

**'I try to forget about the dementia': Realising the resilience of
the person ageing with dementia in social work practice.**

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Declaration

I declare that none of the work contained within this thesis has been submitted for any other degree at any other university. The contents herein have been composed by the candidate, Julie Christie.

Julie Christie

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Abstract

This thesis considers whether the concept of resilience is applicable to people ageing with dementia; and, if so, what the implications are for social work practice. It begins with an exploration of the literature on dementia, resilience and social work. Using a symbolic interactionist approach it then details how the interactions of people with dementia and their social workers can potentially influence the realisation of resilience in practice.

I collected data over a two year period. During this period six dyads comprising a person with dementia and social worker provided rich verbal accounts of their respective experiences. Using narrative analysis the stories of each person with dementia were explored to reveal threats to identity and possible resilience strategies. A resilience lens was applied to the verbal accounts of social workers in order to reveal opportunities and challenges to using resilience in practice.

The findings indicate that identity continues to be of importance to people who are ageing with dementia. The preservation of identity could therefore be re-framed as the outcome of a resilience process. Each person could potentially acquire resources over their life which could help to mitigate threats to identity. This is referred to as the resilience reserve. This thesis details the potential domains of such a reserve. Further, it contains details of possible resilience strategies that a person with dementia might employ within stories of self. These strategies are placed within the context of protective and vulnerability factors in order that a resilience framework can emerge.

This thesis argues for a re-framing of theories of what social work is. This, combined with a definition of resilience, and the development of a resilience practice framework could promote and realise the resilience of the person ageing with dementia.

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Chapter 1: Introduction

This research is focussed on people ageing with dementia. The risk of dementia rises with age (Prince et al., 2013a) and population ageing is stimulating debate in countries throughout the world. In the UK, in 2007, for the first time there were more people over state pension age than there were children (HM Government, 2009). In Scotland, the number of people aged 75+ is projected to increase by 86% by the year 2037 (National Records of Scotland, 2013). Prince et al. described this heightened risk of developing dementia as “*the biggest global public health challenge facing our generation.*” (2013a, p. 5). Although there is some debate about the actual number of people who have dementia at this time (Ferri et al., 2005; Matthews et al., 2016; Wu et al., 2015) the global impact of dementia remains significant. Alzheimer Disease International (Prince et al., 2015) estimated that there were 46.8 million people with dementia worldwide, with numbers projected to almost double every 20 years. This has implications for present and future health, social care and housing provision as well as wider infrastructure as we consider how best to support people to live well. Audit Scotland (2016, p. 5) reported that the current models of care in Scotland are unsustainable and as a result new models are needed to both improve the quality of care and make better use of existing resources.

Why this research?

I have worked with older people and people with dementia for most of my professional life. I qualified as a Registered Mental Nurse in 1992 and after spending some time in the care home sector, moved to a local authority employer to follow my interest in working with people who were living with dementia. In 1996 I became one of the first nurse care managers in Scotland as hospitals for adults with mental health needs and learning disabilities closed through community care reforms, implemented through the NHS and Community Care Act (1990). I worked as part of a social work team assessing the needs of older people. This was at the height of the new managerialism of

social work, where there was an emphasis on the person in receipt of services being re-framed as a consumer (Jacobs et al., 2009) although I was unaware of this at the time. The introduction of care manager posts had been controversial with some research now describing them as obscuring the social work role (Moriarty and Manthorpe, 2016; Romeo, 2014). Despite this I made a career in social work and have spent most of this as a manager of social work teams for older people and hospital social work services.

Parallel to this I was also fortunate enough to be able to pursue academic interests. I completed an MSc in Dementia Studies, the first example of such a degree in the world, in 2002. Following this, I worked closely with the Dementia Services Development Centre as a teaching assistant, trainer and consultant. I also enjoyed a period of secondment at the centre in order to develop resources for acute care staff in the care of people with dementia in hospitals. I completed my social work degree in 2005 and during this time I focussed on work with children and young adults. It was here that I discovered the work of Daniel and Wassell (2002a, 2002b, 2002c) on resilience. At the time I was struck by what a valuable resource their resilience practice guides were. I used this resilience framework within my assessments and court reports and found the concept both challenging and stimulating. Of course, reference to resilience frameworks is now routine practice in this area thanks to the inclusion of this work in the Getting it Right for Every Child guidance (Scottish Government, 2008), however, I came about it quite by chance. After this introduction to resilience I was keen to discuss with colleagues in practice and academia similar frameworks for social workers to use when working with older people and people who had dementia; leading to the realisation that there were no such comparable frameworks. Further, there was some doubt expressed that resilience was in fact applicable to a person living with dementia, and so, my PhD journey began.

I am aware of the political, social and cultural influences, some of which I have outlined above, which have brought me to this field of study. It has developed from my interests in citizenship and dementia, resilience and social work practice. Becoming a social worker later in my career, working with people with dementia has enabled me to reflect on the nature of social work; in particular, asking the question if there are missed opportunities for social workers to apply their knowledge and skills in more creative ways with people living with dementia. My own personal and professional experiences with people who are living with dementia have included reflections on the possibility of resilience. I therefore set out to explore what resilience might mean in the context of living with dementia and how resilience could then be recognised and harnessed by social workers.

Why is this research important?

This research is important for several reasons. Prince et al. (2015) stated that research into dementia within the United Kingdom is underfunded with the government investing eight times less in dementia research than cancer research. Funding the care of people with dementia is also under resourced with two thirds of the cost of dementia provided by people with dementia and their families. Unpaid carers supporting someone with dementia save the UK economy £11 billion a year (Prince et al., 2015). This combination of the numbers of people ageing with dementia, conflicting research priorities and lack of available care has significant implications for the planning and delivery of health and social care services as well other important infrastructure.

A burgeoning argument is that the way in which we think about people with dementia affects our decisions about both the quality and type of support that we might consider appropriate (Downs et al., 2006; Hughes et al., 2006). There is currently no cure for dementia so new ways of understanding the experiences of those with the condition are required if we are to respond not only to the challenges that these changes in demographics will bring but also to

identify potential opportunities where older people are recognised as assets. The concept of resilience could offer such a perspective.

Resilience

Resilience has been described as a “*dynamic process encompassing positive adaptation within the context of significant adversity*” (Luthar et al., 2000, p. 543). I will discuss the significance of identity in both the resilience and the dementia literature. People with dementia can experience adversity due to preconceptions of dependence, loss of self and diminishing capacity based on ageist attitudes and social stigma (Butler, 1969; Kitwood, 1997; Martin and Post, 1992). Despite the investment in research to discover the causes of dementia (Department of Health, 2013) to some extent dementia can be viewed as “*just the story of chronic age-related disease*” (Hughes et al., 2006, p. 1). This research seeks to disrupt this discourse on ageing, dementia and vulnerability, which is only one of a number of discourses which will be explored through this study, and to consider the possibility that resilience might apply to those who are perceived to be most frail.

The social work role with people who are ageing with dementia

Many people ageing with dementia will come into contact with social workers (Social Work Inspection Agency, 2010). Milne et al. (2013) found that the role of social workers with older people was largely ignored. Although there is a developing professional knowledge base in this area (Scottish Social Services Council, 2014; The College of Social Work, 2015) until recently the complexity of social work in the field of older people with dementia has been underestimated (SSSC, 2015). The potential for dementia to disrupt communication and stories of self can make relationship based social work with those who have dementia more difficult to realise in practice. Exploring the possibility of a specific resilience focus is therefore timely.

The Promoting Excellence framework (Scottish Government, 2011a) detailed the knowledge and skills that “*all health and social care staff should aspire to*” (p. 1) and is the core framework for social workers in Scotland who undertake practice with a person living with dementia. The skills levels are divided into four areas from informed through to enhanced skills levels. The social care and social work workforce are supported in this training and skills development programme by the Scottish Social Services Council. Improving practice learning resources have been developed (SSSC and NHS Education for Scotland, 2012; SSSC, 2015). Enhanced resources address learning material around personal outcomes for people with dementia, working with carers, promoting health and wellbeing, issues of rights, support and protection and facilitating supportive environments (SSSC, 2015, p. 3). In addition, the SSSC (2016) has linked learning and skills development in this area to six capabilities which are needed to support good leadership in social services. These are vision; self-leadership; creativity and innovation; collaborating and influencing; motivating and inspiring; and empowering. Social workers are also required to be skilled and knowledgeable in the application of other significant legislation (Social Work Services Strategic Forum, 2015). This includes the Adult with Incapacity (Scotland) Act 2000; the Mental Health (Care and Treatment) Scotland Act 2003; the Adult Support and Protection (Scotland) Act 2007 and the Social Care (Self-directed Support) (Scotland) Act 2013.

The policy context

The Christie Commission report (Scottish Government, 2011b) set out the modernisation agenda for health and social care in Scotland. Key themes included in this report, and now implemented, were the integration of health and social care, an emphasis on health promotion and the self-management of support. The impact of these reforms on the social work profession is significant with tensions around protecting the social work role, integrated business models of care and support, and the values and principles of the social work profession (Hastings and Rogowski, 2014). It is within this context of change and competing ideologies that social workers must make sense of their role and function. Ferguson referred to this as a state of “*ideological conflict*” (2008, p.

10). Barnes and Brannelly (2008), however, stated that rather than being detrimental, managerialist reforms have in fact stimulated the re-emergence of social justice in social work practice for people with dementia as social workers strive to effect change for the person they are working with. It is therefore more important than ever that the professional social work role with people ageing with dementia is revealed and critically examined through research practices.

There has also been a great deal of activity in relation to dementia policy in Scotland and dementia has been recognised as a national priority for the Scottish Government (Scottish Government, 2010a). The first National Dementia Strategy for Scotland was launched in 2010. The aim of this strategy was to deliver world class dementia services in Scotland and it was supported by the launch of a Charter of Rights which consolidated both the human and legal rights of the person with dementia (Cross Party Group on Alzheimer's, 2009). The strategy aimed to increase the number of people with dementia who were given a diagnosis and to enable more timely access to information and support. This included the right to one year of post diagnostic support. There then followed the implementation of the standards of care for dementia (Scottish Government, 2011c); a focus on the skills and knowledge of staff through the 'Promoting Excellence' agenda in both health and social care settings (Scottish Government, 2011a) discussed above; and a 'pillars of support' model which is used when working with a person with dementia (Simmons, 2011).

The five pillars of support are referred to as: understanding dementia; support for planning future care; peer support; maintaining community connections and planning for future decision making (Simmons, 2011). An eight pillars approach was introduced in 2013 in the second Dementia Strategy (Scottish Government, 2013) which focussed on the support needed to live well with dementia as the condition progressed. This included the appointment of a dementia care co-ordinator, who could work across health and social care settings on behalf of the person with dementia, and his or her carer.

The resilience of the person with dementia is referred to within the 'pillars of support' model, although, it is not defined. Kinnaird (2013) stated that implementation of this model in Scotland would "*build the resilience of people with dementia and their carers to enable them to live in the community for as long as possible.*" (p. 5). A third national dementia strategy will be published later in 2016.

Research question

In summary, I set out to understand what resilience might look like in the context of dementia. In answering this question I propose a definition of resilience within the context of dementia. I also explore opportunities for and challenges to using resilience in the context of social work practice with people living with dementia. My underpinning research question is therefore "What can the concept of resilience bring to our understanding of dementia?"

Thesis structure

The thesis is structured as follows. Chapter 1 introduces the thesis and the importance of this research subject. The literature review is contained in chapter 2. The literature is divided into three subject areas of dementia, resilience and social work and is followed by a discussion leading to the research questions. Chapter 3 contains details of the research design, methodology and analysis. Here I discuss the use of symbolic interactionism in the research design and outline the ways in which I approached my research. I discuss my use of narrative analysis and explore the ethical issues raised in undertaking research which uses the intimate stories of people who are living with dementia. I use this chapter to convey how my research approach has been influenced by my social work values, particularly in my use of reflection. The findings are then detailed in chapters 4 and 5. In chapter 4 I present findings from my narrative analysis of the stories told by people ageing with dementia. In chapter 5 I present findings from my analysis of the verbal accounts of social workers, as they talk about their work with people who have

dementia. Finally, chapter 6 hosts my discussion of the findings, their implications and details the contributions to knowledge made by this research.

Chapter 2: Literature Review

The literature review is divided into four sections. The first three sections cover the main topics of dementia, resilience and social work. I will then conclude with a section which reflects on the literature as a whole, defines resilience in the context of dementia and sets out my research questions.

Search strategy

The literature search was undertaken through the following electronic databases; Web of Knowledge; Web of Science; Cochrane; Wiley Inter science; PsycINFO; PsycArticles; ReSearchWeb; Social Care Online; Social Services Abstracts; Social Services Knowledge Scotland; Sociological Abstracts; Google Scholar; ResearchGate; Scopus; Science Direct; Social ; Social Science Citation Index; NHS Scotland Quality Improvement Hub and the Knowledge Network.

The search strategy focussed on resilience, ageing with dementia, and social work. I included the terms '*resilience, resiliency, resilient, hardiness, coping, strengths*'. I then introduced key words '*ageing; old age; older person/people; seniors, senior citizens; aged 65+, older adults; elderly and/or dementia and/or Alzheimer's disease*'. The final stage introduced the key words '*social work and/or social worker(s)*'. I searched for both peer reviewed papers, reports and policy papers in English language published since 1970. My pre-PhD reading informed this date as I was aware a number of key papers on resilience had emerged in the 1970's and 1980's. There were no papers using the explicit combination of terms resilience, person with dementia or Alzheimer's disease and social work or social worker. I did however find one paper that referred to resilience, dementia and social care practitioners.

I returned to the search and focussed on the relationship between resilience and the different key words, for example, resilience and dementia, resilience and ageing, resilience and social work etc. I also looked at the literature on social work and dementia. Approaching the search in this way returned 491 articles. I read the title and abstract of all of the articles and removed papers which focussed on psychometric tests and the resilience of carers and/or staff. I then read each of the remaining articles in detail. As I was interested in the role of the qualified social worker papers which referred to generic social care or non-qualified social work staff were excluded, however, some papers referred to social work students or subjects such as risks, assets and vulnerabilities and I included these for review. I removed duplicates leaving a total of 249 articles and I provide details of the inclusion criteria and the number of articles included under each criterion in Table 1. The literature on resilience revealed that identity was potentially important and so I began an additional search using the key words '*dementia and/or Alzheimer's disease and identity or self or personhood*'. This returned 109 articles. I removed duplicates leaving 76 articles which I read carefully informed by my reading on resilience. In total I reviewed 325 papers (see Table 1).

Table 1. Literature Included in Review

Inclusion criteria	Nos. which met criteria
Resilience	28
Resilience + ageing	66
Resilience + dementia	37
Resilience + dementia + social work	1
Resilience + ageing + social work	1
Resilience + social work	8
Dementia + social work	41
Dementia and Identity	76
Dementia	43
Social Work	24

Part One: Dementia

I have approached this research from a citizenship perspective (Bartlett, 2014; Bartlett and O'Connor, 2007; Bartlett and O'Connor, 2010; Nedlund and Nordh, 2015), however, I will begin this review with an exploration of the different ways of understanding dementia starting with the bio-medical model.

What is dementia?

Dementia can be understood as an umbrella term for the signs and symptoms that indicate there may be changes occurring in the brain. The most common symptoms are changes to memory, thinking, behaviour and the ability to perform everyday tasks (Prince et al., 2014). It is recognised as a specific disease process and is defined in the World Health Organisation International Statistical Classification of Diseases and Related Health Problems (ICD-10) as:-

“a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied and occasionally preceded by deterioration in emotional control, social behaviour or motivation.” (WHO, 1992).

Brain pathology

Dementia is not however the result of a single brain pathology. There are many underlying pathologies, the most common causes of which are Alzheimer's disease, vascular dementia, dementia with Lewy Bodies and frontotemporal dementia (Prince et al., 2014). Alzheimer's disease affects approximately 62% of people with dementia. Vascular dementia affects approximately 17% and around 10% of the population will have a combination of both Alzheimer's disease and vascular dementia (Alzheimer's Society, 2014a). Table 2 provides

an overview of these conditions adapted from Alzheimer Disease International data (Prince et al., 2014, p. 7). Although dementia mainly affects older people, Prince et al. reported that between 2% and 10% of people living with dementia are under the age of 65 years. After this “*the prevalence doubles with every five year increment in age*” (2014, p. 6).

Table 2. Neuropathology of Different Types of Dementia

Condition	Symptoms	Neuropathology
Alzheimer’s disease	Impaired memory, apathy and depression with gradual onset.	Presence of (amyloid) plaques and neurofibrillary tangles within the brain.
Vascular dementia	Similar to Alzheimer’s disease with an emphasis on mood fluctuation and physical frailty. Stepwise progression.	Cerebrovascular disease. Single infarcts (bleeding) in critical regions of the brain or multi-infarcts (bleeds) across the brain.
Dementia with Lewy Bodies	Marked fluctuations in cognitive ability, with visual hallucinations common. Rigidity of movement experienced.	Presence of protein deposits in nerve cells called Lewy Bodies, in the brain.
Frontotemporal dementia	Personality and mood changes. Disinhibition common. Language changes.	Damage to frontal and temporal regions of the brain. No single pathology identified.

