grand narratives' of science and medicine, towards interest in personal narratives and lay knowledge of everyday events (Bury 2001). In its simplest form, the narrative is a story that can be used to represent and interpret an individual's lived experience (Muller 1999). Patient's stories have been a driving force behind shifts in care from medicalization towards a person-centred approach (Kitwood 1997). Narrative is also a method of inquiry and can be used to solicit and analyse personal accounts in the form of stories because they allow the participant to express themselves in their own words, and in this way, narratives can be used as a research tool (Muller 1999) that fulfils the criteria of the IPA stance of seeing the world through the participant's eyes.

The influential factor in adopting a narrative approach to data collection was driven by the need to explore every day experiences of people with memory loss for meaning and understanding. By allowing participants to construct their own narratives in their own words, I could be confident that the factors most important to them would be highlighted without the prejudice of answering set questions that could potentially lead answers (Mason 2009). In allowing participants this freedom to simply talk about their thoughts and feelings, they would often construct mini-narratives to illustrate their points. Popularly, participants would recall stories of noticing their memory loss for the first time, and the context of the occasion. As Radley (2004) predicted, it was often a combination of these two factors that

prompted help-seeking behaviour. For example; most people could recall examples of 'everyday' forgetting that did not give any cause for concern. But either the nature of the item that was forgotten such as a close relative's birthday, or the social context and consequence of forgetting such as not recalling a name of a long term friend at a social gathering, was the prompt to seek help from the GP (Beard, Knauss and Moyer 2009). It is this wider contextual material that was important for this study to capture, as it revealed the social nature of forgetting and the relationship between social location and meanings of memory loss.

Indecision in help-seeking within general health care studies have concluded that often delay is caused by fear of the unknown diagnosis, and fear of being regarded as a 'time waster' if one reports non-specific symptoms or presents without a visible injury or illness such as memory loss (Bury 2001, Radley 2004, Department of Health 2009). One could assume that fear levels would be amplified and shaped by societal knowledge of dementia, lay knowledge, and any experiential knowledge (Radley 2004).

The lifetime experiences therefore were important in creating the meaning of memory loss. As Radley stated in 1991, *'people's lives have a background of health and other aspects of life, and are also grounded in activity'* (Cited in Radley 2004:61). Radley had demonstrated the social nature of health and illness and the significance of experience that in Bourdieusian terms, is forming habitus along with socially constructed ideas from wider societal discourses.

The task therefore, was to capture the thoughts, feelings, understanding, and meaning of memory loss and frame these with the lifetime experiences and the social location of participants further underpinning the choice of IPA over a grounded theory approach. Collecting narratives from people living in the liminal space of early memory loss and

potential dementia diagnosis did prove to be an effective method for uncovering understandings because people could meaningfully discuss their own interpretation of forgetting within their own context. Bury (2001) defined the essence of the value of narratives for this type of research. 'Language and narrative help sustain and create the fabric of everyday life and feature prominently in the repair and restoring of meanings when they are threatened.' (Bury 2001:264). Bury had highlighted the importance of the narrative in constructing meaning and understanding from experience, and in doing so had offered a robust method of exploration of the wider issues associated with illness, as well as the direct experiences of forgetting. Narrative collection was invaluable in exploring issues such as the nature and disruption associated with this chronic disease and it allowed for exploration of the wider issues linked to the illness such as the threat to identity, the social experience and the cultural relevance.

This study was interested in the core narratives that focussed on the connections between the layperson's perspective and the cultural overlay that is attached to dementia and 'suffering' dementia (Bury 2001) in the UK. For some participants this included the chronology of the illness, although for others experiencing memory loss this was often dis-jointed in the telling and the 'life narrative' (Muller 1999) of recollections of the past, and this intertwined with the moral narrative of the changing relationship between the person 'with illness' (Bury 2001) and their social identity. As Bury stated *'under adversity, people often feel the need to re-examine and re-fashion their personal narratives in an attempt to maintain a sense of identity.'* (Bury 2001:264). This re-fashioning of narratives and the decision to take part in the study and recall these narratives was for some, an effort to be seen as a worthy and 'thinking' person at a time when their identity was most under threat. This was not a methodological issue provided I was mindful that this could be the case and is a problem encountered by every study undertaking this kind of research with participants

talking about sensitive topics (Lee 1999). There is always a chance that only certain personality types will volunteer to engage with the research process, thereby creating a slightly distorted outcome, but ethical practice and right to refuse or withdraw from the study will always create this possibility.

The self-selection of the sample related very closely to the culture of *'how people are supposed to act'* (Muller 1999), and for the participants taking part in this research they no doubt had ideas about what an interview should be, notwithstanding the participant literature that was prepared and explained prior to engagement. Layered upon these expectations was possible rehearsal of narratives because it is the embarrassment of forgetting that often causes dementia patients to withdraw socially as evidenced in the testimonies posted on the Alzheimer's Society's online discussion forum 'Talking Point'. Therefore I needed to be mindful of the notion of 'how people are supposed to act' and how they would present themselves (Goffman 1969) in this unusual situation of a research interview. Not only would presentation vary according to social class and gender norms, but also through presentation as a potential dementia patient and participant in research.

Underpinning the approach to narrative research in this study was the interpretavistic-phenomenological assumption that experiences can indeed be relayed through stories that become part of consciousness by being meaningful, human and expressive, and that they can display changes (Squire 2008). For this approach it was not necessary for participant's to give a detailed chronological events based narrative of their condition, although there was occasionally an element of this; but it was more important to gather the personal narrative of the meaning that these experiences produced. This experience-centred approach and the construction of narratives to order our world, *'are not just characteristics of humans, but make us human.'* (Squire 2008:43 emphases in original text).

2.5 Data Collection

The participants' narratives were the primary source of data and needed to be gathered in a methodologically sound way (Mason 2009, Bryman 2004, May 2006, Silverman 1994) and so I conducted guided but unstructured interviews with participants in their own home according to qualitative traditions. Guided unstructured interviews are often referred to in the literature as 'informal' , 'unstandardised', 'life history', biographical', or 'oral history' interviews (May 2006). The interviews that I conducted had elements of all of these factions because they needed to capture something of the person's life story, and their story so far with memory loss, in a structure set by them, and in the setting of their own home for ethical reasons that I will explain in more detail later.

Although all of these types of interviews are considered to be unstructured, they do generally follow a framework upon which to guide the conversation (Mason 2009) and my interviews followed in this tradition. By ethical necessity I had produced a topic guide, so in the purest sense, these interviews were not 'without structure', but they did permit the participants to explore the topic of their memory loss in any fashion that they chose. Some chose to start the interview by telling me about the latest instalment in their story, some started at 'the beginning' of their memory loss story and worked through in a chronological manner, others chose to talk about their life story generally before moving forward to present day. I was fully expecting a range of structures of interviews to be produced as Silverman (1994) had described this type of interview as one in which the experiencing individual actively constructs their social world; therefore the way that it is constructed was as diverse and variable as the group of participants. Subsidiary data relating to locations, conversations before and after the recorder was activated, and observations, were recorded in field notes and used to assist in contextualising the interview data.

The variability within and across the interviews continued as participants relaxed and talked freely. The length of each interview was governed by the participant. The quality of the relationship formed between myself and each participant and relative was a critical feature of narrative elicitation within these home settings. I had taken careful consideration of the possibility of confusing my participants into thinking that I was part of their memory assessment and diagnostic procedures. I had gained access to participants through their contact with the memory clinic, and by definition they were suffering memory loss, so I needed to be careful that they did not confuse me with a medical professional (Surr 2006). Any confusion had obvious ethical considerations which I will address in the following section, but it would also have had methodological problems in the presentation of the narratives. Participants could have imagined that they were presenting evidence of their memory loss to a doctor or other medical professional and so restricted their narratives to medically related facts in a patient/doctor relationship. I was confident that with explanation and reminders, even the most advanced of my 'early stage dementia' participants would be able to distinguish me from other visitors, and this did indeed prove to be the case, and did not cause any particular difficulties.

Traditionally, interviewing dementia patients in any context had been a barrier to their participation in research because of fears that their testimony would be unreliable given the nature of the illness (Allan 2002). A further assumption had existed that memory loss meant that the person would not be able to reliably inform another of factual life events, or express any deeply held beliefs, and this point had rendered them marginalised. However, a growing body of evidence has emerged that is consistent with dementia patients being capable and willing to take part (Wilkinson 2002). McKillop and Wilkinson (2004) moreover argued from a methodological position that people with dementia can provide consistent, reliable and insightful data in a non-pressurised and comfortable environment such as their home.

Whitlatch et al (2005) supported this view and robustly argued that reasons for excluding dementia patients from research could largely be overcome providing appropriate measures were in place and ethical concerns were thoughtfully considered. Sensitivity in working with dementia patients produced two main areas of concern. The first was related to ethical considerations and will be explored later in the chapter, and the second is a methodological sensitivity in order to elicit good quality data from a person experiencing memory loss (Lee 1999).

2.6 Ethical Considerations

A large part of the permission process was taken with dealing with ethical concerns. The NHS Ethics Committee have a legal obligation to protect patients and staff and therefore have to scrutinise any application for research (Health Research Authority 2012). They were particularly concerned with the justification for the study and questioned why I needed specifically to talk to patients rather than clinicians or relatives.

The West Kent Research Ethics Committee that scrutinised my application, supported the view that I should only engage with relatives and carers and not impact upon patients as they regarded them as vulnerable. I successfully argued that early dementia and memory loss did not create such confusion that patients would not be insightful concerning their thoughts and understandings of their referral because the nature of the disease is slow progression. Now that an early diagnostic pathway was available through the memory clinic (KMPT 2010), I could speak to people experiencing memory loss that were currently in the diagnostic process. Because they were attending outpatients appointments and able to complete mental assessment tasks, it would be well within their capabilities to express to me their thoughts personally, without the intervention or assistance of a relative or carer. I was

not judging or assessing what they said in order to make a clinical or moral judgement, I simply wanted to hear their opinions and relate these to their social location.

Another major area of ethical concern was how to gain informed consent from somebody experiencing memory loss. It had traditionally been assumed that memory loss meant that informed consent could not be gained unless there was a lasting power of attorney agreement in place and another person could grant consent on their behalf (Roked and Patel 2008). The assumption had been that because of the lengthy diagnostic process, by the time a person had presented, their illness would have advanced and therefore they would not be able to grant consent. This situation was changed by the early diagnosis process because patients had not yet reached a stage where they could not consent for treatment. I was able to successfully argue that as the Mental Capacity Act (2005) stated that the capacity to make a decision is based upon the type of decision that is required, and the decision to take part in an interview led by the participant is relatively innocuous compared to a treatment decision; patients in this early phase of illness would be very capable of deciding if they wanted to participate. This position is in line with leading charities involved with dementia patients (Lakey 2009, Orellana 2010) who vigorously campaign for continued decision-making for as long as possible as an empowering instrument. Furthermore, as this study did not require any testamentary capacity for legislative purposes such as matters of property or money, or life changing decisions regarding medical treatments, it was a relatively minor decision that had little potential for any lasting adverse consequences and so posed little risk (Roked and Patel 2008).

In order to further minimise any risk to patients of embarrassment at forgetting they had consented, I designed appointment cards and left literature (see appendix 3) with each participant explaining each step of the study from recruitment through to conclusion of the study. In addition, the memory clinic staff were aware of the patient's participation in the

study and where possible, my contact information was also left with a relative should any additional support be required.

The NHS Ethics Committee also questioned my sample number of 20 on ethical grounds, for fear of 'putting patients through research' when it was not necessary. During the early stages of negotiations they were concerned that because this was not a large scale quantitative study, nor a case study it did not have robust methodological underpinnings. However, I explained the use of a purposive sample in capturing a range of social locations across various memory clinics, and the relationship with Hulko's (2004) 'not a big deal' to 'hellish' research. Therefore I could justify purposely seeking men and women from a range of social locations that broadly reflected the cohorts attending the clinic at that time. I conducted a formal presentation to the committee outlining the project and explaining qualitative research of this nature, and they agreed that it was indeed a sound and justifiable project and granted permission. I anticipated that some participants may have chosen to leave the study early, and so I requested permission to contact no more than 25 patients. The NHS Ethics Committee revised this to a figure of 20 patients but in addition allowed relatives and carers to be 'incidentally involved' as co-interviewees if the patient requested their attendance. This represented somewhat of a compromise, however I was confident that 20 participants would generate enough data across a range of social locations to be meaningful. If I had chosen to object at that stage of the permission process, the study would have been further delayed as negotiations continued.

The entire ethical process and negotiations had taken more than 14 months to complete, but I could now be confident that the clinical team supporting the study and my methodology was fit for purpose, pragmatic, and realistic.

2.7 Accessing the Field

Prior to the development of memory clinics, referrals to a variety of outpatient departments resulted in a hidden population of early and as yet, undiagnosed dementia patients (Wright and Lindsay 1995). The National Dementia Strategy (Department of Health 2009) marked a major change in policy regarding dementia services and management by providing a 'one stop shop' in the form of memory clinics. This meant that GPs now had a single point of referral and patients had a greatly reduced waiting period between first symptom and diagnosis. This provided the ideal opportunity to recruit participants to the study at the first point of referral and before they were formally diagnosed approximately eight weeks later (KMPT 2010). As a result of this change in policy, it now became possible to ensure that potential participants would indeed be experiencing noticeable memory loss and that their thoughts regarding the meaning of the referral would be in sharp focus because of the immediacy of their pre-diagnosis contact with services. However, access to NHS patients required a legal clearance from the NHS Ethical Committee based on providing ethical, managerial, and occupational protocols before clearance could be granted. This was a lengthy, torturous and bureaucratic process that became extremely time consuming.

The process of application to the NHS Ethics Committee required a detailed electronic submission through the Integrated Research Application Service (IRAS). IRAS operated a range of filters that screened initial information and created the various documents required to support the application. These included standard documents such as a research protocol and evidence of the researchers qualifications, but also required Site Specific Information (SSI) documents relating to each of the clinics involved in the study. These SSI documents required every NHS member of staff that I may come into contact with during the course of the study, to specify their involvement and give their permission for my presence in their

workplace. Copies of all patient facing literature, including invitations, patient information sheets, consent forms, and appointment cards and thank you cards had to be produced and presented with the application. There was also a requirement to make a separate application to obtain an NHS Research Passport. A Criminal Records Bureau check for vulnerable adults needed to obtained, as did curriculum vitas for all clinicians, and myself, and my academic supervisors. I was also required to complete an Occupational Health Check and receive immunisations and produce blood tests for screening because I would have direct contact with patients. Finally there was also a requirement for approval from the NHS Research and Development Committee regarding the intellectual value and practical value of this study.

The advice from the NHS Research and Development Committee's chairman was that the permission process would inevitably be a lengthy and problematic one because their systems were not designed to deal with deeply qualitative research, but rather were geared towards large scale studies and drug trials. Therefore a small scale qualitative study with a newly recognised patient cohort such as this, was fraught with organisational issues that required resolving.

Consequently, prior to submitting the formal application I needed to make contact with clinicians and their staff that would be willing to allow me to recruit participants from their patient list. This required a series of meetings and presentations to staff that inspired confidence in the robustness of the research, and added value to the clinics' operations. The lead clinicians were operating as gatekeepers to patients and without their support the study could not take place and approval from the ethics committee could not be granted, so it was imperative that I explained to clinicians and their teams, the benefits to patients in taking part and the minimal disruption to normal staff duties.

Through these extensive negotiations, I was able to enlist the full support of two lead clinicians in two separate areas of a single Health and Social Care Trust that looked after a total of twelve clinics in various locations across the county. The responses from these clinicians' teams were extremely diverse. Whilst both lead clinicians wholeheartedly supported the study, one team were extremely reluctant to offer any support and finally withdrew their approval. After seeking feedback from the team leader and leading community pre-diagnostic nurse, I was told that they did not believe that their patients would be capable of taking part in interviews due to their memory loss and confusion, and that the team's workload was too heavy to support any additional, albeit minimal duties. This was very disappointing and the lead clinician provided feedback that she regarded this withdrawal as a missed opportunity for her staff and patients in understanding the impact of social location in the diagnostic process.

However, the other team was very enthusiastic and wholeheartedly offered to support the study, and I was able to secure the help of pre-diagnostic nurses in inviting people to take part. Together we planned a recruitment strategy that would satisfy the ethics committee and support clinic staff and patients. The pre-diagnostic nurses would offer potential participants my invitation literature after their initial assessment of the person's memory problem. Once the nurse had decided that more detailed investigations of the memory problem was required, she would invite the person to the study via my invitation leaflet. If the person was interested, then the nurse would forward me the patient's contact details so that I could telephone them with more information and make arrangements to visit them at home. This system worked very well indeed, and contrary to popular academic and medical predictions, I was able to fulfil my target sample of 20 participants easily.

Since a study that recruited in this way had not been tried before in a memory clinic, and because memory clinics, and therefore a concentration of patients, had not been possible

before, I had sought informal opinion concerning recruitment from a number of sources including the NHS Research and Development Committee, GPs, the lead memory clinic clinicians and nursing staff, academics with medical research knowledge, and a focus group of older people.

The focus group proved to be a very useful and positive step (Bamford 2002). Members were drawn from a group of retired friends belonging to a bowls club. I put the proposal to them in the form of a hypothetical study and asked what would encourage them to take part in research. The overwhelming response was that it should feel like a personal invitation but be presented professionally. Opinions and feelings should be respected, and they should be reassured that the interviews themselves would be friendly and non-judgemental. To this end I prepared a tri-fold invitation leaflet in the form of a question and answer sheet about the study that included a photograph of myself and my contact details, together with a promise not to call again if they changed their mind about taking part (Appendix 1). The NHS Ethics Committee particularly commented upon the sensitive and friendly nature of the invitation material and approved the decision for the pre-diagnostic nurse to make first contact. This was instrumental in gaining the necessary permissions and ultimately the success of the recruitment strategy was born out in more respondents coming forward than I required or had ethical approval to interview. The potential that existed to over recruit by this method defines it as a suitable, ethical and robust approach to recruiting sensitive patients.

2.8 Sampling

Theoretical numbers of participants had been decided for methodological reasons in order to capture a range of social locations that were likely to be represented at memory clinics. The

pre-diagnostic nurse would visit a person at home for their initial assessment following a GP referral. After this assessment and before the nurse left their home, she would invite the person to the study if they fulfilled the research criteria. This criteria was simply that the person was considered as a possible dementia patient and was suffering from memory loss. At this point if the person decided that they did not want to take part, or that they wanted to think about it or discuss participating with a friend or relative, they were free to do so. If the person agreed either at that time, or at a later date, that they would be willing to participate, then the nurse would forward me their details so that I could speak to them directly. The plan was to take a snapshot of the clinic cohort as it occurred, while purposely trying to represent a range of social locations. With the addition of each participant to the study, the balance of social locations in the sample was revised to try and capture any unusual patient profiles. In this sense the sample was purposive, however as potential participants needed to be gathered during a set timeframe set by the ethics committee, it was also largely governed by the sequential presentation of referrals to the clinic. The sampling aim was not to produce an 'average' account of memory loss, but to represent a range of responses, therefore the uniqueness of each person was valuable and actively sought.

The unique features of each of the 20 participants were recorded in table 1 (page 94), which contains demographic information and notes of the special features of each participant.

Table 1: Participant Features

Pseudonym	M/F	Age	Marital status	MMSE	Former occupation	1st visit A	2nd visit B	M/W class	Notes
Joan	F	78	Divorced	26/30	Factory worker Housewife	11/08/11 Alone	16/09/11 Alone	W	Strong family history AD Refused memory clinic. COPD

John	M	72	Married	21/30	Plumber Black cab driver	16/08/11 Wife present	21/09/11 Wife present	W	No family history. Does not accept memory prob. Wife – housewife. Heart probs.
Frank	M	81	Married	27/30	Accountant	9/09/11 Wife Present	7/10/11 Wife present	M	No family history. 'Silver surfer' uses pc as memory aide. Heart & strokes.
Alf	M	69	Single	16/30	Farm Labourer	20/09/11 Alone	**Withdrawn** Mental condition deteriorated.	W	Strong family history AD. Very confused. Epileptic & mild learning difficulties. **Brother of (8)**
Sandra	F	77	Married	29/30	PT Shop assistant Housewife	23/09/11 Husband present	11/11/11 Husband present	M	Depression and anxiety disorders. Husband - Senior consultant in aircraft design. Heart.
Robert	M	88	Widowed 2 yrs	22/30	Lawyer	27/09/11 Alone	Withdrawn Changed mind about further interviews	M	No family history. Neighbour supports. Enjoyed taking part but admitted to hosp-pneumonia
Gwen	F	65	Married	27/30	Care worker	3/10/11 Alone	Only consented to one interview	W	Husband – illiterate, security guard. Recent breast & bowel cancer remission. **Sister of (5)**
Carol	F	59	Married		Business owner	6/10/11 Husband present and translating	Only consented to one interview	M	Cortical basal degeneration (diag 2003). Large business (350 employees). Husband – large business owner.
Steven	M	82	Widowed 7 years		Accountant	18/10/11 Alone	7/12/11 Alone	M	No history of ML. Son supports. Very confused & repetitive.
Vincent	M	83	Widowed 2 yrs	22/30	Commercial pilot	1/11/11 Alone	2/12/11 Alone	M	No history. Son supports. Overseas most of career. Heart probs.
Katie	F	50	Divorced 20 yrs		Salon owner / mobile hairdresser	3/11/11 Alone	8/12/11 Alone	W	Father currently in diagnostic process but no other history. Lives with daughter. Also has

									fibromyalgia & stroke victim.
Patrick	M	84	Married 58 yrs		Senior scientist	4/11/11 Wife present	12/12/11 Wife present	M	No history. Heart probs & multiple surgeries.
Graham	M	85	Divorced Has partner of 12 years		Insurance salesman	7/11/11 Alone	9/12/11 Partner present	W	Mobile home. Heart prob. No family history
David	M	79	Married 51 yrs		Builder	10/11/11 Wife present	Pending – housemove Withdrawn. Ill health	W	Very deaf. Heart probs. Cancer. No family history
Pauline	F	75	Married 50 yrs		Housewife	14/11/11 Husband present	Only consented to one interview	M	Methodist. Resentful of memory prob. Fighting with husband. No family history
Violet	F	81	Widowed 11yrs		Housewife / hairdresser	19/4/12 Alone	28/5/12 Alone	M	Family building business & fruit grower. Socially very active.
Charles	M	72	Married 47 yrs	27/30	Toolmaker unskilled	18/4/12 Wife present	2/7/12 Wife present	W	Deaf. Keen golfer. Very physically active.
Terry	M	76	Twice widowed 16yrs	Est. 22/30	Machine minder- printer	23/4/12 Alone	29/5/12 Alone	M	Married at 50, widowed twice in 10 yrs.
George	M	76	Divorced & re-married spouse		Newsagent business	25/4/12 Partner present	Withdrawn. Ill health	M	Moderate dementia, heart attacks and strokes. Gambling addiction.
May	F	86	Widowed		Factory Worker	8/5/12 Alone	Withdrawn. Ill health	W	Heart problem. Moving in with daughter.

This thesis is concerned with intersectionality and dementia with a particular focus on gender and social class, but other aspects of intersectionality such as ethnicity and sexuality were not deliberately excluded but were not represented. This was not intentional but rather

the result of the sequence of referrals to the memory clinic, therefore I was unable to control the demographic characteristics of those included in the study. This resulted in a heterosexual, white sample which reflected the catchment area of the memory services and was as the memory clinic staff had predicted.

Besides the unique features of each participant there was nonetheless a common feature other than memory loss among the participants, and that was as Clark and Bennett (2013) had predicted, a motivation to participate born of a 'feel good factor' of taking part in research that had the potential to benefit other people in the future. Clark and Bennett identified health settings as of particular interest to older people 'wanting to give something back', and that by doing so there was a sense of stimulation, usefulness, and empowerment. These factors were often verbalised by participants at the end of their interviews and were enacted in my receipt of 'thank you' cards from participants and requests for a summary of this study on completion.

2.9 Topic Selection for Interviews

Topics were selected for the purpose of opening conversation in the interviews and were loosely based around large conceptual areas. These were purposely outlined in layman's terms in the participant invitation literature and information guidance prior to interview (Appendix 1). Broad topics offered as suggested themes for conversation included 'work life, family and friends, interests, daily life, and any other areas important to you' (Participant Information Sheet, Appendix 2). The study was titled 'memory loss study' and it was explained that opinions were being sought regarding the experience of memory loss. In defining topics so vaguely I could be sure that participants would highlight the stories that resonated with them in any given broad area (Mason 2009). Effective co-production of

some narratives took place during conversation in which knowledge was constructed or re-constructed from clarity seeking prompts such as 'can you tell me a little bit more about that?' Accordingly, the knowledge gained was not uncovered or excavated but was assembled from the dis-jointed narratives produced (Mason 2009).

Although topics were broad and vague for participants, they were selected in a meaningful manner relating to the conceptual and theoretical aims of the study. The topics formed the essence of the identifying social features that relate to Bourdieu's (1986) concept of the forms of social, economic and cultural capital. Under the aegis of the topic guide I was able to operationalise social location and identify features that related to the forms of capital.

As Bourdieu (1986) explained, social relationships may be formal or informal and may contain practical, material, or symbolic exchange. They are based on a sense of 'belonging' to a group and so the social capital that an individual holds depends on social connections and the symbolic value of them. This premise led directly to exploration of the participant's social networks and the value that the participant saw in them, and so topics relating to relationships with family, friendships, neighbours, and colleagues, and any club or group memberships were important to explore and naturally arose under the guise of talking about the suggested topics.

The concept of family (Bourdieu 1998 'The family Spirit' in Silva 2005) can be a structuring and a structured force. Structuring; in terms of the development of family members and the social value that a 'good' or 'bad' family holds; and structured, by the public vision of domesticity. Bourdieu explained that the family is crucial for the transmission of capital and its symbolic value stems from the privileges associated with having a 'normal' family. So family is fundamental in reproducing social identity and the transmission of capital in all its forms. Therefore the topic of family was of particular

interest when considering the transmitted meaning of memory loss across generations. Participants frequently referred to earlier generations as they searched for knowledge of memory loss and compared their own current situation to that of their parents and grandparents.

Exploring social capital in fields other than family was also important. The field can be any social setting where class dynamics can be played out such as in the neighbourhood or at work; and it can also be applied more widely to more abstract fields such as politics, and inequalities such as those found in healthcare and education (Silva 2005). These fields contribute to the construction of habitus that could then be observed in disposition or in recalled incidents in the past. Attitudes to these wider social settings made an important contribution to explaining the relationship of memory loss with stigma arising from social norms associated with dementia.

Differences related to gendered responsibilities and practices are entwined in habitus and are reflected in all forms of capital. Consequently, it was important to include daily life as a topic for conversation. The age group of the participants placed them in a specific generation in which male domination and strong gendered household roles had been a prominent feature (Finch and Mason 2001). Bourdieu (2007) in *Masculine Domination* noted many changes in gendered dynamics that have benefitted women in modern society, such as women's increased access to education and entry into the workplace, increased wages, and the development of household technology, as well as the impact of contraception on reducing family size, delaying marriage, normalizing of divorce, and fewer marriages. For the specific generation of participants in this study born circa 1930, I suspected that strong gendered household and work based roles would exist and be played out in retirement. Therefore a discussion of the household was both relevant and significant in establishing the meaning of memory loss.

For people experiencing memory loss and their partners or spouses, there are potential challenges to deeply gendered roles and responsibilities within the family and other social contexts. For this reason I included family as a topic for discussion. I had anticipated that some participants would be single or widowed and would be coping with adopting their partner's role and responsibilities in the household, and others would be in the process of handing over control of household tasks to their partner as their memory loss increased. These were possible areas of investigation that I needed to access, so by simply asking participants to talk about daily life, they were able to volunteer information of their static, changed, or changing roles.

Topics related to cultural capital in the form of interests were also included in our discussions. Bourdieu (1986) described cultural capital as existing in three forms; an embodied state, an objectified state, and an institutionalised state. Therefore the 'mind set' interpreted through gender, cultural consumption of goods such as books, arts, and leisure activities, and education and employment all became areas of interest for the interviews. These provided a 'window' from which to view class status and gendered disposition, and highlight any shifting perspectives as memory loss enters the person's life and impacts upon cultural choices and cultural disposition.

Economic capital has a direct bearing on the cultural capital and social capital available to a person and can be converted directly to money. So topics relating to wealth, possessions and assets were features that could easily be implied and inferred throughout the interview. The interviews took the form of conversations and narrative construction so direct questioning of monetary value was not necessary, as well as potentially threatening for the participant. However, by exploration of housing, possessions, and consumption patterns as well as employment history I was able to provide a meaningful representation of social class.

The topic of daily life also provided an opportunity to explore symbolic capital. Bourdieu had described symbolic capital as 'a recognised power' (1991:72) through symbolic weight that is applied and recognised by the group according to the person's worth in that social circle. He argued that this symbolic power only existed whilst the senders and the receivers of it legitimise it by agreement. This legitimation may stem from language, but equally it may develop from actions and social interactions (Bourdieu 1991). These social interactions carry with them meaning related to the appropriate social structure, and vary with social class and gender difference within classes as well as across classes. Therefore, as memory loss increases in severity and frequency, it becomes more difficult for the person to maintain appropriate social interactions; the person may experience a sense of social legitimation ebbing away and a reduction in symbolic capital that manifests itself as social stigma. Research into gendered responses to health related matters suggest that this may vary between genders, and across social classes (Sixsmith and Bonham 2003, Galdas et al 2005). Exploration of this reduction was achieved by focussing on symbolic structures such as the significance of the meaning of reduction and changed social encounters in terms of frequency and depth of involvement in social activities. These topics relating specifically to the meaning of symptoms therefore became vitally important.

2.10 Fieldwork

I visited and interviewed each participant as they were recruited. This allowed me to appraise each interview in its own context before gathering more data (Mason 2009). The interviews were flexible and unstructured, and conversation was guided initially by the topic guide provided in the patient literature. However, most participants once relaxed in my company digressed as I had predicted and planned. The digressions usually revolved around

expectations of the memory clinic and/or the pre-diagnostic home visit. As I had been invited into people's homes I was mindful of respecting their expectations and welcomed relatives or friends to join us if the participant required their presence.

Interviews varied considerably in length from 45 minutes through to approximately 4 1/2 hours. These extremes in timings were governed by the participants and what they wanted to contribute. I attempted to visit each participant twice. The first visit took place before they had attended the memory clinic, and the second approximately four weeks later after they had attended. This was not always possible because three participants became ill in the interim and withdrew, three agreed to just one interview when they were recruited, and sadly two participants passed away during the interim from other illnesses. However I was still able to gather data on two occasions from twelve participants and on one occasion from the remaining eight respondents, with those that withdrew due to ill health contacted me later to update me on their progress.

I made an active decision to concentrate on the experiences of the participants with memory problems rather than arguably, more 'reliable' data offered by relatives and friends. These others would occasionally interject in the interviews or ask for a word alone aside before or after the interview to stress that their relative had made errors in their account of events. These 'errors' were not important for data analysis or coding, as the focus was on the meaning of the events, and not the chronology or factual correctness of the account.

I was mindful of interviewing potentially vulnerable people about a sensitive topic and therefore I designed the interviews to be free flowing and governed by the participant (Lee 1999). This required me to be open and encouraging in order to elicit narratives of experiences and gain understanding of the meanings being created (Mason 2009). The style of the interviews was very conversational, with narrative prompts when required of 'can you

tell me more about that?' or 'that was interesting' as Charteris-Black and Seale (2010) had

advised. This ensured that the interviewees could finish a story in their own time whilst

being encouraged with nods and murmurs in a conversational style.

Through this informal style of narrative production we could construct meanings together

through our social interaction (Elliott 2005). By adopting a position of interested listener

seeking the participant's knowledge, any power differentials in the relationship were

dispersed and participants were able to explore aspects of their everyday lives and life story

without fear of prejudice or judgement (Bornat 2002). Occasionally participants became

emotional during the interviews when recalling unhappy or distressing memories, or when

discussing their future with memory loss. In these situations I simply tried to be supportive

and encouraging until the episode had passed and the person was ready to move on. I had

fully anticipated that some emotional upheaval would take place through discussing

potentially distressing symptoms, and had planned to mitigate these situations as far as

possible by seeking help or advice for the participant. In the actual events however, the

participants simply wanted me to be supportive.

Managing endings of my relationship with participants posed challenges because of the

personal nature of the interviews and discussion of potentially distressing topics. I managed

these endings from the outset by clearly outlining the research procedures during the

recruitment phase with each participant, and reminding them when my final visit would be

at my confirmation telephone call and at the start of each interview. As Lee-Treweek and

Linhogle (2000) highlighted, managing the emotions of participants and not leaving them

with 'painful baggage' (2000:15), and ensuring that 'participants do not feel let down'

(Centre for Social Justice and Community Action 2012:11) by the researcher are primary

concerns. I sought to ensure that interviews reached natural conclusions by allowing

participants to decide when they had finished discussing their narratives rather than

imposing time limits or subject limits on participants. With these aims in mind, I carefully

negotiated my exits from participants by providing them with contact details should they

want to discuss their participation, and by inviting them to receive a summary of the study's

findings. Participants were also sent a 'thank you' card after my final face to face interaction

that served as a reminder that their contribution was complete. I received emails from some

relatives and thank you cards from some participants shortly after their final interviews that

reassured me that my participants were comfortable with their contribution.

I audio recorded the interviews digitally for later transcription, but I also maintained a

fieldwork notebook of my reflections after each interview. This included my thoughts about

intonation and meaning and non-verbal communication that a hard copy transcription could

not adequately capture. These notes later proved to be of great assistance in clarifying the

meaning of narratives during analysis (Onwuegbuzie, Leech and Collins 2010).

2.11 Coding and Analysis

In accordance with Smith, Flowers and Larkin (2009) I found that some sections of the

transcriptions were richer than others, and therefore required more or less coding as

appropriate. This was not surprising given that during interviews participants would often

become distracted or deviate from the topic at hand and unrelated conversation would take

place. Because of these distractions and often repeated stories due to the nature of memory

loss, there was no need to divide transcriptions into fixed length meaning units for analysis.

The aim was to capture the essence of understanding, and as narratives were produced in an

often disjointed fashion, dividing transcriptions into fixed quantity chunks was a

meaningless exercise. However, it was apparent that I needed to simultaneously code

inductively and deductively with cross references (Fereday and Muir-Cochrane 2006),

therefore I decided to utilise an Nvivo qualitative software package. Nvivo helps with organising the data by providing various coding tools that can create relationships between the concepts that characterise the data set (Edhulund 2011). Nvivo allowed me to explore themes and sub-themes as they were building and map and re-map with ease as concepts were identified. Features of Nvivo that allowed comprehensive notes to be compiled and memos to be created (Beard and Neary 2012) aided identifying narratives that were threaded across interviews, and this was a particularly useful tool.

The analytic process was conducted by transcribing the interviews and considering my field notes alongside to establish corroborative evidence for intonation and meaning in the transcribed text. The codes themselves were not succinct but tended to be small 'mini' commentaries of the meaning of the data. Smith, Flowers and Larkin (2009) proposed that IPA coding could consist of 'free association' as notes are made from whatever comes to mind as the data is repeatedly read through. I adopted this approach and created a coding frame that gradually built towards creating super-ordinate categories that could adequately capture the meanings within the interviews.

As Smith, Flowers and Larkin (2009) advised, descriptive elements were a starting point and were coded according to common themes such as daily life, occupation, interactions with doctors, leisure activities. I then examined the linguistic elements and included my field notes in coding tone and meaning associated with *how* themes were discussed. This allowed me to interpret the transcripts for meaning hidden in tone and emphasis. Lastly, I re-examined the transcripts and coded for abstract comments, metaphors and representations. As transcripts were repeatedly examined, 'bottom up' associations emerged between topics and the importance of specific incidents and flippant comments became apparent. It was these interpretations that revealed the meanings embedded in habitus and were reconstructed as understandings of memory loss.

Coding at different abstraction levels of description, linguistic, emotional and conceptual coding (Giske and Artinian 2007) allowed me to progress a simple theme, for example, 'driving' through the emotional importance of 'ability to drive' into theoretical concepts concerning independence; whilst its relationship to masculinity emerged as particularly relevant for the working class men who were still driving. Similarly, through identifying the importance of the past in terms of prior dementia experiences, it was possible to identify a clear link between noticing memory loss in the present, and subsequent help-seeking behaviour. In forming super-ordinate categories with this method, I was able to more closely examine data at a conceptual level for relevance to social location. This approach to coding showed itself to be robust, logical and nuanced enough to capture the idiosyncrasies contained within each unique account. For example, clear themes emerged from the data that related to concepts of change over time, a sense of self that was embedded in a life lived that shaped the confrontation with memory loss, the preservation of a sense of self, and looking to the future.

This process of analysis had satisfied Schultz's (1970) definitions of meaning and understanding through retrospectively exploring the interpretation of the interview data, according to the meanings that each participant had ascribed. Schultz defined lay-understanding as embedded in the experiential form of common sense knowledge; and sociological understanding as *'the result of a sociologist's subjective interpretation of the phenomena of human conduct which he studies'* (1970 pg 323). These definitions of meaning and understanding allowed me to explore the widely held common sense view that memory loss and dementia is a wholly negative experience, and root it in each participants understanding of their memory loss. The way that the individual's experience was understood was related to each individual's doxic 'taken for granted' knowledge. By focussing on the meanings and understandings and identifying recurring themes within each

interview and across the data set, I was able to examine the intersection with social class and

gender without searching for causal relationships. This ensured that I could grasp the

idiosyncratic variations in the data set, and place them within conceptual categories of forms

of capital, without contamination of the preconceptions created from previous research that

has examined the relationship between social class and dementia (Hulko 2004).

In keeping with the design of this study, I decided to use an Interpretative

Phenomenological Analytic (IPA) approach to analysis, blended with the Bourdieusian

(1986) approach to social location classification. This provided me with the framework to

explore the nuances in the data whilst retaining a rigorous and logical strategy. Fereday and

Muir-Cochrane (2006) made note of the contemporary movement within social analysis of

adopting interdisciplinary and hybrid methods, and concluded that whilst these hybrids left

room for a potential mess to develop, providing they were blended appropriately, they could

be very effective at uncovering otherwise hidden facets of the data.

IPA offered an essentially simple, but methodologically rigorous approach that is often

adopted in healthcare and illness research from the patients' perspectives (Biggerstaff and

Thompson 2008, Radley 2004); but this needed to be framed within nomothetic concepts of

class and gender in such a way that inductive analysis could explore and retain the

idiographic nature of the narratives. The blended approach allowed me to consider

contradictory narratives between participant responses regarding the cause of memory loss,

as each could be regarded as discreet and relative to the individual's interpretation which

complied with the IPA tradition of analysis.