Diagnosis can be complicated given the breadth of underlying pathology, the different time courses of each condition, differing patterns of presenting conditions and the range of symptoms experienced by those affected (Batsch and Mittelman, 2012; Prince et al., 2011, 2014). Research across five countries by Alzheimer Europe (2011) found that for those with Alzheimer's disease a formal diagnosis had only been received by between a third and a half of the actual population who were living with the condition (Blendon et al., 2012). With the exception of vascular dementia we do not know why these changes occur within the brain and in many cases we are not sure how these changes cause the symptoms of dementia to appear (Alzheimer's Society, 2015a). Hence, for example, in dementia with Lewy Bodies it is thought that protein deposits interrupt important chemical messengers (mainly acetylcholine and dopamine) and lead to a loss of connections between nerve cells, but more research is required in order to evidence cause and effect (Alzheimer's Society, 2015b).

The changes that occur in the brain as a result of these pathologies can, in some cases, have started years before the symptoms of dementia. A review in this area by Braak and Braak (1998) indicated that for many people with Alzheimer's disease changes to the brain could have started as early as their fifth decade of life, with noticeable symptoms not appearing until old age. The findings of Bateman et al. (2012) suggested that changes in the brain could have started up to twenty years before the onset of any symptoms. Symptoms of dementia have traditionally been discussed within three broad stages known as early, middle and late (Prince et al, 2013a; Thomas and Milligan, 2015). Using this three stage approach Prince et al. (2013a, p. 25) identified the following broad characteristic features. Early stage symptoms: being forgetful, confusion about time, people and places, difficulty in making decisions and in carrying out everyday tasks. Low mood is also common. Middle stage symptoms: difficulties in communication, needing assistance with personal hygiene, practical assistance with household activities. Sleep disturbance is common and many people may be distressed. Repeated questioning and seeking behaviours can be common. Later stage symptoms: the person is

unable to recognise people and places close to them, unable to eat without assistance, dependence on others for personal care. This discussion of stages and prescriptive behaviours does not however fully describe or explain the experience of dementia for many people as I will now move on to discuss.

Difficulties with the symptom/disease model of dementia

The literature on bio-medical perspectives alone does not reflect the impact on the person at the centre of the neuropathological changes, nor does it explore the experience of the diagnostic process. There are also fundamental issues with attempting to assign people to pre-defined disease stages as this implies that the person is simply a manifestation of the symptoms of dementia. There is, in fact, a complex picture of individuals with multiple experiences which I will explore in this review, which is not reflected in the UK government's research priority of finding a cure for the single condition 'dementia' (Department of Health, 2013). Diagnosis is not straight forward. A range of assessments and scales, blood tests and brain imaging can be undertaken to confirm a diagnosis of dementia (Barrett and Burns, 2014). Despite the literature on dementia as a disease of the brain, there remains debate in some countries as to whether dementia is something that happens to people as part of normal ageing (Braun and Browne, 1998; Downs et al., 2006). There is also the problem that confirmation of a diagnosis of dementia can only be given post mortem, on examination of the structural changes to the brain, despite advances in sophisticated imaging techniques (Alzheimer's Society, 2014b; Hughes et al., 2006). Many people also have more than one disease pathology such as the example of those with both Alzheimer's disease and vascular dementia. There is therefore a tension in the literature between defining and differentiating between *normal* forgetfulness and the "*diagnostic indeterminacy*" of dementia itself, which Hughes et al. (2006, p. 3) stated has yet to be resolved. Yet medical explanations of dementia have dominated our understanding of the condition (Alzheimer's Society, 2014b; Hughes et al. 2006).

There is much debate about the nature of dementia and where expertise in the subject is best located, for example, a disease or mental health model (Innes, 2009, p. 7). However, there is scope to understand dementia from a whole person perspective even where a pre-dominant biomedical model is adopted. Scottish dementia policy, for example (Scottish Government, 2010a; Scottish Government, 2013) placed an equal emphasis on diagnosis, treatment and support to live well in what could be described as a bio-psycho-social approach. Such approaches have been developed because previous narrow neuropsychiatric discourses have resulted in the person with dementia being perceived as changed, or diminished, as a direct result of their dementia (Downs et al., 2006). This leaves no room for recognising that the person may influence the disease trajectory and the discourse can focus on loss, suffering and burden (Hughes et al., 2006). Critics of the neuropathology approach began to highlight the lack of evidence between the changes occurring in the brain and the symptoms assumed to be representative of dementia (Kitwood, 1987; Lyman, 1989, Snowden, 1997). These criticisms led to a call for a wider consideration of dementia, which would also incorporate both environmental factors and the experience of living with dementia (Kitwood, 1990).

A study by Snowden (1997) revealed that the neuropathology discovered in brains post mortem could not always explain levels of functioning during life. Some people with dementia in his study had functioned better than expected in later life compared to the level of brain neuropathology revealed post-mortem. Understanding the complex interplay of factors that can contribute to daily functioning is therefore essential. This can be facilitated through an exploration of the person with dementia within their unique structural and social environments. The biomedical model of understanding dementia, while effectively revealing the disease aetiology cannot fully address the complexity of living with the condition. It is important therefore to examine alternative, complementary perspectives which have emerged in the research literature.

Different ways of thinking about dementia

Social psychology, social disability and citizenship discourses have offered new ways of thinking about dementia. An increasing number of researchers have focussed on the experience of dementia from social psychology perspectives; and in particular the relationship between the experience of dementia and care practices (Goldsmith, 1996; Kitwood, 1997; Sabat, 2001). Kitwood (1997) theorised that people living with dementia were subject to disadvantage as they may be considered by others as non-persons. He discussed this with reference to the term 'personhood' (1997, p. 8) defining this 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*". Personhood is ultimately a combination of the social and the ethical and refers to interaction, status and recognition. Kitwood (1997) argued that by failing to see the person, and focussing on the dementia, practitioners were missing opportunities to connect emotionally with people. The emphasis was therefore on the importance of relationships, care and support as insensitive interactions could have a negative emotional impact on the person (Sabat, 2006).

Kitwood (1997) suggested that people with dementia need comfort, attachment, inclusion, identity, occupation and love, just as we all do. Positive interactions attend to these needs and result in the *emotional wellbeing* of the person with dementia. Negative interactions fail to address these needs and result in *emotional ill-being*. Indicators of emotional ill-being include apathy or withdrawal; intense anger; isolation; agitation and unattended grief (Buckland, 2004; Kitwood and Bredin, 1992). This failure to recognise people with dementia and their needs is referred to by Kitwood as malignant social psychology (1997).

Kaufmann and Engel (2014) undertook an evaluation of Kitwood's model of psychological needs and wellbeing, comparing their findings to self-reports by people with dementia. The authors confirmed that all of the domains identified by Kitwood remained relevant when compared to their participants' reports. They therefore concluded that the views of people with dementia on their subjective wellbeing remained an important source of data in this area. Identity remained important despite participants being described as having moderate or severe dementia by the authors. In particular, people expressed a desire to continue in roles that were important to them within families and wider social networks. They also wanted to be recognised by others and not dismissed as a result of their dementia. The authors recommend that a new domain of *agency* be added to Kitwood's original model. The inclusion of agency is interesting as concerns have been raised that Kitwood's model implies the passivity of the person with dementia and that wellbeing was mostly dependent on the actions of others (Downs, 1997; Nolan et al., 2002; Norman, 2003). This then minimised the role of the person with dementia within relationships and their ability to impact on their own circumstances. Further, a person-centred philosophy could in fact perpetuate exclusion as although it recognises power within inter-personal relationships, it fails to address wider societal issues of ageism and disability (Bartlett and O'Connor, 2007). The role of the individual in responding and adapting to the changes that dementia brings is then not reflected even where the agentic self is recognised. I will explore the agentic self in more detail later in this chapter when I discuss the literature on identity.

The application of the social model of disability to dementia has been used to reveal the structural inequalities that people with dementia experience. The social disability model (Oliver, 1983) considers that people are disadvantaged not as a direct result of their particular condition, for example dementia, but as a result of the negative views and attitudes about those who are different from people in relative positions of power. Oliver's work revealed the structural inequalities that people face in their day to day lives, which restricted their life chances when compared with people without a disability. This resulted in a movement which grew in the 1980s and 1990s, led by those with a disability,

which addressed structural restrictions, such as access to buildings and transport, access to education, social opportunities and practical support to work and take part in family life (Oliver, 1996). Although this work focussed predominantly on physical disability in the 1980s, it was later adopted by people with mental health and learning disabilities in exploring how their lives were affected by negative attitudes and assumptions (Walmsley, 1991). Thomas and Milligan (2015) conducted a review of the use of the social model of disability by researchers within the field of dementia. They concluded that despite some key papers (Beattie et al., 2005; Blackman et al., 2003; Brittain et al., 2010; Davis et al., 2009) this perspective appeared under developed. This is explored further within critical social gerontology and citizenship models.

Citizenship models

Both critical social gerontology and citizenship studies (Bartlett, 2014; Bartlett and O'Connor, 2007, 2010) have attempted to address issues of power, politics and dementia. This includes revealing and addressing power structures, stigma, ageism and lack of opportunity. Bartlett and O'Connor (2007, p. 111) stated that citizenship has a "*pivotal position in disability studies*" as it moves personal experiences of discrimination into a political discourse. This shift is evident where people with dementia are involved in activities to change attitudes, care practices and create life opportunities (Swaffer, 2015, 2016). This is also evident in groups such as the Scottish Dementia Working Group which consists of people living with dementia who contribute to dementia policy direction (Scottish Dementia Working Group, 2008). Bartlett and O'Connor (2007, p. 111) referred to this group as a specific example of people with dementia repositioning themselves as "*active citizens rather than tragic victims*".

Hughes et al. (2006) concluded that the experience of people with dementia must be understood in terms of their relationships with other people, communities and society. Citizenship is therefore an active process where a person with dementia achieves recognition and status through the negotiation of power dynamics (Foucault, 1980; Marx, 1974). However, as this is achieved through everyday interactions (Barnes et al., 2004) new ways of understanding dementia are needed as a person's dementia progresses and the nature of interactions change. There is therefore now a focus on citizenship as everyday practice in dementia research (Bartlett, 2016; Phinney et al., 2016; Ward et al., 2016) alongside more traditional perspectives of democratic citizenship (Sonnicksen, 2016) and the exercise of civic rights (Nedlund and Taghizadeh-Larsson, 2016). Poland and Birt (2016) stated that if personhood (Kitwood, 1997) provided the moral imperative to care, then citizenship now places an emphasis on the promotion of opportunities for the agentic self to emerge.

The struggle for citizenship

A citizenship perspective of dementia (Bartlett and O'Connor, 2007; Bartlett, 2014) has attempted to address how attitudes and inequalities can restrict citizenship status for many. Citizenship can be considered as a political and philosophical ideal where all persons enjoy certain rights and freedoms within society (Ignatieff, 1989) but, as discussed, this is not necessarily realised in real life. Inclusion in citizenship processes such as political discourse and asserting resistance can be difficult for those with dementia to achieve without support. Resistance is often viewed as a negative if demonstrated by those with dementia, where in others it could be seen as an assertion of rights (Ward et al., 2016). Sabat et al. (2004, p. 185) referred to terms such as '*uncooperative, obstinate and aloof*' being used to describe a person with dementia who declined to participate in a group activity. Kelly (2010, p. 274) suggested that people with dementia were often labelled as 'aggressive or challenging' where they demonstrated resistance within care interactions. People with dementia can be disadvantaged both within interpersonal relationships as well as wider political spaces as others can fail to recognise resistance as an assertion of personal power or indeed acknowledge the person's right to resist. The concept

of free will is therefore central to this issue (Watson, 1982). However, free will is seldom applied to those, in this case people with dementia, where it is evidenced to others through participation and reactive responses (Strawson, 1982). Those with a disability can then be disadvantaged as others fail to recognise or properly interpret these responses. I will consider this in the context of Bond et al. (2004) and their work on cognitive citizenship.

Cognitive citizenship

Bond et al. (2004, p. 223) suggested that people with dementia struggle to achieve recognition as citizens where cognitive citizenship is considered as the most important criterion. Cognitive citizenship places an emphasis on both the thinking and agentic self (Bond et al., 2004, p. 222). Citizenship is therefore not a right afforded to all; instead each person often has to demonstrate this ideal of autonomy and agency within relationships with others, and wider society. Where a person has dementia they can be thought of as incapable of such citizenship as they are perceived as unable to give something back in social interactions with others (Gove et al., 2016). This is referred to as a perceived lack of reciprocity (Gove et al., 2016, p. 10) and can lead to exclusion in a wider societal sense and an inevitable loss of status. Marshall and Tibbs (2006), however, stated that citizenship approaches which include people with dementia must be based on reciprocity if we are to recognise the contributions that people living with dementia can make. Nedlund and Nordh (2015) have suggested that all persons with dementia be reframed as “*capable citizens*” (2015, p. 131) and considered as having the potential to influence both their own lives and the content of their citizenship. This opens up the possibility that citizenship can mean different things to different people. Citizenship is, however, not only a right but a responsibility (Bartlett and O’Connor, 2007; 2010) and as such includes a far broader discussion about personal roles, responsibilities and risks (Clarke and Bailey, 2016) and I will return to these issues later in this chapter when I discuss the social work role with people living with dementia.

Narrative and social citizenship

Baldwin (2008) discussed the concept of narrative citizenship. We are, he argued, engaged in citizenship simply through the stories we tell about ourselves and our lives using these to position ourselves relative to others in society. However, this in itself does not necessarily result in rights being recognised or power for the individual concerned as stories, such as those told by people with dementia, can be marginalised by others. The narratives of more powerful individuals can then dictate the nature of citizenship and the narrative of the less powerful can remain hidden. O'Connor and Nedlund (2016) referred to this as social citizenship as there is a focus on the ways in which citizenship is realised or invalidated in relationships with people and places. There have been several recent papers which have considered how people with dementia use narrative citizenship to challenge stereotypes and assumptions about the experience of dementia. Dupios et al. (2016) reflected on the use of the arts by people with dementia to create alternate narratives. Clarke and Bailey (2016) explored the ways in which issues of inclusion and exclusion were reflected in the narratives of place shared by people living with dementia, carers and service providers. They concluded that narrative citizenship is closely linked to identity, wellbeing and resilience, which I will return to later in this review. Phinney et al. (2016) considered how the everyday act of walking freely in your neighbourhood could be re-framed as the exercise of social citizenship in place by people living with dementia.

The domestic sphere of citizenship

Bartlett (2016) raised the importance of the relationships that people with dementia have within their households and families, referring to this as the domestic sphere of citizenship. She advised that this area has been largely neglected by citizenship and dementia studies. However, what occurs within the home, she advised, is as important as what takes place in the larger social spaces that people with dementia inhabit (p. 455). Bartlett, therefore, recommended that domestic citizenship should have a pivotal position in citizenship studies moving forward. Wiersma et al. (2016) discussed a similar theme in their exploration of a participatory-action group in creating a space for

citizenship in the lives of people with dementia. They found that carers and family members can potentially silence the voice of the person with dementia when they are engaged together in group activities. They therefore concluded that groups must take account of this if a space for citizenship is to be realised.

Citizenship in care settings

Several papers have explored aspects of citizenship for people with dementia in the context of care and care settings (Baldwin and Greason, 2016; Brannelly, 2016; Kontos et al, 2016; Ward et al., 2016). Brannelly (2016) stated that the ethics of care must now take citizenship into account. She discussed the need for the timely provision of care and support from the state; a move away from the promotion of independence in favour of an interdependence model; and for attentiveness and responsiveness to be the cornerstones of care which promotes identity. Baldwin and Greason (2016) considered how a re-framing of care tasks as support which facilitates citizenship could help to realise citizenship in practice. They provided the example of transferring a person from his or her bed to a chair stating that this could be re-framed as the facilitation of social citizenship. This, they argued, moves the language of dementia care from support tasks to one of micro-citizenship; micro-citizenship being defined as the ways in which individuals support citizenship through small, everyday acts within relationships (2016, p. 294). Kontos et al. (2016) explored the issue of sexuality and institutionalisation revealing the tensions this area brings in realising citizenship in care settings. Ward et al. (2016) explored the role of the care-based hair salon in the lives of women with dementia. This research emphasised the importance of the 'mundane' in understanding the person with dementia's "*struggle for self-determination, belonging and social participation*" (p. 407).

Summarising the literature on dementia discourses

In the first part of this review I have explored the different and sometimes overlapping discourses which are used to explore and understand the concept of dementia. These varied ways of understanding then shape how we respond both to dementia, and to the person with dementia. Over the past 10 years citizenship as a means of understanding the experience of dementia has grown in interest. Citizenship models take different forms and within this review I have discussed democratic, cognitive, narrative, social and domestic spheres of citizenship. Evolving models of citizenship, although recognising the political aspects of traditional citizenship, also now place an emphasis on the agentic person with dementia who is engaged in citizenship practice in everyday relationships with the people and places in their life. This recognition of the mundane (Ward et al., 2016) physical and social spaces that a person with dementia inhabits can reveal important information about presentations of self. This includes presentation of self through the stories that we create and share in interaction with others. In order to explore citizenship further in relation to resilience I have identified three topics from this literature for further investigation. These are identity (Ricoeur, 1992), the politics of recognition (Taylor, 1994) and positioning (Althusser, 1971).

Identity

Defining identity is a complex task. In relation to dementia there is ongoing debate about what identity means where aspects of the person are assumed to change. There are questions as to whether identity can continue to exist and in what ways (Caddell and Clare, 2010; Hughes et al., 2006). In order to reach an understanding of these discourses I will discuss identity over the life course then look specifically at the different ways identity has been framed in the context of dementia. When exploring the literature it became clear that authors used different words to discuss and explore identity, including personhood (Kitwood, 1997), self (Sabat, 2001), selfhood (Ricoeur, 1992), private and public self (Goffman, 1959), and conceptual self (Caddell and Clare, 2011a; Neisser, 1988). As I discuss the literature I will use the terms that each author did as I explore their work. I will conclude this section detailing a model of

identity in the context of dementia and the terminology with which I will continue this review.