The IPA approach was informed by Schutz's (1899-1959) theory of social phenomenology

that explores social actions within a common-sense and taken-for -granted view of daily

life. Schutz (1970) offered a definition for 'meaning' as something that arises from a

retrospective interpretation, and 'subjective meaning' arising from that ascribed by the individual on their own experiences and actions, whilst 'objective meaning' is imputed by the observer of others' conduct. Schutz goes on to explain that:

> *All human conduct appears in a subjective meaning context...and by contrast, interpretation of the conduct of another person consists of relating the observed conduct to an objective meaning context, consisting of pre-established generalised and typified conceptions* (Schutz 1970 pg 320)

These definitions explained that I could accept the individual's perspective and meaning of their narratives and apply them to Bourdieusian preconceptions of capital and habitus, whilst taking account of the co-constructive nature of unstructured interviews and my role in their subjective meaning.

Schutz (1972) advocated that IPA needed to strive to be logically consistent, and follow a formal set of rules that grounded the subjective nature of the data in the meaning that actions held for the actor. Moreover, that there needed to be consistency between the researcher's constructs and the common sense experiences that form the data set. This premise places IPA firmly as a 'bottom up' method of analysis that is broadly akin to a grounded theory approach of analytic code derivation from the data (Charmaz 2006), but it did not solve the problem of relating these codes to theoretical conceptions of social class and gender. I therefore needed to develop a strategy that retained this vitally important exploration of the meaning of the participants' experiences within *their* common sense interpretations, rather than my own, and that also allowed me to refer to the wider context of social location.

Information that allowed me to refer to social location was largely derived from the participants during the interview process as they disclosed their former occupations,

upbringing and family origins. But it was also imposed from information passed to me by the memory clinic staff in details of current address, gender, age, family obligations and interactions, and details of any lasting power of attorney arrangements that made it necessary for me to notify a third person. Supporters or relatives of participants also frequently contacted me to outline any other information or circumstances that they felt I should be made aware of before my visit. This included such things as health status of the participant, their attitude to women, their attitude to medicine and authority, and the likelihood of disruptive behaviour or anger outbursts that are associated with some dementias. I did not actively seek these interactions with supporters and relatives, but they were often volunteered and originated from the relatives need to assess the risk of their loved one taking part in the study.

In gathering information prior and during the interview from the participant, their supporters and clinic staff, I was also able to construct a framework of social location information for each participant in a 'top down' fashion according to Bourdieusian assumptions of forms of capital and gendered and socially located habitus. Bourdieu and Wacquant (2007) had criticised IPA for failing to take account of pre-reflexive intuitive knowledge gained over time, and taken for granted knowledge, because in its pure application, IPA stops at the level of the meaning in the present. They argued that IPA neglected *'the historical underpinnings of the relation of the immediate fit between subjective and objective structures...'* (Bourdieu and Wacquant 2007 pg 74). This suggested that taken for granted knowledge that is constructed through upbringing and socially constructed and located ideas should also be brought into focus. I was able to refute this criticism by addresing meaning creation based in lifetime experiences.

By adopting this top down and bottom up premise into my coding strategy, I was able to form selective a priori codes that related to social divisions and personal upbringing, as well

as free and subjective-meaning codes that were derived from the data. This coding strategy inevitably led to some data being coded to two or more locations, but by accepting that neither were superior and coding was simultaneous, I had produced an analytic strategy that was the best fit for my research design, that was logical, and most importantly, would be able to address the research question in a robust manner (Mason 2009).

2.12 Researcher Reflexivity

In acknowledging the important role of habitus in informing my participants' accounts of their experiences, I also needed to acknowledge my own habitus shaping my thoughts and feelings towards the participants that I encountered, and in shaping my approach to this research. As a researcher and as an individual I had to accept that I could never be truly neutral or detached because I too am a social being with a personal history. I have my own social origins, and I also have a bias related to my academic field and training (Bourdieu 2010) that informed my decisions concerning the design of the study as an IPA methodology, and adopting a Bourdieusian theoretical lens through which to assess social location. I also have a personal relationship with dementia having witnessed close relatives overcome by dementia but retaining a degree of insight until near the end of their life.

My personal history and habitus have undeniably informed my decisions and have contributed to my methodological choices, however by engaging reflexively with my decisions and choices, I was able to challenge my own assumptions and biases and control them through self-criticism (Bourdieu and Wacquant 2007, Mason 2009). Barnard in 1990:75 stated that *'it* [reflexivity] *should be achieved by subjecting the position of the observer to the same critical analysis as that of the constructed object* [patient] *at hand.'* Through engaging in this way, I was able to address my own biases and limitations in

interpreting the gathered data and thus note Bryman's (2004) warning of being over influenced by my personal experiences.

Bourdieu and Wacquant (2007) were also concerned with intellectual biases that can distort the logic of practice. They argued that pre-suppositions are built into methodology and the disciplines that adopt them. These suppositions are in danger of being fed into data collection and analysis. I wanted to include my observations and conversations with relatives and medical staff in the form of field notes into the data set, which is common practice within this field of research, and qualitative methodologies more widely (Mason 2009). By including material such as this, I was making an assumption that they would add a dimension to the participants' narratives that would enhance and clarify the data (Silverman 1994). But through embracing and reflecting upon this material I could recognise and acknowledge biased positions and look beyond the face value of the content for motivations.

Bourdieu and Wacquant (2007) were also concerned with reflective practice in data analysis and particularly that revolving around coding data. They posited that true reflexive practice requires thought concerning the pragmatics of handling the data and in coding procedures. Although I used the software package Nvivo9 to manage and organise the data, it did not, and could not, assist in decision making regarding what to code and the relationships between coded content. I will return to analysis in more depth later in this chapter.

The importance of reflexivity for this study was therefore twofold. Firstly that I could recognise my own biases and scrutinise my methodological decisions based on my training as a researcher within the social sciences, and my personal history; and secondly, that I could be aware of my control over my practice and respond to the sociological analysis of

the data as themes were created. Bourdieu and Wacquant (2007) quoted Rabinow (1979) that

> *'genuine reflexivity is not produced by engaging in reflections on fieldwork nor does it require the use of the first person to emphasise empathy, or elaborate on texts that situate the observer in the act of observation...rather that reflexivity...uncovers the social at the heart of the individual, the impersonal beneath the intimate, the universe buried deep within the most particular.'* Rabinow 1979 in Bourdieu and Wacquant 2007 :40-44.

Through engaging reflexively with the literature surrounding dementia and patient accounts, I made a decision to gather data through unstructured interviews and allow participants to construct their own narratives of their experiences.

The following five chapters now explain my findings in detail.

Chapter 3: The Changing Person – Where am I going?

3.1 Introduction

Personal biography and the sense of a life lived is ingrained in habitus (Bourdieu 1986) and is central to the concept of personhood (Kitwood 1997). Personal biography is also drawn upon to shape understanding, meaning and expectations of the future (Sanderson and Baily 2013) and illustrates the intrinsic value of personhood played out in their sense of a lived life. Participants used stories that were important to them in their life history as a demonstration of their sense of self, and to explain their understanding of their current situation. Central themes were the importance of past responsibilities, reputation and role; freedoms and restrictions in life choices, and awareness of changes over the lifespan. These themes broadly reflected the intersectionality of socio-cultural dynamics and forms of capital (Bourdieu 1986), and impacted on creating selfhood and finding value in the past and the present, and in shaping future expectations and the continued sense of self.

What exactly composes a sense of self has been a matter of debate in research terms (Zahavi 2008) however there is broad agreement that 'self' is meaningful within individual, interpersonal, and collective experiences (Sabat 2002, Zahavi 2008). Respondents used a mixture of these spheres as illustrations of their social status and self-awareness and demonstrated a range of responses when thinking about how they have arrived at this point in time. In reminiscing freely about the past, respondents highlighted the important features of their life and reflected upon their life story to date by exploring self-selected meaningful and defining experiences (Bornat 2002).

This chapter will first detail how respondents related their past activities to their current sense of self. The desire to be regarded in the present as a useful, sensible, and whole

person was based in the logic of previously held roles and responsibilities and broadly aligns with Goffman's (1969) *'The Presentation of Self in Everyday Life'*. Differences in household roles and employment varied with social location, with men favouring examples in work and social life external to the family, whereas women were focussed more intently on familial relationships and homemaking, even when they had participated in paid employment in the past.

Secondly the freedoms and restrictions associated with life chances revolving around social location (Crompton 2000) are explored. Ideas associated with life choices feed into concepts of reflexivity (Archer 2003, Sayer 2011) demonstrated in participants' considerations of options at pivotal moments in their life story. Close associations between the disciplines of sociology and psychology regarding definitions of inner resilience and personality traits (Stuart-Hamilton 2006) are linked to life chances and life choices, and represent embedded understanding and meaningfulness of memory loss in the present.

Thirdly recognition of change across the life course, and the awareness of ageing as an expression of change are featured in thinking about the future. Changes associated with dementia such as short term memory failure (West 2003, Alzheimer's Society 2013, Department of Health 2009) were starting to be noticed by some participants and relatives, hence their referral to the memory clinic. The data revealed that for some this represented accelerated inevitable decline, but for others it was seen as part and parcel of normal ageing. What is regarded as normal ageing differs according to personal philosophies (Marcoen, Coleman and O'Hanlon 2007), and this is supported in the data gathered.

These three important areas of sense of self, freedoms and choices, and a sense of change, are a useful framework for expressing 'who I was' and 'what gives my life meaning now', and sets expectations of 'who will I become in the future'.

3.2 Reflection – Who was I?

This first section of the changing person chapter introduces the assertion that assembles during the thesis that a link exists between personal history and making sense of memory problems in the present. I will give an account of how personal reflection of the past can be used as a defence against recognising memory loss, or as a tool with which to measure deficit, and I will outline differences associated with social location.

More marginalised people and especially working class men drew upon their previous responsibilities as tangible evidence that they were fully functioning in the present. Continual referral to past achievements, responsibilities, and their life story to date, created a backdrop against which memory loss was placed. This sense of a lived life provides the foundation of the current lived experience as defined by Bourdieu (1986) as habitus, and shapes thinking about the future relating directly to the concept of personhood (Kitwood 1997). It is widely agreed that personhood should take account of personal history (Sanderson and Bailey 2013, Sanderson and Lewis 2012) and the ongoing and constantly developing sense of self (Zahavi 2008); therefore attention needs to be paid to how the past is constructed in the minds of people with memory loss.

The following extract is from Alf, a retired farm labourer with little formal education who summed up his logic of his dementia diagnosis.

> *There's nothing the matter with my memory… I can't make out why they say my memory's gone… I used to go up to Scotland to see the* (horse) *racing. So how the bloody hell can I go all the way to Scotland if I got no memory? I used to go by train, but I have still got to find my way up them haven't I, so how the devil they can say that my memory's gone?* Alf (Farm labourer)

I was able to ascertain later in the interview that Alf had stopped attending race meetings at least two years before our meeting, but Alf's incredulity at the suggestion of memory loss is linked firmly to his past activities. He appeared to dismiss any thoughts about the time scale of when he last attended race meetings or to connect this with his current situation, preferring to resolutely cite his earlier activities as evidence of his current cognitive status.

Similarly, although John acknowledged that he had some memory loss and had reluctantly agreed to a memory assessment, he used his earlier activities as a defence against the stigma associated with dementia, and as a tool for denying his memory problem. In the following extract with me and his wife, John explained how his past activities were evidence of his continued abilities, and his fear of a dementia label. John had been a black cab driver and a plumber.

John: *You know I can do plumbing, I could do electrical, some electrical, minor electrical works, floor laid, tiles, put tiles up, do anything.*

Julie: *So the memory problem doesn't affect those sorts of things that you want to do?*

John: *Doesn't affect me one bit. I've done a showering room in there, it was a cloakroom wasn't it? And I ripped it all out, tiled it all up, put a shower in there, put a basin in there, put a toilet in there, done the floor. I mean you go and have a look at it, it's professional job, done. So I'm not stupid, am I? There's not a lot of men on this site could have done that.*

Wife: *No, it don't mean to say you're stupid because you're getting memory loss do it?*

John: *No but*

Wife: *It happens to thousands of people*

John: *But it does get a stigma with it, doesn't it? It does have a little bit of a*

stigma with it, I don't know, it's just me…With this memory lark, it's all like trivial,

you know, isn't it.

Both John and Alf indicated that stigma of memory loss was a factor in the way they

thought about their difficulties, but both preferred to focus upon activities and competencies

of the past and used them to make sense of the present. On the surface both men in the

context of no official diagnosis, belittled their memory problem with phrases such as '*it's all*

trivial' and *'there's nothing wrong'*, however both had hinted at the stigmatisation of

memory problems, and so I decided to follow this theme in the data, and found that this was

a common feature among the working class men's testimony in particular.

Graham was a retired insurance representative and when asked, positioned himself socially

in the upper working class realm through his explanation of being self-employed in his

working life and 'bettering himself'. He was particularly concerned about maintaining his

driving licence and was archetypal of the male drivers in the working classes in describing

driving accomplishments from decades earlier, and relating the experiences to his current

ability.

 A current driver took you out in one of their lorries, and if he said you were all right,

you were all right. I learnt a lot of things, like in Rye you cannot turn a three ton lorry

from one of the little roads into another little road unless you have to do it two or three

times. But there you are, those are sort of things that they don't teach you in a

book…I'm afraid, I'm very old fashioned in lots of ways and I don't like other people

making decisions for me. I like to make my own decisions with what I know. And I

know whether I'm fit to drive or not…I suppose having worked for myself for so long

and always having to make, you make the decisions, nobody else makes them. Graham

(insurance representative)

Graham's reference to his ability to make decisions for himself was inextricably tied to self-esteem and supported the sense of self. Although this was a slight deviation from the previous examples from Alf and John, Graham also did not consider his memory problem to be significant, and regarded it as only a minor irritation. Because he could draw upon his past skills as a good driver, he was able to defend his position as a good driver in the present. Graham's view then led me to consider how more middle class respondents thought about and incorporated their past into their thinking about the present.

In contrast to the previous men, Patrick, from a middle class upbringing and employment history, drew upon his past in a totally different way, and used his activities and hobbies to help him recognise and address his memory difficulties. Noticing deficits in his activities served as a warning sign that something was not quite right, but did not undermine his self-esteem as it had for Graham, Alf, and John. Patrick was able to tackle the question of his forgetting without feeling so threatened.

I think what probably woke me up to the idea that I, my memory was failing was the, I realised I was putting an excess load on my wife, because she was doing all the reminding for me, remembering for me, and I thought to myself, well this is wrong. I can't load her like this…Well that was the first stage. The second stage was when I realised that working on clocks, making models, working on small machines of various types, I was having trouble getting into the sequence of things. And as it is now I can, I can't remember. I've just been doing some addressing on the chimes here and I can't remember what I've done. And that's when I realised that my memory was getting so faulty. Patrick (Scientist)

By openly acknowledging his memory problem, Patrick was released to seek help and in doing so, he could regain control of the situation. In the following extract, Patrick used his social and cultural capital illustrated in his intellectual abilities, and drew upon his employment as a scientist to form expectations of the memory assessment process. His employment history encompassed great abilities in analysing and problem solving, and he used these skills to make sense of the process.

> *I presume I'm going to arrange an appointment with the clinic, the memory clinic. Well I've seen the doctor. I've seen two of them, the doctor and his assistant. I'm not quite sure how they work, but it was interesting. I don't think they really served any great purpose because basically all they were doing was telling me what I already knew, being a big head (laughter). So it, that in its, that interview in itself wasn't of great interest... they certainly reassured me that they were interested in wanting to do things. Once I've had the scan, then I can get further information on that, thus far, I presume a brain scan...I've had many many scans in my life... [Laboratory] had to give me a check every six months. I suppose, I think it was, must be, to check that I hadn't been contaminated. There's very little risk but they had to check anyway. So I wasn't really worried about it.* Patrick (Scientist)

Patrick was able to construct a logical progression from his memory loss towards medical intervention in a process that the working class men had not been able to engage with. Because he was able to draw upon his past, Patrick had felt able to instigate the medical process himself and freely acknowledged his memory difficulty without feeling threatened because he could relate to medical power without deference. Patrick was drawing upon his middle class background and habitus to engage with medical services on equal terms and address his memory loss as an organic failing without stigma attached.

Social class affects in medical engagement and inequality have been a popular area of health and illness literature and medical sociology since the inter war years (Annandale 2009) and revolve around clinical and layperson narratives of doctor-patient interactions (Delvecchio-Good and Good 2000), however its use in the making sense process of early memory loss is minimal. After considering Patrick's response to medical diagnostic processes, I now turned my attention to other middle class men in the sample for clarity because Patrick's particular scientific background, could have been the dominant feature shaping his response.

Vincent reflected on his career as a commercial pilot and described his job as also his *'life and hobby'*. He elaborated on stories of flying and places he had lived and demonstrated vast awareness of his social position, particularly in poor countries where he had witnessed poverty and employed servants.

> *We were very happy. We had lots of fun and we travelled a lot because I was an airline captain you see. And we went places. We went to South America, we went down to the Persian Gulf, we went to Zambia, we went to Zimbabwe. We went, we went all over the place, and we did enjoy it…we made a lot of money, which is what we were there for…lots of Europeans were very standoffish …they don't talk to them anyway, they'll pass them…but I used to stop and talk to them. Especially when, they'd stand as you went past. …They were earning a pittance…they must have cried when they saw our salaries. A monthly salary probably as much as they earned in a year…extreme poverty there…you ought to give them a tip, that boosted their salary up.* Vincent (Pilot)

When we started to talk about his memory loss, Vincent was very pragmatic.

> *I used to be fumbling with what I was saying and he (doctor) gave me a quick check one day. He says, your memory is going. I said, I know I am, I can't remember*

anything! And he did something for me, organised you people. And I'm very pleased. I haven't seen him since but I'm going to tell him when I see him. It's the best thing you have ever done for me. Because I, it was getting a nuisance. That shows it's a start, it's a nuisance really. I don't want it to get anything more than a nuisance because that pulls you down, you can't remember anything, you can't do anything. Vincent (Pilot)

For the more privileged middle class men, memory loss was presented as an irritation and a nuisance rather than an overwhelming threat to self that needed defending against as in the experiences of the working class men. Memory loss was something that could be negotiated within the sense of self by drawing upon self-efficacy skills to mitigate the situation by actively choosing to seek help. These more privileged men appear to be able to limit the 'hellish' aspects by intellectually reasoning the assessment process and actively choosing to seek help. The choice associated with seeking help is undoubtedly linked to middle class ability to engage with doctors on a socially equal level, thus in this instance, the interpretation of 'who I was' was played out in decision making skills relating to social location.

The women in the sample notwithstanding social location preferred to draw upon their family and home roles rather than paid employment or hobbies to express their sense of personal history and personhood. The importance of family history and responsibility was as central in creating a sense of self as activities had been for all of the men. The women in the study tended to use past family relationships, particularly those with their mother, and the home and housekeeping as markers of their sense of self and as a continuing shield to deflect current difficulties. A typical statement from Sandra illustrates how home and family are intertwined with making sense of memory problems.

And when she (pre-diagnostic nurse) came, she was lovely...And I couldn't believe it. How much better I felt after that. I seem to have got things off my chest. And it did help a lot. I did all the housework, well I tried to (laughs), I've got a big pile of ironing! I've got, all my clothes are clean, all my clothes are clean because I washed them, but I am doing a little bit of ironing every night to get it done. There's clothes galore!..I can't tell you when it started. I don't think it was anything to do with my family, losing my mother or what. I mean she's been gone a long time. Mind you, I wish I had got her to talk to. I think you miss your mum don't you when. All I've got are boys! And you can't talk to them really can you? Not about your mother. Or ask questions about something, so I felt as though, I am always on my own you know. Sandra (housewife)

Sandra had welcomed the home visit as a connection to her continued status within the home. She related her ability to complete her housework with her emotional state, and her sense of 'who she was' was intricately woven within her sense of family history and her womanhood. She clearly identified with her own gender and was lonely for female understanding of the house and home by placing it hierarchically as above the understanding of her male relatives. Sandra was from a middle class and relatively privileged background, unlike May who was also married but had a working class lifestyle and worked in a swimming cap factory at a production line for most of her working life. The women's very different social backgrounds did not affect the relationship between women and the traditional housewife model (Connell 2009). May's account of her personal history was also dominated by her family memories of home and housekeeping and her female identity as a daughter, wife and mother.

I was the eldest of four, the only girl with three brothers younger than me. And in those days if you were a girl you were supposed to help in the home, and that used to bug me because they didn't have to do anything...She (mother) scrubbed the kitchen floor

during the week, but on Saturday that was my job, scrub the kitchen floor, clean all the brass handles on the door knobs while my brothers, off, off…and that's how it was…So it's the way. And yet when I had my daughter I wouldn't let her do anything…It's strange really. But I am a fussy person I must admit. I am a fussy person and I must be doing things. May (Swimming cap factory worker)

May connected her family history with the importance of housekeeping and personal cleanliness. Her sense of the past and her role within the home as a mother dominated her reasoning about her memory loss and helped her to assess her level of deficit.

I mean I can remember to do all these sort of things. The thing that worried me was when my daughter said to me, I won't be seeing you such and such, or this Friday mum or something like that, because I'm going somewhere. You know she'd tell me where she was going, what she had to do, and then after she'd gone I think, God, now why isn't she coming?..so that's what I was feared of… you know, that was the reason I was worried. Because other things, I mean, I don't forget to give myself a good wash down, or I don't forget, you know, all the sorts of things that you do in the home. I don't forget those sorts of things. May (Swimming cap factory worker)

May was most concerned with forgetting her family arrangements because she knew that something important was happening for her daughter to alter their plans. Forgetting something like this represented a milestone in her decline, as the relationship of trust with her daughter was foremost in retaining her sense of self. Her continued ability to do '*all the sorts of things you do in the home*' preserved her perception of usual daily activities and provided a benchmark against which she could measure her cognitive abilities. Using daily activities as a measure of health was meaningful for May in the context of providing reassurance that she was fine and in denying her memory deficit.

In this section I have shown that there is a significant sense of drawing on the past in constructing thought frameworks for confronting memory loss, as well as for giving meaning to personhood. There is a distinguishable variety of uses for the past located in habitus and capital (Bourdieu 1986) for making sense of the present represented as 'proof' of personhood and 'wholeness', and as a tool with which to measure if memory loss is occurring. The significant domains in the past that are used to make sense of the present vary according to gender and social location. Broadly it was becoming apparent that working class men preferred to draw upon their skill sets, middle class men favoured leisure activities which their careers provided the economic capital to fulfil, and women focussed upon family and home. It was apparent that the concept of the passage of time was important not only in the creation of social location, but also in creating the reserves of confidence to engage with the medical world and seek help. Class and gender differentials were starting to suggest that different experiences were related to something other than privilege and marginalisation. The individual life story arising from habitus was starting to feature more than social location per se, and suggested that the arrival at this particular point in time with memory problems could take an extremely individual and heterogeneous route.

3.3 Freedom and Restriction – Who am I?

In an effort to explore the deeper differences in the participants' use of the past, and how it may help make sense of the present, I turned attention to the reflexive life choices based in socially constructed ideas about the life course and expectations of personal development (Archer 2003). Habitus and forms of capital usefully provided a concept for discussing the impact of economics, social relationships, cultural standing (Bourdieu 1986), and the symbolism derived from them. These forms of capital denote the meaning attached to ideas

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associated with life choices, and also relate to psychological concepts of locus and inner resilience and coping (Kobasa 1979, Meichenbaum 2008, He et al 2013). Although these are discussed extensively in psychological theory (Blanchard-Fields and Irion 1988), they have received relatively little attention in sociological literature. Through life story narratives however, they represent embedded understanding and meaningfulness of past life story to make sense of the present (Jamieson 2002) and together with investigating the sense of change, form the core of social gerontology. Answering the questions of 'Who am I now?' and 'what are my choices?' rests on drawing on the past to reach options that feel realistic (Nelis et al 2011). The individual psychology of the person formed part of this sense of self and when dovetailed with social location, helped to create a sense of the present.

As memory loss developed, respondents assessed the effect on their everyday lives in differing ways. A range was displayed with broadly, men taking a more business as usual, problem solving, and habitual approach; whilst women favoured a discussing, planning, and re-organising approach. This was modified according to the level of acceptance of a memory loss problem and gender. However, the freedoms and restrictions associated with social location did have a significant bearing on the interpretation of the choices available in living with memory loss.

Patrick was multiply privileged having come from a 'good middle class family', a good education, stable homelife, and long career as a scientist. He had accepted his memory problem and was comfortable discussing the limitations it had created in his daily life.

I get the impression that I've been through a number of clinics and many doctors and they all seem to gradually form the impression that my memory has gone down. I've become aware of it and just sort of go along, gone along with the pattern. I think it's also just conversation with people. Because I'm not so bad now but at one time I just

couldn't remember words or any damn thing, couldn't remember my own name!

(laughing) I'm exaggerating!.. I'm not a loose thinker, I have to take a subject and

think about it, and I think hard about it and concentrate... also logically, I think men

in engineering, certain types of engineering anyway are probably more built, adapted

to do things. Patrick (Scientist)

Patrick was able to draw upon his inner intellectual resources to approach his memory loss

in a very pragmatic and problem solving way. He reasoned that he could adapt his life to

accommodate his memory loss. On the two occasions that I visited Patrick he did not

express any great discomfort or distress in discussing his memory. This could be attributed

to the early stage of illness, but it seems more likely that this was related to habitus and

gender. Patrick's masculine approach to problem solving, retention of control, and selection

and identification with 'certain types of men' helped him to rationalise his situation as

something that he could in part mitigate by modifying his activities. This was a freedom of

choice that he could rationalise within his gendered expectations of thinking habits, and

exercise in his own assessment of his memory.

Charles viewed his options in a totally different way. He described his memory loss as

'annoying' but was determined to continue as normal in his daily life. He had worked as a

production toolmaker in a toy factory '*to earn a crust*' and described his past employment

as simply to earn money to pay for his family and his golf hobby. Charles fought to describe

his memory problem as simply 'annoying' and nothing more; however his comments belied

a deeper fear of social rejection. This could be associated with the restrictions he had felt

throughout his life in leisure and employment activities. His love of golf was a prominent

feature of his leisure time and he stated many times that '*as long as he gets what he wanted*'

he could deal with anything. He reasoned that he had never '*been a drinker or smoker*' so

the money that would have supported those addictions could legitimately be spent on his

golf hobby. However he clearly regarded golf as a middle class hobby, but one that with careful financial management he could afford to support. For Charles his option to play golf had started as an aspiration that had come to fruition and now defined his leisure time and he was conscious that his love of golf was juxtaposed with his working man social location.

> *Einstein probably forgot some things at some time, went without his pencil or whatever. But it does happen, and I say, I forget more things, I, I go golfing, like today. I forgot my battery for my trolley, and it annoys me. But that sort of thing happens and you don't like people to know about it I suppose, after all, we're all the same under the skin...But I've never, I, it's never bothered, as long as I was getting what I wanted, and I never, I, I, never fought for position. I never. I was quite happy what I was doing, probably my capabilities, but I was quite happy to do that.* Charles (Factory toolmaker)

Charles's view on the surface does suggest his nonchalance regarding his memory loss as he simply describes his annoyance at the limitations it brings. This annoyance was expressed only in relation to his activities however, he did express anger and feelings of inadequacy at forgetting, and this hints at a deeper realisation of stigma that goes beyond his surface expressions. His comment of '*same under the skin*' reveals his knowledge of variances in social location and his acknowledgement that other people may have different perspectives, but he went on to describe how forgetting made him feel.

> *...and more to the point of feeling foolish when you've forgotten for a start. Why don't you remember that? That doesn't help! But that's another thing, and you lose, lose a little bit of, I don't know, you lose a little bit of what you want to do, because you think...I meant to do that yesterday. And you've, you feel a bit foolish. The foolishness comes from me. It's another thing, if it turned round a certain, someone says, oh*

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Christ, can't you remember anything? That's not foolishness, it makes me angry, angry at myself, basically for forgetting, but I only feel foolish when I've thought of it… someone snaps at you, one thing or the other which people do, we all do it, and I still feel foolish and there's a certain amount of anger in it…there's a three way split, I'm angry with them…more angry at me…I just feel foolish. …the anger is probably seemingly normal…I just don't say nothing. Charles (Factory toolmaker)

Charles clearly felt that his memory loss had impacted his psyche because of his referral to anger and the shame he attached to forgetting, and as this affected his activities, it was moderating his concept of 'who he was' at the present time. He felt restricted by his memory loss and described at length his efforts to cover up his deficit particularly in his golfing company. There was a feeling throughout that by moderating his behaviour in order to cover up or cope with his memory problem; Charles could avoid creating socially awkward situations and reduce the stigma of memory loss. The moderation of his behaviour was a choice forced upon him by the threat of making social mistakes, and so a better option was to retreat and avoid situations completely.

Patrick and Charles were both typical examples of their social location and whilst the category that they represent was not large enough to make a wholesale claim, they do suggest that diversity exists in relating social position to memory loss and early dementia. Charles as a more marginalised person demonstrated that surface comments can mask a deeper fear of the stigma and impact of their memory problem, and that the presentation of self (Goffman 1959) as a person who can cope with adversity and reduced life chances is more likely to work towards projecting a dismissive response to memory loss and work on the principle of simply 'having enough' to survive. Whilst Patrick as a more privileged person was able to draw upon inner resources in the comfort of knowing that he could challenge doctors' opinions and if necessary, finance changes in lifestyle and modify his

activities without jeopardising his sense of self. In Patrick's case his memory loss was a problem to be solved, but for Charles it was an attack on his life style.

Choices associated with gender and social location played an important role in assessing the freedoms that were open to participants. The ability to financially support extra help in the home or adaptive equipment such as talking clocks and kitchen white boards that serve as reminder posts, require emotional support and financial support to be successful (Metz and Underwood 2005). Those people who lived alone found this a much more challenging aspect than those living with spouses and partners. As single women tend to be financially poorer than single men in retirement due to a number of social reasons surrounding life expectancy (ONS 2011, 2013), pension availability (Arber and Ginn 2005), and employment history (Hartman 1976), they tend to rely more heavily on family financial support in later life (Department of Health 2009). However women seem more able to access emotional support for making changes in their lifestyle than the men in the sample and is in accordance with many gendered socialisation studies (Skeggs 2002).

Literature concerning the sociology of health and illness (White 2011, McIntyre, Hunt and Sweeting 2004, Lane and Cibula 2000, McElroy and Jezewski 2000, Nettleton 1998) and feminist social policy literature (Naldini 2011, Connell 2009, Pascall 2002, Charles 2000) strongly supports the view that women have a greater network of friend and family relationships that are available for support, and will discuss problems more readily than their male counterparts (Annandale 2009). The women in my sample bore testament to this and frequently referred to discussions with family and friends when talking about their memory problem. This was evident across social classes and was located firmly in female cultural capital.

Violet was a middle class housewife. Her husband had been self-employed in the family fruit growing business and together they had enjoyed a busy and plentiful lifestyle. Violet was widowed and had moved her home to be near her son and his family shortly after her husband's death. She talked at length about the importance of friends and family in supporting her throughout her life, but explained in detail how important these relationships are to her in retirement and when coping with memory problems.

> *I've just lost one of my friends who lived there with us. Rose. We were friends you know, but when you start getting on it does come hard when you start losing friends…The boys. I've only got one and three grandsons, and lots and lots of friends. I've made lots of friends around here. 'You all right Violet?' and they ring up and come and pick me up if we are going out. We went yesterday, out for a meal... I'm lucky, I've got a smashing daughter-in-law…My daughter-in-law says since, I've lost a lot of confidence since I had it (memory loss) and she says I've changed, but I don't know how I've changed…I haven't got the confidence that I had.* Violet (Housewife)

Violet had discussed her memory with her family and friends and made them aware that she was experiencing difficulties and they had responded by providing extra support in the form of daily visits. Violet was representative of most of the widowed women in the sample in revealing her feelings and fears to close relatives, and this aspect was located in women across social classes.

May was also widowed but had a different response from her family when she mentioned her fears concerning her memory.

> Julie*:   Did you discuss it with your daughter?*

> May*:   She know's what I'm like. That's what was worrying me. But she kept saying,*
>
> *Mum, she says, I'm like it…so you know she said everyone, you know has got this sort*
>
> *of thing.*

> Julie: *Why was you particularly worried?*

> May: *Because of the memory. It is to do with, isn't it, Alzheimer's is memory, isn't it.*

 May had been fretting about her memory loss and had decided to talk to her daughter about her concerns, but her daughter's dismissal of her worries had created some anxiety for May so she had resolved to talk to her doctor about it. In May's case her social connections did not satisfactorily function as the support that she required, but she had nevertheless confided in her friend and family network. May was worried and had sought support, and the lack of acknowledgement from her daughter had caused her some distress, therefore the prospect of memory loss and her fear of Alzheimer's disease was clearly regarded as something to be negotiated and caused her to contextualise her future and contemplate death.

> *There's nothing I can do now except go into sheltered accommodation really, because*
>
> *I couldn't stand a move. And I said to my daughter, well I said, if I did, by the time we*
>
> *get it all settled out, I said, I'll be one my way up there (heaven) or down there (hell),*
>
> *so it's no good bothering.* May (Swimming cap factory worker)

May clearly felt that no other options were open to her to support her living at home and so her financial and social restrictions were heavily felt. This sense of social restriction was encountered differently by Gwen. Gwen was also socially located in the working class and was currently married. She was a younger participant at 65 years old and had recently retired. Gwen asked me to read a letter from her GP that supported her own suspicion of an

early dementia diagnosis. She said that she had not told her husband. I asked her to explain why.

> *He's decided to retire next year my husband, and I want us to be together for a long time, and do stuff together, not for him to be cross with me. Because he gets cross with me now when I forget things. No. He had to go through it with his mum...she was a wonderful mum but for weeks she would be ok and then she went to see and do things, and get up, and he would get in from work, and he didn't know how she would be...Sometimes he would get in and there would be no tea for him...He got really cross with her. He didn't mean to, but he gets cross with me sometimes. He doesn't mean it. Because I have always, always been there...afterwards it's just a joke but when you, when he says, he's got that voice, that's when he's cross. He got that voice.* Gwen (Care worker)

Gwen displayed feeling the restrictions of her female role in the household throughout her interview. Her comparison of herself in symptoms and in female housekeeping to her mother-in-law did not allow her the reserves to express her feared decline. She was torn emotionally between seeking professional help for her illness and the implications that would have for her family role and life. Gwen feared that her frailty would be punished in her relationship, and the power that she felt her husband had would be magnified by her memory loss and the vulnerability which would ensue.

Throughout this discussion of freedoms and restrictions in the experience of early memory loss, and through detailing the participants' views, I have explained some occasions in which Hulko's (2004, 2009) continuum of 'not a big deal' to 'hellish' is not supported. These occasions could be related to the stage of illness of my participants compared to Hulko's sample, however, drawing upon social location as a predictor of reaction is rather

more blunt than drawing upon personhood in the widest sense. It is clear that the reaction to memory loss is complex and I have shown that whilst it does seemingly rely to some extent on gendered and class perceptions of intellect, it also rests importantly on material and emotional resources available to mitigate the effects of memory loss. Material and emotional resources are gathered over a lifetime and are constantly developing and shifting as a person ages (Marcoen, Coleman and O'Hanlon) and result in developed reasoning embedded in habitus. Westerhof et al (2003) described the 'paradox' that exists in older age, because disability, ill health and bereavements that characterise this stage of life do not diminish morale as expected, because over a lifetime people have mastered their negative emotions and practiced presenting themselves positively to the world, and have developed expectations of older age that include inevitable decline. This led me to consider the differing expectations of the future among the participants as an indicator of the predicted outcomes of memory loss.

3.4 Assessing the Future – Who will I become?

This section will explain how the participants contemplated the future. Ideas were associated with acknowledging change and ageing across the lifespan, and predicted changes in the future. The threat of dementia created introspection concerning 'who will I become' in a much stronger manner than reflection on normal ageing, partly because of the stigma of dementia, and partly from the lay perception of people with dementia being socially removed from reality. This reflection and deliberation about the future was most prominent in the women sampled. These differences could be related to the previously discussed female ability to seek support and disseminate their thoughts through friends and family, or conjointly, women could have a heightened awareness of dementia through

socialisation because a little over two thirds of all carers are women (Bond and Cabrero 2007). However, according to the UK census (ONS 2011) this is concentrated in the 50-65 years age group, and by retirement men slightly outnumber women as carers and share the burden. Although when considering the concentration of women carers up to age 65 years, they are more likely in retirement to have been exposed to stories about dementia, or have experience of caring for a parent with dementia (Annandale 2009, Arber and Ginn 2005).

The women in this study were unanimous in discussing their worries concerning what dementia would mean for the future, compared to only a third of the men who discussed this point. Although strong gendered differences occurred in the vocalisation of concern this does not necessarily mean that the men were not concerned, but rather that their masculine habitus of being reticent in discussing feelings (Bourdieu 2007) was more likely present.

Expectations of changes over the lifespan were fundamentally entwined with ageing and social location (Coleman 2005, Gubrium 2005), and this in turn had an extensive influence on retirement and coping with ill health in later life. Male participants particularly utilized their perceptions of ageing rather than ill health to theorize about the future. As men are more likely to deny ill health until reaching crisis point (MacIntyre, Hunt and Sweeting 1996) it does not seem surprising that they did not theorize about dementia and preferred to either deny their memory problem or relate it to existing health concerns.

David and his wife were in the process of selling their family home of 50 years and moving to a smaller property when I met them. David had experienced a series of life threatening health problems and reasoned that moving was a good idea.

1960 we got married, so it's getting on a bit. Waking up to the same wife every

morning with a cup of tea in bed. She has, always. But I'm retired now. I used to be a

carpenter and builder years ago, up to ten years ago I suppose, then I retired…but you

can't be sentimental when you've got health problems, financial problems, and perhaps even to move about problems. You just don't, you don't need it. David (Builder)

David's further reasoning for his house move focussed particularly on financial changes that he had experienced since retiring, but his wife reasoned moving house to be a good idea because of their advancing years and health problems. She was focussed on being geographically nearer to their family and shops and neighbours, whereas David was focussed on the financial advantage because of his increasing mobility problems and greater reliance on public transport. He had a strong sense of changes associated with milestones in the life course and appeared to consider this house move in the same manner. This approach was apparent as he discussed the birth of his children and grandchildren and shifting friendship groups as he had aged.

We've (friends) gone our separate ways basically because you do it in, in stages actually, like, I think. You've got, when you're young, your whole life is centred around your children when they are little. And then there's a period of time when they grow up and they don't really need you, and basically you get in their way and cramp their style, as they call it, right? But you've got to learn to back down and go away, that's where your friends come in you see. So you have that period of time, and then the children get married, and then they want you again…so you tend to neglect your friends a bit. Now if they are really good friends they stay, but if they are not then they dwindle away. David (Builder)

When I asked David about his memory he denied that he had any problems on the basis that he has not experienced any noticeable changes. The following extract between David and his wife illustrates how a sense of change is necessary for recognising a memory problem.

> Wife: *Well, you see I'd thought that he had been losing his memory for quite some time, because different things I'd said to him, but I thought he was just being awkward, like a cantankerous old man. But you didn't think there was a problem?*

> David: *No I didn't. No. No I didn't think I had anything wrong at all, no. I didn't take much notice of it.*

> Wife: *He was annoyed with me for saying it though.*

> David: *I didn't feel that I'd lost my memory, because I was still doing things that I wanted to do, and you know. It is very irritating.*

David's wife's comment about ageing and expecting him to be 'awkward' and 'cantankerous' illustrates how memory problems can be construed as 'normal' ageing. It was becoming more obvious to his wife than to David that his memory problem was something other than normal ageing because he felt able to continue with his usual activities, but she noticed his forgetting. As he could not detect a change he had reasoned that no problem existed and was therefore irritated that it had been pointed out. David did not consider his memory loss was 'as significant', but this was due to a failure to recognise his symptom rather than a rationale for his memory loss.

David's testimony illustrates the importance of change and the expectations that are associated with it for the life-course. David expected to downsize his property in retirement, and he expected his health to decline, but he did not expect his memory to become a problem and so this issue became the source of contention and irritation.

Steven was aware of change in his personal life but also change in the social world. He recognised that changes in social institutions occur and that they may involve him, but he reserved the right to disagree with institutional change.

I don't think I've got a memory problem, I don't think. I think they just, look, it's this. This young chap, doctor, and you know, and I think they think, oh he's 82, he must have problems. This is the thing…I know that life is like that these days, and they bring out some new thing, and everyone thinks it's a good idea. Steven (Accountant)

Steven's use of 'these days' and his referral to 'everyone' indicated that he has a strong sense of change over time, and that he included official opinion in his social analysis. Steven went on to describe selling his large family home following the death of his wife and his plans to visit his son overseas indicating a sense of change over time and of planning for the future.

Both David and Steven were characteristic of men in the sample that denied any abnormality of their memory, and displayed a strong awareness of change over the lifespan. This led them both to conclude that the future is about planning their life and activities that are acceptable with their changing circumstances; however this does not include any abnormal memory loss. This masculine outlook on the life-course is depicted in their reflection on the external points of reference for change such as material wealth, friend relationships, and changed personal circumstances, but it did not include any existential reasoning regarding their memory loss.

In contrast, the women in the sample tended to be far more introspective and searched for change associated with abnormality, and projected this trajectory into the future in a far more detailed and comprehensive way by using their self-knowledge and interpersonal relationships as points of reference.

Carol had owned and run a large business employing over 350 people. She was an unusual respondent because she was the second youngest person in the sample at age 59 years and had for several years suffered a brain degeneration disease that had gradually progressed

attacking her motor skills. Carol and her husband lived in a very large and opulent home deep in the countryside. They had enjoyed an extremely wealthy lifestyle and owned several other equally impressive properties and businesses. At the point at which we met, Carol was unable to walk unaided and found talking and controlling her body difficult so her husband interpreted for our interview. Carol described her life and past social relationships, and how she met her husband. She talked at length about their grandchildren and her sadness at her loss of the ability to play with them and care for them in practical ways. Her sense of change over time was very acute as she measured her illness progress by losses in her function and lifestyle. Now that she was also experiencing memory loss, she associated this cognitive decline with dementia and she predicted increasing decline until inevitable death. Her awareness of change did however give her hope for the future.

> *Science moves so quickly these days that we just hope that something will, another drug that will appear and be able to help…Another big thing for us is that we have the back up of the family. Because any of them, if there was a problem, they all say, Oh I will come over, anything we can do.* Carol (businesswoman)

Carol and her husband projected a sense that they were racing medical advancements against her decline, but that the support of the family and the help they provided would remain intact. In this sense her assessment of 'who I will become' was fluid as Gwen's had been in her assessment of surviving existing illnesses, and was mitigated by hope for external forces and the actions of others. Carol's husband commented on their obvious wealth and cultural capital and the advantages that it had given them throughout their life. He continued to assess the future on the same financial terms.

> *I would hate to be in this situation and not be financially stable. You know what I mean? I'm not being funny but if you were relying on help from the state, bloody hell!*

We wouldn't get anything...If it was somebody who was hard up or something, well I hate to think how they would cope. If we wasn't in this sort of situation that we are in, it would be hell. How many people have this, what we've got? Carol's husband.

There was an impression from Carol and her husband that they were planning for and predicting the worst outcome, but hoping for a medical advancement that would have the power to change their future. Carol's sense of change was shaped around her declining functions as well as her memory loss, and the impact that decline was having on her family activities. She had first noticed changes in relation to these activities and had actively sought help from services. This is in contrast to the men in the group who had focussed upon material and practical changes in the world around them, rather than change within themselves.

The working class women in the sample approached the question of the future in a distinctly different way from Carol because they outlined an imagined future of dementia, and each described the meaning of changes that would take place. Joan and Gwen, who both had a strong family history of dementia were able to give detailed descriptions of what dementia meant. They framed this entirely as changes in social behaviour.

Joan: *I feel that if I went the way my memory is at the moment, I might get delegated to the rear seat, you know?*

Julie: Do you mean that people would treat you differently?

Joan*:   I'm not talking to her cos she can't remember half of what you say...they are just lost people aren't they. They are lost, they are gone. They don't know where they are, who they're with, most of them. And I don't want to finish up like that. I'd rather die than finish up like that.*

As Carol had done, Joan located her predicted changes in social relationships. She was aware of change over her lifespan and talked freely about her diverse past experiences. However, when thinking about change in the future, she described her current memory loss as a direct predictor of the future. Her fear of 'delegation' is a powerful descriptor of her future and prepared for her expectation of 'being lost'. Both of these phrases are linked to the reactions of other people to memory problems, so whilst she was aware of changes in herself with regard to her memory, she was more concerned with the changed reactions of the social world towards her.

Gwen had suffered a range of physical health problems and had received good outcomes for them but like Joan, her memory loss represented inevitable decline and social isolation.

> *I got away with, my new knee done, and I got away with my thyroid cos I had that done, and that's all clear now. I got away with having bowel cancer, and now all I need to get away with, but I won't get away with is Alzheimer's. Some of the things that's happening. Sometimes I have odd shoes on! I know it's laughing at the moment, but you get people, even my doctor, when I said about it. Where she said, well people do get forgetful.* Gwen (Care worker)

Gwen had highlighted the inevitability of decline that is associated with Alzheimer's disease and again implied punishment and retribution for her memory loss. She also provided a sense that she could predict her own fate and considered it to be something that she could not 'get away with'. Both Joan and Gwen conveyed a fear that others would lack understanding that memory loss was different to normal ageing and resented the implication that it was 'normal'. They both clearly felt that their memory loss was abnormal and based this opinion in life experiences of caring for relatives because the changes they had witnessed in others were beginning to be recognisable in their own behaviour and this had

created a heightened concern for the future. It seemed that the experiences of women in caring for family and friends, and their shared understanding of memory loss, had impacted their sense of change in some considerable fashion. This finding now directed my attention to exploring how memory loss is confronted.

This section has addressed the theme of 'who I will become'. I have shown that there are gendered differences within the social location in predicting the future when experiencing memory loss. The men in the sample had little or no experience of caring for a relative with dementia in the past and based their understanding of their memory loss in normative language associated with ageing and other illnesses. For men there was a strong sense of change across the lifespan in work and relationships, and this provided the main focus for explaining and predicting change in the future.

Women tended to emphasise and worry about loss of relationships by recognising their memory problems in past experiences in directly caring for relatives, or in vicarious relationships with other dementia sufferers. Their predictions of the future surrounded changes in how they could socially operate and the fear of isolation through others lack of understanding and knowledge, and this was a primary concern.

Social locations relevant to class were of little consequence in predicting changes in the future with the exception of Carol who was very wealthy and had used her financial status to create hope that she would eventually be able to purchase new drugs or treatments that would help her condition. This hope was not available to other women in the sample and so they had to reconcile change with decline in a more direct way.

3.5 Conclusion

Several conclusions can be drawn from considering the changing person. Firstly, there is a relationship and sense of life story of 'who I was, who I am, and who will I become' that relates to personhood. The extent to which memory loss is considered to be a problem is in relation to the sense of self which is inextricable bound to personhood and rooted in habitus. As habitus is constructed throughout the life-course according to experiences and socially constructed ideas (Maton 2008), it is unsurprising that the responses to memory loss are varied. However, broad distinctions can be made according to gender and the concept of change.

Hulko (2009) had suggested that more marginalised people were more likely to dismiss the significance of dementia, and that more privileged people were more likely to view dementia negatively. This is broadly in line with the World Health Organisation's (2012) analysis of trends in diagnosing dementia worldwide. As memory loss is a first symptom of dementia it would seem reasonable to expect the same findings when talking about memory loss with my participants. However, this was not the case. My more marginalised men in particular would deny and make light of their memory loss, but when pressed a little deeper revealed a much more embedded fear that related to the loss of a sense of self and a logic of 'who I am'.

Secondly, the location of 'who I was' varied according broadly to class and gender. Men located their sense of self and worthiness in past activities and skill sets, whilst women tended to focus more upon social relationships and family relationships even when they had a well-established work history. In keeping with research regarding work and gender, and work and social class (Elbororgh-Woytek et al 2013, Mitter S 1985, Walby 1986), I also found that the importance of paid employment is greater for men than women. This is likely

to be influenced by the age group of the sample and may not be repeatable over time as more young women compete in the workforce (ONS 2014,   Elbororgh-Woytek et al 2013) and the shape of family life and family constructions evolve further (Grochowski 2013, Hill 2011, Young and Willmott 1973) and could be restricted largely to this particular generation cohort.

Thirdly, life history and the mini narratives within the interviews that reminisce about the past, form a sense of 'who I am' in the present. Many of the narratives were contradictory as illustrated by the examples discussed in this chapter, for example, some of the men's dismissal of the impact of their memory loss is rooted in a denial process, that is apparent in their constant use of 'who I was'. Whilst for others, there was a sense of acceptance that memory loss is part of old age, or for others, the presentation of self as a knowledgeable and worthy person was enacted in descriptions of activities that were no longer current, but nevertheless, served to promote the sense of self. Hulko (2004) had explained that as social divisions were factored in, the problem of teasing apart the meaning of the dementia experience would become more complex and nuanced. I concur as there are many variants in the responses due to life story and social location as well as prior experiences with dementia.

Fourthly, the concept of privilege appears to be far more nuanced than simply considering intellectual capabilities and is closely related to forms of capital. Privilege brings financial wealth and this does tend to supply and ensure a higher standard of education, but it cannot be overlooked in the context of practical resources such as buying services. There was a distinct sense throughout the responses that privilege brings deeper financial and emotional reserves that can be drawn upon before reaching a crisis point. My respondents were in early stages of the illness and were comfortable in buying help in the form of services and support, and in engaging with the medical world on an equal footing. They also had life

stories in which money had enabled solutions to all manner of difficulties. This concept was so embedded that they could be relaxed when thinking about memory loss as their previous experiences had always shown them to receive good outcomes. The one exception to this was Carol, who also had another progressive and terminal disease in conjunction with her memory loss. She was very wealthy and had not been able to buy a cure for her pre-existing illness and so her memory loss seemed to be a relatively minor problem when compared to her others.

Finally, there are distinct gender differences in thinking about 'who I will become'. Women focussed heavily on socially isolating factors surrounding relationships whilst men focussed on ageing and illness even when they had seemingly accepted that they were experiencing some memory loss. This difference could be located in the female tendency to discuss and seek support for problems from friends and family, whilst men tend to wait for a health crisis before seeking any kind of help (Sabat 2002, Annandale 2009, Bury and Gabe 2004, Hamilton-West et al 2010, Radley 2004). The women in the sample all had either direct experience of caring for a relative with dementia or through stories relayed by friends. This heightened awareness could feasibly account for the gender difference in sensing the meaning of change over time.

This changing person chapter has outlined the importance of life story and explored the major themes relating memory loss to the sense of self. This provides a backdrop against which the nuances of confronting memory loss can be differentiated socially in terms of its attribution, interpretation, and the associated emotional responses. These facets are discussed in the next chapter.

Chapter 4: Confronting Memory Loss - What is happening?

4.1 Introduction

This chapter builds on the sense of change introduced in the previous chapter and extends this to examine a variety of responses when confronting memory loss. The purpose is to argue that personal life histories together with social location are not only incorporated into personhood, but also shape how memory loss is conceptualised. This chapter will conclude that the attribution of memory loss is governed primarily by the emotional proximity of previous experiences of dementia and secondly by social location, and that the current emotional impact is therefore tempered by the meaning associated with memory loss for each individual based on their lifetime experiences.

The first section addresses the acknowledgement and attribution of memory loss and presents the various conclusions that participants reached explaining the cause of their memory loss, relating these to their life experiences and social location. A range of reasons for memory loss were described by respondents that were closely linked to their life experiences. Differing gendered roles in caring greatly impacted on life experiences of dementia and shaped explanations of current memory loss.

The second section continues this discussion, and examines how the attribution of memory loss is understood in terms of interpretation and consequently, in the presentation of self to others. Fear of stigma, feeling socially isolated, existential thinking, and retaining respectability were common themes arising in the interviews. The level and impact of these

considerations acted as important indicators on the sense of urgency to seek help from health professionals.

The final section explores the emotional impact of confronting memory loss and outlines a range of emotional responses that participants revealed. Responses were directly linked to how the memory loss was conceptualised and causally attributed, and this in turn affected the ways in which memory loss was assimilated into the sense of self.

4.2 Acknowledgement and Attribution

This section presents the range of causes that participants articulated; and the degree to which they acknowledged their own memory loss. Most participants could talk about what dementia meant in terms of the behaviour and appearance of others. However, only those respondents with a strong emotional experience of dementia appeared to link their own memory loss with dementia. This was true even following the recent home evaluation from the pre-diagnostic nurse. Though social location had some influence, the overriding factor was whether they had had a personal life story involving dementia.

Sandra was adamant that she knew what her memory loss meant. She described how her own previous medical history had mimicked that of her mother, and how she had cared for her mother with dementia towards the end of her life. She related her memory difficulties to those experienced by her mother and concluded that she too must have dementia.

My mother, she had Alzheimer's I think. We had to put her in a home in the end, because no-one could look after her…she used to walk the streets. Used to go out the house crying her eyes out. Sometimes she used to leave the key in the door, or the door left wide open. This is in the middle of the night!..Like my mother, you know?..What my

mother's had, I've gone through the same things. This is the last one she went through.

Because we both had our wombs taken away, we both went in hospital for other things,

I can't remember what, we had other things go wrong and not long after I went into

hospital with the same thing. So I thought, well, I'm going to follow my mother. I told

the GP, but he said, no things don't go like that…Because I went in and just burst out

crying and he couldn't understand why I was crying. Sandra (Housewife)

Sandra explained that she was disappointed when her GP had not regarded her memory problem as sufficiently serious to suggest dementia. She described it as '*driving her mad*' because she was sure she knew what it was. Sandra had a stable privileged lifestyle and was married to a retired aircraft design consultant. They had been married over 60 years when I met them for interview. Sandra and her husband talked about their history as carers for her mother and presented themselves as 'experts' on dementia because of this experience. With their first-hand knowledge of memory loss as an early dementia symptom, they had insisted to their GP on further investigation of Sandra's memory problem. The close emotional experience of her mother's illness had a clear relationship with Sandra's reasoning of her own memory problem. This prompted me to look more closely at other people with closely bonded dementia experiences.

Gwen made a similar connection between her previous caring roles for her family and as a former care worker, and her current memory loss. Gwen was from a deeply working class background, coming from a large poor single parent family following the early death of her father. She was married at the time of our interview to a security guard who could not read, and she recently retired. She explained that if her memory deteriorated further it would create household problems because she '*read for them both*'. This situation added to her awareness of the need to maintain her cognitive abilities for as long as possible and had prompted Gwen to seek help as soon as she realised that her memory was not working as

well as it had. She described how she had cared for her mother and siblings with dementia and was currently regularly visiting her sister in a dementia care home. As in Sandra's case, Gwen could recognise the early symptoms of dementia from her experienced expert position.

> *My sister has it too. My sister's in a home. She doesn't know me…She doesn't know me, my sister, but it doesn't stop me going to her…My niece took her up a reading book with all different things on it, but it has buttons on it and she tries to get the buttons off and zips and stuff. She will sit there and just play as if we are not there. But she's my sister and I love her…My sister has Alzheimer's, and you know Alf (brother) has. I am convinced that I am going to get it. The things that I do sometimes. It's exactly the same as my mum. I have got a shopping bag and I keep opening it all the way up to make sure everything is in there.* Gwen (Carer)

Both of these women made a firm connection between their lifetime experiences as carers, and recognising their own memory loss, based on confidence in their own expert knowledge. This acted as a powerful prompt to seek help early. These two women are examples of the four women who had a history as primary carers for people with dementia, and demonstrated the powerful nature of the caring experience and emotional impact of witnessing dementia first hand (Whitman 2010). The remaining four women, Violet, Pauline, Carol, and Katie, all linked memory loss to risk of early dementia but preferred to attribute their own memory loss to other concurrent illnesses. However, they had all experienced dementia vicariously through relatives of friends that had been carers, and so had discussed dementia in those friend relationships in the past. All of the women who had been carers themselves had cared for parents, and some had later also cared for siblings. Their caring roles had therefore primarily been in their middle age years and this supports the findings of Whitman (2010) and Connell (2009) that women take most responsibility for

caring at this stage of their lives, and can go some way to explain this apparent particularly female trait of early recognition of their own failing memory and in linking memory loss to dementia.

Charles was the only man, out of twelve in the sample, who actively recognised his memory loss as an early dementia sign. He talked about his father and the memory loss he suffered. Charles and his wife had moved his father to live with them when his memory was failing.

> *He was, he, he was forgetful and, and he, well, I can only speak about him. He withdrew into his self, sort of thing…I don't know whether I will go like that…and he kept saying, didn't he, where's your mum Chas? He used to get scared in the night and I had to go and sleep with him, didn't I? because it's bewildering, isn't it, when you don't know where you are. Well, he certainly wasn't in his own house, he obviously knew that, and I used to go in there, hear him, and I used to go and sleep with him. He's been dead over ten years, which I don't know whether you think that's a long or a short time, to me it's quite a short time…Of course now it's in the news a lot, I'm thinking about Alzheimer's, isn't it.* Charles (factory worker)

Charles had taken an active role in caring for his father and this had heavily influenced his decision to seek a memory assessment for himself when he became aware of forgetting. He had noticed news stories about dementia and had connected his father's difficulties with this media coverage, and had recognised that his own memory problem may have the same cause. Charles was unusual among the male participants by having been a primary carer for a parent. Other men had knowledge of dementia and had known other people with dementia in their lifetime, or were aware from media coverage of memory loss as a dementia symptom, but they had not connected this knowledge to their own memory problem or incorporated it into their sense of self in such a deep way as Charles. Although Charles

reported that he 'knew' he had dementia, he also explored other explanations for his memory loss. Along with all the other respondents, Charles had other health problems for which he was medicated and these confounded his search for meaning somewhat.

...I've been taking statins, which I don't think are doing me any good...I can't seem to get off the ground. Whether it's the statins or not, I don't know, but I'm not taking the statins at the moment and I've, I've only stopped taking them a couple of days, I feel better already...I've stopped eating chocolate, I don't, I haven't had any chocolate for about a fortnight. Charles (Factory worker)

For Charles these alternative explanations were a flippant addition to the main theme of his dementia self-diagnosis. They were in line with the comments of other men in the study who regardless of social location preferred to attribute their memory loss to an existing health problem or with normal ageing expectations. However the defining factor and primary reason given for self-diagnosis was having a previous emotional experience of dementia. As Charles demonstrates this cannot be considered an exclusive domain of femininity, although women were far more likely to have acted as carers in the past. In the absence of a direct dementia experience the other men would seek alternative explanations that were based upon the logic of physical ailments and ageing as normalising explanations. Variations and combinations of these factors were offered as possible causes and were routinely rearranged throughout the interviews as thinking and talking about memory loss intensified.

The following quotes are a selection of the reasons for memory loss that the remaining men offered.

It's just, if I forget to take my tablets. George (Newsagent)

A certain degree of loss before, but the accident has been the, without a doubt at all, the primary cause of the trouble. Patrick (Scientist)

I mean, that accident I had. I think myself, personally, that is the cause of what I'm going through now. I believe that's what it was, and I still believe it! John (Black cab driver and plumber)

I was coming home from work quite normally, fall over on the ice, knocked my head and it was all actually strange to me. Terry (Machine minder)

I thought, I am getting old but the doctor was good. He did it for me and I, well I owe him, getting me as better as he can. I've got diabetes. Vincent (Pilot)

I have had several, well two heart attacks and a stroke and things, and so I think she (wife) mentioned it (memory loss) to the GP. Frank (Accountant)

The above selection of quotations is representative of the 'mechanical' explanations offered by the male respondents linking various incidents and illnesses to their memory loss. Irrespective of social location, men tended to offer these types of explanation either exclusively or in conjunction with normal ageing. However, Steven was sure that his memory problem was related exclusively to ageing.

I think it's my age. I'm, I am 82…Well, I think everybody, especially when they are 82, they suffer a slight memory loss. I know that they are bound to. But I don't think I'm out of the ordinary in that way. Steven (Accountant)

Steven was the only person who steadfastly adhered to an ageing explanation for memory loss although he did not believe his loss to be significant. Most men cited ageing as a contributory factor or as a normalising agent even when like Charles, they had a strong

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dementia caring history, or when they preferred an accident or illness explanation. Ageing was also a popular explanation or contributing factor among the women's testimony.

I mean, he was 90 odd so I presume he was entitled to some (memory loss). Charles (Factory worker)

Well there's no point remembering what you don't want to remember. David (Builder)

We was always told that wasn't we, when you get older you forget things, my mother always used to say, well I'm getting old, that's why I've forgotten. Sandra (Housewife)

Getting old. Well age. Ageing, 74, 75 years is a long time and people didn't live that long did they, at one time. Pauline (Housewife)

Using ageing as a contributory factor was a concept that was permeated throughout social locations without difference. An awareness of cognitive decline with ageing was used as a useful tool and defence for mitigating the impact of memory loss and in confronting the problem. The comfort attained by normalising memory loss as ageing even when other explanations were contemplated and presumed to be main factors, helped with coping with the memory assessment and the related interactions with health professionals as well as in day-to-day life.

Pauline was unusual among the women in resisting any investigation of her memory loss. She attributed her memory loss to ageing but did not consider herself to be suffering any cognitive problems. Pauline was considered by the pre-diagnosis nurse to be the person in the study with the most advanced dementia. Pauline talked about her life story and was aware of time passing. In the following extract Pauline's husband is trying to confront her with her failing memory by asking her age and she is bitterly resisting being exposed in this way.

Pauline: *You watch, he'll say that's wrong. I'm going to say 65 and he's going to say that's wrong.*

Husband: *What? You going to say 65 are you?*

Pauline: *I was yes, that's how it's, that is how it is.*

Husband: *So, well, there's nothing wrong with it* (memory), *you told me.* (confrontational and sarcastic)

Pauline: *1936!*

Husband: *You see that? That is what it's about dear.*

[Argument ensues]

Pauline: *Jack, can you tell me please?*

Husband: *You are 75.*

Pauline: *Yes, I am 75, ok?*

I asked Pauline how she felt when her husband and children told her that she has forgotten something.

Very, very resentful. That maybe I haven't done enough whatever. It's a job to say exactly, I think, oh, I'm not. It's another, resentful, that another thing has been piled on, that is really the core of it. That this is another big problem. I love them dearly, and they know that, but this has happened to me yet again. You know, all these years what they've piled on. I don't know. Anger possibly, but there again being a Christian, I shouldn't really be saying that because that sort of thing is part of life, and I'm meeting perhaps other people, but whatever. It just seems to be one long sort of

haul…I don't feel that unfair, it's just one of those things. It's just meant to be, and that's it. But it has taken its toll. Pauline (Housewife)

Pauline had a strong Christian belief and was an active member of her local Methodist Church. She explained that she had cared for her two daughters with physical disabilities until they married and left home. Her husband had retired at age 48 due to a severe back injury, so she had been the main carer for the family throughout her life. She had also been a member of the St John's Ambulance Brigade since childhood and later as an alternative to a nursing career because she did not feel that she could formally train and be dedicated to her family. Her faith had helped her to cope throughout, but her memory loss had prompted her to question her existential beliefs. Throughout or meeting, Pauline questioned what she had done in her life '*that was so bad, she deserved more trouble'.* It was unclear whether 'trouble' meant family problems, poor health, or her memory loss but she offered this explanation.

Pauline: *I still cope with everything the way I did, but there's no definite sort of, I don't think, poor me or anything like that. I don't think that way at all because being a Christian, that's part of my life and it's whatever… I had noticed it (memory loss), I've got to be honest, yes. Well it's like you go into a shop and you think, oh I've forgotten something, then you get back and you think, Oh I should have got that, sort of thing. It gets to be a habit really and truly.*

Husband: *I mean you ask the same questions many, many times over.*

Pauline: *Well I do now, I have to admit that.*

Husband: *Within two minutes, same questions as you have seen effectively.*

> Pauline: *Possibly, I would perhaps remember the first time and you know*
>
> *something happens and then I get side tracked.*

Pauline's 'admission' of memory loss offered an insight into connecting forgetting with some sort of moral deficit. She appeared to regard her memory problem as a threat to her religious beliefs, and this attacked her existential self-beliefs. She seemed to be framing her explanation in terms of moral retribution, and in this sense, she was struggling to reconcile her experience of memory loss with her religious beliefs, as though it was some kind of divine retribution or punishment. Pauline was clearly and actively trying to mitigate her memory loss by writing reminders on a wall calendar, but her husband interjected that he often had to correct the entries as they could be up to three years out of date. Pauline was visibly upset at this revelation and steadfastly changed the topic of conversation.

Pauline was the participant most distressed by her memory problem and coincidentally or conditionally, she was also the participant with the strongest religious faith. It is impossible to clarify this further in this group of participants as she was unique in her more advanced stage of dementia and in her religious belief. However, Pauline made a strong connection between morality and memory failing in a way that exposed a connection to the stigma associated with memory loss and dementia. This led me in the next section to consider in more depth how memory loss is understood and interpreted.

This section has discussed the various explanations that participants gave for their memory loss. Gender differences in the responses were clearly evident; however this was also very closely tied to caring responsibilities and the female role in caring for relatives, thus creating a close emotional proximity to dementia experiences and reinforcing gendered socialisation theories (Connell 2009). Women seemed much better than men at recognising memory loss as possible dementia, and this could be due to female caring responsibilities and willingness

to share knowledge with friends and family, and in so doing disseminate the experience to a wider female audience.

Men preferred to attribute their memory loss to a mechanical or biomedical failing caused by illness, accident or ageing, often citing examples of confounding health problems. Deterioration with age was a distinct theme and displayed as a potential source for some memory decline even when other factors such as ill health and accidents were present.

Religion and faith appeared to play an important role in existential thinking and questioning 'why me?'. Although this was based on just one participant, her response to the suggestion of memory loss was so dramatic and so closely tied to her Christian belief, it would be imprudent to not make this connection as it exemplifies the connection between the stigma associated with dementia and morality.

By exploring the different attributions for memory loss it enabled me to question the range of interpretations of forgetting and how these are filtered into an individual's comprehension. This shall now be explored in more detail.

4.3 Interpretation and Understanding

This section addresses the understanding that participants had of their memory problem. A variety of understandings were generated according to the supposed cause of memory loss. The feelings and meanings generated were hard to explain for most participants however illustrations were often offered in examples of daily living.

Comprehension of the memory problem was revealed in discussion of socially constructed ideas around ageing and ill health, and in internalised ideas of the sense of self. It was

apparent that a broad range was represented, but these ideas depended heavily on how memory loss was conceptualised.

This section will conclude that selfhood is critical in understanding how memory loss is assimilated into the sense of self. I will suggest that discovering the feelings and beliefs held by the individual concerning the cause of their memory loss, and expressed in emotional responses, are a better indicator of predicting internally held views than marginalisation and privilege continuums.

Firstly I will address issues surrounding remaining respectable. Respectability was a major concern for many participants and revolved around socially constructed ideas about health and illness and ageing that are based in normative thinking. Attributing memory loss in this way appeared to provide comfort and normality, and reduced feelings of alarm and deflected notions of stigma and spoiled identity as explained by Pauline in the previous section. Respectability was used as a shield against the effects of societal stigma.

Secondly, I will examine responses from those who were sure that they knew the cause to be dementia, and their search for information and assessment as an effort to 'prove' they were right to worry about their memory and therefore understood dementia to be a treatable illness if medication was timely administered. This pro-active approach provided respectability, control and self-respect and acted as a defence against 'othering'.

Lastly, I will explore notions of memory loss related to self-criticism. This group of people tended to question why memory loss had happened to them, and question why other people and especially family members, were reacting to them in unprecedented ways. Anxiety was present regarding how other people may judge their memory loss if it were to be revealed.

4.3.1 Remaining Respectable

Respectability was located in cultural and social capital (Bourdieu 1986) through upholding important cultural values and beliefs and through association with others deemed acceptable and respectable. Being socially acceptable created a sense of respectability, and therefore memory loss assessed as usual ageing did not pose any threat to the sense of self over and above that associated with normal ageing expectations; although definitions of 'normal ageing' varied from person to person (Victor C 2005). A sense that cognitive allowances could be made as a person ages were bound into socially constructed perceptions of age and ageing and normative thinking (Marcoen, Coleman and O'Hanlon 2007). Many respondents expressed normalising perspectives in relating their memory loss to ageing even when they suspected dementia or purported that they were unsure of the cause. The following quotations typify this sense of normal cognitive decline with ageing.

I think my memory for my age is reasonable, but I wouldn't claim it is perfect. Steven (Accountant).

Before I was more do anything type, now I think of, but then I think that's my age isn't it. Violet (Housewife).

I know it's not too bad, it's not. Everybody, everybody forgets from time to time, everybody… But as far as I can see, generally with men, if you live long enough, you get some of it (memory loss). And some get a lot of it. Charles (Factory worker).

I think it's a natural thing really. I think it's, everybody, when you get to a certain age, it happens. It's something you can't do nothing about. George (newsagent).

You go upstairs and you think, you sit on the bed, you think, get halfway down the stairs and think, oh I know what I was doing. It's not just me though, everyone does it you know. The old ones. Joan (Factory worker).

Well, I think that everybody gets it (memory loss) as you get older, and there's not much you can do about it. Sandra (Housewife).

These quotations illustrated the widespread belief that memory will decline with ageing and that it cannot be addressed and must be accepted. Cognitive change in ageing is normal (Deary et al 2009, Glisky 2007, Christensen 2001), and in this respect the participants were not wrong. Examples of this type of reasoning were prevalent across class and gendered divisions and suggest a very widely distributed socially constructed idea about ageing relating to expected cognitive decline in line with research from Marcoen, Coleman and O'Hanlon (2007) and Bengtson et al (2005). The sense of 'usualness' offered a comfort and respectability around 'some memory loss', but the tipping point for many was when they felt they had exceeded that which could be construed as 'normal'. Even those who considered their memory loss to be abnormally great and significant in relation to dementia such as Sandra, Joan, and Charles, continued to regard some loss as 'normal'.

Illness or accident was the second most popularly adopted explanation for memory loss, and this was also constructed in such a way as to preserve respectability. It was considered 'normal' to have other conditions in older age and therefore legitimate to be ill. As with ageing, confounding illnesses and accidents offered a refuge for memory loss that was acceptable and authentic. Some participants fluctuated between offering age or illness and accidents as possible causes, suggesting that they all served a similar purpose in creating respectability. The following quotations exemplify this type of 'illness/accident normality'

as a reassurance that memory loss is common and therefore permissible and importantly, respectable.

> *I ought to explain that because it's, that accident* (fall and heart attack) *is the cause of this other trouble as well…and I presume, because of the lack of circulation of blood, the bonce wasn't working properly.* Patrick (Scientist).

> *This fall and broke my hip, oh it was, see even forget that now. And I think after the anaesthetic. I'm sure the anaesthetic does, at my age, does something.* Violet (housewife)

> *Of course the other chap used to come up there with a trailer and I used to have to load it up. And now and again I fell off it, cos I used to have epilepsy. I still have to take pills, but where they got the idea my memory is gone, I don't know!* Alf (farm labourer).

> *Yes, it's still going on now. I still have to go in (to hospital). What is it, a valve or something, something's wrong with the valve. Then I've got to find out what they are going to do with it* (memory). Sandra (Housewife).

All of the participants had co-morbid conditions and so were used to involvement with the medical world, but memory loss and particularly its association with dementia was considered to be an illness that was so qualitatively different that it could not be discussed in the same way as other illnesses. This removal of dementia as an illness outside of respectable and legitimate illnesses appeared to be the factor that created the most fear for participants and held a special relationship to stigma. Stigma associated with mental illness is a firmly established concept (Mental Health Foundation 2014, Lai, Hong and Chee 2001, Byrne 2000, Dubin and Fink 1992), and so it can be expected that if dementia is regarded as

a mental illness rather than an organic one, then it too, would share stigma. Graham had particularly strong views that summarized the separation of dementia from other illnesses.

> *One's physical and one is mental isn't it. I've had a heart bypass and that's medical, so you do what you're told and you have it done. But with the brain, what's going on in here is your own affair and nobody elses…with my bypass they were able to do checks and tell me what, by x-rays and things like that, so it was a positive thing. Memory or psychiatric treatment, to me, is not positive. It's airy fairy. It depends upon, depends upon how you feel about it or how that man, or that person over there feels about it. And because it's not, because it's not hands on. i.e. like chopping your arm off or anything like that. It can only be what different people's imagination makes it to be, because you can't actually put your finger on somebody's head and say, oh your barmy, can you?* Graham (Insurance representative)

Graham's distinction of physical and mental illness was echoed by participants across the social spectrum, but it was working class people in particular who struggled to identify memory as having a possible organic cause. The relationship between memory loss, its potential meaning, and the predicted consequences in social terms were starting to become clearer and hinted at a conceptual link for participants that related their social understanding of dementia to their social location. I decided at this point to explore other examples of dementias as 'separated illnesses'.

Violet also considered dementia to be a different sort of illness that did not attract, and should not be expected to attract, help. This underpinned the notion that dementia is regarded in some quarters as a degrading and stigmatising illness comparable to mental illness, and one that should be dealt with quietly and alone. Violet's testimony supported that of Pauline's reported earlier in the relationship of forgetting with moral failing.

If I was (suffering regular illness), *she* (daughter-in-law) *sends me food round, if she, if I was just ordinary off colour. If I was really ill* (with dementia) *she wouldn't. I think she had too much of it when she was young, looking after her gran…she was a handful.* Violet (Housewife)

Violet went on to explain that her daughter-in-law had caring responsibilities when she was younger and that it had been a horrendous experience for her. Violet clearly recognised that she potentially would need more help in the future but that the nature of the help required would be too emotionally taxing and therefore burdensome for her to expect help from her daughter-in-law. Part of this burden was losing the ability to reciprocate in an everyday conversation.

Terry furthered this theory and explained that dementia is different because people do not know how to talk to you. He was concerned that losing the ability to understand social rules in conversations led to avoidance by others. He outlined his experience of a visit with his father who had dementia and he reflected upon the embarrassment he had felt at his father's memory loss.

I can remember my father, not long before he died his memory went completely haywire…we went to my sister's which, had Christmas there and as we were leaving, we were just saying thank you very much, and his departing words were, I'll see you at Christmas. We'd just spent Christmas there! Well, you feel blooming awful at the time, because you didn't know whether to say to him you've had Christmas. You don't, it's like when it's somebody that close to you like that, you don't know how to handle it, but I don't know how to handle it now I'm doing the same things. I think, oh no! Terry (Machine minder)

Fear of social isolation is a well-documented phenomenon in the dementia literature (Department of Health 2009, Department of Health 2013a, Alzheimer's Society 2010a, Cheston 2004) so Terry's fear at inducing the same embarrassment in others that he had felt with his father was a powerful example of the social transmission of ideas about dementia that depict it as an 'othering' illness that removes people from usual interactions. The resulting social exclusion because of dementia was the source of powerful anxiety for many participants, but identifying the likelihood of one's own memory loss as dementia was very mixed and related directly to previous personal experiences.

4.3.2 Knowing

In line with extensive research and policy literature (Department of Health 2009, 2013a, 2013b, 2013c), the fear of social exclusion and social isolation due to dementia was the most powerful fear and source of anxiety among the respondents. However, it was only those that had a direct experience of dementia that actively sought an early diagnosis. For this group there was a prevalent sense of a need to 'prove' that they had memory loss portrayed as though an outward display of a diagnosis would excuse memory loss and acknowledge their expert understanding and prove that they were not imagining their difficulties. The ability to retain control over when to receive a diagnosis was an intense experience that helped to uphold self –esteem and status as a person who could continue to govern their own destiny.

Gwen had the strongest emotional experiences with dementia of all the participants as she had cared for her mother and several siblings with the illness. She considered herself to be knowledgeable and was anxious to start medication as soon as possible because she had read media reports of dementia drugs that could reduce the speed of decline and '*buy time'*.

Therefore she had forcefully pursued a route to diagnosis through her GP. Her main

motivation was to protect her husband from the effects of her dementia for as long as

possible.

> *I said she* (GP) *put me in for it* (memory assessment) *but that wasn't entirely true. I*
>
> *said she put me in for it but I asked. I asked her because he's decided to retire next*
>
> *year, my husband, and I want, I want us to be together for a long, long time, and do*
>
> *stuff together. Not for him to be cross with me. Because that is what it will be…He had*
>
> *to go through it with his mum. I know. And that is more or less why* (pursuing a
>
> diagnosis). Gwen (Care worker)

Gwen frequently returned to the theme of her help seeking motivation linked to protecting

her husband. Her statements revealed a deeply held belief that she knew what dementia

would do to her sense of self as the condition progressed, and she wished to take charge in

order to minimise the effects for as long as possible. Her strong sense of knowing what was

ahead had been the compelling and motivating force for her engagement with her GP.