Identity over the life course

The development of identity over the lifespan was explored through the work of Erikson (1965, 1968, 1980), who referred to identity as '*ego identity*'. Emilsson (2008, p. 319) stated that Erikson used ego identity to symbolise: "*the psycho-social nature of I formed by biological predisposition and internal organization with social reality.*" Erikson proposed that identity continues to develop beyond childhood and identified eight distinct stages where this occurs over the life cycle. The final stage of '*ego integrity versus despair*' describes a period of self-reflection where each person assesses the contributions and achievements of his or her life, resulting in a sense of completeness or despair. Similarly, Butler (1963) used the phrase '*life review*' to describe the stage of reflection and making sense of one's life story that occurs in older age. Critics of this approach to thinking about ageing (e.g. McCrae and Costa, 1997) highlighted the lack of reference to the individual, existing structural inequalities, issues of power and the impact of each person's unique circumstances. The experiences of older people from lesbian, gay, bisexual and transgender backgrounds, for example, are not represented within such approaches (Ward et al., 2012). Instead, experiences of ageing are discussed as though they are universal, and as a result poor experiences of ageing are attributed as the fault of the individual. This can lead to assumptions that all persons living with dementia will have a poor experience of ageing.

Identity and dementia

The fundamental question of whether a person with dementia continues to have an identity requires a different approach. This review has revealed a vast and varied literature on this subject. Caddell and Clare (2011a) compared the different ways in which identity has been framed in the context of dementia by researchers in this field. They referred to the work of Neisser (1988), who proposed that identity is a combination of sensory data achieved through

interaction with others and our environment (interpersonal and ecological self), and abstract data such as internal representations of the self over the life course (private and extended self). The culmination of this self-knowledge plus information about roles and experiences forms the basis of our identity (conceptual self). Caddell and Clare (2011a) have proposed that this multi-faceted explanation as to how knowledge of the self is achieved could explain identity within the context of dementia, bringing together multiple discourses. In order to explore this further I will focus on identity and dementia in more detail.

Ricoeur (1992, p. 2) considered that there were two distinct ways of thinking about identity: identity as '*sameness*' or '*selfhood*'. Radden and Fordyce (2006, p. 72) explained this distinction with the question "*What am I?*" to represent sameness and "*Who am I?*" to represent selfhood. The emphasis is therefore not on remaining unchanged or the same as before, but rather that it is accepted that even with dementia the person concerned remains that particular person despite the changes brought about by experience of dementia. Caddell and Clare (2011a, p. 199) argued that this could be evidence of the '*extended self*' as it describes the anticipation that our future self will be a continuation of our past self.

Schechtman (1996, p. 74) defined identity as the set of characteristics or attributes that each person has but also the accumulation of their roles, actions and experiences, naming this '*characterisation identity*'. The importance of roles and attributes as components of identity in people with dementia has been identified in three studies (Cohen-Mansfield et al., 2000, 2006, 2010). Recognising the person's roles, actions and experiences over the life course brings an important dimension to the discussion as it situates identity within a story of self over time, where past and present actions and experiences build a picture of the person concerned and contribute to identity maintenance moving forward.

Social construction perspectives of identity and dementia

Building on the earlier work of Sabat and Harré (1992) and Sabat and Collins (1999), Sabat (2001) explored identity through the social construction theory of 'selfhood' and discussed identity as *the self*, suggesting that identity can be manifested on three levels: Self 1, 2 and 3. Sabat defined Self 1 as "*the self of personal identity which is experienced as the continuity of one's own singular point of view from which one perceives, and acts in, in the world.*" (2001, p. 17). Self 2 is similar to Schechtman's description of characterisation identity and consists of those mental and physical attributes, characteristics and qualities which a person thinks makes them unique, for example, tall, intellectual, independent, caring etc. Self 3 is the projected or public self and Sabat advised that this self is different from Self 1 and 2 as it is relationship based. Self 3 relies on the participation of others in recognising, responding to and validating identity and roles. For example, a person might wish to project a Self 3 which reflects their own picture of self within role for example, as an academic, which might not be reflected by the person that they are engaged with. Instead, the other in the relationship may see a vulnerable person with dementia. Caddell and Clare (2010) found that overall there is evidence that all three types of self do persist into the late stages of Alzheimer disease, however they cautioned that evidence of Self 3 seems to be restricted to case study approaches with only one or two participants (Sabat and Collins, 1999; Sabat and Harré, 1992; Sabat, 2002; Sabat et al., 2004).

Without the validation of the other person within interaction the preferred Self 3 might not be realised. In a study undertaken by Hedman et al. (2013) some people with dementia were aware of these tensions in creating a shared public self that they believed accurately represented them. Participants considered that the changes to identity brought about by the dementia were relatively minor. However, they reported that they were conscious of actively projecting a socially acceptable version of self in interaction with others. Therefore, having dementia did change the dynamic of their Self 3 interactions as they were conscious of the need to make a favourable or socially acceptable representation of self in the presence of the other party.

This literature suggested that the co-construction of public identity is not a neutral task. Research has revealed that people with dementia are aware of changes within interactions with others, believing these interactions to be less meaningful from the perspective of the other person as their dementia progresses (Johannessen and Moller, 2013; Sorensson et al., 2008). It was reported that some people living with dementia felt that they had to actively project a better version of self, in order to counter negative attitudes and/or assumptions about their identity, as a result of the label dementia (Hedman et al., 2013; Weeks et al., 2012). These findings can be understood with reference to Goffman (1959) and his work on dramaturgical sociology.

Symbolic interactionist perspectives of identity and dementia

Goffman (1959) used the theatre as a metaphor for presentations of the self in social interaction. People within interaction were considered as social actors and Goffman considered them to have both off-stage and on stage personas which Wolfe (1997) stated were used to represent the distinctions between private and public identities. The importance of this distinction is that the private self contains elements that each person chooses not to reveal to others. Goffman considered that the public self was a “*collaborative manufacture*” (1959, p. 253) which we achieve through adopting a selected or preferred representation of self which he called a “*personal front*” (1959, p. 24); the purpose being to manage the other’s impressions of us. Caddell and Clare (2011a, p. 198) discussed the ‘*private self*’ and the ‘*interpersonal self*’ (p. 200) in their model of identity in dementia which is similar to Goffman’s (1959) description of private and public identities.

Discussion on the realisation of identity, or the interpersonal self, through interaction with others is grounded in symbolic interactionism (Blumer, 1969; Mead, 1934; Stryker, 1968). This perspective focusses on social interaction as a catalyst for meaning in everyday life. There are five main components. First, that individuals are considered as dynamic, changing actors. Second, society is considered as consisting of individuals engaged in social interaction. Third, that

people use both the physical self and the mind to interact with others. Fourth, that people consist of many versions of self that emerge in unique interactions with other people, and finally that reality or truth is determined within interactions between individuals (Charon, 1992, pp. 27-28). This means practically that human beings observe and assess the world, categorising the people and objects they encounter, relative to themselves.

We are therefore constantly defining the things we interact with. We categorise people we meet as to how we know them, for example, as a family member or a stranger. We might then categorise further through observational criteria, for example height or eye colour, and so on. We also prioritise those people and things within our environment that are important to us, so our interactions with an employer, for example, may cause us to present ourselves in a more favourable light. Finally, we derive meaning from our interactions with others by constantly interpreting what is said and how the other person acts towards us. In this way, we apply our own meanings to every interaction and in turn are shaped through our interactions with others (Charon, 1992, p. 25). This emphasis on the social and physical environment and the ways in which it is both influenced by and influences identity is developed further in discussions of the embodied and inter-embodied self.

The embodied and inter-embodied self

The embodied self is based on the premise that selfhood resides in the physical body and that this is as important as cognitive function in locating identity (Kontos, 2003, 2004). Memory alone does not therefore equate to personhood. Instead, the physical space that a person occupies and the ways in which they use their body to interact with the environment are considered as evidence of identity. Likewise, the body is in turn influenced by the social and physical environment in which a person finds themselves. This approach recognises the ways in which people with dementia communicate through their body language, dress, appearance etc. and in turn how the environment influences presentations of self (Kontos and Martin, 2013). The continued importance of

physical appearance and dress to people with dementia has been of interest in recent research (Buse and Twigg, 2015; Twigg, J. 2010; Twigg and Buse, 2013; Ward and Campbell, 2013). This would be an example of the '*ecological self*' where identity is shaped through interaction with the physical environment (Caddell and Clare, 2011a, p. 197).

Jenkins (2014) combined a symbolic interactionist approach with that of the embodied self to describe the collaborative manufacture of identity. He defined self in relation to a person with dementia as an "*inter-embodied self*" (p. 1). Jenkins argued that identity is not constant but is instead created anew in every interaction, unique to that interaction. The creation of the inter-embodied self is a transaction between parties which "*exists in a perpetual process of becoming self*" (2014, p. 133). Controversially, Jenkins argued that the promotion of person centred care is fundamentally flawed as it fails to recognise the continual nature of the changing self. There is, therefore, no one person in any of us. Instead, we are a montage of selves, co-created with others and through environments. The ecological self is therefore born from symbolic interactionist approaches which reflect the person in situation as in continual communication, including through appearance, with the people and things around them.

The agentic self

If the ecological self (Caddell and Clare, 2011a) asserts that communication with our environment is ever present, then the active role of the person with dementia in this process comes under scrutiny. Earlier in this review I considered how being seen as a person capable of agency is used as both a barrier and an opportunity to citizenship, for a person with dementia. Here, I will explore agency in the context of interaction with others as a means of preserving identity.

Sabat (2001, p. 171) explored the concept of the person with dementia as an active agent in the construction of self. He argued that the person with dementia was “*meaning-driven*”, defined as acting out of intention; interpreting events and situations; and as having the ability to evaluate events, situations and actions. This is at odds with traditional medical and psychological views that the cognitive losses of dementia result in an increasing inability to make sense of the social environment (Martin and Post, 1992). If, however, all behaviour is assumed to be meaning-driven then a wider sphere of information regarding the person’s reality becomes available to those engaged in interaction with the individual. Sabat and Harré (1994) and Sabat (2001) found that there was evidence of meaning-driven behaviour even in people with moderate to severe dementia. Cheston and Bender (1999, p. 147) agreed with this view asserting that people with dementia are engaged in an “*active struggle to cope with the threat to their identity*” and the resulting emotional challenges. Radden and Fordyce (2006) found that maintaining identity was an active process for all of us because it is a continuous process as life takes place around us. New experiences occur every day and in order to maintain identity, information must be ignored or absorbed and integrated into the whole story of oneself.

Clare (2003) explained how active decisions to minimise or prioritise these new experiences directly affect the personal identity state of a person with dementia. She referred to this as individuals either “*self-maintaining or self-adjusting*” (2003, p. 1022). Self-maintaining involves minimising and normalising in order to maintain personal identity. Self-adjusting involves acknowledging the issue and redefining this identity, accepting that there are fundamental changes as a result of the condition dementia. The person with dementia is therefore the author of their “*self-narrative*” (Radden and Fordyce, 2006, p. 72). The active nature of self is evident, according to Radden and Fordyce (2006) where people with dementia place an emphasis on aspects of their identity within the stories that they share with others. This act of sharing stories with others is then at the heart of identity within the symbolic interaction process, as it is through such interaction that the

person with dementia can achieve public recognition and validation of preferred personal identities.

The narrative self

Identity, it is theorised, is maintained through the active creation of a “*personal story of which the subject stands as author*” (Radden and Fordyce, 2006, p. 73). Reissman (2008, p. 8) stated that identities are simply stories people tell themselves and others about who they are (and who they are not). Applying Sabat’s (2001) social constructionist perspective to stories suggests that they are projections of private identity and that the sharing of stories is a co-construction of public identities. Interest in the stories of people living with dementia has grown considerably (Angus and Bowen, 2011; Downs, 1997; Jenkins 2014; Keady et al., 2007; Keady and Williams, 2007; Mills, 1997; Nery de Souza- Talarico et al., 2008; Page and Keady, 2010; Pearce et al., 2002; Ramanathan, 1995; Robertson, 2013; Surr, 2006; Swaffer, 2016; Usita et al., 1998; Van Dijkhuizen et al., 2006). Baldwin referred to this as people with dementia finding both their voice and having the opportunity to have this voice heard by others (2008). Page and Keady (2010) reviewed twelve stories told by people with dementia about the experience of dementia written between 1989 and 2007. They found that in all of the stories there was a “*deep rooted rejection of the stigma associated with having dementia*” (2010, p. 522). Gillies and Johnston (2004, p. 439) found similarities between the stories told by people living with dementia and those with cancer in reclaiming identities.

The stories told by people with dementia can be dismissed as non-factual or superficial, assumed to have no substance or purpose (Sabat, 2006; Young, 2010). However, stories are arguably intentional projections of personal identity in order to persuade the other of a public identity. They are not then a simple re-telling of facts or truths. Identities are therefore aspirational and not always factual when they are projected into the social world (Radden and Fordyce, 2006). This is true for all of us and, not just for people living with dementia. As dementia can affect memory, metaphors and stories are often used as a means

of re-editing the past in place of specific details (Page and Keady, 2010; Young, 2010). However, introducing aspiration to the art of storytelling can re-position creative storytelling by people with dementia as part of the human condition and not confabulations as a result of memory loss. Jenkins (2014) commented that identity is not dependent on a unified or coherent story of self. Hence, although the stories themselves may be fragmented, they often have aspirational and emotional significance for the person concerned (Mills, 1997) and are representative of aspects of personal identity. Stories could therefore offer a window into what Caddell and Clare (2011a, p. 200) referred to as the conceptual self of a person with dementia. Robertson (2013) has also linked the importance of the stories that people tell about their everyday lives as containing important information about the quality of their lives, if those listening can understand what they are hearing and its significance. Baldwin (2008) and Clarke and Bailey (2016) discussed the concept of narrative citizenship in the context of dementia and determined that people with dementia negotiate relationships with people, places and institutions through stories of self.

Reaching a definition of identity in dementia

Identity is a complex construct and this is reflected in the various models and varying language used to understand it in the context of dementia. The literature revealed that people ageing with dementia continue to have a sense of *personal identity* even where dementia is described as advanced (Caddell and Clare, 2010). Personal identity can be understood as the culmination of each person's characteristics, actions, experiences and roles. This is a combination of the Self 2 (Sabat, 2001) and Schechtman's model of characterisation identity (1996). People with dementia also have a *public identity* (Goffman, 1959) which is co-produced and negotiated with other parties through interaction, which Sabat referred to as the Self 3 and Caddell and Clare (2011a) referred to as the interpersonal self. For the purposes of this review, the terms I will use henceforth are *personal identity* and *public identity* (Goffman, 1959) in all further discussions which refer to these concepts.

Whilst evidence of identity exists in all of the different models outlined in this section of this review, I will proceed with a symbolic interactionist perspective where the person with dementia is conceptualised as someone who has a personal and public identity; the public identity being revealed through narrative in interaction with others. I have stated that the stories of people with dementia are arguably intentional projections of personal identity in order to persuade the other of a public identity. Narrative study considers that all stories, including the small stories of everyday life, can be viewed as “*social practices that are equally observable, analysable and researcher-researched accountable*” (Georgakopoulou, 2006, p. 129). I will therefore proceed on this basis, situating the stories told by people who have dementia as social practices for study in the preservation of identity. I will explore the factors that impact on the interactions between people who have dementia and others in society in the following section on the politics of recognition and positioning.

The politics of recognition and positioning

Social interaction from a symbolic interactionist perspective essentially involves attributing identities to others (Charon, 1992). We form opinions based on what people say and do, how they look but also what we may have already heard about them. This means that a person can be viewed by another as simply a reflection of their pre-assigned public identity or label. Labelling is part of the process of naming objects that people use as a shortcut to meanings in communication with others (Charon, 1992). Berger and Luckman (1996) explained that although these views are not fixed, where we already have an opinion about another person, we can interpret their acts against the meanings we associate with the labels we have assigned. Where a person has dementia, all of their actions and reactions are at risk of being interpreted as the actions of ‘*a person who has dementia*’. I will explore the labels attached to dementia in more detail when I discuss stigma. This act of attributing identities is part of the process of establishing a public identity and takes place through positioning (Althusser, 1971). Positioning occurs in all social interactions and can be considered as the negotiation of identity between parties.

Positioning is important when discussing identity and dementia if people with dementia are to be understood in terms of their relationships with others. However when a person has dementia they may be unable to reciprocate negotiated power and positioning due to changes in communication, understanding or judgement. They may also be unable to reject negative stereotyping by others. As a result the person's ability to reposition or challenge labels and assumptions, in line with their personal identity, may be compromised (Sabat, 2006). Sabat (2006) referred to malignant positioning within interactions between people who have dementia and people who do not. He later explained this as using positioning to erase identity and ultimately the humanity of the person concerned (Sabat, 2008). This is similar to Kitwood's (1997) theory of malignant social psychology. Having an understanding of how people with dementia are spoken about, acknowledged and included is therefore essential if we are to understand identity within interaction with others. Hall (1996) referred to this as posing the question '*where am I?*' when trying to understand one's identity, relative to others.

Radden and Fordyce (2006) discussed Taylor's (1994) concept of the 'politics of recognition' where specific identities facilitate political and social power within interactions as they are culturally recognised by others. Equally applying a label such as old/elderly or dementia/demented can remove political and social identities from a person prior to any interaction taking place and can result in negative social positioning in any and all interaction. Radden and Fordyce (2006, p. 76) stated that all of us, to different degrees, have a desire to be recognised individually, socially and politically and indeed this is the very point of interacting with others and the world at large. The earlier examples of political activities by people and groups of persons with dementia may be evidence of this (Scottish Dementia Working Group, 2008; Swaffer, 2015). Malignant positioning is also a result of stigma and I will now explore the impact of stigma, ageing and ageism on the personal and public identities of people ageing with dementia.

Stigma

Goffman (1963) defined stigma as a '*spoiled identity*'. Stigma and malignant social positioning have a cyclical relationship. Stigma can permit malignant social positioning as the person concerned is disqualified from full social acceptance. Likewise positioning facilitates the continuation of stigma. Link and Phelan (2001) discussed stigma in relation to four inter-related components. That we label and categorise difference; that dominant groups can label those who are different as having attributes, behaviours or reputations that are undesirable; that these groups are placed in categories; and finally that a loss of status occurs as a result of the aforementioned conditions. Batsch and Mittelman (2012, p. 8) identified three types of stigma that people with dementia experience. These are *self-stigma* which is the internalisation of negative messages about the self, *public stigma* which is the reactions of people to a person with dementia, and *stigma by association* which is where people close to the person with dementia are affected by negative messages.

The current body of research exploring social disability perspectives has identified individual attitudes and institutional practices which act as barriers and perpetuate stigma for people ageing with dementia (Thomas and Milligan, 2015). Individual attitudes revealed included: failure to understand how dementia affects people; failure to recognise the practical difficulties faced by people living with dementia; failure to find ways to communicate; misinterpreting behaviours as symptoms of dementia; ignoring people; and the abuse of people living with dementia echoing the work of Kitwood (1997). Institutional practices included: failure to design for people living with dementia; denial of choice; and perpetuating stigmatising language, images or representations of people with dementia (Thomas and Milligan, 2015, p. 7).

A social attitudes study on dementia undertaken in Scotland in 2014, found that although a substantial amount of respondents held positive views about people with dementia, stigmatising attitudes were also held. This included the view that having dementia is something to be ashamed of, an opinion with which one in eight respondents agreed (Scottish Centre for Social Research and the Life Changes Trust, 2015, p. 61). There is, therefore, a need to address negative societal messages about dementia through addressing structural inequalities and stigmatising messages. The person ageing with dementia could be described as having the attributes associated with an undesirable state of being. Stigma in this case can thus be considered as a symbolic rejection of ageing and disease where the person is no longer recognised as representative of youth, vitality or beauty, which society holds as positive attributes. Although there has been a focus on this in relation to older women (MacDonald and Rich, 1984; McCall, 2005) research has also found that older people of both sexes are aware that their personal appearance can mark them out within society as being “old” and in turn being treated differently (Ward and Holland, 2011).

It can also be argued that stigma is present in the language used to discuss the growing numbers of people ageing with dementia, where words such as epidemic and burden are used to stress the need to act quickly in delaying the onset of dementia (DoH, 2012; Wilson and Fearnley, 2007; WHO, 2012). Materialistic arguments perpetuate the discourse first explored by De Beauvoir in 1977 that older people (with dementia) are considered as a socio-economic and health burden as they no longer contribute to the economy. This argument gives no consideration to the previous contributions made by people throughout their lives, or the role of many older people in contributing in other ways, such as through caring for grandchildren and voluntary work that many people are engaged in (JIT and NHS Health Scotland, 2014). Instead it can perpetuate existing systems of care and support which see many people with dementia moving into institutional care (Prince et al., 2013b). Stigma can therefore be used as a mechanism to maintain the status quo in situations of power and inequality with the literature asserting that many people can internalise these negative messages which then shapes their personal and public identities

(Batsch and Mittelman, 2012; Gove et al., 2016). If stigma is to be addressed and challenged then research that focusses on resilience may offer a helpful perspective.

Stigma, ageing and ageism

Harding and Palfrey (1997, p. 10) argued that the biological process 'ageing' determines how we [society] act in response. Ageing can be associated with dependence, ill-health, and burden (Innes, 2009:19). However, critical social gerontology perspectives consider that this dependence is as a result of limiting life opportunities as we age (Bytheway, 1995; Harding and Palfrey, 1997). Harding and Palfrey asserted that society and the individual are "*inseparable and interdependent*" and that as a result the experience of older people is made real through the process of interaction with other individuals (1997, p. 12). This means that because older people themselves are part of society they are also influenced by stereotypes of the ageing person and may experience ageing according to these expectations.

Butler defined ageism as "*a personal revulsion*" to the biological and social consequences of ageing (1969, p. 243). The culture of ageism can be described as pervasive and can challenge an individual's sense of self (Sinnot, 2009). Sinnot (2009, p. 156) referred to the work of Boss (1999) on ambiguous loss in order to describe this how this can happen. Ambiguous loss is used to explain the anxiety which occurs in periods of uncertainty in a person's life, often resulting in threats to a person's personal and public identities. Sinnot (2009) referred to ageing as a period of uncertainty, and that as such anxiety and anticipatory mourning could be experienced as we grow older.

Bavidge (2006) argued that society is extremely conscious of any cognitive changes in old age. He stated that although some cognitive changes can occur in old age that any sign of shortened attention spans, decreased capacity to solve problems and forgetfulness can promote ageist prejudices as “*we too readily assume that the differences in attitudes and competencies that characterise old age are deteriorations*” (2006, p. 48). These prejudices can also be held by older people about themselves, with any changes assumed to be detrimental, which in turn could contribute to threats to identity (Cuddy et al., 2005). However, the changes that occur in old age are not necessarily negative and there is a body of work on successful ageing (Baltes and Baltes, 1990; Rowe and Khan, 1997) which reflects the life satisfaction achieved by many. I will return to the subject of successful ageing later in this review. Northcott (1982) conducted a study looking at the best years of a person’s life and found that older years appeared to be a period of relatively low pressure and relatively high satisfaction. Ageing is not therefore a homogenous experience (Nikander, 2009, p. 863). Neither is ageing made up of either wholly positive or negative experiences. This is also true for those ageing with dementia (Rhaman, 2014). Instead, ageing with or without dementia is personal, dependent on interactional, situational, social and political factors (Innes, 2009, p. 20). Clarke and Korotchenko (2015) found, for example, that older men in a Canadian study were aware of the potential for ageism, but they did not consider that they had experienced it themselves.

Summary

This section of literature has explored the ways in which stigma, ageing and ageism can shape both the personal and public identities of the older person within social interaction. The literature on positioning defines people as dynamic and active within interactions with others (Charon, 1992, p. 23). This then rejects a limited picture of ageing as a biological process in which the older person is passive. Ageing can instead be viewed as a period of change and transition, consisting of both positive and negative experiences; these being the result of personal, interactional, situational, social and political factors (Innes, 2009, p. 20).

The literature I have reviewed thus far discusses how re-positioning people with dementia from victims of disease to capable citizens which Nedlund and Nordh (2015) advocate, could facilitate an exploration of the impact of power and inequality on the experience of ageing with dementia. Fundamental to this is the subject of identity and in particular the preservation of identity by people living with dementia. This preservation is discussed within the literature as an active process that the person with dementia is engaged in as they live with the experience of being labelled as a '*person with dementia*'. I have discussed the ways in which identity is realised, differentiating between the personal identity of characteristics, roles, actions and experiences; and the public identity, which could be realised in storytelling relationships with others. This is important if the resilience of the person with dementia is to be realised through the symbolic interaction processes of co-creation and validation in relationships with others. I will now continue this review turning my focus to the literature on resilience.

Part Two: Resilience

Within the literature I found a clear link between identity and the concept of resilience (Bonnano et al., 2002; Lifton, 1993). Windle et al., for example, stated that resilience can be defined as the “*preservation of self*” (2008, p. 290). In order to interrogate this further I will explore definitions of resilience and look more closely at the concept and its origins. I will then discuss the literature on resilience within the context of ageing and then dementia.

What is resilience?

The literature on resilience is vast and contradictory (Aburn et al., 2016). It is described in different ways and as different concepts (Anderson, 2015). Allan et al. (2011, p. 1) stated that “*although most scholars and members of the general public have an intuitive understanding of resilience, ambiguities in definition, measurement and application contribute to scientific criticism regarding the usefulness of resilience as a theoretical construct*”. Resilience means different things to different people and is used to mean different things depending on the field of application. Aburn et al. (2016) undertook an integrative review of the empirical literature on resilience from 2000-2015, within the field of nursing practice and research, and concluded that there was no universal definition that could be applied. Some authors consider resilience to be a personality trait (Wagnild and Young, 1993) where the individual has both the ability (and responsibility) to recover from or adjust to, misfortune, change or adversity. Luthar et al. instead stated that resilience is not a characteristic but a “*dynamic process encompassing positive adaptation within the context of significant adversity*” (2000, p. 543). Resilience is not just about adapting to adversity as Hart (2013) argued that resilience itself can potentially alter or transform aspects of adversity for some people. In this way, resilience is a process, a product of the context in which one finds one’s self, and also a catalyst for changing the nature of adversity itself. The two elements considered as essential for resilience to develop are exposure to adversity and the

achievement of positive adaptation in the face of adversity (Luthar et al., 2000, p. 543).

The subjective experience of adversity is important as different personal perspectives mean that adversity is measured and categorised uniquely by each person (Hochhalter et al., 2011). For example, Allen et al. (2011, p. 3) asked if “*daily life disruptions*” are enough to stimulate the resilience process for some people. Resilience can therefore be discussed as both a gradual process or as a turning point in someone’s life (Bennett, 2010). Importantly, resilience is not a remarkable or personal attribute but is an ordinary phenomenon (Masten, 2001) and as such the concept is applicable to all. Bennett (2015, p. 5) found that resilience is discussed in three distinct ways; as a predictor of wellbeing; as a mediator or moderator between adversity and wellbeing and; as an outcome in and of itself.

The components of resilience

The literature commonly refers to the interaction of adversity, vulnerability, risk and protective factors when describing the process of resilience (Mitchell, 2011). However, there is much debate about what each of these terms means and the ways in which they are employed (Wild et al., 2013). Masten (1994) recommended that resilience is used with reference to the maintenance of positive adjustment under challenging life conditions. Resilience does not therefore mean being invulnerable (Netuveli et al., 2008) but rather is about supporting positive outcomes despite adversity (Daniel and Wassell, 2002a, p. 11). Vulnerability is discussed as a state where a person’s “*reserve capacity falls below the threshold needed to cope successfully with the challenges in life*” (Yee- Melichar, 2011, p. 134). In other words, if a person is described as vulnerable they are considered to be at a higher risk of the negative consequences of adversity (Newman, 2004). Risk is associated with threat. Some authors, particularly in relation to children, describe risk as an incident that could result in a threat to development (Masten, 2001). Others, focussing on resilience in adults, refer to threats of disadvantage or harm (Lowenstein,

2009). Risk is commonly understood to be something that increases the likelihood of negative outcomes (Mitchell, 2011), however, what might be a risk for some people can be considered as an opportunity for others (Thomas and Milligan, 2015). Protective factors such as a supportive family can mitigate the negative outcomes of risk. In summary, vulnerability factors increase the likelihood of a negative outcome and protective factors decrease this likelihood (Windle et al., 2008). Vulnerability and protective factors can be considered at individual, family and community levels. The positive interaction of these factors is an important aspect of resilience (Luthar et al., 2000).

Historical context

The body of literature on the subject of resilience historically focused on children. Studies into the outcomes for children of parents with schizophrenia established the concept of childhood resilience (Garmezy, 1974; Masten et al., 1990). Luthar et al. (2000, p. 544) stated that research then broadened to include children and young people and their development in the face of adverse conditions (Garmezy et al., 1984; Luther, 1991; Masten et al., 1990; Rutter, 1983; Werner & Smith, 1977). Not until the 1990s did research on resilience (other than longitudinal studies of children) include adults. Multiple adverse conditions also began to be considered, including socio-economic disadvantage and associated risks (Rutter, 1979; Werner and Smith, 1982, 1992) chronic illness (Manning et al., 2014), socio-cultural factors (Claus-Ehlers, 2008) and catastrophic life events (Norris et al., 2009). Research originally focussed on definitions of resilience and identifying those who were resilient (Luthar et al., 2000; Wild et al., 2013). There is now a much broader focus on the factors that influence resilience, such as environmental influences and the interaction of the person with these factors (Sapountzaki, 2007). However, despite this rich repository of research there remains a lack of consistency in definitions, applications and outcome evidence (Anderson, 2015). Given the earlier literature in this review discussed the threats to identity of ageing and dementia, I will now explore the resilience literature in each of these areas in more detail.

Resilience and ageing

The study of resilience in old age is a developing field, with literature on life events in old age such as the experience of bereavement (Bennett, 2010; Boerner et al., 2005; Bonnano et al., 2002; Foster, 1997; Greve and Staudiner, 2015; Jopp and Rott, 2006; Kinsel, 2005; Montross et al., 2006; Ong et al., 2004, 2006, 2010; Staudinger and Fleeson, 1996; Wallace et al., 2001; Wiles et al., 2012), adjustments to ill-health and disability (Abbema et al., 2015; Becker and Newsom, 2005; Emler et al., 2011; Forstmeier and Maercker, 2008; Hildon et al., 2008; Nakashima and Canda, 2005; Netuveli et al., 2008; Nygren et al., 2005; Windle et al., 2008, 2010; Yang and Wen, 2014) and research that addresses experiences of and adjustments to ageing (Hildon et al., 2010; Janssen et al., 2012; Manning, 2013; Montpetit et al., 2010; Murphy et al., 2015; Randall et al., 2015; Seery et al., 2010; Sprange et al., 2013; Wells, 2010; Windle et al., 2015).

Bennett (2015) undertook an evidence review of emotional and personal resilience in later life and suggested that resilience occurred in the face of significant challenges, whatever these may be, to the person concerned. Bennett advised that resilience could be said to be present where the individual concerned had no obvious stress or distress, still found meaning and satisfaction in life, actively participated in life, and had a sense that their current life was positive (p. 8). Abbema et al. (2015, p. 2212) identified frailty as the most common adversity experienced by older people and defined resilience in old age as successful ageing (Rowe and Khan, 1997). I discuss successful ageing later in this chapter but it generally refers to retaining independence and avoiding ill-health. Hicks and Conner (2014) held a conflicting view and asserted that the concept of resilience should only be used in the context of those older people with long-term illness or disability and not simply to refer to the general experiences of ageing. However, the literature on ageism and stigma highlighted that adversities experienced cannot simply be categorised as a result of ill-health. This view is reflected in the work of Hildon et al. (2010) who found that adverse events in old age included stress in relation to changing life circumstances. The experience of ageing can mean changing health,

changing roles, and differing access to physical and emotional resources, all of which can be framed as adversities (Bauman et al., 2001; Ottmann and Maragoudaki, 2015; Staudinger et al., 1993; Wild et al., 2013).

Ageing can also be a strength in the development of resilience. This was explored by Bowes and Daniel (2010) and Clark et al. (2011). These papers referred to a dimension of resilience which is only understood by considering the self over time. The personal, reflective stories that we share help us to understand ourselves in the context of adversity, including in situations of harm and/or abuse. The link between narrative and resilience was explored by Randall et al. (2015). They discussed narrative openness, a willingness to share expressions of one's self, life, thoughts and views, and autobiographical reasoning, reflection in the context of one's life story, as essential components of resilience in ageing. Examining the process of ageing could then offer new insights into understanding resilience through an exploration of identity and our developing sense of self over the lifespan. Hochhalter et al. (2011) referred to this as our unique "*resilience lens*" (2011, p. 22). They explained that our experiences shape how we view the world and the problems we experience. As older people have access to a broad range of experiences, developed over their life, this could better equip them to deal with adversity. However, this is not a static or universal thing as Hochhalter et al. (2011) also suggested that resilience can fade over time. Other researchers discuss resilience as changing or evolving as we age, with some people becoming more resilient in certain circumstances as they have a lifetime of experiences to refer to (Allen et al., 2011). Several studies have found the presence of resilience in the oldest old in studies of those in their ninth decade and beyond (Alex, 2010; Bauman et al., 2001; Jopp and Rott, 2006; Lapsley et al., 2016; Zeng and Shen, 2010).

Ageing and resilience domains

Within the literature there is reference to the different aspects of an older person's life where resilience may be required or could be undermined. Wild et al. (2013, p. 151) referred to these as cultural, social, physical, environmental, financial, mobility and psychological resilience domains. These domains are compatible with citizenship perspectives on ageing which have identified the ways in which older people can be disadvantaged. Resilience is therefore not a taken for granted, constant state of being, or a solution to all risks in every area of a person's life. It has to be specific, considered on an individual basis, and within the context of each person, at any given time. Sapountzaki (2007) referred to the process of vulnerability redistribution, where the promotion of resilience in one area of a person's life can increase and/or decrease their resilience and vulnerability in other areas of life. An example would be promoting a move to a different housing environment over maintaining existing social networks, which many older people experience in transitions to care home environments (Sury et al., 2013). Sands et al. (2016, p. 3) referred to this as a multi-faceted process with the older person having access to resources that support resilience in some areas of their life and not others. They suggested that targeted commissioning of different types of support for older people that recognises resilience could promote better health and wellbeing. They advocated better use of the third sector in a move away from traditional commissioning models, such as care homes in my earlier example, in order to promote targeted intervention on issues such as loneliness.