Gwen's unusual situation of having cared for so many family members with dementia and

her persistence at seeking her own diagnosis led me to further investigate the notion of

'knowing' what the consequences of memory loss meant for other participants with less

powerful past associations with dementia.

May also displayed a need to seek a diagnosis in order to confirm her belief that she had

dementia. She explained that her mother had been '*a bit funny*' but that '*they never got to*

the bottom of it' but with hindsight May strongly suspected that her mother had dementia

and this had heightened her awareness of the government media campaign to recognise

dementia symptoms early. She had noticed that she was finding remembering difficult and

had connected this to her mother's experience, and this led her to share her worries with her

family. May had been consistently reassured by her family that her memory loss was normal, but she suspected otherwise and resented being told she was imagining her deficit. Whilst well-meaning comments were aimed at reducing her anxiety, they had produced the opposite effect through refusing to corroborate her feelings. Her family were inadvertently creating more anxiety by causing her to question her own judgement about her memory mistakes. Her motivation to receive a diagnosis was therefore partly driven by her desire to be seen as competent in assessing her own mind and related to an effort to 'prove' her suspicions as correct.

> *Because I was thinking of this Alzheimer's. That's what was worrying, that's what was worrying me. But she kept saying to me, mum, she says, I'm like it, she says. I mean she's a social worker. She said, and we are all like it as well at work, she said. But that was the main thing, the Alzheimer's. Because of this memory. It is to do, isn't it, Alzheimer's is memory isn't it. That was the main thing, the main thing , I thought, Oh God, don't tell me I've got that coming on, sort of thing.* May (Factory worker)

Gwen and May both demonstrated the power of knowledge based on experience as a critical factor in assessing one's own memory. Other participants who also self-diagnosed their own memory loss as dementia had strong associations with past dementia experiences, and this produced a continuum of association that linked veracity of pursuit of diagnosis with past dementia experiences. These two factors increased together with the emotional strength of experience. When the emotional experience was vivid, it prompted immediate help-seeking behaviour; when no emotional experience of dementia was present, participants were far more likely to deny their memory problem as relevant and resisted engaging with memory assessment procedures.

4.3.3 Feeling Coerced

Alf, Robert and Pauline all resented their family's opinions that they needed a memory assessment. They all denied any memory problems and cited a lack of impact on their daily life as evidence. A sense prevailed from all three respondents that they felt victimised and bullied at being cajoled into the memory assessment process. Possible explanations that I considered for this reaction were that it represented a strong underlying fear, a personality trait, or an association with the type and stage of dementia that they were experiencing (Alzheimer's Society 2014a, 2014d). I was able to discount underlying fear because there was little evidence in their testimony of any direct knowledge of dementia, or internalisation of layperson understandings of dementia.

They had little in common socially and had diverse stories of early socialisation or evidence of shared common values; however they did all refer to age and ageing but without any great expectation that their memory would be affected. There was nothing to link these three participants other than all being assessed by the pre-diagnostic nurse as being among the most advanced in their dementia within the participant group. It seems more likely that their lack of acknowledgement of their memory problem was related to this because understanding what is happening, and willingness to undergo assessment and assimilating new knowledge is more difficult and traumatic as the illness advances and cognitive functions are reducing (Alzheimer's Society 2014a). This would offer further support for encouraging early diagnosis as a means to mitigate later distress associated with decreasing cognitive function whilst simultaneously coping with the diagnostic process.

Robert particularly exemplified this disconnection between recognising his own memory loss as significant and his subsequent memory assessment. Robert was widowed and had retired almost 30 years earlier from his career as a lawyer. He had enjoyed a privileged

lifestyle and repeatedly referred to *'proper and correct behaviour'* throughout his interview in relation to social interactions. He framed his objection to his memory assessment around this theme and was very upset that his son had organised a GP appointment to consult on his memory. He considered it to be both insulting and demeaning.

> *I can't understand why. Why my son went with me. Took me there! I was old enough!*
>
> *Christ! I blame him for a lot of things like that.* Robert (Lawyer)

Robert was obvious in his resentment at having appointments organised for him and regarded his son's company at such appointments as *'babysitting'*. He did not recognise his own memory loss and resented the intrusion that he felt at receiving home care organised by his son. Robert referred to help that he was receiving at home as *'interference'* and resented forced changes in his hobbies such as the removal of his shotguns. His earlier lifestyle had been one in which he was utterly in charge and so the removal of daily responsibilities from him and cajoling into the memory clinic was met with bitter indignation. His deeply held beliefs concerning social etiquette had become the focus for his misgivings of clinics and services, for example, in his reference to his home carers as *'girls, that call me luvvy or darling! It just isn't on!'*

Robert's career was obvious evidence of his former intellectual abilities and his high social and cultural capital (Bourdieu 1986). It seemed that whilst the habitus of his former years as a well-respected lawyer remained, his ability to recognise and process new information was deeply affected by his memory loss. This had forced a situation in which he could not make sense of his son's concerns for him because of the attack on his ability to recognise that he was forgetting. He could not understand why people that he did not regard as social equals were entering his home seemingly uninvited, or why he had to attend a memory clinic. He could have considered son's actions patronising, but he seemed to place more emphasis

upon insult at allowing carers of a lower class into his home, than the intrusion of their visits. It was these actions that he blamed his son for instigating.

Alf accused his family of '*overstepping the line*' and interfering in organising a memory appointment and in moving him to sheltered accommodation. He often repeated that he didn't know '*why they say my memory is gone*'. As a lifelong bachelor he had been in charge of his decisions throughout his life even though he had lived with his mother and sister until their deaths. He had assumed the role of head of the household and main provider for the family and had enjoyed an active leisure time in pursuing horse racing meeting across the UK. He found the restrictions imposed on him by his house move and the removal of responsibility unbearable.

> *I don't know why they got me shut up in this bloody place!.. I was quite content over the other house, even if I was by myself...He* (brother) *was the one what got me this house. And I don't like it...He comes and took all my bloody money...*(sister) *comes now and again. I don't really get on with her...Only yesterday they were over here. They came over here when the woman from the clinic came over, and, and, they knew more about it than I did. I can't make out why they say my memory's gone.* Alf (Farm Labourer)

Alf struggled to make sense of this change of lifestyle but he knew that his family had been involved in creating his present situation. He remembered his former life with affection and enjoyed recounting stories of his horse racing meetings and tending his large garden but could not recall why he had needed to move to a more secure residence or why he had needed a memory assessment. The progression of the illness had appeared to eliminate his power to philosophise about his situation and so had led him to conclude that he was in fact a victim of his family's wishes.

Pauline as mentioned earlier was married and a lifelong active member of the Methodist church. She had been the main carer for her family all of her married life and she had explained that she had joined St John's Ambulance brigade as a way of satisfying her nursing inclination. This activity along with her family caring role had given her great responsibility and self-command. Pauline and her husband discussed her referral.

> Husband: *It was the GP about two and a half years ago, and had an assessment done then. But since then, things have got somewhat, to my mind, worse. So it was agreed that he set it up with the prospect of having a scan, to see, you know. Because last time a scan was offered but the option was down to us, which is a bit, you know. But this time they may well do the scan which will be to her benefit. It's got to be. It's all right. No jabs. No injections, no nothing you see?*

> Pauline: *I have to admit that I'm very, very resentful of that.*

> Husband: *I know you are dear, and you keep saying that to me.*

> Pauline: *I know I've got to say it because I do feel so uptight.*

> Husband: *You don't remember it being set up, you think I screwed you up and everything, but you were there. And all the rest of it. You agreed with it, to come, because of your memory we went to the doctors, and he asked you for instance, what was the number of the house. And you couldn't come up with it.*

> Pauline: *Well, that's the point isn't it. I can't come up with it.*

Pauline struggled to allow her husband to make decisions on her behalf and whilst her confusion over agreeing to a brain scan can be attributed to her dementia, her sense of losing control and the resentment that followed could be a result of her lifelong habit of being in charge of the family decisions. She felt victimised that she had not been in charge of

instigating an appointment, and as her memory loss had progressed it had become more difficult for her to rationalise this situation.

These three participants share only their stage of illness and a strong lifetime sense of responsibility. They represent a range of social locations and yet all three demonstrated feelings of being bullied, resenting others, and feeling victimised, however, these dynamics may have pre-existed dementia. In the absence of any earlier emotional experiences of dementia, these people had not been able to recognise their memory loss as an early warning sign and so time had passed with their illness progressing until it had reached a point at which relatives had intervened. This point had possibly come later than for most other participants because their habitus had denoted them as strong willed, idealistic, and controlled individuals. Therefore the opportunity to intervene earlier had not been present because they had been able to project an appearance of being in control in the earlier stages of memory loss. This small group were able to identify their earlier capabilities as evidence that they were intelligent people and they used this to defend their position against victimisation.

This section has encapsulated a range of understanding how memory loss is confronted according to its interpretation. Notions of ageing and illness feed into concepts of respectability and for those participants allowed memory loss to be confronted on a more equal footing with other illnesses. 'Knowing' that the memory loss experienced is dementia boosted self-esteem through the opportunity to take control of the situation and seek help, but also created frustration and infuriation if suspicions of dementia were not taken seriously by those around them. Feelings of victimisation appeared to occur when the person had a strong sense of internal locus combined with the illness advancing. The removals of responsibilities from the home and for oneself were major themes for these participants and created great agitation and confusion. These various understandings and

interpretations of memory loss confrontation are indicative of changing emotional states, and it is to this topic I now turn.

4.4 The Shame of Stigma

This last section in the confronting memory loss chapter addresses the emotional impact of experiencing memory loss. I shall illustrate how displayed emotions were filtered by interpreting the immediate world and consequently refined the presentation of self (Goffman 1959). As the world was becoming a more confusing place as memory loss increased, and engagement with memory services introduced uncertainty in self-reliance and self-management; emotions became vitally important in participants' understanding of their memory loss.

The first section focuses on pride and illustrates how conceptualising memory loss as part of normal ageing and illness not only bolsters respectability but in turn protects pride and reduces stigma. These participants could maintain their self-respect whilst acknowledging their decreasing cognitive powers by theorising that memory loss was to be expected. Pride was attached to having lived long enough to experience memory loss and in reflecting on a life lived.

The second section addresses emotions of humiliation, shame and stigma. Feeling foolish created distancing from social activities and led to fear of increased social isolation as the illness progresses. This was represented in a gender divide in the style of conceptualisation. Men tended to talk about feeling foolish in company, whilst women feared the self-imposed isolation that feeling foolish would bring. The displays of emotions related to humiliation were a direct attack on pride and were verbalised plainly by male participants, particularly

those in the working class; whilst the fear of social isolation was a major concern for all the female participants.

The last section reviews the emotion of fear. This was broadly divided into two groups. The first linked fear to denial and resisting confronting memory loss, and the second linked fear to pragmatic decisions to mitigate the effects of the illness.

I will conclude that the emotional impact of confronting memory loss is varied according to social location and gender, and also that personhood and its accompanying life story shaped how memory loss was linked to the inner emotional state.

4.4.1 Protecting Pride

Being able to interpret memory loss as being part of normal ageing, or caused by an illness or an accident removed 'blame' from the self and externalised the cause thereby construing it as something that cannot be avoided given those circumstances. This appeared to allow the person to acknowledge that they have a memory problem and enabled them to seek help because it was 'the logical thing to do'. In reasoning their memory loss in this way, participants were able to maintain their pride in themselves and even bolster self-esteem by actively seeking help thereby presenting them as somewhat heroic. This overt link between seeking help and keeping pride intact was most obvious among the middle class participants, and particularly the male participants.

Frank was an accountant and had suffered heart attacks and a stroke in the past that had forced his early retirement however he had remained active as a volunteer accountant for the scouting movement. Frank explained how he and his wife had noticed his memory was deteriorating. He described feeling angry and frustrated with himself before he sought help.

I should think it's about over the last two years…Fi (wife) *was more concerned about it than I was because, I think she would agree that I am quite a placid person really. But at times when I, you know,* (shouting) *Oh for God's sake! And I get really mad and uptight and angry with myself. Fi was obviously very concerned because of my heart attacks and a stroke and things…because Fi has told me and I will ask her, and she will say, oh I told you that, and it's odd. We have argued, yes. I've got the marks to show for it!* (laughing). Frank (Accountant)

Frank talked about his reasoning that heart attacks and strokes cause memory loss because *'it's all vascular'.* He was very at ease talking about his memory, so I was keen to find out how he was able to feel so relaxed given that he had described strong negative feelings of anger earlier.

There have been times when I have argued with her, that's what I mean. And then I have thought quite probably, you know, it's that (she is correct). *But since I have spoken about it, and especially since I've seen the doctor,..I find I accept it better now. If you like, it's been more out in the open. I've come out!* (laughing)…*It didn't bother me too much really. I don't ever feel ashamed or anything about it, no, because there is damn all I can do about it.* Frank (Accountant)

Frank was able to normalise his memory loss as ageing and his acceptance of it as an inherent feature of his personality. This together with his GP visit had enabled him to talk about his memory as a medical problem rather than as personal failing and so he could maintain his pride as he was absolved of 'blame'. In linking his memory problem to his vascular illnesses he could rationalise his memory loss and make sense of his logical decision to seek help. In Frank's second interview he talked about his visit to the memory clinic and the possibilities of his diagnosis.

We had quite a good session…He thought it was, in his opinion, it was probably the flow of that part of your brain that deals with memory. Yes, probably that because of my other heart things and arterial fibrillation, I suppose. That sort of thing. He didn't think it would be anything like a tumour…I thought the bad news would be that it was the early signs of dementia, but he more or less said it was to do with the flow of blood to the brain, which can be treated with medication. I'm getting medication for that sort of thing anyway for my heart. Frank (Accountant)

Frank dispelled the idea that his memory loss could be dementia and focussed his attention on his other health problems as the most likely explanation. His comments about his current medication and the likelihood of receiving more medication appeared to support his hypothesis that his conditions were related and therefore out of his control and firmly in the medical realm. This empowered him and allowed him to retain his pride by giving an explanation of his memory loss that was not seen as a personal failing.

I found Frank's account of his consultation rather disturbing as the consultant had previously divulged that he often disclosed a dementia diagnosis to patients as a 'blood flow' problem, or 'brain shrinkage' to reduce the impact of the diagnosis. This approach was in line with broad concern over giving too much information at diagnosis leading to psychological damage (Patnick 2006), however, giving Frank this 'alternative diagnosis' enabled him to retain his pride and maintain his belief that his memory and his other conditions were related.

Vincent also approached his memory loss as an external illness and not inherently part of him. He was a retired commercial pilot, and had lived alone since his wife entered a nursing home around ten years prior to her death two years ago. Vincent regarded intervention as a positive step and proof of his own conclusion that his memory was failing. This was

important to him because in the absence of his wife, he had to rely on others to corroborate his thoughts.

> *Because the only person I get frustrated with is with yourself. And you may say something to people who are here and they may think, oh my gosh, he's bad tempered. But I don't. I gently do it. It doesn't bother me very much. Nothing bothers me to it for a lot of the time. I'm not too bad actually, but sometimes I'll get a block, boom! And I'm hoping now that when I go to these meetings up the hospital, that it will slow me down and it will do a lot of good for me…I could have gone on another four to five, six years and done nothing and, by the time they've got you, you're in a bad way. And that's the, that's the, and I think this is what happens to lots of people. They get in a bad way and it's almost too difficult to do anything.* Vincent (Pilot)

Vincent was keen to distance himself from others who did not seek help. He constructed this around his own control over seeking help and taking preventative action, and in doing so he was able to maintain his pride in independent thinking. Vincent was keen to tell me about his long standing gym membership and the benefits that his self-help measures had brought for his health.

> *I said to my wife one day, guess what? I'm going to try the gym. She said, you are what! You've never done any exercise in your life, just drink some beer! She said I'll give you a month…I was 22 years in the one I just changed…and that's about the best thing I ever did. I weigh just ten stones, 140lbs. I don't watch my weight. I have two meals a day, I don't drink any more, I don't smoke. And it's doing my health good, and I feel maybe I will live another 18 months now.* Vincent (Pilot)

Vincent returned to the theme of maintaining his health at various points throughout our meeting which suggests that his ability to take charge of his health was an obvious source of

pride for him. His diet and exercise programme also enhanced his sense of control which

dovetails with his background as a pilot. Because it was so important for him to reveal his

healthy lifestyle, Vincent could voice his belief that his memory problem was connected to

age and his heart problems and diabetes and not due to any cause of his own making.

> *I've had a double bypass, I've had two or three operations since I've been home* (in
>
> England)…*I've got diabetes…you know I'm getting old. 82, 83.* Vincent (Pilot)

The importance of resolving 'blame' for memory loss was a feature expressed most

prominently among the middle class men. Not being responsible for one's own memory loss

acted as a buffer against assessing forgetting as a personal failing and helped to retain pride

by constructing it around expectations of their other illnesses. Those people who could not

construct their memory loss in this way and who did not have the inner resources to draw

upon, constructed their emotional response to memory loss around an entirely different

emotion, that of humiliation.

4.4.2 Feeling Foolish

Feeling foolish and humiliated at having forgotten something was expressed by participants

from all social locations, and is presumably a common theme outside of this study too. Most

participants were very early in the illness trajectory and so had retained knowledge of social

skills. It was the fear of breaching these social rules of conduct and conversation that

created humiliation.

Charles explained how feeling foolish was an internal state but that it could easily switch to

anger at an external prompt.

> *More to the point of feeling foolish when you've forgotten for a start. Why don't you*
>
> *remember that? That doesn't help. And you lose, you lose a little bit of, I don't know,*

you lose a little bit of what you want to do, because you think to yourself, well, I was

going to do that today or tomorrow, and tomorrows gone. And you've, you feel a little

bit foolish. The foolishness comes from me. It's another thing. If it turned around a

certain, someone says, Oh Christ! Can't you remember anything? That's not

foolishness, it doesn't make you feel, it makes me feel angry, angry at myself basically

for forgetting. But I only feel foolish when I've thought of it. Charles (Factory worker)

This quotation from Charles demonstrated how closely linked emotional responses are to the social world even at a time when common beliefs would suggest that people are losing the ability to maintain social rules and are presumed to not care about them (Department of Health 2009). The early stage of memory loss had created a situation in which errors could easily be made in social engagements but self-doubt existed firstly about whether one would notice it in time to correct it, and secondly whether others would notice it first and think them strange.

Sandra was so worried about the humiliation of forgetting that she had chosen to withdraw from her friendship groups to avoid feeling foolish.

I've got no-one now. I mean, I speak to my neighbours but not all that much, and I'm

more or less staying indoors, more than ever…I used to go out for dinners and that

when anybody's birthday, but I don't now. I got frightened and I got nervous so I

couldn't go any more. The only thing that worries me, when you go to say something,

something like hello, and you feel such an idiot. It's horrible isn't it, you, you know the

face but you can't put a name and they're looking at you as though I've gone

mad…because some people can be cruel with things like that can't they, start calling

us Mad Annie or something. Sandra (Housewife)

Charles and Sandra were typical of expressing these 'foolish' feelings and fear of the

consequences of breaking the acceptable social norms of behaviour that would result in

social isolation. The following quotations represent a sample of many of the comments from

participants that supported this notion of feeing foolish.

But to hear some people speak you, you'd think I was sort of round the twist. Steven

(Accountant)

As long as they are not going to send me to the loony bin, I'm not worried. Graham

(Insurance representative)

I'm going doolally! Pauline (Housewife)

It takes my confidence away a bit… I'm not that stupid! Violet (Housewife)

You feel such a blooming fool. Terry (Machine minder)

Because they (doctors) probably think, oh my God, what an idiot she is or something.

Katie (Hairdresser)

Humiliation at forgetting socially acceptable behaviour and conversation were the main

reasons given for withdrawing from social relationships and social encounters across the

sample, and led directly to feelings of fear and anxiety. The emotional impact of feeling

socially acceptable and the distress when it was threatened was the controlling factor in

governing social interactions. Social slips did not have to actually take place for the

participants to start withdrawing from social activities, rather it was the threat of committing

a social faux pas that created enough anxiety to change social behaviour.

4.4.3 Anxiety and Fear

Anxiety and being fearful was constructed around social withdrawal and isolation rather than the illness itself. As well as internalising the fear of humiliation, participants worried about the reaction of other people around them. This was represented in close friend and family relationships and in wider casual relationships. Anxiety surrounded being marginalised by society as well as originating from self-withdrawal. The men and women in the sample focussed their attention on different types of relationships to illustrate this phenomenon.

Women discussed casual social interactions and described removal from daily activities such as shopping and hairdressing visits, and could 'stage' social withdrawal by the type of relationships that were under threat. They tended to map social withdrawal from the remote relationships first and sense a progression towards closer ones, until finally fear was present concerning the loss of the sense of self and very close family bonds. The loss of which would mean that they had been removed from society completely.

Joan had been a worker on a factory production line and had divorced over 40 years ago. She had been a working single parent in an era when this was not so socially acceptable, and had suffered various prejudicial comments and discrimination throughout her life. But her fear of dementia was clearly over and above any of her other experiences in generating anxiety. She talked about what it meant to be demented.

> *Well over the years you see several people with it. It's not a regular thing but you, you go to the hairdressers and they come in and their husband sits them in a chair…and they don't talk, they don't talk, they've got nothing, no conversation, nothing, they just sit there and have it done…and it's as though, it's like a shadow coming in…it'd be no*

good talking to them because they won't be able to answer you and that. Joan (Factory worker)

Joan had received a preliminary diagnosis of dementia, so I asked her what would happen if her diagnosis was confirmed.

Joan: *Might want to lock me up somewhere, fit me in, away from the family. And the family are far enough spread...I try not to think about it...I feel that if I went, the way my memory is at the moment, I might get delegated to the rear seat.*

Julie: Do you mean that the family would look at you differently?

Joan: *I'm not taking to her cos she can't remember half of what you say.*

Joan illustrated this reduction of the social world from wider relationships like those at the hairdressers, to close family relationships and not being spoken to as the natural progression of dementia. Joan's initial answer that she might be 'locked up' depicts the total othering that she felt dementia generated. The phrase 'locked up' suggests an unworthiness to be in society and in close contact with her family, as well as a fear of residential care. This suggests that she considered dementia to be highly stigmatising necessitating removal from society.

May supported Joan's opinion of dementia as an othering illness. She was from a working class background and had been widowed approximately two years earlier and since then her relationship with her daughter had become more important to her emotional wellbeing. May explained how her forgetting affected her relationship with her daughter.

I'm a practical person, I don't expect to live forever and I don't want to anyway, so you know, whatever there might be wrong in the blood or what, I don't know, but that doesn't bother me...the thing that worried me was when my daughter said to me, I

won't be seeing you such and such, or this Friday, or something like that because I'm

going somewhere. You know, she'd tell me where she was going, what she had to do

and then after she'd gone I think, God, now why isn't she coming? Why isn't she

coming to see me? Why aren't I seeing her? She was telling me and I couldn't

remember…so that's what I was feared of…I suppose in the end I know that I probably

would have to go in a home…Not be my own boss. Not boss, but in charge sort of

thing. In charge of what I want to do. In charge of my life. Maybe that's it. May

(Factory worker)

May's opening statement that she knew that life was finite and that physical illnesses were inevitable underlined the distinction that was made between anxiety over expected events and those that were hard to quantify such as memory loss. She talked at length about her anxiety over forgetting her daughter and grandchildren and echoed Joan's anxiety over being sent away or 'going into a home'. These concerns were very common among all of the women regardless of social class. The working class men however had another focus for their anxiety.

Working class men tended to particularly worry more about their wider social relationships, and especially those involving hobbies and leisure activities. The desire to be thought of as a man that deserves respect was the benchmark for decline. To lose respect by being unable to socialise, or to be thought of as a 'lesser person', was the ultimate fear. Charles expressed this thought very eloquently.

A man's word is everything. If, if you lose that and it don't mean anything then you

have nothing. You're finished. Charles (Factory worker)

Charles' assessment of masculinity was echoed by other working class men and indicated that anxiety surrounded losing respect and value in the eyes of others. This thought was

manifested repeatedly in those that were drivers. John was a black cab driver and a plumber and epitomised the working class men that were drivers. Driving was seen by this group as a leisure activity, a necessity, and a mark of their masculinity and of responsibility. Fear and anxiety were primarily focussed on driving cessation over and above the loss of relationships.

> *I've had a test with a black cab. And you go up Lambeth and they test you, and they give you a hard test and if you don't pass, you don't get. You don't become a cab driver, you know, and that's it. I passed it first time and went through…they definitely wouldn't let you drive a cab if you was a little bit, they don't do that. Because it's all run by the police…well it's a natural thing for us to do. We get in the car and do it but, it's just going to be.. It's going to be hard (stopping driving)…I will fight against it. I will have a row…At the end of the day if I do, I do, well, have to get over it won't I. But I will do everything I can to keep it.* John (Black cab driver and plumber)

John's statement that he would 'fight against it' and pledge to 'do everything I can to keep it' indicates his strength of feeling. I put it to John that he could buy taxi travel and as a former cab driver himself, I thought this would offer him an easy retreat from his statements, but he resisted and insisted that stopping driving would indicate to others that he had declined beyond help and his social standing and respectability would be damaged.

> *Well, see, you say that* (Take a taxi) *but it's not, it's not straight forward. See, we take* (neighbour) *up the road and that and they would think like, oh he's on his way out!* John (Black cab driver and plumber)

Anxiety and fear concerning public perception featured prominently among the working class participants of both genders. Although anxiety and fear was manifested in various ways, the underlying theme was concerning changes in lifestyle and the restrictions in all

socialising that dementia would bring. As demonstrated by the above testimonies, these could be familial, leisure, housing, wider social relationships, and friend relationship settings.

4.5 Conclusion

This chapter has addressed issues surrounding confronting memory loss. How this is acknowledged and to what it is attributed shape the understanding and meaning associated with it. How memory loss was conceptualised and its relevance to normal ageing and illness shaped the participants interpretation and governed the emotional impact of forgetting, and the memory assessment process. Any previous emotional experiences of dementia served to prime participants' awareness and prompted activity to seek help. Frustration ensued if family and friends did not concur with this course of action. If no previous experiences were available, participants denied any memory problem and contact with services until much later in the illness trajectory.

The emotional impact that was generated from noticing memory loss varied largely according to gender. Men worried about feeling foolish and women were more anxious about losing family relationships demonstrating that anxiety and fear is located in the understanding of the consequences of memory loss rather than simply being ill. Stigma and respectability were dominant features of anxiety and fear illustrated in the association between memory loss and removal from society.

These emotions and the reasoning and understanding that initially take place are constantly under review as the illness progresses and a diagnosis is pursued. This was apparent in the shifting explanations given for memory loss and as information from the pre-diagnostic

nurse was gathered and considered. The movement into this next stage revolved around

resolving uncertainty and finding balance in emotions and conceptual thinking.

Chapter 5: Negotiating Uncertainty. What does this mean for me today?

5.1 Introduction

This chapter discusses the participants' attempts to find certainty in their changing world. Uncertainty surrounded making sense of the meaning of forgetting represented by reducing responsibilities as memory loss progressed. This was a fluid making-sense process that ebbed and flowed as meaning and understanding of norms and values were created and (re)negotiated. Participants from differing social locations presented different examples, however, control and loss, what is considered 'normal', and reconciling changes, emerged clearly as dominant themes.

The first section of the chapter details the fluidity of reasoning in attributing memory loss, and the emotional flux that is linked to the process of finding balance and negotiating uncertainty. Reasoning what is happening to the memory was a very fluid and variable process. Participants frequently changed their mind about the attribution of their memory loss between interviews and during conversation as they reasoned and thought through their uncertainty. This feature was prominently represented as participants considered multiple explanations for their memory loss before settling on their primary causal explanation.

The second section addresses issues of retaining and losing control. These issues were manifested in leisure activities, in relationships, and in issues of balancing assistance with independence. There was a strong desire to maintain control but uncertainty as to how that could be achieved in the longer term. Working class men were most concerned about controlling their driving cessation, and faced uncertainty regarding whether they would be forced by others to stop driving as a result of their memory assessment. This issue was not

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such a feature of the women's narratives as only one woman, Violet, was still driving and most had never been drivers. Violet considered her driving cessation in very different terms and it did not appear to hold the same powerful relationship with control and loss that it held for the working class men.

Middle class men focussed issues of control upon whether or not they would have to curtail their leisure activities even when in reality some activities had already long since ceased. Notably, driving cessation did not hold high significance for the middle class men, but this could be due to all of this group having ceased driving some months or years before the study, and they could have already reconciled this loss. Women across social locations held family responsibilities and the household diary as their focal point for uncertainty and identity, and the possibility of forgetting an important event was the source of embarrassment and humiliation, and caused them to question their ability to continue as an independent person.

The third section explores the balance to be found in negotiating what is normal and what is unusual. Major topics of concern were the degree of normality of mental and physical illness, balancing forgetting in normal ageing against forgetting in dementia. Deciding what 'normal' means created uncertainty in participants as they tried to interpret their memory loss and identify abnormal behaviour.

The last section discusses the interview process. For many participants, the interviews became an intervention because it inadvertently created a catalyst for reflecting on normality and what normal means. This allowed them space to reflect and discuss their illness with friends and relatives.

5.2 Ebb and Flow of Meaning Making.

This section describes the fluid process of reasoning and meaning making that took place in negotiating memory loss at this early stage of illness and entry into the medical diagnosis process. The possible causes of memory loss journeyed through a very confusing, fluid and variable thought process. Participants frequently changed their minds between interviews and sometimes even during conversation about attribution, and offered several explanations before settling on their primary accounts of their reason for suffering memory loss. Often the extremes were explored first on a scale of 'nothing wrong' through to 'advanced dementia' before they could settle on the best fit for their memory loss in terms of describing their problem and finding an explanation that they could reconcile with their current thought processes. Uncertainty was created in this process of balancing evidence gained in current daily living against internally held beliefs about dementia which varied according to life experiences of dementia.

Violet exemplified this uncertain search for attribution as she explored various causes of her memory loss before deciding that it could be attributed to an illness. She had little direct experience of dementia but was aware of the government campaign concerning the significance of memory loss and the need to report this to her GP. Violet demonstrated that without prior knowledge of dementia, she had to search for various plausible explanations for her memory loss, before finally deciding that it was most likely to be caused by an anaesthetic.

I'm better now, but I hadn't been well, and I'm sure it was the operation. I broke my

hip. I'm sure the anaesthetic had a lot to do with it and that's how it started to. I mean

I do forget things now, but then, when you are 80 odd you do. And that's when it

started…I get forgetful now but I write everything down, but I did go through a bad bit

where I, and I got, I couldn't be bothered. Violet (Housewife)

Violet was unsure if her age, her hip operation, or being ill could be the cause of her memory loss and she eventually settled on a reaction to anaesthetic as the cause. This seemed logical to her even though it was not the most recent event. Violet was typical among participants in searching for an explanation for symptoms that seemed the best fit whilst being the least threatening. Violet was very usual in including age as a possible cause or contributory factor. Age was the most consistent explanation offered perhaps because it carries a degree of certainty and 'makes sense' in the context of the body ageing and declining. In addition, shame is not attached to ageing because it is a natural process and not a mental illness, therefore it is more comfortable as an explanation.

Only two people were adamant that age was the sole cause of their memory loss although doubt was implied through their actions of information seeking. Ageing popularly figured in all discussions, even when the participant ultimately decided upon a different cause. Ageing was the only explanation that could be offered with any certainty because participants were all aware of the passage of time as they reflected on their lifetime experiences. Therefore for those that recognised that their memory loss was not usual ageing, feelings of uncertainty were created as they searched for alternative explanations.

Steven was one of the two men sampled who were adamant that their memory loss was linked to their age only. He often repeated that '*it was to be expected at 82 or 83'*. The suggestion of a memory clinic appointment and the home visit from the pre-diagnostic nurse had irritated Steven and he regarded it with suspicion and as a waste of time. Even as he expressed his certainty that his memory loss was linked to his age, he had decided to seek more information from the internet about memory clinics, and this suggests that he was at

least curious about memory loss and needed more information, or possibly even doubtful

that something other than age could cause it.

> *I just don't want to get involved. I'm all right. It's a bit, memory clinics, I didn't know*
>
> *they existed before. I looked them up on the internet and there's quite a lot about them.*
>
> *I don't know. I think it's my age, I'm 82, whether that's the reason I don't know…they*
>
> *think I've got problems with my memory, but they're not problems which are, they*
>
> *might have been problems if I was about 50 years younger, but they're not problems*
>
> *when you are 82*. Steven (Accountant)

Clearly Steven knew that his memory function was reducing and he reasoned this as

connected to his age, but the suggestion from other people that he may have a problem had

prompted him to seek information. Steven accepted and expected problems as he aged and

was comforted that memory loss could be part of that process. However, he did not consider

his leg ulcers to be linked to being older and this indicated that memory loss held a special

significance in reasoning the ageing process. Ageing and ulcers are organic and biological

conditions, whereas memory clinics seemed to suggest mental illness to Steven. This led me

to consider the differentiation between physical health that can be seen and touched, and

mental health that is 'hidden' from view. This confusion appeared to contribute to the

uncertainty that surrounded the normality of memory loss in ageing, and it is negotiating

uncertainty that created an emotional upheaval as doubts and fears concerning the cause of

the memory loss took hold.

5.2.1 Emotional tangle

In addition to the introduction of doubt concerning the cause, the liminal period between

noticing memory loss and receiving a diagnosis created an unstable period with all

associated emotions that possible explanations generated. For those that could attribute their

memory loss with any certainty to an illness, event, or dementia, this seemed superficially less so, although I did not have to probe very deeply before tangled emotions of fear, anger, humiliation, and relief became more apparent. This struggle for reconciling current memory loss with the popular depiction of the dementia patient seemed to be at the root of tangled emotions and the attempt to decipher meaning.

John was mystified about the connection between his memory loss and dementia that the visit from the pre-diagnostic nurse had generated, as at first he did not accept that he had any significant loss, and he then chose to attribute his loss to a car accident that he had suffered some years previously. His thought process then led him to consider dementia and what that would mean.

> *Well, you think about it. Are you going to end up like a vegetable or something like that, which I, I wouldn't like. But you know, if you had dementia, and you can't do this and you can't do that, I'd rather, you know, take a tablet. I think if your quality of life goes down so bad, what's the point? What's the point? I mean, I have got an excellent quality of life at the moment, ain't we?* John (Black cab driver and plumber)

John did not equate his memory problems with dementia because it held a very clear meaning for him, and he knew that he did not fit with his own description of a demented person, but he also had accepted that his memory was failing and that there must be an explanation. His phrase, 'take a tablet' and the intonation with which it was said, indicated that he meant suicide, and reveals the dread that he associated with dementia. It was difficult for him to reconcile this image of a demented person with his life at the moment. His statement of his 'excellent quality of life' was supported with lengthy descriptions of his activities in retirement as a gardener and handyman at his mobile home site and his social

life. In a sense he was fighting the popular image of dementia, even whilst he knew that his pre-diagnostic memory assessment had indicated it in the present and future.

Graham exemplified the 'take it in your stride' philosophy whilst silently gathering evidence of his good memory and fighting against changes that would indicate dementia.

> *If you've got a problem and you look at the problem and you can't do anything about it then forget it. But that's my way. If you can't, there's no point in keep worrying away at something if you can't do anything to affect it. If you can do something to affect it, well that's different. It's the lazy way out I suppose, well, that's the way it's always been.* Graham (Insurance representative)

Graham was very upset at the prospect of giving up driving and had spoken for some time about his desire to continue driving. He recounted many imagined future conversations with 'the memory people' so his protestation that he only worried about things he can affect, and that dementia is something that cannot be affected do not match up. His response betrayed his anxiety and emotional struggle to accept his failing memory.

In the above quotations both John and Graham clearly displayed the internal struggle to come to terms with memory loss in the very early stages pre-diagnosis. This supports literature concerning negotiating liminal states that suggests patients benchmark indictors of recovery and decline (Grytten and Maseide 2005) as they pass uncertainly through phases of illness. A sense of a passage between health and illness that held special meaning at this particular stage of life was being constructed. This 'trying to make sense' phase was the underlying cause of uncertainty and the source of much confusion and bewilderment, and led the participants to constantly re-appraise their memory problem and search for alternative explanations as they struggled to come to terms with their memory loss.

5.2.2 State of Flux

The search for explanations for memory loss other than dementia created anxiety and a drive for a logical justification for forgetting and making social mistakes. Conversations often started with certainties being expressed in recalling stories from the past, but doubts would eventually emerge when recalling incidents of forgetting. Doubt manifested itself in various emotional responses that could be effectively grouped as anger and humiliation with some participants reporting feeling bullied and victimised. There was no doubt that my participants were experiencing problems revolving around daily interactions and activities.

In interviews in which relatives were present, participants would often defer to their supporter for corroboration of a point, even when they had initially been quite sure of their statements. This presented as an almost habitual response to doubting their own ability to remember things correctly and suggests a much deeper assimilation of forgetting into personhood and identity than had previously been explored in the literature. Sabat (2002) described the sense of self of comprising of personal pronouns, mental and physical attributes, and relationships. As conversation in the interviews turned towards addressing examples of forgetting, working class men were particularly forthright in offering examples of justification for their memory loss that did not include a dementia explanation but referred directly to their mental and physical attributes and relationships with others.

This extract concerns an exchange between John and his wife and illustrated the negotiation that takes place in recalling events and the emotional instability that forgetting generated. He offers an example of his relationship with his wife, and displays his mental attributes in remembering his childhood.

John: *I think my wife she finds it sometimes annoying if I ask her the same question a couple of times. And she says, you just asked me that, but you know, it's not a great deal. It ain't, is it, really?*

Wife: *Not to you it ain't!*

John: *Yeah, I know that!*

Wife: *You don't realise how many times you ask me the same question, that's what I'm trying to say.*

John: *Everybody has memory loss at a certain age, even I do, but it don't mean. I can go back years ago to my childhood but it's silly little things that sometimes I put things down and I don't know where I put them, but I think that's part of getting old! What else can it be? …I mean, that accident I had. I think, myself, personally, that is the cause of what I'm going through now. I believe that's what it was. And I still believe it!.. I hit my head on the back of the seat, you know, the headrest, and you know, from now on I get you know, aches. Don't I?*

Wife: *Mm*

John: *And I think that could be the cause of my memory loss. I think so. I mean. I mean. I might be wrong, but, but, alright. It's either that accident or a natural process of getting old. That's all I can say.*

John used his sense of self to journey through a myriad of emotions in his desire to project himself in a positive way, and as he started to vocalise his reasoning, he began to question his own certainty of the car accident as the cause of his memory loss. He tried to support his own hypothesis but as his wife does not corroborate his story, he then searched for another more suitable explanation as if arguing with himself, before deciding that more than

one factor could be the cause. To John either his car accident or ageing appeared to be the best explanation, and these represented a compromise between his wife's opinion and his own, and one that sounds logical to explain to me as an outsider.