Resilience, ageing and protective factors

Protective factors in ageing are referred to as the buffers of old age (Wagnild and Young, 1993). This work was further developed by Wagnild (2003) and Windle et al. (2008) respectively. Again, as in much of the literature on ageing and resilience, there is a great deal of debate about what constitutes a protective factor. Resilience literature refers to three essential building blocks: a secure base that provides a sense of security and belonging; good self-esteem that supports an internal sense of worth and competence and a sense of self-efficacy that facilitates a sense of mastery and control over one's circumstances

and environment (Daniel et al., 2010). Gutheil and Congress (2000) identified four key areas. These were: individual protective factors of having a sense of purpose which leads to finding meaning in life events; control or a belief that one can influence events and then taking action based on this belief; seeing threats as challenges or opportunities and also having access to social supports. Abbema et al. (2015) discussed a combination of internal and external resources. Internal resources included having an adaptable personality, finding meaningfulness in everyday life, being able to self-care, having a sense of personal and social competence, self-determination, having life experiences to refer to, and having positive emotions. External resources included: having secure relationships, social support, family cohesions and environmental support in supportive neighbourhoods and communities. Bonanno (2004), Gallo et al. (2005) and Windle et al. (2008) focussed on internal or individual protective factors. These included: hardiness, self-enhancement, positive affect and humour (Bonanno, 2004), mastery, self-esteem and optimism (Gallo et al., 2005) and self-esteem, inter-personal control and competence (Windle et al., 2008).

Two studies, one in America and the other in Australasia focussed on resilience in place. Wells (2010) undertook a study on older adults living in rural, suburban and urban areas of New York State in America. The purpose of the study was first, to determine if resilience varied in these different groups. Second, to determine if the relationships of socio-demographic factors (age, income, education, marital and employment status), social networks, health status, and resilience varied across the three locations. Wells concluded that there was no difference in resilience levels across the three different environments and identified that protective factors, such as strong social ties and perceptions of good mental and physical health, were of more importance. However, this study found an association between higher levels of resilience and low income, which could be linked to the experience gained through living with adversity. Other studies have linked higher financial income to resilience through associations with security and access to resources (Hardy et al., 2004).

Wiles et al. (2012) held focus groups about resilience and ageing in two different New Zealand communities. Older people were asked about their understanding of resilience and how it applied to their lives, and, in particular, aspects of ageing. They found that individual protective factors included a positive attitude, looking at the positive things in people's lives, having a purpose and keeping busy. Society and community factors included access to family and friends.

The literature did not reveal any one position on protective factors in old age. This was also reflected in the following studies which attempted to synthesise the available data. Van Kessel (2013) undertook a meta-synthesis of qualitative descriptions of resilience in older people, looking for reference to internal and external resilience resources. He found reference to internal factors of self-care, spirituality, orientation to the future, previous life experiences, meaning making, caring for others, and acceptance to feature prominently in the literature. External factors included social support and the ability to access care. Hicks and Conner (2014) reviewed 46 papers from 1990-2012 which discussed resilience in the context of older people and considered the words and phrases used to reflect individual and societal protective factors. Their findings were that resilience could be discussed in relation to both core individual attributes and specific protective factors. Core attributes were coping and adaptation to change (27 papers), hardiness discussed in terms of endurance, survival and coping with hardship (17 papers), and self-concept (12 papers). Self-concept was linked to several other aspects of self and included self-esteem, self-acceptance and interestingly self-discipline. The protective factors identified were life experiences: including coping with change (10 papers), activity linked to physical functioning and perceptions of fitness (9 papers), and social support (7 papers). They suggested a model where protective factors mitigate the effects of adversity, so that the impact is lessened and then the core resilience attributes detailed above, and related to hardiness and adaptation to change, facilitate future coping.

Ottmann and Maragoudaki (2015, p. 2089) discussed the “*resilience strategies*” of older people. Based on the responses of 25 older Australian adults they suggested that core resilience strategies are employed by older people and that they consist of coping, cognitive and social elements. They identified two strategies: re-ablement and holding on. Their findings indicated that in a re-ablement strategy the person set goals in order to achieve their previous level of functioning. Holding on occurred where the person concerned had a life-long disability. Here resilience was defined as accepting new limitations, challenging what was possible and rejecting help that undermined one’s sense of control (2015, p. 2091). The authors referred to this as holding on to aspects of life that the person treasured. Given my review of the earlier literature in this study it is feasible that the strategies employed to hold on, could also be applied to the preservation of personal and public identities.

The concept of resilience emerges from the above literature as a process achieved in the context of adversity. It is the ability to adjust positively in the face of risk, and to achieve better than expected outcomes (Masten, 1994). Resilience can also be discussed as a strategy employed by the older person in the face of disability and ill-health (Ottmann and Maragoudaki, 2015). Resilience can thus be understood as a complex interaction of risks, vulnerability and protective factors (Luthar et al., 2000). Applying resilience to the context of ageing offers new opportunities to understand both resilience and the ageing experience. For some people, dementia will be part of this experience and I will therefore now explore the concept of resilience in the context of dementia and in particular will focus on those aspects of resilience with relevance to the subject of identity and dementia.

Resilience and dementia

A focus on coping and adjusting

Research into resilience and older adults has only recently begun to consider people ageing with dementia (Wild et al., 2013). Within the dementia literature resilience is predominantly discussed in relation to carers and care-giving (See for example, Dias et al., 2015; Donnellan, 2015; Joling et al., 2015; Kramer, 2000; Smerglia et al., 2007; Wilks and Croom, 2008). The importance of social and family support features strongly in this research area (Garrity, 2006; Smerglia et al., 2007; Wilks and Croom, 2008). There is a body of literature on coping with and adjusting to dementia (Cheston and Bender, 1999; Clare, 2003; Clare and Shakespeare, 2004; Keady et al., 2007; Nery de Souza- Talarico et al., 2008; Van Dijkhuizen et al., 2006) and the link between identity, coping and dementia (Caddell and Clare, 2011b; Clare, 2002; Cotrell and Hooker, 2005; De Boer et al., 2007; Pearce et al., 2002). This literature did not explicitly use the term resilience although it referred to coping with the symptoms of cognitive impairment and striving to stay the same despite the cognitive impairment. Van Dijkhuizen et al. (2006, p. 80), for example, identified themes that impact on successfully coming to terms with memory loss. These were achieving disconnection from the past, having supportive family relationships, friends and neighbours, retaining social roles, maintaining familiarity, minimising and avoiding challenges, acceptance that things have changed, normalising and problem solving.

The work of Clare (2003) and Clare and Shakespeare (2004) discussed coming to terms with dementia through distinct stages of self maintenance and adjustment. Pearce et al. (2002) discussed the balance between the desire to remain unchanged and the need to re-appraise self in the face of dementia. Similarly Keady et al. (2007) described coping with dementia for many people as an act of 'keeping balance'. Stages of keeping balance were identified as; getting help and feeling the loss associated with dementia, accepting that the self has changed, not accepting fault or blame for the condition, piecing things together anew, trusting people and obtaining a diagnosis (2007, p. 358). An

overview of these various studies allows the development of a picture of identity as a continuum, with adjustment and crisis at opposing ends. Crisis is defined by Parker (2007) as the point where a person's problem-solving and learned coping mechanisms fail to reduce the impact of an emotionally hazardous event (2007, p. 117). The ways in which individuals respond depends on their own personal understanding of the situation. Introducing a resilience discourse therefore offers insights into personal understanding and the continual experience of adjustment by people living with dementia in the preservation of personal and public self.

Broadening this discussion to mental health more generally, Jacobson (1993) found that people coming to terms with mental health issues reached a unique understanding of their situation, which can be discussed as a personal theory. The themes that Jacobson identified as contributing to personal theories were also located in the dementia literature on coping and adjusting. These were biological, traumatic, environmental, spiritual, political, and dehumanizing ways of understanding situations. Each model is outlined briefly below along with some examples of where similar models appear in the dementia literature.

- Biological models - understanding the "disease" and the treatment options. This assisted with control of symptoms and importantly assisted the person in differentiating between the "disease" and the "self". This is discussed by Cheston and Bender (1999); Clare (2003); Clare and Shakespeare (2004); Keady et al. (2007); Nery de Souza- Talarico et al. (2008) and Van Dijkhuizen et al. (2006).
- Abuse or trauma models - the person's difficulties are a result of the trauma of the condition and any behaviour or emotion is as a result of physical, psychological and/or emotional pain. There then follows an emphasis on "pain management" to gain control over the condition. This model is covered in detail through the work of Clare (2003), Clare and Shakespeare (2004) and Clare et al. (2011b) and Sabat (2006).

- Environmental models - the person understands that aspects of his or her condition are improved or antagonised by environmental factors. Influencing the environment therefore improves the condition. The effects of the environment on the symptoms of dementia have been well documented (Kitwood, 1997; Sabat, 2006; SCIE, 2013). The effects of the social and political environment have been discussed throughout this review.
- Gaining control over the condition. Clare (2003) found evidence of this when exploring threats to self in early stage Alzheimer's disease. This is also covered in detail by Keady et al. (2007).
- Spiritual or philosophical models - the self is viewed as in transcendence: the condition viewed as either spiritual crisis or opportunity. Religion and spirituality have been explored for people with Alzheimer's disease by Stuckey (2006). Windle et al. (2008) also concluded that spirituality and self-acceptance emerged as important features of resilience in people aged over 50years.
- Political models - the condition is socially constructed to exclude those who don't conform to societal norms of thought, cognition, behaviour or emotion. The resolution lies in exposing this and reform (Harding and Palfrey, 1997). This has been discussed throughout this review and in particular with reference to the positioning of people with dementia routinely as incapable citizens (Bond et al., 2004; Nedlund and Nordh, 2015).
- Spirit breaking or dehumanising models - loss of personhood as a result of the condition. Inter-personal relationships which recognise the person are considered as holding the solution (see for example, Kitwood, 1997).

This literature demonstrates the research interest in understanding the ways in which people respond to the experience of dementia. This is discussed as coping and adjusting and appears to have a focus on personal understandings and explanations. What follows will refer more explicitly to resilience and the person with dementia.

Resilience and dementia: definitions and applications

Harris and Keady (2008) stated that moving to a resilience discourse would change social perceptions of dementia. Yet, despite this, the literature attempting to understand resilience in dementia remains relatively rare and there remains a focus on those in the earlier stages of dementia. Bailey et al. (2013) advised that there is also a narrow focus on individual attributes of resilience and a focus on strengths. They recommend that research should focus on resilience in the context of living within risk situations rather than focussing on unsafe people. For example, Harris (2008) explored the role of resilience in two case studies of people living with early-stage dementia. She defined resilience as self-reports of “*doing okay*” (2008, p. 49) and identified dementia as being an adverse event in people’s lives. Through a series of open-ended questions, Harris identified vulnerability and protective factors in the lives of each participant which promoted a continued sense of doing okay. Protective factors identified were positive attitude, good problem-solving and coping skills, positive self-concept, the use of community resources, and positive long-term relationships with families. Vulnerability factors included having other serious health issues, caregiver burden, denial, increased social isolation, instability in financial and/or living arrangements.

MacKinlay (2012) discussed the role of spirituality with people who have dementia, suggesting that there was a specific role for spiritual reminiscence in preserving beliefs, and in turn promoting resilience. Matchar and Gwyther (2014) explored the role of education and support groups for people with early stage dementia. The person with dementia attended the group with their carer. They interviewed 35 dyads from four support groups and determined that such groups can promote resilience through the provision of information and social engagement for both the person with dementia and their carer. Casey and Murphy (2015) conducted semi structured interviews with eight people described as having mild dementia. The purpose was to explore perceptions of resilience from the perspectives of people with dementia and to identify the factors that facilitated or hindered their capacity to develop resilience. Their findings were that internal and external factors influenced participants’

resilience. These included personal factors, enduring relationships, social support and community engagement. They concluded that people with dementia have the capacity to be resilient and that building resilience is an important aspect of working with people who have dementia.

Clarke and Bailey (2016) considered the importance of place in enabling resilience for people with dementia. This research explored the everyday experiences of living with dementia in rural and semi-urban communities. The study recruited 13 people with dementia. 12 of the participants also had a family member participate in the research. The study used a combination of diary entries and interviews with the person with dementia, their family and six stakeholders who were working in the public and charitable sectors within the same geographic area. The narrative experiences of the participants, both those with dementia and the other parties, revealed five themes that reflect the role of place in the lives of the participants. These were: the perceptions and others about dementia (others knowing and responding); socially withdrawing from difficult environments (such as busy places) and feelings of exclusion; the challenge between sustaining previous lifestyle choices and changing activities that were now associated with risk e.g. going out alone; negotiating feelings of belonging in the local community whilst at the same time feeling estranged as a result of dementia; and, engaging the right services and supports at the right time. In summary, this paper highlighted the ways in which place can be a threat to identity but can also support identity when a person has dementia, as the individual and their family negotiate changing roles and relationships in familiar places.

Other research has explored how older people acquire skills and reserves that they can then draw on to cope with living with dementia. Forstmeier and Maercker (2008) researched resilience with reference to '*motivational reserve*'. In effect, that people build a reserve of motivational skills that can then be employed to minimize the impact of dementia. This sample was not exclusive to people with dementia and included a wide age range of participants aged from 60-94 years. Of the 147 participants only 14 people were described as having a cognitive impairment. This is not classified further. It included those living independently and people resident in care settings. Estimates of mid-life motivational abilities were made using data about people's occupations and occupational performance. They found that there was a possible link between motivational abilities in mid-life and those in later life and that apathy was associated with lower resilience in later life. Ottmann and Maragoudaki (2015) also identified motivation as essential in the resilience strategies of older people.

Clare et al. (2011) discussed resilience in the context of compensatory strategies and '*cognitive reserve*' (Katzman et al., 1988; Stern et al., 2003). Cognitive reserve theory considers that people living with dementia may be able to compensate for the loss of some neural functioning where the brain finds different ways to respond to loss of function in one area by employing reserves from another. This capacity for compensation is developed through the accumulation of skills and knowledge acquired as a result of complex mental functions over a lifetime. Life experiences, social activities and social networks could also contribute to this reserve. Stern et al. (2003) hypothesised that cognitive reserve could delay the onset of difficulties for some people with dementia. Clare et al. (2011) considered that neural compensation which promotes prolonged independence could be a major contributing factor in the resilience of people living with dementia and, further, that it may be possible for people who have dementia to retain some capacity to continue to develop compensation strategies whilst living with dementia. It is suggested that interventions such as memory training can promote the further development of the cognitive reserve or can help people to use their existing cognitive reserve

in different ways to better effect, including feeling more in control of their circumstances (Clare et al., 2011). Randomized controlled trials (Clare et al., 2010) have been used to compare self-reports from people with dementia attending these interventions to those who have not, however further research is required in order to see results over a longer time period and with a larger population.

Hulko (2009) did not specifically research resilience in her study but did pose questions about reserve capacity. She sought the views of eight people with dementia about the experience of living with dementia. She used intersectionality (Crenshaw Williams, 1989) to understand the different experiences revealed. Intersectionality explores the inter-locking systems of oppression and power that people experience through racism, sexism, ageism to name but a few. So, for example, a white, older woman could not claim to speak for the experiences of all women on feminist issues. This is because there may be experience of gender discrimination but not racial discrimination, where the person concerned could be in a position of privilege. Oppression as a result of ageism may be experienced when comparing a white, older woman to that of a white, middle aged woman and so on. This work highlights the individuality of each experience through the politics of recognition and identity. Hulko (2009, p. 140) stated that older people who have experience of coping with oppression in their lives prior to dementia may be able to apply this developed resilience to the context of their dementia. As a result some people may experience dementia as just "*one more hurdle*" in life. This could be the first example of reserve capacity for resilience, developed through intersectionality experiences over the life course, conversely, some people in positions of predominant privilege over the life course may have less well developed resilience and as a result struggle with the loss of status or recognition that dementia can bring.

Other authors focussed on the environments in which resilience can be recognised and developed. Purves et al. (2011) explored the use of multimedia technologies, such as video records, to facilitate narrative and engagement. This approach focussed on the importance of hearing the stories of people with dementia as a means of fostering resilience. They stated that resilience is supported in people with dementia through creating "*interactional environments*" which is a term first used by O'Connor et al. (2007) to describe a broadening vision for dementia support. Whilst this paper focussed on how to facilitate stories the work of Angus and Bowen-Osborne (2014) explored how the story itself is a means of understanding resilience. They provided a case study of a single person with dementia, Janet, who also had a life-long disability and analysed the story told for insights into the speaker's experiences. The authors described this story as spontaneously produced and constructed over several meetings. In between meetings the researcher linked aspects of the stories told in order to make sense of and create a structured whole. The focus of the paper is on this method rather than a detailed study on resilience. Although the authors did not identify what resilience is they do state that the story told reveals "*immeasurable resources of resilience built up over time and provided some insights into how Janet might continue to utilise these resources to meet the demands and contradictions embedded in living with dementia*" (2014, p. 157).

In summary, I have found that there is little research into what the concept of resilience can bring to our understanding of dementia. Resilience has been variously described as a set of characteristics, as a process, as a strategy and as a perspective, with no single agreed definition or application within the resilience field at this time (Anderson, 2015). The interplay between life experience, previous knowledge and skills and social factors, including networks and access to resources is not well understood. There is a research focus on resilience in early stage dementia with the aim of providing evidence to support better functioning or a longer period of independence but presently there is insufficient evidence to support the early positive findings in this area. There is also a growing unease that a focus on the individual as resilient or not,

places an onus on the person themselves to be a better version of themselves. There is then a duty on the person ageing with dementia to publically state that they will fight the condition (Casey and Murphy, 2015) as to say otherwise becomes socially unacceptable. Therefore, being seen to become dependent or to appear to be in crisis is a personal failure. After all, a discussion about resilience in the context of dementia is ultimately to consider resilience within the context of physical and mental decline (Clare et al., 2011). As a result defining the better than expected outcome is difficult within this context. A focus on what is achieved through adjustment is required, rather than externally imposed measures that may be incongruent with the realities of physical and mental changes. Further, a simple analogy of resilient, independent people living with dementia does not take into account the political aspects where people and not situations are discussed as risky (Bailey et al., 2013). Resilience is therefore not a neutral term and cannot be looked at in a vacuum. Choices are made politically about what it is, how it is recognised, and how it should be employed. Symbolic interaction tools of positioning and the politics of recognition as discussed earlier in this review are central to this debate. It is through these social processes that identities are both created and sustained. In order to explore this I will now look at the literature on survival in the context of dementia. Survival is used to describe both the act of coping but also the preservation of identity in difficult situations. I will therefore explore this in more detail and consider how the positioning of people ageing with dementia as survivors could change the current discourse.

The person with dementia as survivor

Lifton (1993, p. 81) advised that “*a survivor is one who has encountered death literally or figuratively*”. This, he stated, results in feelings of separation from individuals, communities and principles; of disintegration (of falling apart or the fear of falling apart); and of stasis or immobility. These feelings of separation have also been referred to in the earlier part of this literature review where ageing and ambiguous loss were explored. This similarity is continued as Lifton stated that central to survivor identity is the re-constitution of the self in the face of loss (1993, p. 81). Van Dijkhuizen et al. (2006) linked issues of self directly

with coping responses in people who have dementia. Cheston and Bender (1999) also stated that coping involves the person with dementia finding a balance between denying or ignoring the stress issue; developing an awareness of the threat; acknowledging the threat; and in some cases failing to survive and being overwhelmed by the threat. This sense of being overwhelmed, or failing to survive, is referred to as crisis (Parker, 2007; Roberts, 1991).

Survival can be achieved in different ways. For example, Nery de Souza-Talarico et al. (2008) found that people who have Alzheimer's disease can select defensive styles to cope with stress events. The authors theorised that where the person appeared unrealistic about their circumstances this could have been the employment of a protective mechanism against the negative emotions of stressful events. This, they argued, could then be re-framed as a coping mechanism. Clare and Shakespeare (2004) also referred to people with dementia being *unrealistic* as a form of psychological resistance. However, the literature on resilience has revealed the importance of adjustment (Masten, 1994). Therefore, denials of and resistance to the changes experienced when living with dementia, even as a survival strategy, is not reflective of a resilient response. Instead, these more rigid responses leave little room for adjustments within the story of self. By focussing on adjustment as an essential component of resilience we can then start to differentiate between coping and survival discourse in dementia and the concept of resilience.

Application of the survivor identity does, however, offer an opportunity to reframe and redefine the actions of people with dementia. Keady et al. (2007) defined survival as a process of losing, finding and keeping balance. Balance is lost when stress events occur; finding balance involves the personal realization that coping is possible through past experience. Keeping balance is the employment of these previous skills or the employment of new skills either personally or with support from others. Central to this is that the person has to position themselves within a survivor and not a victim discourse. This model

presented the status quo as the desired state for survival and suggested that there was a relationship between experiences of coping in the past and implementation of coping skills in the present. It also emphasised the importance of positioning.

Jaworska (1997) considered that there is evidence of survival where the person with dementia continues to value the same things in his/her life, even where they are unable to remember details of this life. In contrast through developing the work of Ricoeur (1992) on identity and Parfitt (1984) on personal survival, Radden and Fordyce (2006) clarified that survival for people with dementia is not about evidencing sameness to others. Instead, survival of a single attribute may entitle us to "*pronounce some degree of survival between the earlier person that we knew and the much changed person with dementia we now encounter*" (2006, p. 78). The person ageing with dementia therefore survives where aspects of the personal self as survivor are revealed, and the public self as survivor is co-produced through the sharing of stories of self with others. However, it may be more appropriate to refer to the person as '*surviving*' rather than as '*survivor*' as the literature suggests that dementia is a continual process of change. Each person with dementia could potentially be engaged in a process of continual adjustment, and where adjustments do occur they could be considered as contributing to a resilience reserve where positive personal outcomes are achieved, no matter the size or scale. For those individuals adjusting to the threats experienced when ageing with dementia could be considered as the process of resilience.

Similar concepts and their relationship to resilience

When reviewing the literature in this area I uncovered similar concepts such as successful ageing (Rowe and Khan, 1997), salutogenesis (Antonovsky, 1979) and recovery (Daley et al., 2012) and it is therefore important to explore how these concepts differ from, or are similar to, resilience.

Resilience can be used inter-changeably with terms such as successful (Havighurst, 1961; Rowe and Khan, 1997), active (Walker, 2006) or productive ageing (Butler, 1969). These concepts tend to have a focus on the absence of chronic disease, identifying the risk factors for chronic disease; and the promotion of wellbeing. Older people who then experience ill-health can then, by comparison, be considered as having aged unsuccessfully or unproductively. Socio-psychological models of successful ageing focus less on biological processes and disability and more on general life satisfaction, participation and functioning (Bowling and Dieppe, 2005). The indicators applied to determine successful ageing have been debated widely and could be argued to promote ageist attitudes (Hicks and Conner, 2014). For example, independence and good levels of cognitive functioning are considered as indicators of successful ageing (Bowling and Dieppe, 2005). This can place an unrealistic responsibility on the older person to demonstrate good health and/or functioning; and that conditions such as dementia might then be seen as a failing on the part of the person concerned (Bavidge, 2006). By comparison, resilience is not measured as the absence of ill-health or adversities, instead it is concerned with the ways in which people achieve better than expected outcomes despite these challenges.

Salutogenesis emerged within the context of a public health focus on disease and the causal or risk factors for disease such as smoking and cancer (Lindstrom and Eriksson, 2006). Antonovsky (1979, 1987, 1991) theorized that stress and disease were around us all, all of the time. Given this, he was interested in the ways in which people avoided ill-health. He concluded that disease (pathogenesis) and health (salutogenesis) were at opposing ends of a continuum and considered the factors that prevented a decline towards disease. He concluded that healthier people make sense of the world, use the resources at their disposal, and see their lives as meaningful and making sense. He referred to this understanding of the risks and resources within one's life as having a 'sense of coherence' and to the resources that people then utilise to resist disease as 'general resistance resources' (Antonovsky, 1987).

Some authors have attempted to align elements of resilience and salutogenesis for example, Hicks and Conner (2014) have suggested that resilience is in fact 'sense of coherence'. However, criticisms of the salutogenic approach appear to challenge this. For example, critics state that salutogenesis has failed to take account of people who have limited access to resources as a result of restricted life opportunities such as poverty (Harrop et al., 2009). It also has a focus on health creation (the literal translation of the term salutogenesis) however the absence of ill-health does not necessarily equate to wellbeing. For example, salutogenesis had been used by Friedland et al. (2001) to explore and explain why not everyone who ages goes on to experience dementia. This research located the absence of dementia as the salutogenic goal and placed dementia at the disease end of the spectrum as an example of pathogenesis. Equally a condition such as dementia which is progressive does not fit easily within a discourse that focusses on an absence of ill-health. This is similar to the criticisms of successful ageing.

Unlike resilience salutogenesis has a primary focus on the person in the present, and is less concerned with the contribution that history and biography make (Harrop et al., 2009). This approach therefore fails to include the development of resilience over time or the potential for resilience reserves. People with dementia who experience threats may experience some loss of control or sense of meaning at different times as explored in this review. A resilience focus would then be as to how the person is able to adjust to each loss, not the avoidance of loss as is suggested through the salutogenic model. Taylor (2004) concluded that salutogenesis tends to be associated with those who are well educated and in positions of social or financial privilege whom Hulko (2009) found might in fact be less resilient when a condition such as dementia is experienced. Both Harrop et al. (2009) and Windle (2011) concluded that resilience and salutogenesis were related concepts but distinct discourses.

Recovery, like resilience, has no single definition. It is described by Anthony (1993) as a personal process of changing one's attitudes, values and goals in order to live a more hopeful and satisfying life, with the symptoms of mental ill-health. A review of 97 papers (Leamy et al., 2011) to determine the key components of recovery found three distinct characteristics. These are the recovery journey, the recovery processes and recovery stages. The goal of recovery is not the absence of the mental health condition instead the focus is the process of re-evaluating one's position and moving forward with hope (South London and Maudsley NHS Foundation Trust et al., 2010).

Recovery in the context of dementia has been defined by Daley et al. (2012) as the recovery of self. They interviewed 11 people with a diagnosis of dementia, describing 7 as having mild dementia and 4 as having moderate dementia. The purpose of the interview was to determine the impact of the condition on each person's life. For those with mild dementia the biggest impact was reported in everyday activities and living with memory loss. However, this did not include self-reports of those participants with moderate dementia, who were described as unable to articulate views on impact. The people who did contribute equated recovery to maintaining a sense of self. This research concluded that the locus of recovery moves from the person with dementia to others, such as spousal carers, as dementia progresses. Recovery in dementia was therefore proposed as an outcome of caring relationships, instigated and supported by others, not the person concerned. Hill et al. (2010) explored the similarities between recovery and person centred care in dementia. They concluded that although they have a common purpose, it was not always possible to achieve hope given the progressive nature of dementia.

Bonnano (2004) found that there were clear differences between recovery and resilience. Recovery concerns long periods of ill-health or ill-being, followed by a gradual return to pre-event health. Resilience, by comparison, is characterised by the nature of the response to shorter interruptions to wellbeing or function. Norris et al. (2009) concurred with this. Their research on the

outcomes for adults who had experienced trauma found that the resilience process involved continual adjustments, and was more sensitive to subtle changes in wellbeing or stress experiences. Recovery, by comparison was reported as an upward trajectory towards pre-event levels of wellbeing. This helps us to understand recovery as a path towards a new life view whereas resilience is a variable which can influence this journey (Norris et al., 2009).

Having reviewed successful ageing, salutogenesis and recovery I have found that although they are related to resilience they emerge as distinct concepts and I will therefore proceed on this basis.

Summarising the literature on resilience

The review of the literature on resilience has highlighted the different definitions and applications of the concept. Resilience is not a neutral concept, it is defined by different groups and applied in different ways to achieve specific outcomes. There is a very small literature dealing with the subject of resilience and dementia, and a lack of agreement on what might constitute vulnerability and protective factors for a person with dementia over and above what is discussed in the literature on older adults. Resilience is a complex process which includes the interaction of vulnerability and protective factors and is context specific, not a fixed state. To this end, level of need or support, or independence is not an indicator of resilience as it could be indicated in the ways in which each person adjusts to such needs. Bailey et al. (2013) rightly emphasised that there remains a focus on people with dementia as inherently risky people rather than people living in risky situations.

Interesting debates are emerging, however, around reserve capacity or resilience reserve which focus on the skills and resources that people acquire over the lifespan in order to mitigate and respond creatively to the challenges of the potential loss of self. In particular, considering how those who have experienced loss of recognition over the life course might harness this

experience in the present is an extremely interesting idea worthy of further development. These debates are of extreme relevance to the social work role and process which I will explore in the next section. In trying to understand resilience from the perspective of dementia, I have determined that ageing with dementia can be life adversity (or as a series of adversities), where individuals risk the loss of self as a result of the symptoms of dementia and the attitudes of others and wider society. This can be loss of self with reference to personal identity as well as the loss of recognition of valued public identities as a result of stigma and ageism. Loss of identity is a negative outcome for the person concerned. Therefore the preservation of identity, in the face of dementia, can be viewed as an outcome of a resilience process. Having considered the literature I posit that the resilience process is supported by a resilience reserve, a personal bank of skills, experiences, knowledge, and resources which may act as a buffer and facilitate adjustments in situations of adversity or risk. All of this takes place within a wider context where the public identities of people ageing with dementia can be framed around vulnerability and the need for protection. The implications of these findings for social work practice will be the focus of the following sections of this review.

Part Three: Social work with people ageing with dementia

What is social work?

Payne (2014) advised that there is no single definition of social work. Social work is constructed through several interactions: namely those interactions between people and social workers, with social workers and their organisations, and between social workers and other professionals or organisations. The International Federation of Social Workers (2014) stated that:-

“Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing.”

In Scotland, a social worker is defined in the Regulation of Care (Scotland) Act (2001) as a person who has an entitling social work qualification. Social workers have a range of powers and duties which they undertake across a range of legislations, the primary statute being the Social Work (Scotland) Act (1968). Social work is undertaken in complex situations, where practitioners protect individuals and promote their wellbeing. Social workers are expected to consider cultural, racial and ethnic identity; risk, resilience and rights; language differences; legal obligations and statutory responsibilities to protect vulnerable individuals (Scottish Executive, 2003, p. 27). The Social Work Services Strategic Forum (2015) stated that the promotion of human rights and social justice through tackling inequality and disadvantage is one of the key principles that underpins all public services in Scotland. O'Connor et al. (2006) stated that social work is put into practice through the interaction of self in relation to others, the use of assessment as process and content, and the employment of

a range of intervention methods. I will explore each of these aspects within this review.

Social workers must achieve a balance between promoting self-determination and independence for the individual whilst ensuring that those people who require protection from themselves or from others receive it. This can be described as maintaining the balance between social justice and social control (Gilmour et al., 2003). Approaches to achieving this fall into what Payne (2014, p. 19) described as three distinct theories of what social work is. These are the empowerment model, the social change model and the problem-solving model. Empowerment models see social workers as helping people to understand their situation and as a result to gain personal power (Dominelli, 2009). Social change models facilitate learning and co-operation approaches as those in need are considered as being caught in power relationships within society. Change is possible through the transfer of power to the most oppressed (Payne, 2014, p. 19). Problem-solving models view social work as operating within the welfare state, responding to individual needs with the aim of restoring stability in people's lives and, by default, maintaining the existing social systems. Social workers can adopt different aspects of each model in different circumstances. The practice of social work is then undertaken using approaches that support each particular theoretical perspective.

These differences in perspective can be seen in the following example of an older man identified through the assessment process as being lonely and at risk of isolation. A problem-solving perspective could focus on resources to combat loneliness, such as a referral to a day centre or a befriender. An empowerment perspective could involve working with the person concerned to identify why he was lonely and what could be changed to enable him to feel less isolated. Intervention might then include therapeutic work to better understand self and assistance to access social resources. A social change perspective would prioritise addressing the ways in which society contributes to the isolation of older people through restricted opportunities, in this example restricted social

activities. Intervention might then include challenging poor transport provision or ageist assumptions about older people in order to ensure equal access to community resources such as leisure centres. Practitioners could incorporate elements of all three approaches.

Social work theories, definitions and practice models are influenced and constructed through social policy and politics, whether in support of or as a challenge to the policies of the day. The present social work role has been shaped by modernisation reforms in health and social care (Ferguson and Woodward, 2009; Jacobs et al., 2009). For example, many local authorities have implemented eligibility criteria in order to deliver services to those assessed most at need as they manage reduced budgets. This is an example of the new bureaucracy of social work in neo-liberal times according to Hastings and Rogowski (2014). Manthorpe et al. (2008) discussed this as leading to tensions between the demands for business efficiency and core values of anti-oppressive and empowering practice. I will return to these issues later in this review. I will now look specifically at the literature on social work and dementia.

Social work and dementia

The literature on dementia is divided into three main categories: social work practice, including communication, assessment practice and intervention models (Adams and Gardiner, 2005; Fawcett and Reynolds, 2010; Gould and Kendall, 2007; Hardwick, 2009; Kerr et al., 2005; Larsson and Österholm, 2014; Manthorpe and Ilffe, 2005, 2009; Marshall and Tibbs, 2006; Nolan et al., 2002; Österholm and Hydén, 2016; Österholm and Samuelsson, 2014; Parker, 2007; Tibbs, 2001; Wilson et al., 2009; Young, 2010), social work research - into topics such as safeguarding or adult protection practice and the implementation of personal budgets (Dwyer, 2010; Emilsson, 2005; Emilsson, 2012; Manthorpe et al., 2004, 2008; Manthorpe and Martineau, 2016; Manthorpe and Samsi, 2013; Means et al., 2002; Werner and Landau, 2011) and social work education (Kane 2004, 2008; Larkin, 2007; Parker, 2001a, 2001b, 2006). From these papers I have summarised key topics of positioning in practice, assessment

and issues of risk, vulnerability and protection and I will now discuss each in turn.

Positioning in practice

In his study into the views of social work students on older adults, Kane (2008, p. 45) found that older people were perceived by social work students to be frail, vulnerable and with questionable resilience. This paper building on Kane (2004) raised issues of identity, recognition and positioning. Kane stated that although social work education teaches practitioners to view individuals from a strengths perspective, social work students still hold some ageist attitudes that affect assessment and intervention choices in their work with older people (2004, p. 778). His findings indicated that this practice is often justified by students as there is a perception that all older people are or will become incompetent. Conditions such as dementia are seen to confirm this. The concern is then raised that these views lead to continued positioning of older people as having no resilient resources and resultant therapeutic nihilism in post qualifying practice i.e. there is no cure for incapacity therefore there are no social work intervention options other than to manage the person and their presenting situation. Moriarty and Manthorpe (2016) found that research on the effectiveness of social workers with people who have dementia was limited to an examination of care management and service provision. For example, as recently as 2010, Golightley wrote that the role of the social worker in dementia care is to work as part of a multi-disciplinary team that provides support services. He stated that the role included '*arranging welfare benefits, providing information and explanation of the user's situation to family, neighbours and others, arranging and financing social support systems and eventually specialist nursing care if necessary*' (2010, p. 33) succinctly positioning the person with dementia as passive and possessing no personal agency. However, although the developing social work agenda on practice continues to refer to care management and the practical support of people with dementia the professional discourse does now also include reference to strengths and relationship based practice, as well as risk assessment, risk management and protection (SSSC, 2014: TCSW, 2015).