Like John, Charles used his conversation with his wife to reassure himself that his failing memory could have explanations other than dementia but she did not confirm this idea. In the following extract he tried to recall if he ever knew anybody that had dementia and then discussed his rights at the memory clinic assessment.

> Wife: *He does actually know two other people with memory problems, but they are my relatives and he sees very little of them.*

> Charles: *Well, they are both men.*

> Wife: *No! Aunty Carol and Aunty Vi.*

> Charles: *Yeah, well, yeah, because they are getting on for 90, aren't they?*

> Wife: *Well, makes it all right then does it?*

> Charles: *No it doesn't. But it's understandable, isn't it?*

> Wife: *They've both had strokes, so they have got that vascular.*

> Charles: *Well, as far as I know I've not had a stroke, but I suppose you could have a mini stroke and not know it? I don't know.*

> Wife: *For a start it seems to me obvious that you need to speak to somebody close to the person involved and not just the person…if you have got a memory problem, you're not going to remember things that are relevant, where somebody close to you will know.*

> Charles: *Yeah, well that's a different, that's a different thing. Because I don't have to have you there, nor does most men probably. Well, how do you get on this, if, if, if I can't?*

> Wife: *Well you would have to manage without them, but the doctor*

> Charles: *That's right! If I didn't want you there, as you say, I may well have thought, oh ok, that's fair enough, that seems all right. But they can't, they can't make me bring you. The medical services can't do that.*

This extract shows the forcefulness that can occur in relatives concerned to get an early assessment for their loved one, and how this can be interpreted by the person with memory loss as bullying and cajoling. Charles's emotional range was represented in the excusing and reasoning involved in trying to make sense of the appropriateness of attending the clinic. He seemed to feel that bad news would be received, and resisted the offer of his wife attending with him as a slight against his masculinity by his referral to 'most men'. The intonations present in this conversation were akin to a child/parent relationship rather than a husband/wife relationship and Charles appeared to sense this shift and resent the offer of accompanying him to the clinic.

Partners were not present in all interviews (detailed in table 1 pg 95), but it would be naïve to assume that the state of flux and range of competing emotions engendered by negotiating with partners were not present in others at other times. The challenge from a partner appeared to act as a catalyst for emotional negotiation and meaning making. However, in single interviews other participants experienced a similar range of competing emotions as they reasoned and changed their mind about the meaning of memory loss. This ranged from a default position of blaming ageing as either the sole or contributory factor, through to those that were sure they were experiencing dementia. More subtle emotional responses to

uncertainty were more easily observed when I considered issues of control and loss, and it is this area that I will now address.

5.3 Negotiating Control and Loss.

This section explores the desire to maintain and retain control whilst mourning cognitive and physical losses. Participants represented actual losses and the fear of loss in recalling past activities and current daily activities, in relationships, and when thinking about independence. These were represented differently according to social class and gendered locations. Emotions such as embarrassment and loss of confidence were primary concerns for women in tasks such as keeping the household diaries and maintaining the home; men tended to focus on loss of self-esteem and loss of pride associated with physical tasks and group memberships. There was a further class divide amongst the men regarding driving cessation. The working class men sampled who were currently driving defended their control to make choices concerning cessation and this was the source of great anxiety, whilst the men in the middle classes had either already chosen to stop driving or were relaxed about stopping driving. This distinctive pattern suggested that class status was indeed closely embedded in selfhood and was played out in a sense of control over one's world, and therefore this point deserved further scrutiny.

All of the middle class male group except Frank had been drivers, and all had chosen to stop driving in the year before I met them. Driving cessation was mentioned in passing but the focus of activities that represented the importance of control and loss most forcefully for this group were those connected to leisure activities. For example, Robert was a retired lawyer and he described his discomfort at the removal of his shotgun from his house.

I always had a gun. Well, I used to shoot clay pigeons, and they are very strict aren't they. You have to hide it and, I had to hide it in the loft and lock it up. This chap said to me, a very nice policemen, not in uniform, in ordinary clothes,.. he said to me, Mr Smith, do you really think you need it? Need a gun at your age? I said, Oh! Do I need a gun at my age? If I want a gun, provided it is done properly there's nothing to stop me having one! I've had it for...40 years!..He said, I'm not suggesting that you rush off and sell it, and I said, I wouldn't do that! So he said, well, what do you kill with it? We have got an awful lot of lovely birds here and we have cultured them...and we don't want them killed, and the squirrels will get them. He went on and on in his very very quiet voice, so I said, I will give it to my son...I don't think really I made the right decision. It was good decision but I don't think it was the right one because I never bring it out unless there's a squirrel handy. Robert (Lawyer)

Robert returned to the subject of his gun and shooting squirrels several times throughout our conversation. His indignance at being questioned about the guns valid use '*at his age*' and his subsequent appraisal of giving the gun away as '*a good decision but not the right decision*' illustrates his uncertainty at being cajoled into relinquishing his gun ownership. Although he clearly focussed on his squirrel problem to explain his thoughts, he was evidently questioning his social standing as a man 'of age'. His sense of loss was tied to his recognition that other people were judging him to be unfit to own a gun, and his subsequent relinquishment of it is evidence of his compliance and self-doubt. This illustration of the need to retain control over something that was as symbolically important as driving for working class men, was also prevalent among the middle class men, and presented itself in a variety of activities.

George had owned a chain of newsagents and enjoyed a relatively wealthy lifestyle. He explained that he had gradually passed ownership of his businesses and property to his son

in an effort to protect assets for the family inheritance. George now lived in a large

imposing property owned by his son. George had also been an avid gambler throughout his

life and now that he had retired, small stake gambling was the main focus of his daily

activities. George agreed to talk to me on the basis that I would leave by the time his next

horse race was shown on the television that afternoon. He described gambling as his only

activity.

> *Well there's not much else, what else can I do? It takes over your life, doesn't it*
>
> (memory loss). *And that's because I was always, I was always at the shop. And that*
>
> *was open. I used to open it in the morning at about half past five I think it was,*
>
> *something like that in the morning. Very early mornings. And you used to be then, go*
>
> *through the day then. But I used to love it. You don't mind doing anything do you, if*
>
> *you like it. Just the actual work of it I suppose. And making money. See and that's the*
>
> *way I've gone all through my life. There's always ways and means of making things*
>
> *better, you know, earning more money. And now my way of making money is on the*
>
> *telly with the, watching the horses winning, and football. I have a bet nearly every day.*
>
> George (Newsagent)

George felt able to retain control of his life if he could still 'earn money'. In his view this

meant being able to gamble. By being able to place bets he could retain control of his life

and continue to pay for things that his family wanted. This was obviously an important part

of his self-esteem as he gave long descriptions of holidays and items that he had provided

for his family through his gambling activities. The point to be made is not about gambling

per se, but rather that it provided a sense of control in his daily activities.

> *If you've got money there you can spend. You know, if you win. Give it to, whatever*
>
> *they want, and then I'll get them what they want.* George (Newsagent)

George discussed his annoyance at forgetting with his partner. Like many other men in the sample he had always deferred to his partner for matters concerning the family.

> George: *Well, you're annoyed with yourself for not being able to remember, I suppose, you know. And you just try, try and find out what it was I forgot. Can't remember birthdays and things like that. I can't remember. I remember my own (laughter).*

> Partner: *You've never had to remember them, have you?*

> George: *No, as you've always.*

> Partner: *I've always done it.*

> George: *You've always dealt with them, see, that's probably why I don't know.*

By deferring to his partner's past responsibilities for remembering family events, George was able to retain control of this aspect of his life and absolve his uncertainty regarding family occasions by deferring to his partners responsibility for them. This illustration of gendered roles, and his lifelong compliance with it meant that he did not sense any difficulty in forgetting such things. However, his ability to continue to earn money through gambling gave him a sense of control in his life at a time when his mobility and cognitive capabilities were reducing and he was becoming more reliant upon help from others.

George's relationship with his partner and reliance on her remembering for both of them was fairly typical of most of the men sampled from all social locations and is a phenomenon that is well documented in literature concerning gendered roles in the household (Neuman 2013, Marks, Lam Bun and McHale 2009, Sullivan 2004, Young and Wilmott 1973). This deferral to the women for family responsibility of household business was a masculine trait and in itself did not give great cause for concern among the men when these items were

forgotten because it was considered usual, but for the women sampled, remembering household diary dates was very important. Controlling the diaries and the prospect of forgetting important family dates and appointments was a sign of losing control of their life. Many times during interviews with women of all social locations, they would produce calendars and diaries as 'proof' of their competence and control of the household. May was particularly keen to show her calendar and prove her control by pointing out my appointment with her.

> *I've got a calendar out there, everything is written down there. When I've got to take my books back and all that sort of thing. But other than that, I don't forget to, do all that I've got to do here, or cook a dinner or anything like that. See, you are on the calendar. I thought now, I've got someone coming this afternoon, I thought, oh yes, that's it.* May (Factory worker)

May was able to deal with the uncertainty created by her memory loss by being confident that she could produce evidence of her daily commitments on her calendar. Her assertion that she could remember to cook a dinner was her proof that she was in control, and her display of her calendar was evidence that she could remember to use it as a tool for remembering and therefore staying in control. The fact that she used a calendar and felt the need to show it to me and to mention that she could remember cooking a dinner was evidence that she was conscious of losing control and was taking steps to retain control and prevent loss for as long as possible.

Katie was the youngest participant at age 50 years and she also described using a calendar to keep track of family events but was worried that she could not always make sense of the entries as she was not always sure which day she should be looking at. For Katie keeping control of her housework was the key feature of retaining control in her life and preventing

uncertainty from undermining her self-esteem. She recalled an event that had challenged her

housekeeping responsibilities and described how it had created uncertainty in her self-

reliance.

> *I know my memory's bad. I know. I'm realising it more every day now. Like my mum*
>
> *says, well write things on calendars. Well, I forget to look at the calendar. Sometimes*
>
> *with tablets, I go to get my night ones out and I'll have about three morning ones in*
>
> *the packets and I think, God! Haven't I taken them for three mornings! But I could*
>
> *swear I had…and if I'm distracted from what I'm doing, I totally forget about it and*
>
> *leave it…I nearly burst in tears the other week. I turned the iron on, I must have*
>
> *turned it, well, I thought I'd turned it off and I took the pillowcases off and threw the*
>
> *pillows on the ironing board…about an hour later my friend said, I can smell burning*
>
> *and it was starting to scorch the pillows.* Katie (Hairdresser)

As Katie and May illustrate, gendered roles concerning control were played out in the

domains of the traditional household. However driving cessation was a particular concern

for the working class men in the sample. Driving appeared to hold a very particular and

definite marker for control that was also tied to masculinity among this group, and cessation

was fought against vigorously. For older participants it was traditional for the man to drive

and this was further reinforced as a masculine activity in those that had driven

professionally. Violet was the only woman still driving and this activity did not hold the

same issues for her as for the men in this particular group. The professional driving roles of

John and Graham, the employment necessity of driving for Alf, Charles and David, and the

pleasure of driving for Terry marked the working class men as the only group in which all

of the participants felt strongly about maintaining driving. John outlined his uncertain

feelings about deciding when to stop driving. He adopted a 'common-sense' approach that

he could justify and one which can be perceived as evidence of his continued ability, even though he suspected that he was not as competent as he once was.

> *Well, I don't know. Whether they want me to do a test or what, I don't know. They haven't said. It's just my personal feeling, that's all. I haven't even asked them or whatever. I've not asked them because I don't want to bring the subject up because I don't know. So I'm just going to wait until things happen or whatever...if you know that you're not well enough to drive a car, you wouldn't would you? It's only a basic rule isn't it...really you would put everybody in danger, you wouldn't do that would you? I've been driving all me life...so that I feel like that I still can drive safely because I don't go mad on the motorway. I only go 50 or 60 mile an hour...our son calls me Steady Eddy.* John (Black cab driver and plumber)

John's protestation that he would not endanger anybody through his driving and insistence that he could decide when to stop driving transformed it into a representation of his competence more generally, and as an indicator of his common sense. He then supported his comments with corroborative evidence from his son's nickname for him 'Steady Eddy'. The threat he felt at asking at the memory clinic about continuing driving, and his reluctance to discuss it with them suggests that he was at least starting to realise that he was feeling uncomfortable driving but was not yet ready to reveal it. Driving cessation for those with dementia is enshrined in legal restrictions as a 'notifiable' condition. DVLA insist that if a doctor has told a person to stop driving, then they must declare it (DVLA 2014). There is a clause that states that if the licence is surrendered voluntarily, then it can be returned sooner, however dementia is a degenerative condition and as such, it is highly unlikely that once a licence is surrendered, it would be re-instated. John's statement of driving all my life was indicative of the close bond he felt between driving and his masculine identity, and his ability to make decisions. He was fearful of losing his driving licence and I sensed that John

was representing a tension between seeking advice and not wanting advice for fear of the consequences.

Graham like John was also concerned with being judged by others for his activities and not memory loss. Graham was particularly concerned with his driving abilities and frequently returned to this subject throughout our meetings. His preoccupation with talking about driving and his fear of cessation was a distinct indicator of the importance and meaning that driving held for him. Graham believed that he would be a 'lesser man' if he was forced to stop driving. The element of force was the factor that indicated loss of control and lack of decision making, and it was this factor that was tied so intricately to respect. He briefly considered not driving in terms of how inconvenient it would be, but quickly returned to his favourite subject of the unfairness of being judged. His primary concern was that the memory clinic would judge him as unfit to drive and remove this control from his life. He defended himself and questioned the authority of memory clinic staff to judge his driving ability.

> *Some of them might drive cars and they might drive cars terribly badly and, if people like that are judging you, then in a way it's not fair.* Graham (Insurance representative)

Graham was typical of all the working class men sampled in connecting driving status to concepts of independence and the threat of being prevented from driving as a personal attack. The prospect of stopping driving on the judgement of other people was almost too much to bear as he regarded it not just in practical terms, but also as a threat to his masculinity. Graham linked his skill of driving to his position as the 'main driver' on holidays and head of the household demonstrating that he regarded driving as part of his family status.

John and Graham illustrated the issue of tensions between seeking help with memory loss and fearing the consequences of interventions. This raised the question of when assistance becomes interference and this is discussed in the next section.

5.3.1 Assistance or Interference?

John's discussions with his wife in the following extracts depict the tension that existed between their narratives as they both presented very different versions of events. This tension and strain was represented in most spousal relationships as partners vocalised their concerns over memory loss. Partners were frequently relied upon to corroborate stories of achievements however minor, or deflect attention from memory loss by delegating responsibilities to their spouse. This shifting of responsibility and externalisation of seeking confirmation changed the nature of the dyads from partner relationships and moved them towards supporter and sufferer relationships thus creating tension between regarding offers of help as assistance or undermining interference. Whilst spousal input helped to illuminate the reasoning of the participant, in line with my IPA approach and the study design, I was foregrounding the participant's meanings over those of others.

> *John: …with this memory lark, it's all like trivial, you know. I mean, I know it gets*
>
> *on your nerves cos I might keep asking the same question, cos I, I suppose it does get*
>
> *on her nerves. But if you can live with one another for like 47 years like we have,*
>
> *minor problems aren't a very big problem. I know she does have a moan, but we get*
>
> *over it, don't we?*
>
> *Wife: Oh yeah, yeah, but if they can help you?*
>
> *John: Well, yeah* (clearly irritated)

From John's point of view his repeated asking was not a 'big problem', but for his wife it was a devastating development and illustrates that he did not regard memory loss as a 'big deal', even when those around him consider it to be so.

> *Wife: To be truthful between me and you, me and my daughter done it. I had to go to the doctor last year cos he wouldn't do nothing about it. He makes my life hell! He really does!.. He don't know the days of the week. There's loads of things he can't, we sat watching telly the other night, and he watches Emmerdale every night and he don't know what's going on. Nothing seems to be sinking in, and he's trying to use me as his memory. And he won't have it that he's that bad you know.*

This power shift within partnerships is a phenomenon that is well documented in the literature concerning people with moderate dementia in caring relationships with their partners (Whitman 2010), however it is much less realised in the very early stages of memory loss. This supports the notion that early intervention is not only important for early diagnosis but also in supporting familial relationships and particularly spousal relationships.

Relationships were starting to become strained and uncertainty followed as new roles were negotiated in order to assimilate memory loss into everyday living. The progressive shift towards seeking support from partners and others was a marker of concern for those worried about their potential loss of independence. Questioning when help or assistance becomes dependency or interference was an important marker of uncertainty creation across the entire sample.

Alf lived alone and had discussed his decision to give up driving and giving control of his finances to his brother, but he strongly objected to family members having unlimited access to his house. For Alf this was a clear boundary of independence and a sign of his control being removed.

I used to have, you know, go up all round the park a few hours. Then came back here and I found my brother and sister in here! I don't want anybody in here! It's MY house! I have to pay for it, so why should they be in it? Alf (Farm labourer)

Alf's sister had explained to me separately that he was very upset with her for entering his house uninvited, but she explained that as he had not answered his telephone for several hours, she had become worried and had decided to investigate his whereabouts together with her older brother. As Alf had relinquished control of his finances and accommodation to his siblings, and had stopped driving, it seems reasonable that his siblings should have access to his house for safety reasons. But for Alf this represented interference rather than assistance. Finding a balance between these things is an uncertain domain and therefore it is necessary to negotiate assistance very carefully by giving consideration to habitus and personhood. Alf had lived his life as a bachelor and had spent most of his life outdoors. He explained that he no longer had access to a garden that he could tend and that he missed roaming the fields near his previous home. So for Alf a visit to the park for several hours seemed a perfectly normal excursion, but for his family this represented him wandering and potentially getting lost if he was alone, and therefore raised fears for his wellbeing. His perception of risk was clearly affected by his lack of understanding of his memory loss.

Steven had lived alone for several years and explained that as an accountant he was used to independent thinking and being in charge of his own life. Steven focussed his accusations of interference upon the memory clinic and the medical world in general. He regarded clinics with suspicion and assessments as a threat to his independence.

I get the feeling about the whole thing that once you get involved, you wouldn't have much time for anything else, because of this bloody thing (tapping head), *you know?*

So I'm not, as you probably gathered, I, I'm not over the moon over it. Steven

(Accountant)

Steven reiterated this sentiment several times. He resented any interference in his daily

schedule and clearly balanced whether anything could be gained from attending the clinic

against this perceived interference.

My thinking about the clinic is a bit on the sceptical side, I think you know? Steven

(Accountant)

Steven was suspicious of offers of help and construed them as implying that he was failing.

Coupled with this was his insistence that his memory problem was due to his age and

nothing else, hence his resentment at the suggestion of attending the memory clinic for

abnormal forgetting.

Patrick was also unconvinced about the value of clinics and questioned whether the benefits

outweighed the intrusion into his life.

A frame, a walking frame with wheels. And I was going to a clinic where I was

walking with one of those and doing exercises supposedly. I'm afraid I was extremely

un-cooperative to cut it fine! It seemed like, It seemed like a lot of nonsense to me. But,

and in that clinic too they used to give us a little lesson on things to do and things to

avoid. Be careful if you sit on the edge of the bed, be careful you don't slide off it.

Well, trying to teach me a situation like that seemed absolutely nonsense to me and it

used to get on my nerves a little bit. It's so obvious! Patrick (Scientist)

Patrick clearly felt patronised and infantilised at receiving what he considered to be obvious

advice from services. Steven and Patrick were both in middle class senior position

occupations before retirement and so a link can be drawn from their former organisational

roles to their attitude to receiving basic advice, however not all of the men in this group followed this pattern. Vincent as a former pilot was actively seeking advice and willingly attending the memory clinic. For Vincent, the line of assistance crossing into interference was plainly conceived in maintaining his choices.

Vincent explained at length that he was a wealthy man who had worked abroad for most of his career and that he had enjoyed a busy retirement. He blamed his failing eyesight for many of his difficulties and used this as the deciding factor in relinquishing his independence when the right time came, but with the proviso that he would decide where to go and what to do, demonstrating his anxiety about the future.

> *I feel that at least I've got enough money now. I keep thinking, what happens if my eyes go? I can't, I can't, I'll have to go into a nursing home but I am trying not to because I have promised the house to the kids when they get. But if not, I'll have to, I'll have to go into a nursing home, sell this and go into a nursing home. And that's the big one. So I want to be comfortable. I don't want to go into a nursing home where it's a bit blinking rubbish nursing home. I don't want to do that. I want to go, If I'm going to spend it, I'll go into a nice place because I've worked hard enough for it.*
> Vincent (Pilot)

Uncertainty surrounding control and loss took form in daily activities and responsibilities and these varied according to gender and class and in boundaries of interference or assistance. Male participants delegated responsibilities to partners as a way of deflecting the impact of their memory loss, whilst women worked harder to create self-help in the form of calendars to protect daily living. Tensions reflected in gender roles prior to memory loss existed in regard of receiving help. For some it was construed as useful and helpful whilst for others it implied frailty and interference in their daily life. Spousal roles were becoming

confused as more help was given and partners struggled to find acceptable ways for help to

be administered without undermining or devaluing the partnership, however, dependency

was starting to become apparent. The variety of activities and examples offered by

participants about the nature of control and loss indicated the multi-faceted and complex

issue of living with memory loss. Although participants offered concrete examples of

uncertainty in activities it was becoming clearer that conceptual thinking and abstract ideas

surrounding what is regarded as 'normal' behaviour were becoming confused.

5.4 Creating a 'New Normal'

This section discusses negotiating uncertainty when normality was challenged. Participants

tried to find balance by justifying their decisions in assessing normality. All participants

talked about change and their awareness of change across the lifespan as previously

discussed in chapter 3, but they still needed to resolve the meaning of their memory loss

within the context of normal changes. A way of doing this was to search for a balance

between that which they considered to be normal, and that which they considered unusual. It

was the unusual that warranted greater discussion and greater resolution. Themes emerged

from the interviews that attempted to define normality and these served as benchmarks for

observing changes in normal behaviours. Benchmarks largely surrounded daily activities in

relation to expectations of change and ageing. As previously discussed the normality of

memory loss associated with age was a prominent feature among all participants as they

often distanced themselves from their memory loss 'problem' by associating it with normal

ageing. However uncertainty crept into the discussion when participants began to describe

other people with memory loss and then struggled to disassociate themselves from these

'other people'. This required balancing what they knew of dementia against their own

behaviour and created an attempt to mitigate the consequences of forgetting. Finding

balance between recognising their own memory loss and with it the associated meaning and

normalising memory loss was a powerful theme evidenced through daily activities.

Vincent had sought help for his memory problem and was working at incorporating it into

his daily life to create a 'new normal'.

> *This is me, you've seen, this is how I am most days. I've had one or two little problems*
>
> *with it. Like, what was I saying, and I'll stop, and then I'm not too bad. And I don't get*
>
> *cross, this has helped me.* (advice leaflet) *I know I've only had it a week but I've read*
>
> *it three or four times, and I do that, and it helps. That helps me to live. I think if you've*
>
> *got something I can learn from, then I'm going to conquer this and it'll get better…*
>
> *and if I didn't go* (to the clinic) *I think I'd go downhill…and of course I'm an old*
>
> *bugger now.* Vincent (Pilot)

Vincent's use of his advice and information literature and attendance at the clinic had been

incorporated into his daily routine and had given him hope that he could take action to slow

the effects of his memory loss. His referral to being old as well as having a memory

problem helped him to normalise his forgetting and by paying attention to his information

leaflet, he was gaining a sense of control through his proactive behaviour. In creating a new

normal, Vincent had constructed an emotional environment in which he could make sense

of and rationalise his memory loss whilst reducing his frustration and anger at forgetting

resulting in more comfortable daily functioning.

Pauline had resolved to accept help and acknowledge her memory loss as she tried to

construct a new normal in daily life. She had bitterly resented her family's intervention and

instigation of assessing her memory, but she decided that the best way to resolve this inner

turmoil was by deciding to manage her forgetting and to accept that she needed some help.

I don't think I had any complaints about the doctors, none at all. I think they're

marvellous. They're doing a marvellous job and although I have to admit I was

resentful at this stage when my husband obviously felt that he had to get advice, and

I'm pleased he has done. But he's doing his best for him, for me, but I'm beginning to

take it all in my stride now and wondering what day or the next day is. I mean

obviously it is different, and I've accepted the fact that it's different, and I've not sort

of gone deep into it at all, no not at all. Pauline (Housewife)

Her resolution to 'take things in her stride' and normalise her days was described as a

conscious decision and not a feeling that had evolved over time. Her acceptance of a

'difference' was an acknowledgement of her problem, but was resisted through her refusal to

fully engage with her expectations of the future. This was manifested in her reluctance to 'go

deep into it' and demonstrates her efforts to normalise her problem by accepting that

investigating her memory problem is 'for the best'.

Adapting to perceived changes and assimilating them into daily life in a way that could be

negotiated and explained helped to create a sense of normality. Violet was the only woman

who was still driving occasionally and she used this example to normalise her forgetting and

balance her upset at driving cessation with a common sense approach to finance.

I'm losing a little bit of confidence…my son says, mum you can't do it, it's not you

can't, you're not as quick as, mentally are you, your reactions…I won't let them take

my independence away, I won't give up my car when I can still drive safely. I don't go

far now…I sometimes think though, do I want to do it? I can catch a bus if I need to

go…I've been looking at my insurance…do I keep the car just for going to the shops?

It's an expense…so I'm really thinking about it. I've got all my papers in there, it's all

due now and I don't enjoy driving any more. Violet (Housewife)

Violet illustrated clearly how negotiating a way to contain her upset could be balanced in practical terms by a common sense approach. This made her decision to stop driving superficially a financial one and therefore she could maintain her social position as a legitimate driver albeit without a car; but she obviously felt that finances were a better reason for stopping driving than forgetting. In this way she could balance her upset at recognising that she was experiencing difficulties with driving, with a 'normal' reason for driving cessation.

Violet's comment that she 'doesn't enjoy driving anymore' suggested an awareness of change over time that is linked to ageing. Her more recent preference for using public transport belayed her protests at giving up driving her car and her contention with the suggestion from her son that she should stop driving. Whilst driving was tied closely to independence for Violet, she did not display the same level of driving assimilation into her sense of self as displayed by the working class men. For them it appeared to represent something of their core identity, whilst for Violet it was an additional attribute and not central to her sense of self as illustrated by her willingness to use public transport and her admission of not liking driving. Violet was keen to maintain her social contacts and offered many examples of social activities in which she felt she ranked more favourably than others. Driving cessation was just one example of her daily activities that allowed for comparisons, and this led me to explore further the concept of comparable ageing.

5.4.1 Am I Ageing Normally?

All the participants expressed a belief that mental decline is inevitable within the ageing process, but there was some uncertainty concerning how much memory loss is acceptable. Most participants engaged in comparing themselves to others and used this as a measure of balance to assess whether they were 'ageing well' or 'ageing badly'. This required an

evaluation of what normal ageing is, and whether the memory loss they were experiencing could be considered normal.

Sandra was quite sure that she had dementia as she compared herself to her late mother, nevertheless she still regarded some of her memory loss to be connected to normal ageing. This dichotomy between memory loss associated with age and that associated with dementia, even in somebody who is quite sure of their diagnosis demonstrated the uncertainty that alternative explanations can induce.

> *We was always told that wasn't we. When you get older you forget things. My mother used to say, well I'm getting old, that's why I've forgotten… She had Alzheimer's…I'm going to follow my mother…She* (pre-diagnostic nurse) *said something about me, and I was a lot better than she was. Which I thought, oh that's unusual! She was asking for things, she had got a biro, and pointed to her rings, and what else, I had to draw something but I got it the wrong way up…so I thought well, perhaps I'm not so bad. Maybe I'm just lazy (*laughs). Sandra (housewife)

In Sandra's case the flippant comment from the pre-diagnostic nurse of 'being better than she was' had been amplified into holding deeper meaning and had prompted a search for more evidence of her memory loss being something other than dementia. Sandra quickly dismissed this idea again when she went back to talking about her mother's memory loss experience however her consideration of alternatives illustrated the acceptability of some memory loss with age and the need for self-appraisal. Sandra considered normal ageing processes and 'being lazy' in her self-assessment, but she used the comment from the nurse to support her hypothesis that she was 'not so bad'.

Katie (age 50 years) was the youngest participant and strongly associated memory loss with ageing. Although she was experiencing young onset dementia, she searched for other

illnesses to blame for her memory loss because she did not consider herself old enough for a

dementia diagnosis. She had a long medical history of fibromyalgia and stroke, and she was

currently being assessed for a multiple sclerosis diagnosis. Her young age added to her

confusion and doubt of a dementia diagnosis.

> *He* (doctor) *was really nice. We were, me and my daughter, were there about an hour*
>
> *and a half. He said he's very sorry I'm going through this sort of thing at my age and*
>
> *everything... he said I was the youngest one...my daughter said they're acting like*
>
> *you've got it, and they haven't actually said...he said there's about 120 types of*
>
> *dementia, but I can't diagnose which one until I have your brain scans...I just need*
>
> *the answer because it's still, otherwise it's still not closure for me...I don't know,*
>
> *because I think that's what made me confused. I thought , well, is he saying I've got*
>
> *it? Or haven't I?..I don't know if it's all dementia or it's just memory loss is different.*
>
> *I don't know.* Katie (Hairdresser)

Katie clearly expressed her need to know her diagnosis and the problems of 'drip feeding' a

diagnosis in causing more confusion and frustration. As she had a complicated medical

history, she was uncertain if her memory problem was related to her existing problems or if

it was a symptom of early onset dementia. Her young age created doubt in her consideration

of dementia as the cause of her memory loss, even when she reported that the doctor had

explained that there were many types of dementia and he needed her brain scan to decide

which variety she was experiencing. Katie was clearly comparing her situation to that of

other people in order to make an assessment of the likelihood of her dementia diagnosis

being correct.

Steven compared himself quite favourably with others of his age and was sure that his

memory loss could only be explained by normal ageing. Therefore he was uncertain

whether he would receive any benefit from attending the clinic. For Steven, there was no diagnosis to be fearful of or to be considered because he was sure that he was simply getting older and that his memory abilities were within a normal range given his age group.

> *Well, I don't think my memory is chronic. Not really. But at 82 or whatever it is. I think I'm 83 now actually, I went. I can't even remember my age you see? You do tend to forget things you know…I suppose like lots of other people, you tend to think to yourself, do I need it?* (memory clinic appointment) *Probably I do. I don't know. But it's, I think my memory's reasonable for my age. But I forget things the same as everybody does, yeah.* Steven (Accountant)

Steven was the most certain of an ageing explanation of all of the participants, but he still had small doubts as to whether he was 'the same as everybody else.' His comment of wondering if he needed an appointment hints at inner uncertainty, and his repetition of his statement that his memory is usual suggests that he was searching to convincing himself that this was so. Although his repetition could be a symptom of his memory loss, he did not repeat other phrases in the same fashion so it is reasonable to assume that this repetition was for effective language and not because of forgetting. Steven had separated his other ailments from his memory loss in attributing it to age, and appeared to make a qualitative distinction between memory as a mental attribution associated with ageing, and illness as a physical condition. By doing this, Steven could compare himself more favourably with others of his age and locate himself firmly in the 'normal' category. This distinction between physical and mental illness was a feature more generally of the male participants' appraisals of memory and the nature of health and illness.

5.4.2 Defining Physical and Mental Illness

A major theme of uncertainty surrounded what is regarded as normal in mental and physical health (Kobau and Zack 2013). Mildred Blaxter (1984) underlined the dichotomy between the biomedical model and the more holistic and social model of health. She pointed out that in western society people are socialised to think in more biomedical terms when considering 'fixing' the body, but often in more holistic terms when considering the mind. The question of defining 'health' has been problematic, as simply stating 'not ill' does not take into account issues of well-being, subjectivity and culture. It is not surprising that since academics, lay persons, doctors and politicians cannot adequately define 'health' that my participants demonstrated a range of meanings too.

Memory loss for some was strongly associated with poor mental health and revealed strong language such as 'going mental' (Martinez 2014). These views were widespread among those without a close emotional experience of dementia. Participants could be separated into those with or without direct dementia experiences. This supports the idea that the narrative arc of one's own life is central in the formation of ideas about dementia, and in creating (un)certainty about the future with memory loss.

Men from all social locations appeared uncertain about the nature of memory loss and sought to categorise it as either a physical or mental illness. Middle class men preferred to understand memory as a mechanical and organic failing and therefore placed it in a physical illness realm albeit with conditions attached concerning the untouchable nature of the mind. Working class men struggled to understand memory in this way and therefore were faced with more uncertainty about the nature of their own memory loss. Lay understandings were therefore based upon subjective personal interpretations of memory loss that may or may not incorporate scientific biomedical knowledge. Graham as a working class man explained

his reasoning concerning memory loss and explained the unseen and therefore hard to negotiate aspect of cognition.

> *Memory, or psychiatric treatment to me, is not positive. It's airy fairy, it depends upon, it depends upon how you feel about it…because it's not, it's not hands on, i.e. like chopping your arm off or anything like that…you can't put your finger on somebody's head and say, oh you're barmy, can you?.. as long as they are not going to send me to the loony bin, I'm not worried!.. so there's nothing physical in it, it's all mental.* Graham (Insurance representative)

For the working class men, the prospect of 'something mental' being diagnosed seemed more frightening than a physical illness perhaps because of the untouchable nature of thought processes. However for most of the men across social locations they were able to be quite nonchalant about their existing physical illness, but mental illness generated a mystifying concept that had stigma attached. The more middle class men were able to reason mental illness as a physical complaint and so seemed somewhat protected from the stigmatising notions because they did not equate their memory loss with mental illness.

Patrick as a scientist, although taking a mechanical view of the brain and its function, still felt that memory was something that could not easily fit within the medical world.

> *But the psychologist is not necessarily a doctor, is it? Is he? I thought a psychologist it's more of an ancillary thing to medicine, not?* Patrick (Scientist)

Patrick's description of 'an ancillary thing' suggests that he was distancing himself from his memory loss and downgrading its possible consequences thus creating a hierarchy of illness in which physical illness was primary and mental illness was secondary. By foregrounding his reasoning of memory loss as physical and organic, Patrick was able to view it as a

treatable problem. His clear separation of psychology from physicality suggested that matters of the mind were not in the medical realm, and therefore could be reasoned as less impactful than physical illness.

Frank was a retired accountant. He reasoned dementia as a mental illness rather than a physical illness. He was clear in relaying his discussions with his doctor that dementia as a mental condition meant mental deterioration, whilst the prospect of a physical condition such as a tumour meant treatment could be offered. Frank discussed his consultation with his doctor.

> *He started off with the good news. He started off and he said he thought it was the flow of blood to my brain. That's what he thought it was. And so, and then as it grew, it went on to shrinkage, could be shrinkage, and it could be dementia, and a tumour…I don't know, but in a way it dampened down the effect of the things that were to come…there's always been a chance I could just probably have another heart attack or a stroke or something, and you learn to live with that sort of approach to life or death…I tell you what it does mean to me, that if I thought I was going to have it* (dementia) *I would like to make one of these living wills, that I wouldn't want any medication, no I don't want to be a nuisance to everybody…my only feeling about dementia is that, that if I have a tumour, well you either get it taken out or you don't, and it's a gamble…but if I knew I was going to have a mental complaint that was going to get gradually worse and worse, I wouldn't want any more medication or medical treatment, because that's it.* Frank (Accountant)

Frank was clear in his description of dementia as a 'mental complaint' that this meant removal from his social life and 'a nuisance' to his family. His misunderstanding of 'shrinkage' as a different physical condition reveals his uncertainty surrounding dementia

and shows that clear information is required for understanding treatment and prognosis of dementia at this early stage of memory loss. His desire to create a living will underlines the benefits of early diagnosis for some in being able to plan for the future, but the creation of uncertainty by providing an ambiguous diagnosis undermines control and delays planning. These unresolved ideas contribute to a state of confusion and flux and lead to meaning making being negotiated in a fluid way that ebbs and flows between certainty and confusion.

5.5 Conclusion

This chapter has explored how the negotiation of uncertainty is influenced by gender, social class and importantly by previous dementia experience. Negotiating uncertainty produced a fluid emotional state that fluctuated between anxiety, dismay, resolve, and self-belief according to the individual's attribution of their own memory loss. This in turn was related to issues such as loss of independence and driving cessation causing participants to immediately question their own judgement before settling on an explanation that felt logical and emotional acceptable.

Uncertainty was present in negotiating daily activities and particularly focussed upon the continued ability to undertake usual socialisation. Uncertainty was mitigated through gaining an element of control over choices that were real or imagined in the reduction of activities. Justifying choices helped to resolve uncertainty because it offered a logic that could be explained to others and that felt sensible.

Finding a balance between the normal and unusual was a concern particularly for working class men. They generally regarded memory loss as an unseen and therefore uncertain state.

Comparisons were drawn by these participants between physical and mental illness, and memory loss was strongly associated with the stigmatising language of 'loony, barmy, and going mental'. This finding was in stark contrast to that of middle class men who regarded their memory loss as an organic breakdown. Some uncertainty existed for this group concerning how they would be regarded socially with a mental illness, and some questioning of the legitimacy of psychiatrists to be called doctors was present demonstrating misperception of the cause and treatment of memory loss. This also demonstrated the confusion that exists in lay understanding of dementia as an organic brain disease, or a mental illness, or simply as a product of normal ageing. Findings so far had led me to believe that the preservation of self-hood was a critical feature of negotiating the meaning of memory loss, and this is the focus of the next chapter.

Chapter 6: Preserving self – I am still me!

6.1 Introduction

The preservation of self and management of identity were important features in creating meaning for a future with memory loss and a possible dementia diagnosis (Brannelly 2011). Regardless of how the memory loss was attributed, all participants thought that their memory problem would not reduce over time. Some hoped it would not worsen but most predicted that it would increase. Therefore how they conducted themselves in public and in private became a matter of concern for the present and increasingly, for the future. Fear was associated with the possibility that inappropriate speech or behaviour would reveal to others their status as a person with dementia, and they would therefore suffer the negative connotations associated with a stigmatising illness.

Participants' appraised and compared themselves to other people in a struggle to retain respect when memory mistakes occurred. Retaining respect and feeling valued played a major role in preserving selfhood as discussed in the previous chapter; but the over-riding meaning in preserving the self was of controlling social situations by attempting to conceal any social slips. Self-judgement and comparing to others was important in assessing whether social mistakes were at risk of being made or in judging if they had been made and required some excusive remarks. Fear of being judged by others and the stigma associated with dementia and ageing were dominant themes when thinking about self-preservation (Campbell et al 2008).

The maintenance of both ascribed and achieved status as an aspect of preserving self was a major theme and was represented in different household roles according to social location. Preserving status as the primary homemaker, head of household, or the position in the

extended family became a metaphor for worthiness and self-esteem. This implied that a judgement concerning morality was a feature in preserving selfhood. Various activities were used to evidence self-preservation and these activities had longevity and were rooted in habitus. Dementia and by association memory loss are stigmatising conditions, and if they are in addition seen to cause a loss of engagement with normal activities, it is a blow to self-worth and feeds self-stigmatisation and reduces self-defined status.

The first section of this chapter addresses concerns about respect. The importance for men of retaining respect was manifested in activities as extensions of masculinity. The seeking of their opinion by others and particularly by other men was considered to be evidence of their worthiness to be respected. Masculinity presented a strong connection between feeling respected and the ability to cope with adversity.

The second section examines coping. Women particularly expressed 'coping well' as a worthy attribute for respect and this was filtered throughout discussions about family and friends. Faced with coping with memory problems, women tended to discuss coping openly, adopting the philosophical attitude of taking one day at a time. This overt representation of coping was tied to preserving feminine status within household roles. The implication was that by 'coping well' one was maintaining self-identity, at the same time as achieving heroic accreditation for maintaining the home whilst faced with adversity.

The third section explains how men and women compared themselves to others in order to establish whether they were above or below average. This was a source of both comfort and distress. There was a need to confirm that other people were worse and this served to boost morale and self-esteem. Most participants preferred to focus on those that were worse and to measure their own prowess against this standard, rather than fully fit people or themselves when young. This is consistent with existing literature regarding self-ranking (Idler, Hudson

and Leventhal 1999). Men tended to cite physical comparisons, whilst women focussed more upon family and social connections, for example women identified family members that were particularly supportive and especially mentioned daughters in law, when comparing their own situation to that of their friends and acquaintances.

The fourth section is concerned with the need to cover up or deflect attention away from social mistakes and demonstrates an awareness that control can be gained by limiting social interactions, and in doing so protect the public persona and aid self-preservation. There was an awareness demonstrated of presenting oneself favourably in public and private consistent with Goffman's (1959) work on the presentation of self.

The final section discusses stigma. Stigma associated with dementia and ageing combined and were important in constructing a sense of infantilization for respondents. Stigma was fought against through defending the sense of self by referring to activities and personal biography.

6.2 Respect

Being respected was an important feature for all participants and was especially so for the men in the sample. Retaining respect was seen as a leading feature in the preservation of self and the threatened loss of respect was seen as an erosion of self-hood and independence. For the working class men, respect of their opinion and community standing were primary features. John explained the importance of respect for his opinion and the meaning that it held.

> *When your opinion isn't asked for any more, then, then you know, you're finished, aren't you?* John (Black cab driver and plumber)

John's comment on his worthiness was based largely on the respect shown to him by others seeking his opinion. His maintenance of his self-hood was built upon his social standing and was demonstrated by the respect shown by others in seeking his opinion. Social capital based in exchange has been shown to boost morale (Cheung and Chan 2010) and the reciprocal nature of offering advice that is valued by others was present in many of the interviews with men. During our second meeting we were interrupted by the site manager of the mobile home park in which John lived. The manager reported to John that he had organised a service agreement for the site's electric entrance gates. John returned to our interview after this brief conversation and reported that he had requested the gate service and that in his opinion regular maintenance was necessary. He stressed that he had instigated the servicing and that because his opinion was respected by the site manager, it had been organised. This notion of giving good advice and the evidence that it had been acted upon was important reassurance that his opinion was worthy of respect. John also cited other examples such as advising on plumbing and do-it-yourself jobs for neighbours as evidence that he was widely respected in his community.

John also gained prestige in discussing the achievements of his children and he framed this as a reflection of his masculinity and worthiness. He offered his children's achievements as evidence of his respectability and was keen to present himself as an instigator of their accomplishments.

So we are very lucky that we've two good children, both done well for themselves, so, how bad's that! I mean that's pretty good isn't it? So it's only by our guidance that it happened though didn't it?.. well, we are quite proud of our children and we haven't got a worry of them being, not without money, or whatever. They're sensible aren't they. They've both have houses…so we feel they have done success and we feel that

we've been part of that to help them. Because we've always helped them, along the

line, and we still are now. John (Black cab driver and plumber)

John's comment that they are still helping their adult children is a sign of his ongoing desire to be regarded as helpful and useful, and these qualities are inevitably interwoven with achieving respect and as an indicator that he should be judged upon his deeds and opinion rather than his memory loss. This was important to him as it underpinned his status within his family and confirmed his role as head of the household at a time when he evidently felt under threat.

Alf was the only working class man to have already ceased driving at the time of interview. Alf was deeply affected by this loss and clearly mourned his lack of autonomy and linked this to his driving cessation.

My life's much worse since they kept, and they sent me, people saying my memory's

gone, my memory's gone. You can't do nothing. They say you mustn't drive your car,

you can't do this and you mustn't do that. Well, I sold my car a while ago. I took it

over the garage and let them have it. Alf (Farm labourer)

Alf clearly regarded these restrictions on his freedom of movement and on his freedom to choose as belittling. He described how his family had encouraged him to give up driving and move from his family house to a small flat in town so that he could access buses and shops without the use of a car, but he saw this as a control measure and evidence of even greater loss of independence and a lack of respect for his wishes.

We had a nice garden up there. He (brother) says give it up, we will get you a flat, and

he got this place, but what have you got to do? You sit here and watch all that bloody

traffic down there, well sod that! I only been to Snodland twice since I been here...

What you got here? Nothing!.. My brother got me this bloody place…I don't know

how I'm going to get out of it…I had a car, used to go racing every Saturday. Alf

(Farm labourer)

Alf mourned his loss of independence and the associated respect for his own decision

making. He was representative of the male working class attitude of respect being tied to a

sense of independence gained through the qualification of being a driver and regarded the

removal of his car as an insult. For many of the working class men, having lived through an

age in schooling in which many left school without formal qualifications, the passing of the

driving test was in some cases the only formal qualification that they held (Choi et al 2012).

This could be the source of their distinctive protective behaviour towards retaining this

qualification and the associated perceived respect that the driving licence held.

The group of middle class men sampled differed on this point of driving and it did not hold

the same meaning as a symbol of masculinity, respect, and intellect. This could be explained

by the wealth of other formal qualifications that the professional men held in their work

roles and in their educational career. Driving cessation did not pose any financial or

practical threat either because they had a lifetime career during which time they had become

accustomed to using taxi services as a matter of convenience and considered them to be

value for money.

This middle class grouping were far more concerned with respect gained from social

activities and group memberships that were either tangible in the form of present

memberships, or socially constructed through ideas of associations with past memberships

and social capital. Tangible memberships included gun ownership, choir memberships,

scouting membership, and gym memberships. Whilst socially constructed membership was

dominated by the habitus associated with middle class behaviours and expectations of their

own and others intellect. Steven illustrated this point beautifully when he was discussing his

lack of enthusiasm for the memory clinic.

> *…because quite clever educated people are a bit sceptical, I would say about this sort*
>
> *of thing. Others would love it. But there we go.* Steven (Accountant)

His use of 'others' clearly sets him apart and places him in the 'quite clever educated' group

as a matter of obvious transparency. His self-definition as an educated man was supported

by his account of his working career as an accountant. In stark contrast to the working class

male group, the middle class men had all stopped driving some months or years before our

meeting, and this was not regarded as the major sign of respect that it had been for the

working class group. This could be due to the inner self confidence and self-belief that is

constructed through middle class habitus. In other words, the middle class group did not feel

threatened by this loss as they had ample resources to overcome the issue of independence

by simply being able to financially afford to buy taxi services and seeing using these

services as a usual and normal part of everyday life. The inner confidence generated from a

lifetime of professionalism appeared to create resilience to the threat of losses and by having

built an inner reserve of self-confidence that was generated through intellect. In short, there

is more in reserve to draw upon in terms of self-confidence, intellect, financial resources,

and wherewithal before there is an overt threat to retaining self-respect and being respected

by others.

Generally this middle class grouping were more likely to have been, or to currently be,

involved in organised activities than their working class peers. The social aspects of group

memberships and the social networking involved with those activities provided a reserve of

knowledge and a comfort zone for a gradual retreat from social life without it becoming a

forced issue and a sign of a lack of respect. I suspected that this was related to their ability

to control their social life and choose when and how to withdraw rather than choices being

forced upon them. Even when coercion was in place to restrict activities, this group

acknowledged that they could not be forced and displayed an awareness of rights that the

working class group did not recognise. Robert's interaction with a police officer reported in

the previous chapter (Chapter 5 section 5) displayed his intellectual reasoning for retaining

his gun ownership and his retention of respect for his wishes.

> *…and he (police officer) said to me Mr Smith do you really think you really need it? A*
>
> *gun at your age? If I want a gun, provided it's done properly there's nothing to stop*
>
> *me having one.* Robert (Lawyer)

The importance of respect was overtly linked to retaining skills and independence in the

working class male grouping and was less obvious in the middle class grouping This finding

could change as the illness progresses and the differences between working and middle class

men could become smaller as the inner reserve of the middle class respondents is dwindled

by the advancement of memory loss and the challenge to respect assaults intellectual

abilities. At a later stage of the illness we may find that the middle class men have 'caught

up' the working class group in their level of anxiety over retaining respect and mark it with

something other than driving. This is beyond the scope of this study and would require

investigation in the later stages of the illness.

6.3 Coping

The terms 'coping' and 'coping well' were vocalised predominantly by the women of all

social locations, and appeared to have the same kind of significance that respect had for men

in retaining selfhood. Women tended to use these terms more openly than men, who

preferred to imply coping in their illustrations of daily life. Coping for the women was seen as an example of their emotional prowess and ability to maintain their household and family oriented roles. 'Coping well' lent itself to heroic overtones as a sign of the ability to overcome adversity. Pauline had described herself as 'a coper' and listed different situations that had occurred in her life such as her children's' illnesses and her husband's early retirement due to ill health as evidence of her heroic coping ability.

> *You just cope and take it in your stride that's it, that's meant to be, whatever...I don't go round thinking, oh poor little me, another thing going wrong, like that's not my nature especially having , as I said, being in St John's from a young age. I mean, I have compassion.* Pauline (Housewife)

Pauline clearly outlined her philosophy of coping and admonished pitying oneself as a failing of character. She drew upon her past in the St John's Ambulance Brigade to justify her reasoning and to further her self-esteem and preserve her identity. The majority of the women concurred with this self-maintenance and resolved style of coping.

> *I can't do what I want to do and get around and all that now that I'd like to do, but, I make myself do it...just make the most of what's left and get on with it the best you can.* May (Factory worker)

May displayed a stoicism concerning her lifetime experiences that was echoed by Joan.

> *It gets annoying when I have to keep saying what is it today? And when did you say they were coming? But you just deal with it. Can't do anything else, can you?* Joan (Factory worker)

In contrast, male coping patterns were more subtly represented and expressed far more in hope for the future than in immediate coping. The belief that things would improve was a

powerful commander of the sense of self and maintenance of identity. Steven was able to maintain his identity as a well-travelled man and attentive father by planning to travel to Canada in order to visit his son at some undefined point in the future.

> *I'm going, I'm not going out to Canada this autumn or winter because I've got these things on my legs. That one's cleared up. There's still an ulcer on that one, but the doctor thinks they'll be cleared up by next spring and I might go out to Canada then. And my son's in Canada you see.* Steven (Accountant)

Steven was quite hostile to the suggestion that he had any memory loss and used his physical condition as the deciding factor in curtailing his travel arrangements rather than his failing memory. His hope to visit his son in Canada in the following months served as a coping mechanism for mitigating his present housebound situation which was in part induced by his memory problem and partly by his physical condition. He had explained that his memory difficulties were expected at his age and that he did get confused if he went out alone, but this had no impact upon his travel plans.

Vincent also used hope for the future to cope with his current situation. He had actively sought help for his memory problem and was keen to attend the clinic and gather any advice available. His hope aided his identity maintenance as a man who could take charge and influence his own future.

> *I'm not too bad actually but sometimes I will get a block, boom. But I'm getting these notes which are brilliant. And I'm hoping now, when I go to these meetings* (memory clinic) *up the hospital, that it will slow me down and it will do a lot of good for me. I don't need a lot, I don't think.* Vincent (Pilot)

His insistence that he 'didn't need a lot' was a deliberate downplay of his difficulties as he had spent some time outlining examples of his memory failing. He was able to cope with these incidents because he was actively seeking help for himself and in doing so, was taking charge of his situation and was hopeful for the future and aiding his preservation of selfhood.

In the examples given, both men and women presented coping strategies as a form of stoicism and heroism and as a mechanism for providing reasonable explanations for difficulties in daily living. Comparing oneself to others formed part of the judgement of 'coping well' and in retaining a sense of self-worth.

6.4 Comparing

Comparing oneself to others and drawing comfort from the knowledge that other people may be in a worse situation is a well-documented phenomenon within the social psychology literature (Pahl and Eiser 2006). The concept of 'othering' is an important sociological aspect of this as imaginary demarcation lines are drawn between the self and the world around us. Constructing the Other in opposition and as separate or rejected is abject, but viewing identity and sensing a change in the identity of oneself as perceived by others, is a 'floating signifier' of othering (Dervin 2011). In this sense, memory loss can be considered a floating signifier of othering people with dementia, and disassociating oneself with the popular image of a dementia sufferer.

This ties closely with comparing in the sense that to see oneself as different, and separate, one must compare. Knowing that we compare favourably can boost self-esteem, but comparing can also create dissatisfaction with ones lot if we think we compare badly

(Giddens 2006). It was popular among all the participants to rate themselves as either 'normal' or 'slightly better' than other people in most areas of their life. I did not use a specific self-rating scale as this was not a specified area of research within this project, but rather it is a concept that evolved from the meanings constructed by the participants.

Comparing was expressed most strongly through masculine and feminine identities. Men tended to locate comparing in physical realms and skill sets, whilst women tended to compare family support and social activity. These domains all served the purpose of enabling direct or imagined comparisons between participants' own memory loss and general wellbeing including ageing, and that of other people. Participants only compared themselves to others that they considered to be worse; and when talking about the nature of dementia and what a dementia patient 'looks like', it was those without direct experience that provided the most powerful imagery regardless of their social location. Therefore a division could be seen between those people who simply compared their own situation to that of others, and those who compared themselves to the popular image of a dementia sufferer.

Vincent was a retired pilot and understood that presenting himself well compared to other people was an important feature of his social interactions. He discussed attending the clinic.

> *They're* (clinic staff) *busy, and they are tired, but if they see you are working extra hard to try and be good, to be fit, maybe they will help you. You have got to, and smart. When I go in, when I go in, I'll, you see I've got my trousers on with my nice creasing, I try and go in, and I wear that coat. I go in smart and I see my hairs done properly. And I'm not, when he looks at me, he can see, oh he's ok. I don't go in with a bit of a weeks or two weeks shavings on and I haven't cleaned my teeth since August.*

You know, I try to do my best. Now if you can do that, you stand a chance. Maybe he'll

do a little extra for you. Vincent (Pilot)

Vincent was very aware that it was socially important for him to present himself in a certain way and that cleanliness and smartness represented a kind of reciprocal respect between himself and the clinic staff that less smartly dressed people would not be able to achieve. His concern with his appearance may have been influenced by his background as a pilot where uniform denotes authority and competence, therefore by dressing smartly he was presenting himself as a 'good' patient and morally deserving of their time and expertise. The physicality of his appearance was important for him as a marker of his intellect and as a demonstration of his ability to look after his personal hygiene. Goffman (1959) discussed the importance of the presentation of self and how this can feed into stigma. By actively and consciously thinking about his presentation, Vincent was alleviating the effect of attending a potentially stigmatising clinic appointment, and distancing himself from being compared to the popular dementia image, and of appearing undeserving.

Patrick was an educated man and had a long scientific career and had lived and worked in Europe for most of his working life before retiring at home in the UK. He talked about attending a cardiac support group and compared himself to other members of the group.

I was quite surprised really. Because we were all of a similar age and what people of

that age are doing taking careful note of the remarks that were being made and so on.

I used to think to myself, surely he's got more intelligence than that? People who

looked more fit than me at the time, but they were still listening intently and enjoying

it. Patrick (Scientist)

Patrick's obvious comparison and awareness that other people were physically fitter than he was, was overridden in his assessment of the group by his own intellect, and led him to

conclude that he compared favourably to others. He distanced himself from other people in the group by focussing on intellect rather than the cardiac support and advice that was being offered to all the members of the group equally. Patrick did not internalise his cardiac group membership and regarded it as a fleeting and transitory phase of his cardiac recovery. He was able to do this through his othering of his fellow group members. Patrick's refusal to internalise his group membership also extended to his attendance at the memory clinic, and he went on to compare himself to a patient he had observed at the memory clinic and discussed this observation with his wife during our interview.

Patrick: *There was a very old man.*

Wife: *It's relative Patrick, you're 84! and I don't think he was older than you.*

(Respondent laughs)

Patrick: *Well, he looked old, as far as he was leaning on his stick, and he was rather a short man with his son. His behaviour was very old, very ancient.*

Wife: *He was very pleasant when we said hello, the old chap.*

Patrick: *Well, the old boy was, I would have said, considerably worse than me in his general demeanour and I rather think that the other one was his son, or whoever it was, was a bit fed up with them.*

Wife: *But I think it depends on the amount of stimulation you, they have as to how withdrawn they become, don't you think so?*

Patrick: *I mean we have friends coming in and out, the family come, we have, part of the family, my son-in-law was here yesterday and he and I banter with each other and its' all stimulation to interest life in general.*

> Wife: *And Patrick shouts at the television when there's somebody he doesn't like on*
>
> *there!* (laughter)

Patrick demonstrated that he was aware that other people may not have the same relationship with family that he enjoyed, but he could not help but compare the 'old boy' directly with himself, and concluded that this other man 'was worse in his demeanour'. I revisited the topic of this interaction later in the interview and Patrick elaborated that 'demeanour' meant awareness of his surroundings and interactions with his companion. At his wife's suggestion that maybe other people 'lack stimulation' Patrick was happy to launch into an example of his busy family life and his light-hearted banter with his son-in-law as evidence of his own interest in life. Following this exchange Patrick and his wife talked at length about their son-in-law and his professional achievements as if to explain why they regarded him as equal intellectually with Patrick and therefore able to 'banter' with him. The importance that was placed on these interactions was an indicator of the definitions that Patrick was applying to his own social position, and this helped him to distance himself and 'other' the man he had met at the memory clinic.

Talking about family was a popular way of building self-esteem through their reflected achievements, and was represented across social locations. Charles was a working class man and a retired factory toolmaker and had very strong emotional bonds with his daughter and grandchildren. His love for his family was extended to promoting them to me and were an important feature of his interviews.

> *You're more likely to talk about your grandchildren than you are your own child,*
>
> *because we've (friends) all got grandchildren. God was showing off when he made*
>
> *mine!* Charles (Factory worker)

In the following extract Charles reflected on how his memory loss had impacted his detailed knowledge of family members and important family dates and the distress that forgetting such things caused. He then attempted to relate this to age and compared himself to others in his social group.

Because I wouldn't know how many times I lost my memory on that, I wouldn't know…like my daughter's birthday, sometimes they say, well, it was, it was, it was the 17th January, and then you think, no, probably the 6th, and of course I knew that off by heart, and now I don't…well, then you feel a little bit less of yourself, not, not, not, not mature, I don't mean that. As a man, you feel a little bit less, a little bit, I suppose, a little bit frightened really because you don't know where it is all going to lead. I mean I play golf with a lot of people my age and a bit older and quite often somebody says, Hope I can remember the way home tonight. And we all have a little sniggles to ourselves, but we're all, we're all roughly the same age. Charles (Factory worker)

Charles was using his knowledge of the possibility that other people also have problems with memory that are related to age alone, but as he chose to foreground forgetting his daughter's date of birth as an example, it suggested that he was aware that this level of forgetting may mean that something other than normal ageing is to blame. Not remembering the date of his daughter's birthday was a milestone in his forgetting, and he used this to emphasise that these issues are quite separate from usual ageing and the light-hearted mockery of normal ageing. Charles made an important distinction between 'forgetting' in which he was unaware, and 'not remembering' in which he felt 'less of a man'.

I retrieved numerous examples from men and women of all class locations discussing the achievements of their families and basking in the reflected distinctions of their family's accomplishments. This appeared to serve as a boost to self-esteem and was an obvious

source of pride. Charles was typical of the male respondents in outlining is families

achievements. Women however were very specific in directly comparing their family and

friendship circles to those of real or imagined 'others'. Violet often repeated her

thankfulness for her supportive family and particularly her daughter-in-law.

> *I've got all my friends are much younger, which I'm lucky, and they keep you, and as I*
>
> *say, I've got a lovely daughter-in-law and the boys. My youngest grandson, he's*
>
> *lovely, he's 20, and he comes, and he's very good, they're all good. I'm lucky, when I*
>
> *hear some people!* Violet (Housewife)

Her comment of 'when I hear some people' is a reflection of her awareness that other

people do not enjoy the same kind of social interactions as she. All of the women sampled

discussed and compared their family circumstances in far more detail than their male peers.

May was a typical example of detailing the tasks her daughter undertakes to support her.

> *She does all the grass and when we buy things, she does all the planting...my husband,*
>
> *his ashes are in the church so twice a year...my daughter takes me there...my*
>
> *daughter sees me once a week and cuts the grass, and takes me shopping, and to the*
>
> *doctor...my daughter takes me if there's anything I need in the way of clothing or*
>
> *anything like that...my daughter, she works hard and keeps her home nice and that.*
> May (Factory worker)

May and Violet both lived alone but the women living with spouses also embarked on these

detailed descriptions of help from adult children and grandchildren in a far more detailed

way than the men. Sandra and her husband had two sons and she talked at length about their

achievements but confessed that she had always wished for a daughter as well. Sandra had

experienced a very close relationship with her mother whom she described in great detail,

but she now focussed her attention on her daughters-in-law and grand-daughters. She gave

long explanations of cake making and companionship, and she explained that in her opinion women can understand women far better than her husband or any men generally ever could. She often repeated how lucky other women were to have daughters.

> *I've always wanted a daughter because when my mother was with me, when I was little and I grew to be a teenager, me and my mother used to go around the town and do the shopping and all that you know. I used to take her for a cup of tea and she used to buy me a cake, it went on lovely like that…boys don't speak to you like that. You see with a daughter, you can tell her things that you don't want the others to know, but with a son. They are good kids, I mean they do things for me and all that, they are worrying themselves sick about what's going on with me, so I said, I will be all right…but I would have gone to my daughter then, but I mean, daughters are different in all ways aren't they.* Sandra (Housewife)

Sandra's comparison of her interactions with her sons to that of her imagined relationship with a daughter, was closely tied to the support that she felt was lacking for her memory loss. A daughter seemed to represent investment in her future in terms of care needs in a way that her sons could not fulfil. She had spent some time comparing her sons to other men and detailing their career and relationship choices and was clearly very proud of their achievements, but her strongly gendered approach to confiding her thoughts was reserved for women and particularly for a daughter she could totally trust. This reliance on women to best understand her feelings was demonstrated again at the end of our meetings.

> *I've enjoyed today. Do you know I feel a lot better now you have been? I can talk to you. Some people you can't talk to…I don't know what to do with myself otherwise. You know, you feel stupid when you go to speak to somebody…you are doing a grand job, and it's been lovely to have some female company.* Sandra (Housewife)

Sandra's need to compare her familial relationships with those of others directly relates to personhood and identity management (Kitwood 1997). Her experience of memory loss had heavily influenced her comparative assessments of her relationships with her sons and husband with an imagined 'ideal' relationship with a daughter whilst managing and negotiating her memory loss. Her appreciation of female company and the statement that she 'felt better' after talking to another woman underlined her need to feel understood. She had decided that only another woman could truly understand how she was feeling, even though by her own acknowledgement, her sons and husband had been supporting her.

For all participants comparing themselves to others in a multitude of ways helped to define their current familial roles and served as a management mechanism for preserving the self. In Sandra's case she did not compare herself well to other women by lacking a daughters' support, and this appeared to be related to her emotional desolation and reduced her confidence to interact socially. Sandra talked at length about her fear of engaging socially with other people and cited this a major reason for withdrawing from social engagements. Sandra was not alone in choosing to manage her sense of self by withdrawing, so I decided to explore this point further.

6.5 Deflecting Attention

As explained previously all participants had a sense of the past and who they once were in their working lives, and the changes they had experienced across their life course. Awareness of change was considered a normal feature of ageing, and most expected to slow down in older age. However social withdrawal gathered pace as memory loss increased. Withdrawing socially and its relationship with quality of life is a well-documented phenomenon in the dementia literature (Alzheimer's Society 2010b, Milne and Peet 2008,

Snyder 2010) but has been considerably less explored at this early stage of illness. The tactic employed to greater or lesser extent by all participants was to deflect attention from social mistakes by limiting the amount and type of social interactions they engaged in. In separating and carefully choosing when to engage socially participants were demonstrating an awareness of a public and a private persona, and that the private could be hidden from public view by carefully controlling their wider social circle. Presenting oneself in the best light and production of alternate 'selves' depending on the social situation was described by Goffman (1959) as akin to actors on a stage adopting various persona according to the demand. Participants managed this presentation of the self by choosing carefully who they would interact with, when, and in what capacity. As nervousness and self-doubts grew concerning forgetting, they chose to withdraw from social situations that could potentially lead to social errors and embarrassment.

Explanations for why they had chosen to withdraw varied according to social locations. Women were far more likely to acknowledge their difficulties in social situations and take overt steps to minimise any embarrassment. Men were more inclined to refuse to acknowledge their withdrawal but nevertheless, took steps to reduce their social actions and gave alternative explanations for this revised behaviour. The scale of the withdrawal ranged from withdrawing from most social activities outside the home through to minimal withdrawal by carefully selecting which events to avoid. This range broadly corresponded to the living arrangements of the participants. Those that lived alone were far more disposed to faster and greater social withdrawal than those that lived either with an adult child or spouse. This underpins the necessity of person centred care approaches in taking account of individual living arrangements and supports the premise that living arrangements serve as an important indicator of the level and quality of social interactions taking place. Although

it would seem clear that living with another person enhances the social life of a person with memory loss, the quality of those interactions is reduced if they are not handled sensitively.

Katie lived with her adult daughter and was supported by a close friend who spent many hours of every day with her. She also had a close and supportive extended family, but she still felt that she could not interact fully with those outside her home for fear of confusion and the humiliation that would be created. This feature was particularly concerning for Katie as her background as a hairdresser had afforded her social skills which she valued in 'small talk' within fleeting and intermittent relationships with customers. She was particularly concerned if more than one person would be speaking at once as she had great difficulty in filtering and paying attention to more than one conversation.

> *So, and if I do go to other people's houses and that, I don't really talk. I sit there and listen but I don't, I'm like in the background.* Katie (Hairdresser)

Katie had described herself as outgoing and gregarious throughout her life, and her career as a hairdresser had demanded social skills and multi-tasking in conversation, practice and thought. This retracted position that she now described of being 'in the background' was a major change for her and demonstrated the devastation of self that early memory loss can create. Even with the support of her friend and daughter, she found socialising a daunting and nerve wracking experience and this reduced the quality of those interactions and pleasure when engaging socially.

Joan lived with her son and discussed how she could not talk about her memory loss with him for fear of creating a problem. Her son worked long hours and she was alone for most of each day. Her fear that she will be 'a problem' seemed to be all encompassing and about who she is.

No, I still haven't talked to him (son). No. I don't want to mention it, no. I don't want

to be a problem. Joan (Factory worker)

Joan went on to describe how talking about problems with remembering was too private and

too scary to discuss because *'people don't want to hear it'* implying that it is not a socially

acceptable topic of conversation even for family discussion so it is better to avoid it. She

had almost completely retreated from venturing outside her home other than to attend

hospital outpatient and doctor's appointments.

I'd rather keep myself as I am. I can't remember very much, you could say something

to me and ten minutes later I'd have forgotten what you said. Well, I'm on my own

here all day. My son goes out to work at five in the morning and doesn't get back til

nine at night, so I've nobody to talk to, only the dog and he doesn't answer me a lot!..I

used to get on well with the woman next door. One day we were talking, and it was

only a short chat like…and she packed up whatever she had, washing or something,

and walked in the door and she hasn't spoken to me since. That's about three months

ago…I don't know what triggered it, she just snapped. Joan (Factory worker)

Joan appeared to be aware that she may have said something to instigate her neighbour

distancing herself but she could not be sure, so she had decided to avoid the situation again

by staying indoors. Her obvious dissatisfaction with staying inside however was apparent in

her lack of human conversation through mentioning her dog. Joan was very fearful of social

activity and recounted stories of other people who had ventured out alone when they had

dementia and used this as further reasons why she chose to stay at home.

There was a bloke out on the marshes somewhere only a few months back…and he

didn't know who he was or where he was going. He didn't even know he was on the

marshes…I would never go out on my own, not now…got nowhere I can walk as far as

the hill and back again, but I can't even walk the dog because he's so lively. He'd pull

me over, so I don't think I could take him for a walk. I love you coming, and I'm short

of visitors. I don't know anybody down here. Joan (Factory worker)

Joan used the problems of managing her dog by herself on a walk as the reason for her

decision to stay home but also related her interactions with her neighbour as her reasons for

non-engagement socially. She justified her situation of being home bound by searching for

practical reasons why she could not venture out, but she was also mindful of the stories she

had heard about 'the man on the marshes' and was fearful that she could be discovered in a

similar situation. The result of being found in a similar situation meant that she would no

longer be able to live at home, so in an effort to preserve her living at home for as long as

possible she chose to remain indoors, illustrating the important effect of memory loss on

long term care leading to Joan's active decision to withdraw.

Terry's social withdrawal was related to living alone and coping with grief after the death of

his second wife. Since her death, Terry had moved house to be geographically nearer to his

sister with whom he had always had a close emotional bond. He had worked until retirement

as a machine minder and had enjoyed an active social life through his working men's club

and dog owners club. He had recently decided to leave both of these clubs but he explained

this in terms of his bereavement rather than his memory loss, even though his wife had

passed away some years before his house move and decision to stop attending the clubs. He

recounted a story of his uncle who had dementia and how he did not want to create the same

nuisance for his sister.

I don't go round there unless, how can I put it, I'm invited or it's something

prearranged because I think you can make yourself a damned nuisance. I know my

father had a brother living in Chelmsford. He used to turn up all hours of the evening

and night, poor old chap really. You can look back and see it. He used to knock on the

door and he used to say, the Supreme Being has sent me to see you… The people over

the road opposite me, they're nice. She's a doctor. They're very nice. Chap next door

to me, he talks. She's nice next door, but we just pass the time of day really. I should

go to the clubs but I haven't done. I've been told I should do. I used to be out a lot,

but…you take a knock. Terry (Machine minder)

Terry clearly wanted to disassociate himself from his uncle's behaviour and his way of

controlling this was to disengage socially. He could preserve his public persona with his

neighbours and control the interactions with his family to maintain his sense of self and

independence by regulating his social interactions. By limiting his social engagements, he

was also limiting the possibility of making a social faux pas and drawing attention to his

single living arrangements. He expressed his loneliness many times during our meetings and

this led me to ask him why he had chosen to allow me to visit. He explained that the pre-

diagnostic nurse had thought that the opportunity to talk with me would help him gain some

confidence to explain to his family how he was feeling. This did indeed appear to be the

case when I later received a telephone call from Terry's sister explaining that they had

together been able to discuss his situation and arrange regular visits as a compromise

between Terry remaining independent and feeling that he was 'being a nuisance'.

Those that lived with spouses were far more inclined to be socially active but acknowledged

that they were reliant on their spouse for governing the situations and conversations with

others as they arose. Charles relied on his wife to corroborate his memory of events.

I can talk the hind leg off a donkey. But of course, I could probably, the following day,

I might not remember. Unless someone says, didn't you remember last week we were

talking about that, then I might not remember it…I mean, Iris would probably have

more, she wanted to do, whether she does or not, but she'll have more input into that than what I can. Because how many times I have lost my memory, I wouldn't know…Sometimes, I, I don't know what to make of it really. Being serious. How bad is it? What seems frivolous to me doesn't seem to Iris or whatever. I don't know. I don't know. Charles (Factory toolmaker)

Charles was socially active at his local golf club and had maintained friendships in that setting, but his wife recounted instances in which he refused to meet new people. She suspected that it was because he was frightened that he would not remember them on another occasion. By only engaging socially in a setting with which he deeply familiar and by refusing to be confused with new relationships, he was able to control his social withdrawal without it impinging on his sense of self, and in doing so preserve his identity and present himself positively to those around him. He freely acknowledged that he would forget, but questioned how important this was as he was managing his golf friendships satisfactorily and enjoying his activities.

Sandra lived with her husband and had almost totally withdrawn from socialising other than with her immediate family. She would reluctantly visit shops with her husband but would not dare to leave the home alone. In the following extract Sandra and her husband describe the change in her social activities since her memory loss had become more noticeable.

Husband: *No we haven't been out for some time. But when you worked at the shop, you had your own set of friends then, didn't you?*

Sandra: *Yes.*

Husband: *And occasionally go out with people I worked with, we went out.*

Julie: What about now?

Sandra: *Shopping and things like that, he always takes me. We have always done*

that since you retired, haven't we?

Husband: *We have to get there first, so I have to take her.*

Sandra: *Tesco's. I've been there this week and I don't like it…we can laugh and*

joke, but sometimes I feel really miserable. I sort of shout. And then I think, what am I

shouting at him for?

Sandra was aware that she was shouting and felt threatened when she left her home, but was

unable to equate her 'laugh and joke' with feeling comfortable in social situations. She

clearly recognised that leaving the house together was an activity that preceded her memory

loss and had become a habit since her husband's retirement, but she clearly felt that

choosing to only leave the house together was quite different from not being able to leave

the house without him. Sandra gave many more examples of refusing to leave the house

without her husband including visiting the local corner shop, walking the dog or leaving the

front garden to speak to neighbours. She felt that if she encountered anybody on one of

these visits she would not be able to cope alone.

Husband: *We don't go out often, but it's not a problem. I don't think so anyway.*

Sandra: *As long as he is with me I go out. I hang on to his arm and we walk like that.*

I asked Sandra why she had allowed me to come and speak to her about her memory as she

was so fearful of meeting new people.

Well, I was waiting for you because she (pre-diagnostic nurse) *said there's another*

person who would like to see you as well, and you will be all right with her because

she understands, so this was arranged. Sandra (Housewife)

Sandra's agreement to allow me to visit her was directly related to her need to explain her

feelings and was reinforced by her conviction that only another woman could understand

how she felt. Sandra was very reliant on her husband for confidence and approval of her

behaviour and he joined us for our meetings. She partly blamed her heart condition for not

walking alone and said she gets breathless occasionally, but she explained that she used this

as an excuse to reduce the level and quantity of her interactions. This was common

deflective tactic to handle social interactions and justify withdrawing without overtly

acknowledging memory loss. Blaming an existing condition or set of circumstances felt

much more manageable and normalised the withdrawal of social activity. There was a

prevailing sense that gradual social withdrawal was expected with ageing and retirement but

the protestations of deliberately excusing social encounters was firmly connected to the

memory loss and the meaning that forgetting created.

6.6 Stigma and Infantilization

There is no doubt that dementia is a stigmatising illness that overlays the stigma of normal

ageing (Victor 2005). Normal ageing carries a certain stigma in western society that

portrays older people as a drain on resources and expensive to care for, as costs to the

economy are frequently reporting the UK's ageing demographic. This is coupled with ageist

attitudes and infantilization of older people by services (Kontos 2009). Older people are

often thought to be mentally deteriorating, outdated, and inconsequential to all but their

immediate family. This popular image of a failing older person is at odds however with the

alternative consumerist view of ageing and retirement as a time to be spending money on

holidays, volunteering, and living well. The consumer market that targets older people for

mobility aids alone is considered to be worth between £430m and £530m (Office of Fair

Trading 2011), in addition to the aggressive marketing of insurances, holidays, and other

products that target older people. These conflicting depictions of older people are further

confused by memory loss and the possible meanings that it created for my participants. This

often led participants to question whether their experience was normal ageing and therefore

acceptable albeit with conditions, or dementia and included the associated stigma.

Memory loss by close associating is recognised as the first step in a dementia illness and

therefore is stigmatising even before diagnosis. Participants were widely aware of this

stigmatised indisposition and sought to distance themselves from it through the withdrawal

and self-preservation techniques such as ensuring respect and presenting coping heroically.

This was consistently used as an antidote to shame associated with stigma as outlined earlier

in this chapter.

Stigma was the key factor in creating a diminishment of self and in governing social

withdrawal and creating tactics for managing the situation that did not relate to dementia per

se. Hence the progression through phases of the need to retain respect, develop coping

tactics, comparing oneself as a way of seeking reassurance, and finally withdrawing from

social life. These phases are prevalent in this early pre-diagnosis stage of dementia, and

were acted upon as soon as memory loss was noticed and importantly, was thought to be

noticeable by others. The participants clearly demonstrated that their own awareness of their

memory deficits happened very early and before other people close to them had expressed

any concern. The participants in many cases were expressing self-stigmatisation and acting

upon this in an effort to deflect wider societal stigma that they supposed would be generated

by their memory mistakes.

Goffman (1968) had argued that a person with a stigma was 'not quite human' (pg 15) and

went on to explain that wider society feels a need to explain the inferiority of other people in

terms of danger either to themselves or others. Therefore the need to explain memory problems away as normal ageing and /or demonstrate competence in daily life becomes a crucial way of deflecting perceived danger and preventing the 'othering' that can occur as a result of a stigmatising condition.

6.7 Conclusion

The preservation of self was an important feature of living with memory loss. The importance of retaining respect and deflecting memory mistakes was particularly important for men whilst women were far more focussed on retaining respect through demonstrating their coping abilities. Women often cited examples when they been forced to cope throughout their life and presented this as heroism by comparing their abilities to cope with that of other people. This comparison technique was also used to compare family situations and family achievements that could be reflected through their earlier parental responsibly when bringing up their children.