The issue of positioning was the subject of the 2014 paper by Österholm and Samuelsson. They analysed interactions in five assessment meetings between social workers and a person with dementia, with a family member or friend also in attendance. They identified six phenomena taking place in these meetings that worked to position the person with dementia as less competent than the person without dementia. This included: ignoring the person with dementia; voicing the feelings, capacity or opinion of the person with dementia from the social worker's perspective; posing questions that implied a lack of competence on behalf of the person with dementia; using the diagnosis of dementia to ascribe or justify a less competent position within the interaction; facilitating the person with dementia placing themselves as less competent and finally using what the authors describe as '*elderspeak*' (p. 16). This was signalled by phrases such as "we" as in "we think that's best" implying that prior discussions and decisions have already been made and using the person's first name routinely without checking that it was appropriate to do so. The researchers state that this can be a positioning tool to "*create a sense of diminution*" (p. 17).

Positioning occurs due to a complex interaction of factors that include the politics of recognition (Taylor, 1994) and our use of frames to make sense of the world around us. These are important issues in social work practice with older people. Sullivan (2009, p. 1309) identified three interrelated components:-

- The interpreting human being (in this case the social worker) and their beliefs, feelings, ideas and understanding.
- The behaviour or action and the interaction (in this case the action of the person with dementia and the interaction between the person with dementia and their social worker).
- The presentation of self by the social worker (for example, as the competent social worker).

Social work knowledge is therefore influenced by learning, values and beliefs, personal and professional experiences. Sullivan (2009, p. 1310) stated that professional knowledge and meanings are confirmed through continual social interaction and that this then becomes the “*individual or collective’s framework of frames – or their belief system*”. Sullivan’s (2009) findings indicated that social workers are uncomfortable with ambiguity and as a result continually strive to create meaning in keeping with their role as assessors. Frames and positioning facilitate this process by providing a point of reference for interpretation. This facilitates a sense of professional control within ambiguous situations.

Assessment

Opportunities for identifying resilience sit within the broader framework of interpretation or finding meaning. Within social work, assessment is the mechanism for determining meaning. O’Connor et al. (2006, p. 79) with reference to the work of Sheppard (1995) stated that assessment is the systematic application of theoretical, personal, empirical and procedural knowledge. This is referred to as the assessment process (O’Conner et al., 2006). This process is central to social work practice as it is used to identify needs, risks, aspirations and strengths, the outcome of which is to produce a written assessment record with the purpose of care planning (O’Conner et al., 2006). Crisp et al. (2007) determined, however, that because assessment is so closely aligned with resource allocation it can often be approached as a checklist focussing on need and risk. The bureaucratic function of the document can then be prioritised over the analytical role of assessment in process and practice. If assessments are approached as simply checklists for resources then social work practice could develop to identify and record deficits and risk within assessment, over and above strengths. Prioritisation of bureaucratic process, and the potential for social workers to position people negatively within interaction (Österholm and Samuelsson, 2014) could work together to deny the older person with dementia the right to challenge assessments with their own perspectives and opinions.

If the assessment process is the mechanism for finding meaning in social work practice it can thus be considered as part of a social process. Assessments are generated through the social practice of social work: social work being both a conceptual and an organisational, procedural function. Looking in more detail at the process of generating an assessment I have referred to the work of Goffman (1981) on text. Within any document there is a principle and an author. Goffman (1981) identified the 'principle' as the person whom the text is about and the 'author' as the person who generated the text. The author, in this case the social worker, must make decisions about what is included in the written assessment record and what is omitted. The content of any assessment document is an interpretation of the interaction between the social worker, the person with dementia and the other participants in the process. It then follows that the extent to which the voices of participants are represented in the final document text is at the discretion of the social worker as author. This appears to be reflected by Österholm and Hydén (2016) who analysed the narratives from 15 assessment meetings between social workers, a person with dementia and family member. Their focus was on the ways in which the autobiographical stories of people with dementia were represented within the assessment process. They explored how the person with dementia's story could be minimised or challenged by the other parties present, or where the person's story was narrated by the family carer. They found that the story told was used by social workers within assessments in three ways. These were: to promote a good relationship within the assessment meeting with the person concerned; justification for care services within the social work organisation and to describe experiences about previous care within the assessment document. They challenged the description of these stories as autobiographical due to the influences described and concluded that more awareness of the positioning of people with dementia within assessment processes and assessments records was therefore required by care managers.

Whittington reported that assessments represent the “*entry of an intentionally rational and systematic approach to the encounter between a social worker and people seeking help or services, who may be individuals, couples, families, groups or communities*” (2007, p. 15). He identified two distinct assessment styles which social workers employed when undertaking assessments. These were ‘technically competent’ and ‘critical thinker’. Technically competent practitioners placed an emphasis on need, eligibility and organisational process. Critical thinkers were more likely to produce assessments that reflected the individuality of the person and their situation, but also to reveal contested areas of process and practice. However, critical approaches may not be as effective in securing resources where there is a focus on structural inequalities over and above the perceived limitations of need and risk for the individual. Whittington (2007) referred to this tension as realism versus idealism.

This debate on the impact of realism at the expense of more critical approaches is ongoing in social work discourse. Webb (2001) determined that technically competent approaches, which he referred to as techno-rational, failed to acknowledge the important dynamic of inter-personal relationships between social workers and the people that they are working with. This dynamic is essential according to O’Connor et al. (2006) who stated that social work is put into practice through the interaction of self in relation to others. The perceived loss of identity, communication changes and lack of apparent continuity that occur when a person has dementia can mean that inter-personal relationships appear more difficult to put into practice. In such cases social workers can rely more heavily on social frames of reference and practice wisdom to make sense of each interaction. Gould and Kendall (2007) advised that these individual views about identity, self and professional frames have the power to shape not only individual social worker practice but also collective social and organisational responses to people with dementia and their families. This highlights the importance of social work practice that takes account of evolving models of citizenship such as that described by Nedlund and Nordh (2015).

Stories within assessment practice

Approaching assessment from a narrative or storytelling perspective provides a vehicle for generating co-constructed meaning. Young (2010, p. 193) stated that this moves the focus to the *person's* construction of the meaning of their experiences, and not that of the interviewer. Roscoe et al. (2011) found that the use of narrative in social work practice is an under developed field. However, they argued that stories are socially and culturally located and as such critical examination of stories as narrative is a valid social work practice (p. 50). In this way narrative citizenship can be revealed as the stories of people living with dementia are contextualised, through social work knowledge and practice, within personal, interpersonal and political constructs. This builds on the work of Clarke and Bailey (2016) through the development of an explicit, professional social work model, and in doing so differentiates the role of the social worker from that of generic social care approaches.

There can be practical difficulties in hearing the stories of people with dementia. For example, Young suggested that social workers often listen for chronological or logical connections in narrative. As a result stories that are considered illogical, disjointed or confused are often dismissed or used as evidence of cognitive decline within assessments (2010, p. 200). However all stories have the potential to reveal important information about character, themes and personal values. Stories can often also offer an insight into the person's sense of self at the point of the interaction. Interestingly, White and Epston (1990, p. 29) stated that choosing to recall your story out of the traditional chronological sequence can in some instances be an act of resistance against dominant discourses. Young (2010) developed this view by stating that this can result in opportunities for unique outcomes and personal solutions with the opportunity for more effective, meaningful social work practice. Biography is also a way of finding out about important relationships, attachments and discovering stories of resilience and survival.

Iverson et al. (2005) reported that a collaborative dialogue approach results in transformative outcomes for the person concerned. They stated that this occurs in three ways. First, by challenging existing realities; second, by realising new realities and finally, and perhaps most importantly, realising the potential for continuous dialogue. The inner world of a person with dementia cannot be characterised without reference to the external world as all thoughts and intentions relate to the person's social world (Hughes, 2008). It therefore follows that the content of a person's thoughts are conveyed to others through both words and actions, including behaviour and non-verbal communication. Even when the wrong words are used gestures, tone of voice and expression can convey what a person is thinking and feeling (Hughes, 2008). Social workers can therefore engage with the individual, using stories to explore and validate resilient identities in hidden discourse. Elements of personal, professional and organisational identities are then features of any interaction undertaken as a social worker.

Social work accounts of others

With reference to this reading I reflected on how social work practice with people living with dementia could be framed as "*an unproblematic field of experience and set of practices which are accepted without question*" (Langellier and Peterson, 2004, p. 157). Social workers' accounts routinely represent 'the other' (in this case the person ageing with dementia) in their daily practice. White (2002) explored this in her work with social workers in child care settings. She found that speakers persuade listeners of the attribution of causality, in the way in which they give accounts of the people that they are working with. They do this in a way that is institutionally and culturally recognisable to those within that system. These stories are built on shared understandings or social frames which are unspoken, but hinted at through the use of a story structure that is recognisable and often relies on key phrases. An example would be to construct an account by beginning with biographical data, then medical information and moving on to discuss social issues. Risks to the individuals concerned also featured prominently as motivating factors for timescales and resource provision.

Issues of risk and protection

The interest in risk management and protection practice is also reflected in social work literature regarding practice with people who have dementia. Recent legislation such as the Adult with Incapacity (Scotland) Act (2000), the Mental Health (Care and Treatment) Scotland Act, 2003, the Mental Capacity Act 2005, and the Adult Support and Protection (Scotland) Act 2007 appear to have influenced this in particular with adults who may lack capacity (Dwyer, 2010; Kaplan and Bryan, 2009; McDonald et al., 2008; Stanley and Manthorpe, 2009; Van Dom et al., 2010) and in dealing with issues of risk, risk management, safeguarding and dementia (De Witt et al., 2009; Green, 2008; Kemshall, 2010; Manthorpe and Martineau, 2016; Manthorpe and Moriarty, 2010; Manthorpe and Samsi, 2013).

The Report of the 21st Century Social Work Review in Scotland (Scottish Executive) suggested in 2006 that the social work profession was lacking in confidence, increasingly risk averse and lacking autonomy. Sherwood-Johnston (2016) explored the complex relationship that exists between policy, practice and issues of protection and vulnerability. Two distinct discourses are suggested within this work. A discovery approach reflects the assumption that such legislation is required because persons (in this case with dementia) are at risk and professionals must respond to this. A constructionist approach analyses how identities such as vulnerable or resilient can be constructed through processes. I have discussed this throughout this review with reference to dementia. Although resilience has been explored with reference to social work practice (see for example, Daniel et al., 1999; Daniel and Wassell, 2002a, 2002b, 2002c; Fraser et al., 1999; Greene, 2002; Norman, 2000) there remains a lack of clarity about the relationship between risk, vulnerability and protection with reference to the social work practice which takes place with people ageing with dementia.

Barry (2007) stated that the literature on community care is highly critical of the emphasis on risk over and above care and treatment models and recommends policy and practice initiatives that demonstrate confidence and commitment to encouraging people rather than restricting capacities. Robinson et al. (2007) compared the views of people with dementia and professionals regarding risk. They found that professionals focus on the physical domain of risk such as harm, whereas people with dementia focus on the biographical domain such as loss of identity (2007, p. 401). Clarke et al. (2010) interviewed 55 people with dementia, carers and practitioners in order to identify contested areas of risk perspective. They identified contested areas as friendships, smoking, going out, domestic arrangements, occupation and activity. They concluded that continuing to engage in such activities was important for the identity of the person concerned. This then opens up a new perspective on risk management as a building block in the continuity of self, placing social workers at the heart of this through their practice relationships and responsibilities. Clarke and Bailey (2016, p. 436) stated that more needs to be known about how people living with dementia and the significant people in their lives define and manage risk, and how they then in turn draw on their own resilience to foster a sense of wellbeing and achieve a good quality of life.

McDonald et al. (2008) identified three different roles adopted by social workers when working with people with dementia. These roles were described as *legal representatives*, *protectors* and *advocates* (2008, pp. 32-34). *Legal representatives* were positivist practitioners who sought structure, routine and prescribed responses to issues that arose. *Protectors* viewed those who lacked capacity as unable to foresee and take precaution against obvious risks. They therefore sought to persuade people with dementia to accept less risk associated activities. The third role of *advocate* was described as being explicitly person centred. Advocates had an acute awareness of the social construction of the identity *person with dementia* which resulted in a risk enablement approach such as that promoted through the findings of Clarke et al. (2010). Manthorpe (2004, p. 142) also explored this issue explicitly linking

risk averse practice and dementia to a wider discourse of ageism and oppression. To consider risk enablement and resilience as possibilities for people with dementia is to openly challenge these powerful constructs. Manthorpe cautioned that if people with dementia are seen as “*personifications of risk then there is a greater likelihood that fear and ignorance will govern assessment and risk management*” (2004, p. 148). This is similar to the themes raised by Bailey et al. (2013) that people with dementia are inherently viewed as risky people. The roles adopted by social workers in their work with a person with dementia therefore have a direct impact on practice and outcomes.

Summary

Within this section of literature I have discussed the definition of a social worker in Scotland and explored the ways in which ideological and bureaucratic factors can contribute to this. Social workers have an important role working with people ageing with dementia but they undertake this work within a changing landscape and the profession has acknowledged that more provision must be made to support social workers in their work with people ageing with dementia (SSSC, 2014; TCSW, 2015). However, I found a lack of focus in the current literature on building an evidence base for social workers to use resilience in their work with people ageing with dementia despite a policy outcome in many of the supporting documents that promotes resilience. The relationships that social workers have with people ageing with dementia are the basis on which identities are created, shared and validated. Social workers must therefore be able to understand reflections of identity within the stories told by people with dementia, and to understand their significance within a resilience context. I will explore this in more detail in the literature review conclusion as I now move to a discussion summarising my findings, highlighting the gaps I have found in the current knowledge and finally focussing on my research questions.

Part Four: Discussion and conclusions

This review has considered a range of literature on the subjects of ageing with dementia, resilience and social work with people ageing with dementia. Dementia is a syndrome of the brain which results in a range of signs and symptoms, the most common of which is short-term memory loss. There are many conditions which cause dementia and diagnosis can be a complex process, with little reference to a person's existing skills and life experiences, both past and present. People with dementia can be described as 'sufferers' or as a 'burden' to those who care for them, and to wider society in practical and economic terms. I have suggested that re-positioning people with dementia from victims of disease to citizens with the capacity for resilience (Clarke and Bailey, 2016; Nedlund and Nordh, 2015) could facilitate an exploration of the impact of power and inequality on the experience of ageing with dementia, in both everyday relationships and situations, as well as in wider society. Further, the nature of citizenship itself and the ways in which people living with dementia reveal their citizenship is an evolving discussion. Fundamental to this is the subject of identity and in particular the preservation of identity in people living with dementia. This preservation is shown within the literature to be an active process that the person with dementia is engaged in as they live with the experience of being labelled 'person with dementia'.

In order to explore this I have considered the literature on the ways in which identity is realised, differentiating between the personal identity of characteristics, roles, actions and experiences and public identity which is realised in storytelling relationships with others. A public identity that includes the potential for resilience can arguably only be realised through symbolic interaction processes of co-creation; and validation of resilience in relationships with others. This could be achieved through the sharing of stories of self (Radden and Fordyce, 2006, p. 73). The small stories of everyday life, can be viewed as observable social practices (Georgakopoulou, 2006, p. 129) eligible for study as narratives which contribute to the preservation of identity in people

who have dementia. This has been referred to within the context of both narrative and social citizenship (Baldwin, 2008; O'Connor and Nedlund, 2016).

The review of relevant literature on resilience has highlighted its different definitions and applications. Resilience is not a neutral concept rather it is defined by different groups and applied in different ways to achieve specific outcomes. Resilience is a process and not a personality trait. It is also an ordinary phenomenon, and therefore the possibility of resilience in the context of ageing with dementia is valid. Resilience is described as a complex interaction of adversity, risk and protective factors (Luthar et al., 2000). In trying to understand resilience from the perspective of dementia, ageing with dementia can be considered as a life adversity, where individuals risk the loss of identity. This can occur as a result of the attitudes of others and wider society, which arise through ageism, stigma and self-stigma. This perceived loss of identity can be considered as a negative outcome for the person ageing with dementia. Therefore, I have concluded that the preservation of identity, in the face of dementia, could be viewed as the outcome of a resilience process.

The literature has suggested that resilience could be understood as the accumulation of a personal bank of skills, experiences, knowledge, and resources built over the life course. I have referred to this collectively as a resilience reserve with reference to the work of Clare et al. (2011), Forstmeier and Maercker (2008) and Hulko (2009). This reserve could then facilitate adjustments in situations of risk to self, to preserve those aspects of personal and public identity which are important to each individual. All of this takes place within the wider context of ageing with dementia, where people can be seen as vulnerable and in need of protection. The political aspects of resilience and the condition dementia are therefore of particular importance in understanding how people experience interaction with other individuals, organisations and society.