The men in the group worried about being judged as incompetent, and this was a deciding factor in engaging publicly. If there was a danger of social mistakes, then men would prefer to not engage rather than risk being thought of as failing. All participants offered insight into the gradual process and acknowledgement of social withdrawal associated with ageing and retirement, but the overriding sense was that memory loss had increased the rate of withdrawal considerably. Those that lived alone had withdrawn more quickly than those living with spouses or adults children. Living alone appeared to increase self-judgement and fear of social mistakes and so led more quickly to consideration of the stigma associated with memory loss.

Stigma both from the social world and self-arising from socially constructed ideas about

dementia increased fear and withdrawal considerably. The struggle to preserve the self was

a major event in the trajectory of the memory loss. How losses were measured and

identified was the next logical step in defining the memory loss experience, and it is this to

which I now turn my attention.

Chapter 7: Shifting the Boundaries – I will know I'm bad when…

7.1 Introduction

This chapter is concerned with the activities that participants used as convincers and proof of current competence and responsibility, and the markers they identified as being pivotal in recognising decline. These markers set the parameters of acceptable levels of competence and the boundaries beyond which decline was irrefutable. As parameters were approached they shifted and changed according to a re-evaluation process, and new parameters were then set as if to provide a 'buffer zone' against accepting decline. These changed parameters were justified and re-evaluated as a choice rather than as a forced rule as a protection against reaching the conclusion that recognition of deterioration had indeed been reached. This struggle to maintain effective personhood was demonstrated ultimately in the fluid positioning and re-evaluation process of 'knowing when I am bad'.

The first section of this chapter addresses the meanings that were attached to daily and occasional activities that convinced participants of continued competence and responsibility. Being construed as a responsible person in any form bolstered self-esteem and led to each individual setting their own boundaries beyond which they would consider themselves to be in decline. This included convincers of responsibility which were located primarily in external activities such as babysitting duties, driving and volunteering; being capable of partaking in activities such as hobbies, holidays and do-it-yourself; and continuing in daily activities such as dog walking, shopping, personal hygiene, and family events.

The second section sets out the boundaries that participants identified and used as markers of decline. This involved comparing and measuring self attributes that were related to the

internalisation of markers as a reflection of self-judged morality and existential thinking. Participants were concerned with the meaning of their own life in relation to becoming a burden on their loved ones, not knowing that they had forgotten, and when to effectively give up trying to remember.

The final section is concerned with the process of changing the boundaries between competences and recognising decline. This shifting of boundaries and re-evaluation of reduced activities took the forms of adaption, of choosing, and of retaining the right to change one's mind. These were important in retaining a sense of control into the future and provided a self-induced liminal space in which to re-assess the future.

This chapter underpins the earlier discussions in this thesis concerning the importance of personhood as memory loss increases and people enter a liminal space between onset and diagnosis. During my contact with participants, they reflected on their life to make sense of the perceived versions of the future. During this reflective process, convincers of current competence that were based on drawing from the past, alongside heightened awareness of continuing current activities took place despite increased memory difficulties. Markers of decline were outlined and set as the parameters of 'normality' and referred to at some unspecified point in the future. These were regarded as the 'knowing there is something wrong' situation. However, these markers were re-evaluated and re- negotiated according to personality, life story, and social position as memory loss increased and the initial markers were within sight.

7.2 Convincers of Competence

This section of this chapter addresses the meaning that was attached to daily and occasional activities that acted as convincers of current competence and is arranged around themes of responsibility, capability, and competency. These issues were dominantly used as convincers of continued personhood and as a defence against perceived memory loss across all social locations. Working class respondents tended to strive more for recognition from others, almost as though achieved statuses proved their wholeness, whereas middle class respondents tended to be more confident that their ascribed status and achieved status through past history of employment and leisure activities, gave them a kudos that acted as a cushioning effect to challenges to selfhood.

7.2.1 Responsibility and Boundary Setting

Retaining responsibilities was important for all participants, not just because it linked with independence, but also because it set tangible evidence that they were still 'whole' people. Being construed as a responsible person in any form bolstered self-esteem and led to each individual setting their own boundaries beyond which they would consider themselves to be in decline. This included such things as convincers of responsibility which were primarily cited in external activities such as babysitting duties, driving and volunteering; and being capable of partaking in activities such as hobbies, holidays and do-it-yourself; and continuing in daily activities such as dog walking, shopping, personal hygiene, and family events.

Responsibility was regarded by the participants as the most important factor in retaining self-esteem and decision making abilities. Being regarded as a responsible person held a special meaning for self-esteem and was used in setting the boundaries of what it means to be a whole person. If responsibilities were reduced this was seen as an attack on self-worth

and a marker that their intellect and status was dissipating. Violet expressed her annoyance at her capability to assess the contents of her fridge being called into question.

> *My son will often look in my fridge, which is a bit bare. Mum, you need so and so. And I say, for goodness sake! I go every day. I like to go out. If I've got stuff in the fridge then I don't need to, but if I need it, makes you go out…I keep occupied with what I've got to do…It keeps you, you could. I make myself go out because otherwise you sit here, watch that wretched television, I'd be lost without it, but you can sit here and get miserable. I like to think, oh I need bread. I'll walk up the road… My son will look in my fridge, you haven't bought so and so. I said, oh for goodness sake! It does irritate me.* Violet (Housewife)

Violet did not like her judgement of her fridge contents to be questioned because this represented her ability to look after herself responsibly. She applied a clear logic to the reasons why her fridge was so empty and resisted her son's advice because she felt irritated at his implication that she was failing to look after herself properly. She recognised the importance for her to engage socially and maintain her ability to shop alone, and reasoned that by deliberately keeping her fridge contents to a minimum, she needed to continue to think about menus, and she was guaranteed of some social interaction every day. She clearly displayed different risk rationalities to her son, but felt she could explain her reasoning satisfactorily and therefore her empty fridge was not a concern for her.

John also saw daily activities as a representation of responsibility and therefore a measure of his abilities. He talked about his responsibility to pay the household bills for himself and his wife and used this as evidence that they both compared favourably to other people in similar situations.

…because we have direct debits, so with direct debits you haven't got to do much have you. We're sensible enough to take that opportunity. Instead of going up and paying it in the bank or whatever, you get the bank to pay it in, don't you. So we try and do the modern things as we come along…so we're not people that are getting old and having difficulties. Really, if we got to understand something, we sit down and sort it out between us. Or if I can't understand something, I go and get advice. I just do the natural things you should do. John (Black cab driver and plumber)

John's normalising of advice seeking demonstrates his awareness of being responsible and getting help when needed. This is contrary to most of his remaining testimony that he is '*his own man*' and gives advice rather than receives it. His willingness to assert that he does seek help in certain circumstances and distancing from other 'old people' suggests that he is very aware of acceptable public behaviour and that his assertion is testimony to his responsible and sensible attitude. He used the direct debit system as an example of his responsible attitude and connection with 'modern things', and this served to assure him that he was still metaphorically keeping up and therefore not experiencing any great difficulties.

The properties of the responsibility crucial for this self-assessment were measured primarily in external daily activities. Responsibility or being considered responsible was tied very closely to feeling worthy and trusted. The concept of worthiness has already been explored in earlier chapters in the guise of personhood (Chapter 1.1.1), existential thinking (Chapter 4.2), and respectability (Chapter 6.2). Trust in oneself and being trusted was a key feature used as reassurance that they were indeed considered to be responsible. Being trusted to drive by official judgements, and trusting oneself to drive, were the main features of the working class men's testimony.

Terry was very fearful that his driving license would be taken from him if his memory got worse. His worthiness to drive was based in his vast driving experience and was evidence to him that he could drive safely and responsibly. He clearly linked this ability and responsibility to his masculinity as he discussed different cars.

> *That is my biggest fear that they say, you can't drive. That would finish me completely. I've been driving since I was 18. I passed my test on a five tonner when I was in National Service, so I've always had cars, and I've always, they say it's a male chauvinists' thing, but I always have big cars…I upset somebody once by saying, you don't drive minis, you wear them. And they weren't very amused.* Terry (Machine minder)

In making fun of small cars he was expressing his self-judged superior knowledge and therefore he assumed a worthiness to criticise others. In freely acknowledging his 'male chauvinist' comment he expressed his masculinity and this explains that his fear of driving being taken away is a reflection on his identity as a responsible man.

Responsibilities in daily activities were considered the pivotal point at which if one could no longer perform without supervision, they could be regarded as mentally declining. This point was a universal feature of the interviews. To bolster the sense of responsibility in daily living, participants frequently drew upon examples from their past in work or activities in their middle years, and these were then supported with examples from current activities. Participants drew upon these earlier examples in order to establish their personality and status as a responsible person, and in order to enhance their current status. This extended the themes identified earlier of a sense of the past informing the present and shaping thinking about the future. John offered many examples of his trustworthiness and responsible man status by drawing on his working life.

> *There might be £500, £1000 behind the counter. All in cash, so you had to be*
>
> *established…you had to be known, and you had to be, you know, genuine.* John (Black
>
> cab driver and plumber)

John enthusiastically discussed his working life and his responsibilities and trustworthiness. This sense of pride in his employment underpinned his attitude to self and convinced him of his continued abilities. Being a responsible person was crucial to John's self-esteem. As detailed earlier, he had encountered a visit during our interview from his mobile home site manager to seek advice and report progress on a service contract for the site's main gates. John's self-esteem was totally entwined with his sense of masculinity, and with it responsibility, pride, and capability both in the past and in the present, and by inference, into the future.

7.2.2 Capability

Being considered a capable person was intimately connected to responsibility but subtle differences were evident. The overt demonstration of capability was used as a defence mechanism and a feature that could be easily externally identified and quantified for other people to see. Pointing out that one was capable of doing something was seen in itself as evidence that cognition was satisfactory. Being considered responsible was demonstrated in concern for trust emanating from others, and in self-trust to complete daily activities. Other people's concern over capability was the cause for much irritation and anxiety among the participants, whereas responsibility was vocalised less overtly and was represented more in activities rather than being expressly discussed. Alf reacted incredulously at his family's suggestion that he was experiencing memory loss.

> *Why they keep saying my memory's gone, my memory's gone, nothing the matter with*
>
> *my memory!* Alf (Farm Labourer)

Alf was assessed by the pre-diagnostic nurse as certainly suffering with moderate dementia even before his formal diagnosis was made. He was very confused and constantly repeated himself, but he was very clear that he did not believe that anything was wrong with his memory. He was adamant that he was capable of going out alone even when he was faced with the evidence from his family who were concerned that he had been missing for several hours on a particular occasion. He maintained that they had no right to question his whereabouts because he was capable of finding his way home. Alf frequently cited his travelling associated with his love of horse racing as proof that his memory was intact, but he conceded that he had not been to race meetings for at least two years. Nevertheless, he insisted that as he had navigated his way across the UK to race courses, this in itself was evidence of his capability. In doing this he was drawing on his past and his self-identification as his convincer that he was indeed capable. He rigidly stayed with this conclusion even in the face of overwhelming evidence to the contrary from his family and health professionals and in his self-admission that he had been unable to undertake these activities for some period of time.

Being convinced of one's capability by citing specific examples was a trait expressed mainly by the working class participants. Alf used his horse racing activities and John discussed his gardening and handyman activities as specific examples to convince themselves and to convince me of their capability to function normally. Both of these men resisted any challenge to revise their capability due to their memory loss. Alf resolutely denied any memory loss, however John had acknowledged some memory difficulties, but denied any major effect of memory loss. This point is fundamental in understanding the meaning of memory loss for these men. Memory loss was clearly posing a challenge to their masculinity and the sense of self, but whether it was totally denied or reluctantly acknowledged, the memory loss effects were refuted by examples of past and current

activity. The focus therefore shifted from what can no longer be done, to what capabilities remain. This finding was in contrast to the middle class participants who had an inner self assurance that did not require overt explanation, but was more embedded in their general understanding of status related competency rather than capability.

7.2.3 Competency

Middle class responses differed from those of working class respondents in the aspect of capability. Being capable of something was not enough, but being competent held a more definite meaning for this group as a convincer that they were coping well and had not yet reached a stage of inevitable decline. When competency to perform activities to their usual standard had reduced in their regard, but capability to perform 'good enough' remained, this group of participants felt threatened and retreated from social contact to a more home focussed way of life.

Sandra illustrated how lack of competence is harder to come to terms with than a lack of capability.

> *I've lost all my confidence. Mind you, when I went the hospital and I came out, it took me ages just to walk down the road. I didn't want to come out of the house…I'm like jelly aren't I, as soon as I get through the door.* Sandra (Housewife)

Sandra would only venture from her house with her husband to support her. She was clearly physically capable of leaving the house but she felt that she lacked the competence to deal with any social encounters that may arise, so she chose to stay at home as much as possible and avoid any uncomfortable situations. Prior to noticing her memory loss, she had enjoyed a busy social life circulating with her husband in the company of professional people. Her confidence in her competence to engage in social activities had been damaged when she had

realised that she had forgotten names of friends and past social events in conversations and had felt embarrassed. Lack of competency was therefore intricately interwoven with feeling embarrassment.

Unlike Sandra, Violet considered herself to be capable and competent in most things and used her driving to explicate her point. Violet was the only middle class woman in the sample to be driving. She explained how her capability and continued competence to drive was important for her wellbeing.

> *I'm fine. I don't forget to eat, I don't forget to go shopping and things, I still drive…I've got young friends, I'm lucky there. But, and, these women won't drive, and I do say to one, you are a fool, because if anything happened to your husband, you are stuck! And so I am so glad I kept it up…I don't drive as much as I used to…I go here and there, and I go to Sainsbury's. I go and have a coffee with friends.* Violet (Housewife)

Violet's advice offered to her friend demonstrates her confidence in her own ability to drive. Her association of forgetting to eat with ability to drive hints at her self-assessment of her capabilities and competencies and led her to conclude that she is both capable and in addition, competent enough to offer advice. She later considered the boundaries of her driving and conceded that she no longer liked to drive any distance, but reasoned that as her family and friends now lived locally, she did not consider reducing her driving as a competency issue but rather as a circumstantial issue. This illustrated a shifting of conceptualisation of the importance of driving from representing independence and ability, to a mere convenience.

Vincent explained that he was more than capable and competent at managing the housework since his wife had died and he also regarded this work as circumstantial, forced by his

wife's illness and subsequent death, rather than planned. He described how he had carried

shopping bags since retiring as a pilot when his wife was alive, and that now he had to do

his own shopping, cooking, and housework.

> *I'm living on my own…I'm always happy indoors. I've got something to do and I keep*
>
> *this relatively tidy. My wife always used to say, Vincent, this house looks like a bomb's*
>
> *dropped and I've only been away two days (laughter). But I took over when she was*
>
> *ill. It was not easy. Looking after housekeeping and cooking and cleaning and*
>
> *shopping. I took over all the work that she used to do…she taught me in a way*
>
> *because after I retired, I always went shopping with her, and I carried the bags and*
>
> *bought the coffee…I'm not a cook…*(today) *I was cooking myself…so chopped pork*
>
> *and fried the onions, boiled potatoes, boiled cabbage, onion gravy, as I am stirring it*
>
> *up, and that was really good!…But I do it all.* Vincent (Pilot)

Vincent was very keen to demonstrate how clean and tidy his house was and insisted on

showing me around as if to underline his respectability and confirm his ability to complete

daily activities. Despite his self-acknowledged memory loss, Vincent ardently believed

himself to be capable and competent in looking after himself. He had set the boundary of his

competence at no longer being able to complete daily activities. These were relatively new

skills for Vincent since his retirement and wife's illness and this gave them a special

meaning for measuring learning in addition to existing competency.

The special meaning for Vincent was derived from his ability to learn new skills. He had not

taken care of household duties prior to his wife's illness, but these circumstances had forced

this responsibility upon him. He felt that he had coped well and had learned how to

complete daily living tasks to a competent level, and it was this assurance that he could

learn that encouraged his self-assessment of his competency.

7.3 Markers of Decline

The precise markers at which participants considered memory decline to be a problem varied considerably across the study group. However, the effect of the memory problem on family relationships and the attack on the sense of self were of primary concern, moreover consideration was given throughout to a sense of 'not knowing' and this became a common denominator for marking decline. This led participants' to question how they would know when they had reached a point of 'not knowing' and illustrated a different facet of uncertainty, discussed earlier in Chapter 5. This sense of not knowing was the primary feature in worry for the future. 'Not knowing' had overtones of loss of independence, not just simply in activities and decision making as previously discussed, but also in a far deeper meaning of fear of forgetting who loved ones are and yet relying on those family members for support and care decisions. Concepts of being a burden on loved ones, giving up, and total disengagement from reality, were offered as features of 'not knowing' and therefore served as markers of decline.

7.3.1 Not Knowing

'Not knowing' was the most popular marker offered of irretrievable decline. This was the most feared feature of a future with dementia and was represented across all social locations. Charles wondered what it would be like to lose his memory to this extent.

> *I mean, obviously, if you have lost your memory enough, I presume, they don't remember anything...but of course I suppose, there are people who can't even remember that. I don't know. Can they not remember it? I mean, if you have interest in this* (indicates a cup of tea) *can you not remember to drink a cup of tea? How to do it? Make a cup of tea?.. I might put the cup down and wander off over there and read a book and come back and it's cold. But then that's another thing. I think everybody*

does that from time to time…You can forget that you have forgotten – Charles (Factory

toolmaker)

Charles was at first convinced that he knew what losing memory could be like, but he

gradually changed his mind as he talked and described the distinction between everyday

forgetting such as forgetting to drink a cup of tea due to distraction by an intellectual

activity like reading and simply forgetting *how* to drink tea. This point at which 'forgetting'

became 'not knowing' was the important marker for the meaning of memory loss reaching

an irretrievable situation. John also made this distinction and highlighted his own memory

loss as 'not a big problem' and irretrievable memory loss as 'being like a cabbage'.

> *Yes, I know I have got a problem, but to me, at this present time, it ain't a big*
>
> *problem. It ain't a massive problem that I'm losing a lot of education or, I can digest*
>
> *anything that's on television. I can talk to you, and I can talk to the fellows on the*
>
> *(mobile home) site. I know what I'm talking about…But I would have thought if you*
>
> *lose, if it got worse and bad then I might, I don't know, but I've never seen a person*
>
> *who's got severe memory loss. I've never come across, so I wouldn't know, but I'm*
>
> *just surmising. I'm just surmising that I would be like a cabbage or whatever.* John
>
> (Black cab driver and plumber)

The distinction in memory loss regard is the tipping point at which thinking about further

memory loss becomes threatening, and as demonstrated by my participants, the knowledge,

meaning, and the predicted outcome of increased memory loss has embedded meaning in

habitus and lifetime experiences.

7.3.2 Being a Burden.

Participants often considered the prospect of being a burden to loved ones. Gender differences in considering this point were noticeable. Men representing all social classes talked about physical dependency for personal care as their primary concern, whilst women worried about this issue and in addition their mental dependency and the effect that it would have on their loved one's lives. Usually women were referring to female adult children and spouses as primary carers. For women the relationship and responsibility shift from parent/child to dependent/carer was an uncomfortable prediction and one that they resisted through insistence of maintaining independence for as long as possible. Even when they had close loving and supportive relationships with their children and were currently receiving practical help and emotional support, they regarded the power shift in the relationship as the marker of decline. The boundary shift in the relationship centred on the provision of personal care as this was considered the point at which forgetting became a health and safety issue rather than a negotiable and resolvable practical issue.

Violet was widowed and enjoyed a geographically and emotionally close relationship with her son and daughter in-law. She described how they supported her in practical activities such as gardening and shopping, and provided continued daily contact with her either by telephone or face-to-face. However, she was concerned that at some point in the future they would also be looking after her personal needs. This was manifested in her repeatedly returning to the theme of cleanliness.

> *I want to keep, as long as I can look after myself, keep myself clean…well you keep your bathroom clean, and you change your beds once a week…I feel I have to be careful because I don't want to rely on the children, they have got enough to do…I don't want to be a burden.* Violet (Housewife)

Violet emphasised how her care would impact on the children, and she identified specific

tasks that would mark a decline in her condition that would require care from others. For

Violet this was an inability to look after hygiene. She was comfortable with the considerable

practical help that she was receiving from her children in tasks around the home and garden,

but the demarcation line for recognising decline for Violet was personal care and cleaning

her home. These tasks held a special meaning for her that related to morality and

respectability. This was evident in her use of the word 'burden' and her qualification of this

in 'they have got enough to do' suggesting that asking for and requiring this type of help

was morally dishonourable. This suggests that requesting additional assistance from them

would constitute a much greater commitment that had overtones and qualities that were

distinctly different from practical help with general tasks. She had successfully separated

general help from personal care, and in doing so had identified the marker of decline as

'being a burden'.

Participants across the sample described differences between offering help and receiving

help. Most participants were happy to offer help of any kind to another person and outlined

circumstances under which they thought helping another was acceptable, but they were

reluctant to receive help for themselves. This concept provided a second demarcation line

and boundary of decline. John was typical of this and discussed how helping another person

suffering any kind of mental or physical impairment should be a usual and normal situation;

however he did not relate this to himself as a receiver of any kind of help.

> *I mean in everyday life, if someone can't get up the stairs or something, then you help*
>
> *them, don't you. If someone had a wheelchair, oh come on, I will help you…I do think*
>
> *about It* (memory loss)*, because it's going to change our life really. So it's got to be*
>
> *thought out and what we are going to do, if and when it happens, but it ain't happened*
>
> *yet so.* John (Black cab driver and plumber)

John was careful to point out that he was not at that stage of needing help or needing to decide what to do next, although he was clearly mindful of the need to consider such things through his use of 'it's going to change our life'. There was an inevitability around this phrase that suggests that far from dismissing making decisions for another date in the future, John was considering how his life would change and what help he would need. John went on to consider asking for help with his memory and taking family advice to defer some household decision making to his wife.

> *I'm always hesitant or I want to look at it and convince myself that I'm doing the right thing. So I'm not going to jump into things, everybody that tells me things, ain't always right, are they?* John (Black cab driver and plumber)

This illustrates self-stigmatisation and the dichotomised argument between actions that are deemed appropriate and morally acceptable for others and those that apply to the self. John could readily offer help and advice to others but struggled to come to terms with seeking or accepting help for himself. Deferring the decision making that he was finding difficult to his wife was a change that he resisted. In part this was related to his masculine sense of self that he was head of the household and should retain the power and ability to make decisions, but also this reduction in power that was an obvious marker of his memory problem attacked his self-imposed boundary of selfhood. This has implications when considering person centred care and highlights the difficulty in assessing a person's wishes by how they perceive others.

7.3.3 Giving Up

John turned his attention to the meaning of the markers that denote mental decline. He did not consider his memory problem to be at a critical point yet but had thought about the point at which his life would become meaningless.

I think the old pills might come out! Pills. I'm going to lose, leave this, lose this planet.

But that would come into your mind, wouldn't it. That if you was a vegetable, what's

the point? John (Black cab driver and plumber)

As he was considering an end point to his life due to his memory loss, he continued to

reason according to his current capacity and assumed that he would retain the power to 'get

the pills out'. He overlooked that the situation that he described as being 'a vegetable'

would prevent him from taking any action. He was unwilling to think about putting into

place any plan for the future because he was hindered by his masculine pride and self-doubt

in dealing with the present. This sense of dealing with the present only and addressing

issues as they arise was a trait among the working class men. The middle class men

preferred to tackle the prospect of future decline by planning ahead and therefore retaining a

sense of control over predicted deterioration. Frank approached this issue with a typical

middle male class perspective of taking charge of the situation and ensuring that his wishes

will be carried out.

I would like to make one of those living wills. Living wills. That I wouldn't want any

medication or, I don't want to be a nuisance to everybody…all life's a gamble, but if I

knew that I was going to have a complaint, a mental complaint that was gradually

going to get worse and worse, I wouldn't want any more medication or

treatment…what I'm concerned about is losing not necessarily physical faculties but

my mental faculty. Well, I don't want to be sitting here and people having to wipe my

bum. If I'm honest, but I'd rather just go to sleep. Frank (Accountant)

Frank was discussing this in his second interview after he had received his diagnosis of

'brain shrinkage'. He clearly did not want to equate this diagnosis with dementia because he

was talking about the possibility of a future 'mental complaint', but he had considered what

mental deterioration would mean and how he would like to plan his future. He had clearly thought about his end of life care in the context of increased memory loss supporting Samsi and Manthorpe's (2011) findings that older people have a preference for planning decision making preferences such as funeral arrangements over health and social care plans.

This split decision between the working class and middle class men regarding thinking about the future suggests that disclosing a diagnosis fully may be beneficial for some people with regard to forward planning but maybe too painful for others to consider at this stage of early memory loss. Both men arrived at the decision that they would rather die than reach that stage of illness but the journey towards that point was considered very differently.

Giving up was not a feature in the testimony of most of the women sampled. The women focussed much more on dealing with problems rather than surrendering and did not identify a marker that signalled that it was time to give up. This could be an era specific feature that will not be repeated in the future as women of this particular generation tended to be part of a male dominated family and social group. For these women leaving work was not so heavily loaded with significance and they considered their home role to continue until the end of life. As the shape of families has changed (Young and Willmott 1973) and is changing (ONS 2011) and women are taking more prominent roles outside of the home, this may not be repeated. The women thought about the future and continuing with memory problems but they did not consider it to be the end of their life as the men had, and giving up and end of life were not issues that were raised. The women talked more about giving up responsibilities for the housework and family diary, and the reduction of family activities as the marker that they had deteriorated. Carol mourned her ability to run the household as her memory had deteriorated. Carol had problems with speech as she had a rare type of dementia associated with cortical-basal degeneration and so her husband interpreted.

She couldn't join in, so she felt isolated because you know subjects change so quick

and they had all moved on… even the grandchildren now, they all know what Nanny

Carol is like. Carol always had so much patience with them. More than I have. And

she used to sit and play with the elder two for ages and bundle around with them, but

literally as we got the third, the less she could do it…Carol used to do all the

shopping, everything. Same as every woman does, and like gardening, she would go

out and buy the plants and I would help. I mean she was always busy and this is a big

house anyway to keep clean, and we had a busy social life and lots of holidays. Carol

(businesswoman)

Carol recognised how her memory loss had deeply affected her daily life and grieved for the

activities that she had needed to give up but this was a more superficial 'giving up' of

activities and not the spiritual giving up than the men had described. Carol had the most

advanced dementia of all the women and had lost many abilities including her ability to

perform her own personal care, but the marker for her was moving further away as her

condition declined. She had previously considered not being able to maintain her household

chores as her marker, but now that she moved beyond that phase and could no longer speak

or look after personal care, her marker had moved to not recognising her husband or family.

The exception among the women was Joan who had a strong family history with dementia

and remembered her grandmother and mother and their experiences with the illness. She

used this experience to draw upon when talking about the point at which she would consider

death preferable.

They're just lost people aren't they. They're lost, gone. They don't know where they

are, who they're with, most of them. And I don't, I don't want to finish up like that. I'd

rather die than finish up like that. Joan (Factory worker)

Joan was heavily focussed on her relationships in this discussion and feared losing the ability to know who her family were. Her appraisal that she would rather die than be in that situation leads back to the question of at which point one would know that they no longer knew who people were. It is beyond the scope of this thesis to explore the journey of participants into the future in order to answer this question, but the suggestion in the data is that this point is in fact unreachable because of its indefinable nature. Constant re-evaluation was taking place throughout this early stage as memory loss became more noticeable. Boundaries were being revised and re-set as realisation dawned that their lives were changing in relation to their memory loss.

7.4 Shifting Boundaries and Re-evaluating

This final section of the empirical chapters explores the process of changing the boundaries of knowing, and recognising decreasing competencies. Knowing I am bad when… was moved further away as participants re-evaluated their situation and recalled previous activities. This builds on the markers of decline explained in the previous section, to explore how these markers could be changed to suit changing understanding and meanings in order to preserve the sense of self as cognitive decline increased.

Participants changed the significance of activities as markers of decline and reformed them as adapting to ageing, justification of new choices due to external factors, and attribution to simple fickleness. Provided that a logical explanation other than increased memory loss could be presented concerning the reduction of an activity, a sense of control was retained. Projection into a liminal state could be circumvented by justification of changing markers, and then using these changes as a tool to preserve normality. This re-evaluation process of markers as something less threatening is recognised in policy drives that encourage take up

of benefits and services for those that need them, but do not recognize themselves as being in need (Carers UK 2013). A current example is the Dementia Challenge campaign (Department of Health 2012-present) that encourages people to regard memory loss as worthy of reporting to the GP and not as part of normal ageing.

For those who had retired early due to ill health, boundaries of change were embedded in their concept of ill health. They had been forced to retire earlier than they had planned and so varied from the main group by blaming the reduction of their activities on their other health problems to the exclusion of memory loss and ageing. Adapting to changes and choosing to alter activities were primary features of this re-evaluation process.

7.4.1 Adapting

Many participants considered their changes in activities to be governed by a process of adaption to ageing and retirement. This was present even when they had continued usual activities after retirement for some time. Construing reducing activities and withdrawing from the social world as part of the process of ageing gave the participants a sense of normality concerning their memory loss. In this way it could be regarded as part of a normal and usual process and so provided a comfort zone for early memory loss. This 'usualness' of memory loss with age was contributing to the earlier described notions of uncertainty as participants tried to separate the normal from the unusual. By using the concept of change over the life-course and the personal sense of history and change, participants could logically conclude that they were adapting to their memory loss rather than actively reducing their social engagements. This philosophy was wide ranging and present across all social locations and supports Kim and Kim (2008) in their assertion that cultural capital in the form of social relations and health are main determinants of quality of life. They argue

that satisfaction and happiness are closely related to reason and emotion, therefore by justifying reasons for changes, emotions can be protected and quality of life upheld.

Graham outlined his reasons for reducing his social and physical activities but strongly denied any influence on his decision due to his memory loss. He spent some considerable time during the interview discussing his love of Scotland and Yorkshire and his frequent visits to friends there '*two, three, four times a year*'. After discussing his experience with the home visit from the pre-diagnostic nurse he returned to talking about his friends in Yorkshire and the current frequency of his visits.

> *I suppose the* (friends) *that you could call near as friends, are the two in Northern England that we go and stay with, or used to stay with. I can't remember their names now. We haven't seen them for a couple, two or three years now. We used to, we used to stay, but they weren't friends as such, we used to just stay there for the night on our way up* (to Scotland)…*well, we don't any longer but we used to occasionally go and see them, when we were up that way...It's a question now of being too far to drive really.* Graham (Insurance representative)

Graham had presented himself initially as somebody who enjoyed frequent trips away from home and had detailed his love of driving as his hobby. He had readily told me long stories of trips to Yorkshire as though they were taking place in recent times. It was only as he started to consider his memory loss that he revised his opinion to state that they had not visited in the last two or three years and revised the status of his friends to 'just people they stayed with'. He concluded that although he could not remember the friends names, he had decided not to visit Yorkshire because of the driving. Being too far to drive provided a logical and comfortable reason for not visiting that fitted with his re-evaluation of driving

distances and this fitted with expectations of and adapting to ageing, but that did not have to take account of his memory loss.

The significance of moving house had increased for some participants after they had been widowed, and Violet and Terry particularly identified this as an important feature of their life story for generating understanding of their current situation. Violet had moved house following the death of her husband to be near her son and his family. She had talked a great deal about her social life in her former home and her small dog. The dog had moved with her to her current home but had since died. Violet discussed the companionship she had enjoyed with her dog and how she had adapted to change. She justified her decision to not own a dog after extolling the virtues of dog ownership for some considerable length of time.

> *I loved living down there, because I used to find, I've got nowhere to walk here. Whereas down there you just walk... I do miss that, and of course, I had the little dog. I've been told, I was, when Snowy died, no more. You're not having any more. It's too much responsibility, which is true because when I went into hospital to have my hip, My son had to have it and I thought, it's not fair on them. So when Snowy got to 14, that was it, but I do miss her because she would sit by that front door waiting for me…my daughter-in-law doesn't like animals enough to have them indoors. She's too house proud and so I wouldn't have any more.* Violet (Housewife)

Violet had adapted to her new home and justified her decision not to have another dog based on her son and daughter-in-laws views. She had moved house to be nearer to them for support and so felt that she needed to adapt to their views on dog ownership. As she discussed the responsibility of dog ownership and her experience of her hip replacement, she could recognise that in exceptional circumstances her family would have to care for her dog, but she did not relate this reasoning at all to her memory loss. She could justify her

decision on practical grounds of short periods away from home such as a hospital stay rather than her possible reduced inability to care for a dog in the longer term.

Terry had also moved house following the death of his second wife. He had twice been widowed in a ten year period and had decided to move to be nearer his sister and her family for emotional support following his bereavement. He recalled his life in his former home and his reasons for moving.

> *We moved to Wales because I had all those redundancies. And then when I was in Wales I lost two wives in ten years. My sister lives* (locally) *so I thought the most sensible thing to do is to move back near my sister, but not so close as to be a damned nuisance…I hated leaving Wales because it was so lovely there and I had a house with, it had quite a lot of land and I had a standard poodle that was known everywhere. He was quite a character on his own!.. I've only got myself to worry about…I think a lot of it* (memory loss) *is being on your own.* Terry (Machine minder)

Terry had attempted to adapt to widowhood by moving to be near his family, but he did not want to be 'a nuisance' and so construed his decision to not socialise as connected to this fact. He went on to describe in detail how he felt *'put out'* when people pointed out to him that he had forgotten, and described how he avoided social encounters for fear of being considered stupid, but he continued to attribute his social withdrawal to his wife's death. Early in our first meeting Terry had attributed his memory loss quite forcibly to an accident slipping on ice in which he suffered a head injury some years earlier. This explanation for his memory loss was side-lined as his explanation as being considered by others as a recluse through self-exclusion and grief, was preferable to being considered as having a failing memory. He had adapted his way of living to counter both his grief and his memory loss although he preferred to focus attention on the former and allow his memory loss to be an

almost incidental part of his life. By considering that he had adapted to widowhood, Terry had successfully shifted focus away from his memory problem by citing all other upheavals in his life.

7.4.2 The Importance of Choice

Expressing the power to choose was important in retaining control. When participants felt that they had choices or could construe altered activities as their free choice, they were far happier than when 'choices' were forced upon them. This was related to independence and the retention of a sense of self. If the choice could be associated with a situation beyond their control and linked with a sensible and logical outcome, then this served to preserve the sense of self and retain self-respect and independence. If the situation was out of their control, then this served to absolve them from any blame and overtones of moral judgement. There appeared to be an element of existential association between memory loss and being somehow a 'bad' person or being blamed and deserving of this situation.

David had chosen to move from his large rural self-built home of over 40 years to a smaller bungalow nearer the town. Both he and his wife were sad to be leaving their home but had decided that it was wise choice given his failing general health and the lack of community facilities in their small village.

> *It is a wrench really but it's got to happen, hasn't it really. Well, the house is too big,*
>
> *see there's four bedrooms and only two of us. And basically we haven't got the money*
>
> *to keep it going. I've been living on my savings now, I suppose, for 15 years, you*
>
> *know, other than what we get off the government, and let's face it, it's peanuts…It's*
>
> *health reasons and financial reasons and really and truly, work wise, we don't want*
>
> *the work. I don't want the garden, so much of it…so we are moving to a little two*
>
> *bedroom bungalow…nearer to the hospital I have to attend so often, if neither of us*

can drive again, you never know, there's buses…there's a supermarket there, there's

Waitrose, there's a chemist, there's a doctors, there's a dentist, everything there. It's

like, very handy. David (Builder)

David and his wife considered all of the advantages of the house move in terms of finance

and convenience and construed this as a good choice that was within their discretion to

make at this time. David went on to deny that he had a memory problem but he did

acknowledge his considerable list of other ill health conditions and cited these among his

reasons for moving. David was able to normalise moving by comparing to his friends and he

concluded that they were *'about the same, downsizing and moving away'*. David's wife

however had a slightly different view of the situation. She recognised David's problems

with memory and was worried that if they did not move now, his condition would worsen

and they would not be able to move in the future.

Well, it is a problem. Because we looked at the house today, like yesterday, we'd look

at a house yesterday. When I'd say well compare that one yesterday with this one

we've seen today, I can't remember a thing about it, he said. And he couldn't

remember what, where it was, what type of door it had got, absolutely nothing. Now

that became one hell of a problem for me trying to find us somewhere to live. And this

one we've bought now, he don't remember it, it will all be new to him when we get

there. (David's wife)

David was satisfied that moving house was a good choice for their circumstances but

conceded that he knew nothing of his new home except that it had not got a shed. He was

cross about that and had resolved to buy one as soon as they had moved. In retaining his

choices, he was empowered to normalise his decision by comparing to friends situations,

and in justifying his choice by planning additions to his new property he could retain control

in his life. Through focussing on the financial gain in moving he could bypass his memory difficulties and justify his choice to move house.

Violet justified her consideration to giving up driving by relating it to the cost of car insurance. As car insurance is a legal requirement that cannot be evaded she cites the expense of it as the reason to consider stopping driving even as she decided that she no longer felt so confident about driving. By making the choice to cease driving about finances, she avoided having to confront her memory loss as affecting her judgement as a driver. Violet considered the boundaries of her driving.

> *I wouldn't go to the shopping place. Can't remember what it's called anyway, that's how bad it is. I wouldn't go, the one near the tunnel, Bluewater. I wouldn't take the car like that. I go here, I go to Sainsbury's…I'm really thinking whether do I want to keep my car with the expense…for the few times, for. I'm just doing the insurance again and I think, do I really need it? I can walk to Waitrose so I can do everything my, and I think for the amount of insurance and tax and things, do I want it? I was discussing it with my son over the weekend, what to do about it.* Violet (Housewife)

Violet was deliberating not about the car insurance and other bills per se, but whether the car represented something else. If she could resolve this dilemma by deciding that it was too expensive to keep then she could successfully avoid the issue of whether the car represented more than her independent travel and in fact was a symbol of her declining memory. By stressing that she could retain independence by using buses and organising travel with friends and family, she could remain in charge of her decisions without being forced to acknowledge that her memory problem was part of the decision.

In applying external factors to the decision making process and justifying choices, self-preservation could be protected. Joan would not leave her house alone. She talked at length

about neighbours she could see from her window and the cars that were parked in the street. She outlined that her son took her shopping or collected shopping for her, and that a friend always accompanied her to hospital and doctor appointments. She delivered an image of an outgoing lady who enjoyed company but when I asked her if she ever left home alone she retreated to a defensive position of construing the idea as a crazy one and offered her explanation.

> *I'd got nowhere I could exercise, got nowhere I can walk because of the hill! I suppose*
> *I could walk as far as the hill and back again but I can't even walk the dog because*
> *he's so lively. He'd pull me over! So I don't think I could take him for a walk, no, no.*
> Joan (Factory worker)

Joan centred her explanation of staying at home on walking the dog as if that would be the only option for leaving the house. This was a perfect justification as her choice but she also tied it very tightly to the external factor of a large hill near her house that she felt unable to walk. She had also talked about examples of people with memory loss being found wandering and had expressed her fear of suffering the same fate, but when thinking about leaving the house as a planned trip, she reverted to discussing her dog and her inability to control him if he pulled on the lead. Through making her decision to stay indoors about the difficulties with walking up a steep hill and the physical difficulties of controlling her dog, Joan could avoid thinking about her fear of getting lost.

Using choices that sound plausible and logical as a way of mitigating the effect of memory loss made retreating and withdrawing a more control driven process that retained the participant as the central decision maker. The need to stay in control of personal decisions for as long as possible was prevalent throughout all the participants' testimony and is well

documented within the literature (O'Connor and Purves 2009) and is now widely recognised in policy (Department of Health 2009).

7.5 Conclusion

This chapter has addressed the difficulties associated with finding a personally acceptable explanation for reducing activities and re-assessing markers of decline as choices rather than forced actions. Convincers of competence were used to bolster self-esteem by retaining discussion of past activities as if they exist in the present. 'Knowing when I am bad' was relatively easy for participants to identify and clear examples were given of the understanding of knowing, but participants struggled in recognising these boundaries in their own lives. By changing the emphasis of decisions forced by their memory loss towards free choices they were able to retain control and a sense of self, and justify their changing circumstances in a logical fashion. By using external factors such as finances and geographical location they were absolved of any need to justify a choice in relation to themselves and could explain these as sound decisions based on logic.

Shifting boundaries of knowing and moving the parameters as they were approached provided a buffer zone in which re-negotiation of boundaries could take place. Thus, it was possible to protect the sense of self and retain a sense of control even when clearly others were starting to take over and make decisions on their behalf.

Chapter 8: Conclusion and Implications

8.1 Introduction

This study set out to explore the influence of social location on the dementia experience from the perspective of the person with dementia. It sought to foreground the meanings and understandings that individuals hold of their own experience of memory loss with an intersectional focus on social class and gender. This study used the concept of personhood as a starting point, and foregrounded individuality to explore the heterogeneity of experiences. The general policy literature surrounding dementia has traditionally approached this illness from a homogenous perspective, although more recently, research literature has moved towards appreciating the heterogeneous nature of embedded understandings and meanings in dementia experiences (Hulko 2009). This study sought to answer this question:

What influences the differential nature of the experience and meaning of dementia?

Earlier work by Hulko (2004) brought differences in dementia experiences related to social location into focus, and highlighted the need for more research in this area. Differences in understandings of illness interactions in relation to social location were already established in the health and illness sociological literature (Barry and Yuill 2011, Charteris-Black and Seale 2010, Lane and Cibula 2000, Hunt and Sweeting 1996), but had not been applied in this way to people with dementia. Dementia mainly occurs in older age, and respondents drew upon their long biography to construct meanings of illness, and part of this was their embedded knowledge of dementia and what it means to experience dementia. Bourdieu established a theoretical lens of habitus built over lifetime embedded knowledge, for

viewing social location (Bourdieu 1986). This was a useful and important tool for understanding how meanings could be constructed from life experiences.

Intersectionality provides a view of interlocking meanings, and helps to explain how our social location is related to sociological concepts of identity, subjectivity and the self, played out through factors such as social class and gender. Foregrounding the subjective experience of meaning making and respecting habitus allowed me to engage with the values of personhood and individuality, and move away from the homogenous values of previous research in this area.

The main empirical findings are explained throughout Chapter 3 The Changing Person, Chapter 4 Confronting memory Loss, Chapter 5 Negotiating Uncertainty, Chapter 6 Preserving Self, and finally, Chapter 7 Shifting the Boundaries. This section will synthesize these findings to answer the research question.

8.2. Sense of Change and Expectations

The social science perspective on ageing and change has shifted somewhat from its early days of a focus on 'old age', towards a more complete picture of ageing over the life course (Westerhof and Tulle 2008, Bytheway 2011, Edmondson and von Kondratowitz 2009). The implication of this is that change is to be expected and is normal. Phillipson and Baars (2007) argued that ageing needs to be considered from a cohort position that understands that people born at different points in time will necessarily move through the life cycle within different contexts and social environments. As Riley (1999) explained '*the lives of those growing old today cannot be the same as the lives of those who grew old in the past or of those who will grow old in the future'* (pg 333). This is important to note in the context of this study because these respondents have lived a long life at a time in which there has

arguably been more social changes than at other points in history (Edmunds and Turner 2005). This includes the rise of feminism, increased technology, and the creation and development of the welfare state have influenced habitus and expectations of ageing.

Expectations of being old involve a reduction of stability in physical and mental capability, and the age structuring of roles and resources such as health, wealth and family affect what individuals expect, hope and fear, across their lives (Herzog and Markus 1999). My findings are in line with this view, however what was considered to be 'normal ageing' was contested across the participants. Some drew upon earlier dementia experiences of caring to self-diagnose their dementia, whilst others viewed it wholly as part of the normal trajectory through the life course.

The intersection of ageing with dementia was very strongly represented throughout this study. Examples of ageist comments and behaviours by services were reported, and supported Kontos (2009) in her description of the infantilisation of older adults. However, for some the expectation of ageist behaviours was considered part and parcel of growing older and was represented in comments relating to the individual's own age. The implications were that being regarded by society as 'old and a bit silly' was normal, although it was simultaneously fought against in the struggles to maintain independence and respectability.

Bourdieu (1984) recognised when he discussed 'The habitus and the space of life styles' that individuals have a point of view dependent upon their position within the social space that they are operating. In such a way habitus is constructed and given meaning by classifiable practices and the judgements used in classification. By translating this theory to the group of people involved in this study, it is possible to understand that at any given point in time they will classify their memory loss according to their immediate judgements, but

that these judgements will inevitably be based in habitus constructed from conditions of existence that have been built across the life time. Therefore, in addition to the intersection of broad social locations, personal life story and the classifications and judgements built over time will also inform 'who I was', 'who I am today', and 'who I will become'.

Hulko (2009) suggested that more marginalised people were more likely to find their dementia experience 'not a big deal' or a 'nuisance' and that this was related to their levels of oppression as defined by marginalising factors of intersectionality. I however found a strong relationship tied to a fear reaction particularly in the marginalised men of the group. They used their sense of the past and of change to theorise firstly that their memory loss was insignificant, but secondly that memory loss 'could not' be a problem given that they had been employed and useful and respected men, and they expected their social position as head of the family to continue into the future. Their own classification of being a 'sound man' (John, black cab driver) and the judgments that this held in terms of reliability, worthiness and respectability led these men in particular to reject the notion of memory loss being related to dementia and the fear that it popularly holds in the wider social consciousness. These men drew upon their sense of self in the past to inform the present, and to theorise about the future.

In contrast, the more privileged of the group used their sense of the past and the present to predict that medicine could and would probably help them, and that by investing some finances in aids and mobility, the effects of their memory loss could be mitigated; and so at this point in time they did not consider themselves to be in a wholly declining situation. For this group, the classification of memory loss and the subsequent judgement of it could be mitigated at this stage of illness by financial application and intellectual reasoning that medicine would provide some help. They equally did not equate their own memory loss

with that of the popular image of a dementia patient, but were better able to use their past and current situation to suppose for better outcomes in the future.

There was however a significant difference in appraisal of expectations among those that had a close emotional experience of dementia in the past, regardless of social locations. This group drew upon their life story to explain their concerns about their memory loss in the present. The use of prior experiences in recognising alarming health issues has been recorded in other illnesses such as diabetes (Jowsey, Ward and Gradner 2013) and some cancers (Macdonald, Watt and Macleod 2013) and so this finding in this context is unsurprising. However, what is surprising is that western socialisation has created an expectation of cognitive decline in ageing to such an extent that for those without this 'expert', prior knowledge derived from a previous experience, most will dismiss memory loss as part of normal ageing, or attribute it to something else such as a concurrent illness or an earlier accident. Previous experiences had created 'expert knowledge' of dementia that was used to help-seek at an early stage, and remain in control of their personal biography.

8.3: Participant's Theories of Memory Loss

Expert knowledge gained from earlier experiences was a distinct factor in theorising memory loss for participants. The home visit from the pre-diagnostic nurse prior to taking part in this study had forced all participants to think about the cause of their memory loss because they were asked directly by the nurse 'what do you think may be causing this?' (KMPT Memory Assessment Service Model). It was interesting to note and perhaps deserves further exploration in a future study, that although participants were asked quite bluntly by the nurse, they reportedly often replied to her inquiry with a range of humorous responses such as 'my wife hit me', 'I eat too much sugar too!', 'good living'; but when in

interview with me, participants often held quite definite ideas that they had not wanted to disclose to the nurse for fear of 'sounding stupid' (Terry, machine minder; Frank, accountant; Katie, hairdresser).

It was clear that a range of responses to attribution were present that did not easily equate with social location or indeed forms of oppression as expressed from an intersectional approach as Hulko had described (2009). I re-visited Bourdieu (1984) in search of an alternative explanation rooted in habitus and forms of capital that could explain why people with similar social locations could offer such diverse attributions for their own memory loss, given that lifestyle and socialisation through agreed classifications and judgements would support similar capital holdings, and therefore the notion that broad similarities should apply. Bourdieu offered this:

> *'The dialectic of conditions and habitus is the basis of an alchemy which transforms the distribution of capital, the balance sheet of a power relation, into a system of perceived differences, distinctive properties, that is, a distribution of symbolic capital, legitimate capital, whose objective truth is misrecognized.'* (Bourdieu 1984 pg 168)

This point of symbolic and legitimate capital appeared to hold the key to this question of disparity between answers. As my participants held different views of the symbolism of memory loss, and therefore its legitimacy as a respectable illness, then this could account for the range of responses to the question of attribution. For those with no prior history of dementia experiences, they would be reliant on the popular depictions of dementia, which are usually advanced cases, and they would not align themselves with this image.

Attribution of memory loss to a legitimate cause was a feature of all of the participants' testimony, but what was regarded as legitimate varied according to prior dementia

experiences. For those with a strong emotional history of caring for somebody with dementia, dementia was a legitimate explanation and self-worth and respectability was to be gained from help-seeking based on their 'expert' position as a first hand witness. There was a drive and a need for their suspicions to be confirmed as this removed responsibility for memory loss as a personal failing, to that of a symptom of an illness over which they had no control. Therefore they could be 'legitimately forgetting'.

For others, finding an attribution for their memory loss was more problematic and they searched their life story for potential explanations. Those that could identify a concurrent or previous illness or accident found it relatively easy to make memory loss 'fit' with this theory. Examples were given such as 'a bang on the head' or 'heart trouble and 'it's all vascular'. For those that could not identify such an event, they used expectations of normal ageing and cognitive 'slowing down' as a useful attribution.

Normal ageing figured heavily in legitimising memory loss through the expectation that it was 'normal' and 'usual' to forget for older people. Dementia experiences are usually reported by outsiders reporting on or about others, rather than the insiders who actually experience the illness. The notable exception is of course that published insider accounts are usually produced from a very narrow socio-cultural perspective of white middle class people. There is a comparison of this point to be drawn against the concept of expectations of ageing. Research of ageing is usually carried out by people much younger who will project their own classifications and judgements onto participants. We live in a society of all ages and therefore we are exposed to people chronologically older and younger than ourselves constantly. However conceptions of ageing are socially constructed as well as biological.

The social construction of retirement and old age were important in this study as an explanation contributing to the range of expectations of old age. The major shift in the perceptions of retirement due to the inception of the welfare state, could be influential in constructing expectations of old age for my participants. They often compared themselves to older relatives and talked of grandparents and parents and their experience of old age, but of course those generations of people would have been older and retired either before or in the first few years of the welfare state's existence. Therefore the meaning and expectations of old age and deterioration are based on habitus and the symbolic capital of age, and could explain why ageing featured so heavily as a cause of memory loss rather than an expectation of healthy ageing as one would expect with increased life expectancy and better general health of the nation than in previous generations.

The major changes in welfare in the UK throughout the twentieth and so far in the twenty-first century are relevant and specific to this particular cohort of older people, and so citing ageing as a cause of memory loss could be a cohort specific feature. This is beyond the scope of this study but is noteworthy for future research. The key feature of all attributions whether, old age, illness, accident or dementia was that respectability was maintained and pride remained intact.

8.4: Uncertainty and Personhood

Views and preoccupations vary by social location and this was apparent in the stark differences in the views of the more working class men than all other groups. These men struggled to find a balance between that which could be regarded as 'normal' and that of the 'unusual'. A common feature for this group was the unseen nature of the mind and the confusion between the physiological function of the brain and psychology. This group

particularly associated stigmatising terminology such as 'loony', 'barmy', 'going round the twist' with memory loss and the fear that these descriptions generated. Uncertainty surrounding the maintenance of their social position was particularly alarming for this sub-group and manifested in discussion about maintaining choices and control. Without exception all male drivers offered fear connected to driving cessation that implied their position as 'man of the house' and being in charge of the family mobility was threatened. Driving did not feature in this way for any of the other sub groups, leading me to tentatively conclude that driving has a much deeper meaning connected to worthiness and masculinity for this group for others.

Driving cessation in early stage dementia is currently under researched, but it was a powerful source of anxiety and fear when combined with memory loss. Talbot et al (2005) studied the relationship between driving for older adults attending a memory clinic and found it to be an important skill, and cessation to be associated with depression, anxiety and isolation. The uncertainty generated by the possibility of driving cessation was enough to create strong emotional responses from all my working class men suggesting that for this particular cohort of men who were also in many cases had been the only driver in the family, this marked an additional challenge to masculinity. Bartley and O'Neill (2010) have highlighted that the associations between driving, transportation and successful ageing are currently poorly understood as the focus has been upon public transport and transportation, rather than driving cessation per se, therefore this current study adds some weight towards arguing for a better understanding of intersectionality and driving cessation.

Driving could represent a proxy for adulthood and independence because it often marks initiation into adulthood, and decline in older age. This dovetails with literature relating to liminality and the 'rite of passage' into another state of being (Turner 1969). Driving, therefore, becomes a significant marker of adulthood and productive life, and its

withdrawal, a representation of reduced capability and worthlessness. This is amplified by the legal requirements to notify DVLA of a dementia diagnosis and the compulsory surrender of a driving licence (DVLA 2014). Thus fear and uncertainty was also associated with removal of decision making, and so stopping driving is no longer a 'choice' to be made, but a response to imposed regulations by society that has decided a person is inadequate to drive. Whilst advice to stop driving is considered 'helpful' by relatives worried about their loved one becoming confused when driving, it was not viewed as 'helpful' by those with probable dementia that were still driving.

Uncertainty for all people in the group also revolved around negotiating 'help'. This was broadly construed as either interference or assistance with clear boundaries set for each. Broadly speaking, assistance was invited and related to choices and empowerment, whilst interference was regarded as negative and undermining. Help that could be justified by a logic of empowerment was related to retaining a sense of control and planning, whilst help that was cajoled or forced was emotionally rejected and created anxiety and resentment. Generally widowed and divorced women were much more likely to receive help from relatives and care agencies and this could be explained by their socialisation and reliance upon their husband throughout their lives. Single, widowed and divorced men were the least likely to regard help as assistance and often rejected offers as interference, especially if the help involved access to their home, contributing to their sense of loss of control and a hellish experience. The link between accepting help and the meaning that doing so held, was firmly located in a sense of preserving the self.

8.5: Preserving Selfhood

Participants used various tactics to preserve their sense of self such as coping strategies and self-selected social withdrawal to preserve respect and reduce stigma. The retention of respect was of primary concern for all of the group but the sources from which respect could be gained differed according to social location. Men were primarily concerned with retaining the respect of other men, and this was particularly apparent in more marginalised men who were concerned with retaining the respect of their peers. More privileged men appeared to derive respect as a given entity related to their previous social, economic and cultural capital. They already possessed an awareness that they were ranked socially higher than others but for those in lower social locations respect was a major concern.

For the women in the group, respect was derived from their ability to maintain a clean home and in relationships with family over those of outsiders. This dovetails with previous evidence of traditional female roles in the home (Skeggs 1997) and social capital afforded to women of this particular generation, underlining once again the generational nature of this research. In other words, the social location is not a fixed point but is changing and fluid over time as the symbolic capital evolves and categories and judgements develop over time.

Preservation of self by planned social withdrawal was a prominent feature related to control and empowerment. Once the person had decided that they were at risk of producing social faux pas by forgetting, they actively chose to avoid social situations that could expose memory loss. All participants that considered themselves to be at risk of social errors gave examples of limiting engagements by either the number of people in one place, or the quantity of engagements. This finding could explain the importance that is placed through social capital on social engagements (Bourdieu 1986).

Generally, more privileged men relied upon their former social activities as markers of social withdrawal and connected this intellectually to evidence that their social world was shrinking, and could contribute to a 'hellish' description of the memory loss experience. However, few in my sample offered any overt signs of distress at this social shrinking, and preferred to express it as part of the expected life course. This again supports Hulko (2009) in agreeing that experiences are not necessarily negative and that social location is important in defining what is to be lost, but this led me to consider which markers of decline are important in defining when that point has been reached.

8.6 (Re)constructing Competence Markers

All participants could imagine a point at which their memory loss would mean total loss of self. This was constructed around a sense of 'when I don't know anymore'. The features that defined this imagined point, were largely and unsurprisingly clustered around concepts of being a burden on loved ones. However this was distinguished from 'help' and assistance or interference as discussed in section 8.4, and held a much deeper meaning related to personal care and 'being a vegetable'. Literature around caring and being cared for suggests that personal care does have a special meaning related to the sense of self (Alzheimer's Society 2013, Age UK 2014).

The group often cited examples of past achievements to emphasise that they were 'not there yet' and to bolster self-esteem through recalling stories of skills, hobbies and life events as evidence. When I asked them to think about the last time that they had engaged in some of these activities it would often be years before, and yet they were still closely tied to the sense of self and 'being somebody'.

Decisions that had been made because of increased memory loss were renegotiated as 'choice' constructed around other circumstances. For example, ceasing driving for those that had, and thinking about stopping driving was constructed around the financial cost of owning and running a car and convenience, rather than as a sign of increasing memory loss. In Boudieusian (1986) terms, the capital associated with car driving and ownership had been renegotiated by judgements.

Re-evaluation of the importance of activities was taking place and providing a logical explanation could be given, the group were satisfied that this was normal and usual practice and therefore the threat to self was minimised. In relation to Hulko's (2009) study, this could suggest that her group classified as more marginalised could have been better at renegotiating their future, and did not feel as threatened as those more privileged. This would support the notion that she outlined and is confirmed in the psychological literature, that resilience as an acquired characteristic can serve to supply a reserve related to socio-emotional resilience. As Hulko (2009) surmised, it may be that those who have experienced disadvantage in their lives are better able to defend against dementia as another social hurdle. The psychological literature (Kobasa 1979) suggests that any emotional difficulties (not just social difficulties) that are overcome, can increase resilience and provide emotional buffers. I agree with this view, given that my participants that had experienced dementia caring roles were far more able to recognise their memory loss as a concern and seek help sooner than those without experiences. One explanation could be that this group of participants had developed an emotional hardiness towards memory loss and viewed it as something that could be managed effectively if they were proactive in help seeking, rather than taking a strong avoidance course of action. This finding suggests that something other than social location provides the marker for the differences in the experience of memory loss.

8.7 Study Limitations

This study has uncovered some complexities of the dementia experience that have not been addressed in the past, but there are two limitations of note in this study. Firstly, the thesis is concerned with intersectionality and social class and gender were explored in the context of ageing, however other intersections such as sexuality and ethnicity did not feature. This was due to the demographic mix of the memory clinic service from which the sample was drawn combined with the purposive but largely sequential sampling that was required to be applied.

The staff in the memory clinic team had discussed potential limitations for the study due to the cohort demographics with me prior to data collection, and they had reported that at that time they had not received any referrals for people from ethnic minority groups, and none were received during the data collection phase. In addition, the clinic did not specifically collect information regarding sexuality from their patient group at that time other than in terms of next of kin. In the eventuality, all of the participants in my sample reported heterosexual relationships. This was not the result of specific questioning during interviews, but the topic was raised naturally during the course of conversation.

Other important intersections such as religion and disability were present although in very limited contexts. Only one participant, Pauline, discussed her religious beliefs and the connection with her meaning making of memory loss. Pauline, was also among the most advanced with her cognitive difficulties and this made it difficult for her to 'stay on topic' during her interview. As the interviews were designed to be free flowing and governed by the participant in terms of the ordering, range, and depth of topics covered, it proved difficult to steer Pauline to deeper discussions of her existential thinking, although this was clearly present in her data and reported in chapter four. Other participants did not raise

religion or religious belief as a feature of 'what was important to them' and so this aspect would warrant future investigation.

Similarly disability was only discussed in terms of co-morbid conditions and the relationship that these had to the potential diagnosis that participants thought they would receive. Alf had epilepsy from his childhood but considered this to have no effect at all on his present cognitive difficulties. Alf, like Pauline, was in the most advanced group with his cognitive problems and this could have influenced his ability to assess his memory loss in relation to his epilepsy. A future study could examine this specialist intersection in more detail. Although these limitations resulted in a sample group that did not reflect all aspects of intersectionality, I can be confident by the evidence from the experience of the memory clinic staff that the sample did reflect the catchment of the clinic as widely as possible.

Secondly, this thesis is concerned with early stage dementia and has used memory loss and a likely diagnosis based on the pre-diagnostic assessment as the indicators for early stage dementia, but without being privy to the final diagnosis of all of my participants, I cannot be sure that all did receive a dementia diagnosis and not another. The implication, therefore, is that the meaning of their memory loss may have been skewed by the clinical and organic progression of another disorder or illness. The disclosure to me of each eventual diagnosis was not part of the ethical approval, and all the participants, whether they were told their likely diagnosis during the study or not, had finished their contribution to the study by the time they would have received a definitive diagnosis some six to eight weeks later. This limitation can be defended however through the discussions that the participants had of the *meaning* of memory loss. Dementia was never mentioned during interviews unless the participant raised it, but if it was raised, this demonstrates the strong connections between memory loss and dementia in popular discourses.

8.8 Interviewers as Therapists

It became very evident throughout the data collection period and in the period after each interview that my participants had found some benefits from discussing their memory difficulties in this qualitative interview format. I had sensed during interviews that participants enjoyed reminiscing and sharing the stories of their life as they had frequently talked at length and without interruption. When they had discussed issues that they perceived to be emotionally threatening such as their assumptions of memory loss, the opinion of others, the possible implications for the future, and recalling upsetting episodes in their life, they after appraised these upsetting sections as 'therapy' and reported that having somebody acting as an interested listener had allowed them to verbalise their fears and worries. Those that were interviewed twice all cited this aspect as important in their decision of allowing me to visit again, whilst those who were interviewed just once often sent a thank you card or email thanking me for taking the time to listen.

There is a growing body of literature that is exploring this concept of research interviews as therapy arising from earlier work by Gale (1992) and more recently in a special edition of *Qualitative Inquiry* (Issue 9, 2013) in which Bondi (2013) discusses the relationship of qualitative research and psychotherapy. She concludes that whilst these two types of interviews 'circulate differently … loss is therefore intrinsic to our capacity for curiosity and reflection on our lives.' (2013:9). This could explain the importance of allowing participants to reflect on their lives whilst considering their current memory loss that resulted in such rich data and a therapeutic space for participants to reflect.

A consequence of the creation of a reflective space for participants was that ending interviews gained more significance. As Bondi (2013) explained, becoming an interested and active listener involves making fresh meanings for the researcher, therefore ethical

responsibilities are created to manage endings. I worked to accomplish 'good' endings by using Bondi's (2013) advice, by making sure that the purpose of the interviews was clarified at every opportunity, and that reminders were present in the form of written material after I had left the participant's home. The importance of this unexpected development of interviews as particular spaces is discussed in more detail in the following section

8.9 Interviews as Reflective Space

Jamieson and Victor (2002) emphasised that because the interviewee is an active part of the research process, their willing participation means that the conduct of the interview itself is also a feature of the research process and the meanings that are created. Therefore our social locations and relationship also became part of the interview process. Participants commonly expressed views that the interview process had allowed them time and space within which they could reflect and resolve some uncertainties. The interviews had provided the opportunity to talk about their feelings of memory loss and engage family and friends more frankly in their own assessments by providing an opening for discussion (Bornat 2000). This opening up of thoughts and feelings assisted participants and relatives in coming to terms with what they felt was happening to them. Most reported that these discussions with family and friends had been instigated when others had asked them how the interview had progressed. They reported that they found themselves talking through our discussions and this had provided the catalyst for opening conversations with others about their thoughts and feelings, which had previously remained hidden.

I examined the responses from those participants who were interviewed twice with at least a three week interval between to ascertain the frequency of changing attribution or modification of original attribution and found that all could more comfortably discuss

dementia in relation to their own memory loss. Only Frank had been given a more definite

dementia diagnosis, but because the word 'dementia' had not been used, as discussed earlier

in Chapter four, section four; he was sure that his diagnosis was related to his existing

illnesses. Others suspected that a dementia diagnosis may be given as they had been visited

by the pre-diagnostic nurse, and they had read the supporting literature supplied by the

clinic. This reduction of anxiety could be in part attributable to time passing and a 'getting

used to the idea' process, or that engagement with services had qualified their memory loss

as a legitimate illness and therefore respectable; or it could be related to the opening up of

discussion and thought processes by the taking part in the study. Most likely a combination

of all of these factors contributed, but undoubtedly taking part in the study had inadvertently

created an intervention that made it permissible to think about their memory loss as a real

phenomenon and not as a figment of imagination. Appreciation of participating in the study

was expressed across participants of all social locations, and some enquired about the

possibility of continuing the interviews after the study had finished because they felt taking

part had created a tangible benefit.

Patrick spoke for himself and his wife.

> *I think I am right in saying we are very happy when you come. For the simple reason*
>
> *that you talk with us and ask questions, sensible talk all the time, and that eventually*
>
> *gets through for me and makes me think, well I have still got bit of a brain anyway.*
> Patrick (Scientist)

Patrick's use of 'sensible talk' and 'bit of a brain' indicated that by thinking about his

memory loss he had been able to resolve some of his emotional responses, and by using his

intellect he had been able to reason that as he can think deeply about memory loss, it had not

affected his reasoning powers. His appreciation of 'sensible talk' implied that his self-esteem

was protected by his opinion being valued by another person external to his family, and that participating in a study had provided value to his memory loss.

John also spoke about his experience as a participant.

> *I'm sitting here and I'm relaxed, and I can talk to you. I feel I can talk to you about anything. But when I meet somebody and I go somewhere, I'm just naturally on my guard. I don't know why, but I feel that until I can get their trust…but I always treat everybody, whatever class or creed or whatever I will always treat them with respect…because you have come down here, and done this and everything else, it's actually, it's all pretty professional, so I'm happy with that…and I don't want to be talking with people that think, I don't know if this bloke knows what he's talking about…all I can say, I'm always giving people advice, but all I would say to everybody is treat everybody as you would like to be treated, but the point to me is, people will be able to communicate because you've got a way of talking to people, and making them feel easy, and that's all you want…whereas you can't tell some people because they are too straight-laced.* John (Black cab driver and plumber)

I considered this high praise indeed, but importantly John's comments also point to a general misconception and lack of communication at this early stage of memory loss, and the apprehension that is dovetailed with engaging with services and the uncertainty that surrounds this stage of illness pre-diagnosis. The space between interviews gave consideration and reflective time for participants to think about their feelings and assisted in reducing anxiety by resolving some uncertainty of whether their memory problem is 'real' or not. Because John's opinion had been sought and valued, he had gained insight and was able to advise others in a similar situation. This bolstered his self-esteem and returned value to his opinion at a time when he had clearly felt his personhood to be threatened.

Skeggs (2002) highlighted how the social positioning and subjectivity of the researcher can impact upon the relationships built with participants. This was indeed present in their ability to open up to me and not feel awkward in discussing their thoughts, because I was able to use my own social location to either seek 'higher' opinion from those in the middle classes, or 'be like' those in the working classes. In interviews I consistently applied an attitude of seeking their 'expert knowledge' without prejudice, and this approach proved fruitful in generating meanings and understandings.

Frank and Sandra had both revealed that they had felt misunderstood and confused when family members had played down their memory loss. Common comments among all the participants were that family members and friends often responded to a serious conversation about forgetting with flippant and dismissal answers of 'everybody is like it' or 'there's nothing wrong with you' and that the opportunity to be taken seriously was all that was required to resolve their uncertainty concerning questioning their own mental health. This dismissal was the cause of anxiety, even though relatives were most likely trying to protect them and stop them being upset. They both expressed pleasure at participating and being able to talk about their memory loss.

I've enjoyed you coming actually, and talking about it. Frank (Accountant)

I have enjoyed talking to you and getting things out. Sandra (Housewife)

The interviews had provided an opportunity to express their concerns and fears in a constructive way (Brannen 1988) that was not about assessment or diagnosis but about thoughts and feelings. I sensed that the interviews and the reflection period following interviews in which most participants had discussed participating with friends and family, had served to help with organising and identifying feelings and expectations for the future.

Gwen had been very fearful of her husband discovering her pursuit of a diagnosis so she had not discussed her memory loss and fears with any friends or family before our meeting. She talked about feeling scared for herself but protective of her family and husband in particular, and her desire to protect them from the consequences of her memory loss for as long as possible. She was clearly negotiating a mixed emotional state but participating had given her perspective and clarity in her situation.

> *I have really enjoyed it, and getting it all out there. Off my chest sort of thing. I am glad to talk to somebody about it at last because you can't always do it.* Gwen (Carer)

When I asked Gwen to elaborate on why she couldn't talk about her memory with relatives, she said it was because so many of her family members had dementia and it would be too upsetting for the remaining family. Gwen sent me a thank you card after our interview expressing her appreciation of the opportunity to discuss her memory and with an update that she had been diagnosed with early stage dementia. Her comment 'off my chest' reveals the weight of anxiety and emotional turmoil that talking about memory loss in a supportive and constructive way can assist with reducing.

Relatives often contacted me between the two interview visits or after our last meeting to express thanks that they had been able to engage in discussion about memory loss with their relative because of their participation. This was especially the case from the relatives of respondents that had been particularly hostile and denied their memory loss in the first instance. The inclusion of relatives in this study was incidental in this regard but reveals the importance of supporting people with memory loss through this early stage by openly discussing their feelings without confrontation.

It was never my intention to perform an intervention in this study but it is inescapable that talking about memory loss provided a positive intervention for participants. The benefit of

taking part in qualitative interviews has been noted on a number of occasions (Phellas 2012, Opdenakker 2006, Hutchinson, Wilson and Skodal-Wilson 1994, McNamee 1988). Not all participants expressed their contentment with the interview process so overtly, but I did not receive any negative feedback or notions of regret from the clinic, or participants, or relatives concerning taking part.

8.7 Implications for Policy, Practice and Research.

Person centred care is purported to be practiced throughout care settings, but the implication of this study's findings is that it should be extended to pre-diagnostic and early diagnosis phases of client contact. Taking account of individual biography is pivotal in establishing the prior knowledge of the person with memory loss of dementia, and could shape their response to investigations and the diagnostic process. The importance of the level of disruption of biographical flow requires investigation and acknowledgement in policy because as demonstrated in the empirical chapters, participants will use their sense of self to determine their reaction and conclusions concerning medical intervention for memory problems, and meaning is embedded in habitus. As Bartlett and O'Connor (2007) argue, Kitwood's (1997) ideas of ill and well-being, and their connection with personhood and person-centred care, are still of contemporary interest and relevance. This study is one such example which illustrates these important concepts and their place in modern memory clinic services.

Implications for practice relate primarily to the first home visit by the pre-diagnostic nurse. Time taken at this stage to explore the individual's knowledge and assumptions of memory loss and its association with dementia, could potentially allow for educational resources to be directed in a more targeted fashion to those in most need. As home visits are costly in

terms of finances and waiting times, a limited amount of time is given to 'patients' to construct their narratives and meaning making which could influence outcomes and decision making adversely. By giving people more time to construct their personal narratives, not only can a better understanding of each client be constructed, but also potentially more beneficial decisions can be achieved which would be better for the client and ultimately reduce the demand on service resources. By taking time at this early stage of the diagnostic process, a more holistic picture of each client can be built that services could more adequately match, such as being mindful of which people are most likely to be resistant to interventions, and which most likely to take up additional advice and suggestions. Thus there is potential for people to be able to live at home longer, engage with services in a more meaningful way, and have their choices supported through person centred care.

To encourage dementia friendly communities, bodies such as the Local Government Association (2012) and The International Longevity Centre-UK (2014) are aiming to reduce stigma and support the well-being of people with dementia in mild to moderate stages. Therefore increasing discussion of the very stages of the illness at the first opportunities as demonstrated in this current study, will enhance this aim and reduce stigma by opening conversation with the person and encouraging discussion with those around them.

Future research needs to further examine the importance of selfhood and personal biography in the creation of the subjective meaning of experience. Several strands of investigation using intersectionality as a theoretical lens can be identified that could prove to be fruitful, namely in (1) considering generational attitudes towards mental health and memory loss (rather than dementia), (2) including driving cessation in relation to liminality and the dementia experience in the context of biographical flow, and (3) the impact of raised

awareness and expectations through public information campaigns on the biographical flow in association with the stigma associated with memory loss.

8.8 Concluding Comments

In summary, policy acknowledgement of a variety of possible individual experiences is required, and recognition that memory loss is not always regarded as wholly negative because for some, it represents ageing. When factoring in prior life experience and the habitus generated from a Bourdieusian (1986) perspective, implications for policy were created that should establish at the earliest opportunity previous dementia experiences as an indicator of emotional response, and likelihood of engagement with services, therefore suggesting that individual life story is important in addition to social location and forms of capital.

My evidence suggests that prior dementia experiences influence early presentation to the medical world, and the understanding and meaning of memory loss. Those with close experiences help seek earlier and actively seek support and diagnosis and treatment as a defence against what they know is to follow, and this activity maintains their control and empowers. Those without experience rely upon lay perceptions of dementia and memory loss, and experience greater self-stigmatisation and fear. They actively seek to distance themselves from the popular lay image of a person with dementia, and will attribute memory loss to a variety of other causes. This in turn means that they are likely to present later in the disease trajectory, as noted in the correlation between more advanced disease and attribution of memory loss in Chapter 3. Working class men without prior knowledge or experience of dementia, are more likely to feel that their masculinity is under threat and will fight to maintain the status quo and defend their sense of self than other groups.

This study has offered an evaluative perspective of the dementia experience and concluded

that heterogeneity does exist in experiences and responses to memory loss and that

differences in experience are related to social class and gender but also to prior dementia

experiences. Powerful differences are apparent in the meaning making and understanding of

memory loss and its relationship to dementia, which is framed primarily around the impact

of meanings on biographical flow. As a direct consequence of this finding, I can conclude

that policy needs to be mindful of the diversity in responses, and given the small scale of

this study, that further research is required in this area to establish if diversity of meaning

making in dementia is also present in relation to social intersections other than those

explored in this study.

9. Appendices

1: Participant Invitation

2: Participant Information Sheet

3: Appointment Card

Please can you help?

by providing your opinion in a research project to understand what memory loss means for you.

I hope to meet you soon!

Julie Peet

Researcher: Memory Loss Study

University of Kent

NHS Kent and Medway
NHS and Social Care Partnership Trust

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Invitation V1: prepared September 2010

University of Kent

Memory Loss Study

Invitation To Patients and Relatives

NHS West Kent   NHS Kent and Medway NHS and Social Care Partnership Trust   NHS Eastern and Coastal Kent

Who is conducting the research?

Hello. My name is Julie Peet, I am a PhD researcher from the University of Kent. I am investigating how memory loss affects your life and the lives of people dear to you. I have permission from the NHS to contact you because you may be able to help.

I need your help. I want to invite people with memory loss and their families to take part in this research project. You have been asked to take part because you or somebody close to you has been referred to a memory clinic recently.

The aim of the project is to try and work out how different people cope with the experience of memory loss. I would like to talk to you about what memory loss has meant for you, and I would be grateful if you would share your thoughts with me.

Your opinion is very important in this research. Please can you help?

Where will we meet?

We can meet at your home or another place of your choosing.

How long will it take?

About an hour, but it can be as short or long as you like.

Is this a 'one off' visit?

It can be, or we can talk things over in more than one meeting. It is up to you.

Can I take a break or stop talking altogether?

Yes, whenever you would like to and you don't have to explain why.

Will it be confidential?

Yes. All your personal details will be kept strictly confidential and nothing will identify you in the study—I will change your name. This is separate from your memory clinic visits, and I shall not be reporting your information to the clinic. If you would like a family member or friend present, that is fine.

How will you record what I say?

I would like to voice record your story so that it will save time and I can write it down accurately afterwards.

What will happen to my contribution?

I will combine it with other people's stories to form the study. If you would like a summary of the study's findings when it is over, I will be happy to send you a copy.

What if I change my mind after?

That is fine. You can withdraw from the study whenever you like, and you don't have to say why.

How do I get involved?

If you are interested to find out more about the study; please fill in the reply slip enclosed with this leaflet and put it in the reply envelope and post it back. I will telephone you and answer any questions you have before I come to visit.

Can I telephone the researcher?

Yes. Please feel free to call me on my direct mobile number: 07988 137277 or email me: jp281@kent.ac.uk

Memory Loss Study

Topic Guide for Participants

Thank you for expressing an interest in taking part in this study. The purpose of this study is to try to work out how different people react to memory loss. This means that I would like to ask you to talk about your experiences and the things that are important to you. This sheet sets out the type of topics that are included in this study. If you would like to add other topics because you feel they are important to your experience of memory loss; then I will be very happy to include them. We may talk about these topics in any order that you feel is comfortable. I look forward to hearing your stories.

Julie Peet

Your experience of memory loss concerning:

Work life
Family and friends
Interests
Daily life
Other areas important to you

If you have further questions about the study, or would like to talk to me about a concern, please contact me using the details below.

Julie Peet
Researcher: Memory Loss Study
SSPSSR
Gillingham Building
University of Kent
Chatham Maritime
ME4 4AG

07988 137277
jp281@kent.ac.uk

Memory Loss Study

University of Kent

Visit Card

This study wants to hear your story and opinion about memory loss.

Thank you for agreeing to meet me on……..

Date_____ Time _____

Julie Peet
Mobile: 07988137277
Email: jp281@kent.ac.uk

School of Social Policy, Sociology
and Social Research
University of Kent
Gillingham Building
Medway Maritime
Kent ME4 4AG

NHS
Kent and Medway
NHS and Social Care Partnership Trust

Please contact me if you would like to cancel or postpone.

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