It is also important to recognise resilience as different from other responses such as denial, which although may be employed as a self-protecting mechanism, does not facilitate adjustment responses. It is equally important to distinguish resilience from similar and overlapping concepts such as successful ageing, recovery and salutogenesis which I have addressed within this review. In order to clearly state this I have arrived at a definition of resilience within the context of ageing with dementia as: “*adjustment in the face of the threats to personal and public identity experienced when ageing with dementia*”.

Social workers have an important role working with people ageing with dementia. I have discussed the definition of a social worker in Scotland and the nature of social work practice in Scotland and, explored the ways in which political, ideological and personal factors contribute to this. The profession has acknowledged that more provision must be made to support social workers in their work with people ageing with dementia (SSSC, 2014, 2015; TCSW, 2015). I found a lack of focus in the current literature on building an evidence base for social workers to use resilience in their work with people ageing with dementia despite a policy context that refers to the promotion of resilience. The literature has suggested that a symbolic interactionist perspective on the relationships that social workers have with people ageing with dementia can support a new approach. Also, that the resilience of the person with dementia could be co-produced, and therefore is dependent on social workers being able to recognise reflections of identity within the stories told by people with dementia, and then to understand their significance within a resilience context. Practice relationships are therefore the basis on which identities can be created, shared and validated. Social workers are dynamic, active participants within interactions with people ageing with dementia. Social workers and people with dementia are therefore co-participants in the construction and validation of *each other's* identity. I have established through this review that the accounts of social workers about people with dementia could offer insights into positioning and the creation of the public identity ‘person with dementia’.

In conclusion, this review has highlighted the following gaps in knowledge. There is a lack of focus in the literature on the subject of resilience in the context of ageing with dementia and social work practice. Neither is there agreement within the literature on resilience and dementia as to a definition of resilience, the identification of protective and risk factors, nor the way in which these factors may interact. This research will contribute to the existing knowledge in this area by exploring what the concept of resilience can bring to our understanding of dementia; through exploring how the stories told by people ageing with dementia can reveal resilience and/or resilience strategies; and finally to explore to what extent social workers recognise and respond to resilience in practice.

Research questions

My research questions are therefore:-

1. *What can the concept of resilience bring to our understanding of dementia?*
2. *In what ways do persons ageing with dementia demonstrate resilience in their stories?*
3. *To what extent do social workers recognise and apply the concept of resilience in their practice with persons ageing with dementia?*

The next chapter will focus on the research design employed to answer the questions posed.

Chapter 3: Research Design

I will now discuss the methodological approach employed to answer the research questions. I will introduce the research design and discuss the rationale for this. I will discuss in detail my approach to sample selection, data collection, data management and analysis. This will include discussion on issues of consent, ethics and accountability.

Overview

The research was undertaken from a symbolic interactionist perspective, using a narrative methodology and employing thematic analysis. I recruited six dyads of person with dementia and his or her respective social worker. I used semi-structured interviews to capture the stories told by each person with dementia. The purpose of this was to explore the ways in which people with dementia might demonstrate resilience in their stories. I also conducted semi-structured interviews with social workers to record their accounts of social work practice with a person with dementia. I anticipated that this would reveal how the public identities of people with dementia were created and sustained, and whether resilience played a role in this process.

Methodological approach

The literature review revealed the importance of identity in all three of my main subject areas of resilience, dementia and social work practice. Symbolic interactionism provided a means of understanding identity, and explaining how public identities are created and influenced. I therefore decided that applying a symbolic interactionist (Mead, 1934) approach to my research methodology would be in keeping with the findings of the literature review. As stated within the literature this perspective focusses on social interaction as the catalyst for meaning in everyday life. Knowledge is gained through the personal experience of interaction and therefore to understand any situation it has to be viewed from the perspective of the specific individuals or groups involved. This

approach considers individuals to be dynamic social actors engaged in the sharing of stories in order to create social meaning. Social meanings are not static, objective or neutral as meaning is formed and then reflected on (Harding and Palfrey, 1997, p. 10). Structural inequalities and issues of power influence this process. Individual stories have a central role in this process as it is through our shared accounts that reality is constructed (Gergen and Gergen, 1991). Given my focus on stories as both integral to the resilience process and as a means of preserving identity in dementia, I selected a narrative research method that would allow me to record the stories told by people ageing with dementia.

Narrative research

Narrative research is a qualitative research approach that deals in and with stories (Roberts, 2002). Polkinghorne (1988, p. 1) considered narrative as the “*primary scheme by which human existence is rendered meaningful*”. Storytelling, as narrative, considers stories as the vehicle for creating order out of our many and varied experiences and emotions. This starts in childhood and continues through all stages of our life (Moen, 2006, p. 1). Narrative research therefore involves the collection of people’s stories in order to understand how we experience the world (Moen, 2006, p. 1). Kerby (1991, p. 33) stated that it is through telling stories that we make sense of our lives. Therefore, using stories as units of analysis reveals the connections people make between different events in their life (Hydén, 2010, p. 33). This, in turn, can reveal aspects of identity. The stories told by people ageing with dementia are as important as those told by anyone else and also offer such insights (Muller, 1999).

The narrative moment

Plummer (1995, p. 19) described this interest in personal storytelling as a legitimate means of knowledge production as “*the narrative moment*”. Personal stories can be differentiated from ordinary conversation when used as narratives. This is recognised in the following ways. First there is always a narrator and an intended audience (Roberts, 2002). Toolan (1988, pp. 4-5) also stated that stories can have a degree of artificial fabrication and displacement. That is, that the narrator can refer to things or events which are removed in space and time from both the speaker and the addressee. Stories have dramatic license where the teller can emphasise events and people to better illustrate their own personal perspective. Narratives also have a trajectory, they are intended and expected to go somewhere and have a resolution or conclusion (Reissman, 2008). When a person has dementia, changes to communication can mean that the trajectory or plot direction might not always be clear. However, listening for the moral or point of the story can open up a wider sphere of information about the person and their life (Hydén, 2010; Labov, 1972). Although storytelling is context-bound, meanings can be created anew as stories are re-visited by different audiences or viewed in different formats. So, for example, new meanings arise in the relationship between story, researcher and transcript; story, text and reader etc. (Reissman, 2008, p. 139). This approach therefore positions the participants within wider societal and relational flows (Hydén, 2010; Smith and Sparkes, 2008).

Reissman and Quinney (2005, p. 394) advised that narrative research encompasses many different styles and techniques. They viewed this as a continuum, where at one end entire life histories are explored in anthropology, through to focussed social linguistics studies (see Robertson, 2013). My interest in hearing the personal stories of the person with dementia, through a semi-structured interview process (Minister, 1991; Mishler, 1986, 1999), sits within the middle of this narrative research continuum. Although this approach uses a conversational style of interview (Resissman, 1993) preparation is required in order to facilitate the dialogue. Fraser (2004, p. 184) stressed the importance of preparation in selecting participants, understanding a person’s

social context and individual communication styles. She also stated that trust, sensitivity to time and honesty about the nature of the research are vital. Importantly an appreciation of the politics of making new knowledge also has to be addressed. I attend to all of these issues when I discuss the practical aspects of my methodology.

Narrative research and dementia

Storytelling as narrative research is often used when trying to understand how people respond to biographical disruption, caused by illness or trauma (Labov and Waletzky, 1967; Langellier and Sullivan, 1998; Langer, 1991; Plummer, 2001a, 2001b; Reissman, 2008; Williams, 1984). Williams (1984) wrote on the subject of narrative disruption but importantly on the issue of reconstruction through storytelling. The experience of adversity can cause disparate events to be pulled together into a new story plot, which then takes a new direction, different to that of the pre-trauma story. I considered that ageing and dementia could be viewed as life disruptions and that a resilience lens applied to the stories of people ageing with dementia could reveal the process by which adjustments, if any, are achieved. Similarly the stories that people choose to tell become tools in the management of impressions of self by others (Goffman, 1959). This is revealed as the teller does not restrict stories of self to the source of disruption. Instead, they remain part of a wider social context. For example, Langellier and Sullivan (1998) found that the stories told by women who had breast cancer were contextualised within rich life stories, family histories, family dynamics, and communities of work (p. 78).

Ottmann and Maragoudaki (2014) used a narrative approach to explore if older people had resilience strategies which could be employed in response to threats in old age. Randall et al. (2015) combined both standardized resilience scales and narrative analysis approaches in their study. Following completion of the resilience scale, those involved participated in a qualitative interview process. The researchers then compared the narratives of the best and lowest scoring participants. This second phase of analysis included by the researchers, indicates that there is a deeper level of understanding available about resilience through the inclusion of narratives. They concluded that narrative openness was an important factor in the resilience process.

The literature review revealed that interest in the narratives of people living with dementia has grown considerably. In my review I introduced Angus and Bowen (2011) who concentrated on the power of a single story in their 'relationship-centred' approach to narrative. Building on the work of Ramanathan (1995) they focussed on the connection between the story teller with dementia and the listener in realising a coherent plot together (p. 112). They deconstructed the story into smaller units and identified the central story themes. The story is considered as a stage on which the person with dementia can "*explain, entertain, inform, defend, complain and confirm or challenge the status quo.*" (p. 116) or allow their story plot to unfold. The role of the researcher is both to gather data and to provide structure, sequence and meaning in order that the story becomes intelligible to others. In this way, the story themes reveal important insights into personal identity and public identity aspirations that otherwise might not be available.

Hearing the accounts of social workers

In addition to this I planned to examine the oral accounts of social workers on social work practice with a person living with dementia. The reason for gathering data in the form of the professional account was to reflect the reality of day to day discussions and practice in a social work setting. These verbal accounts of others form the basis of decision making in a variety of settings and are an accumulation and summary of assessment outcomes and interaction processes (White, 2002). Building on my literature review I considered that thematic analysis of these accounts could offer insights into the identities of people ageing with dementia from a social work perspective. I also wanted to focus specifically on expressions of resilience and applications of resilience frameworks within these accounts. In this way the interview content recorded with the social work participants was quite distinct from that generated with the people living with dementia. I engaged with the identity 'social worker' and recorded a very specific account from this perspective. I employed a purposive sampling approach which I will now discuss, starting with ethical considerations.

Ethics

Research ethics is the application of ethical principles to all research activities. This includes the research design and its application, treatment of others and the use of resources and research outputs. This research was planned and implemented in accordance with the principles of the Economic Social Research Council Framework for Research Ethics (ESRC, 2010); Code of Good Research Practice (University of Stirling, 2009), the School of Applied Social Science Ethics Handbook (2010) and the principles and values that guide the professional code of conduct for social service workers and their employers (Scottish Social Services Council, 2009). These include fairness, honesty, accuracy, efficiency, objectivity, beneficence, non-maleficence, justice, respect and autonomy. The project was subject to the scrutiny of the School of Applied Social Science Research Ethics Committee. It was also scrutinised at local level using the Local Authority research protocol. I shared details of the project and the initial design with local interest groups. For example, an outline of the project was shared with a local advocacy project and Alzheimer Scotland in order that the views of people

with dementia were taken into account in the research planning process (Appendix 1). I will now consider the different ethical issues in more detail.

Specifically in relation to dementia I referred to the Nuffield Council for Bioethics guidance on research with people who have dementia (2009), the Charter of Rights for People who have Dementia and their Carers in Scotland (Cross Party Group on Alzheimer's, 2010), and the Standards of Care for People who have Dementia in Scotland (Scottish Government, 2011c). In particular, Standard Two states that a person with dementia has the right to be regarded as a unique individual and to be treated with dignity and respect (Scottish Government, 2011c: 13). This standard is evidenced through a quality of life outcome indicator that states that "*People with dementia feel empowered and enabled to exercise rights and choice, maintain their identity and to be treated with dignity and equity.*" (Scottish Government, 2011c, p. 10). I also referred to the values framework developed by Cox et al. (1998, p. 23). This framework identified five core values that should be employed when working with people who have dementia, and I believe these to be integral to demonstrating ethical standards in research with people ageing with dementia. They are:-

- Maximising personal control
- Enabling choice
- Respecting dignity
- Preserving continuity
- Promoting equity

I previously explored these values with reference to reflective research practice (Christie, 2007, p. 200). Social workers use reflection to maintain an ethical focus in practice. It is the process of thinking through actions before proceeding. It is also however the act of revisiting decisions and actions, considering the associated thoughts and feelings and identifying the implications and outcomes of actions (Payne 2002, p.124). Sometimes points of reflection occur in the moment. So reflection can take place prior to acting, in

the moment of interaction and in the period following actions through the review of outcomes. Ethical practice relies on an integral use of reflection (Christie, 2007, p. 209). It is for this reason that I have referred to ethical issues as they arose throughout each part of the research process. This provides a real time perspective on the sensitivity required in narrative research and in research with people ageing with dementia. In addition, I was mindful that there can be a risk of harm to any individual through participation in research of such a personal nature. I have therefore identified and addressed issues of potential harm throughout the research process. This approach is representative of the values and principles of the registered social worker (Scottish Social Services Council, 2009).

Research sample and access to participants

As my research questions centred on the resilience of the person with dementia, and the role of the social worker in realising resilience, I focussed my research sample on these two groups. I decided not to include any other parties, for example carers, as I wanted to focus on the ways in which resilience could be revealed by both people with dementia, and social workers, in their own words. My review of the literature also indicated that there was more existing research about the views of carers than there was about the views of people with dementia and their social workers. A purposive sampling approach was therefore adopted. In order to explore the experiences of ageing with dementia I recruited people living with dementia, who were over the age of 65 years and who were in contact with a social worker. I then recruited the social worker, who was in contact with the person ageing with dementia in order to explore their professional oral accounts of working with a person who has dementia. The people recruited were all residents of the same local authority area. The social workers recruited were employed under different contract arrangements with the same local authority, and would be working in different teams. This was dependent on where the person with dementia was receiving their social work input from, and in this way reflected the variety of experiences that people with dementia have in their engagement with social work professionals.

At the outset of this study I had considered using the written assessment record as a data source. This influenced my initial decision to select participants in dyads. However, following my review of the literature, and in particular the work of White (2002), I determined that the oral accounts of social workers as they spoke about their work with a person with dementia was an under-researched area. White's work (2002) revealed the power that the spoken account has in organisational processes. I therefore decided to focus my data collection on the social workers' oral accounts. The dyadic relationship between the person with dementia and the social worker does, however, remain important. I anticipated that the stories told by the person with dementia and the oral accounts provided by the social workers could have details, scenarios and people in common. This could then offer new insights into the perspectives of those with dementia and social workers, potentially revealing important information on positioning and the politics of recognition (Taylor, 1994).

I considered that a minimum of five dyads of person with dementia and social worker would be required to validate the research process. There is no protocol for the number of people who should be involved in a narrative research study. Studies range from one person to large groups of forty or fifty. The researcher makes the decision on the number of people to be included based on the need to emphasise individual stories or to seek connections across a range of stories. I was interested in individual stories primarily but would also highlight similarities in accounts where they arose. I started with five dyads and planned my time accordingly. I also planned to review the stories gathered as I progressed through the fieldwork to ensure I had a breadth of data to explore. In this way additional dyads could be recruited as the fieldwork continued where I felt this was necessary.

After following the local authority research protocol I was given access to the Social Work Information system in order to search for potential research participants. I was able to do this as I was familiar with the system and was an employee of the local authority in question. I will return to the positive and

negative aspects of this position later in this chapter. I searched for potential participants over the age of 65 years through the social work office in the specified local authority between January 2012 and January 2013. This provided me with a pool of 302 people which included both men and women who had been identified by the Social Work Screening service as having a diagnosis of dementia, requiring an assessment of need and that had an allocated social worker. In order to find five participants who met my recruitment criteria (see below) I highlighted every 30th person from the list of names generated. I then recruited each person in turn in the order that their name appeared. The social worker sample selection was then in effect dictated by the person with dementia. By this I mean that after recruiting each person with dementia, I then approached their social worker to discuss their own inclusion. All of the social work participants held a recognised social work qualification.

Recruitment

The recruitment process was much more straightforward than I had anticipated. I selected potential participants who met my stated criteria and considered carefully their circumstances, issues of mental capacity, and whether they preferred to be approached directly or through a representative. All of this information was available through the Social Work Information system. I then approached the person concerned accordingly. Inclusion was dependent on how willing each person was to disclose stories and aspects of their life to me, but also on establishing that shared communication between myself and the individual was possible. This issue was addressed prior to data collection when I met with the person concerned and advocate or family representative. At this meeting we talked about what would be involved in the research process and any communication issues were addressed at this stage. I provided written information about the project (Appendix 2) to assist in this process.

An important part of this stage involved explaining that although I was employed by the local authority my research was independent of any local authority influence and that I had no role in providing support. I therefore emphasised to participants that any decisions they made either to be involved in or to opt out of the project (at any stage) would in no way influence the service or support that they received from the Social Work Department. All of the participants were also advised that any information given would be confidential and non-identifying. Written consent was sought from each participant, in the presence of an independent advocate or named other, where this was the person's choice (Appendix 2). Separate information was also developed and provided through an independent advocacy organisation (Appendix 3).

I also ascertained whether the person concerned was comfortable with the use of the word 'dementia' and talking about aspects of their life with me. All of the participants had the capacity to consent, however I ensured that where a welfare proxy was named that they were also fully engaged. The Adult with Incapacity Scotland (2000) Act part V states that a welfare proxy can consent on behalf of the person they are representing however engagement with the individual remains essential. I employed process consent (Usher and Arthur, 1998) and re-visited the subject of consent on each interaction with the research participant. Contact details of independent advocacy were provided in all cases, so that the person concerned could discuss the project with an independent party at any point in the process. Participants were also able to withdraw at any time. A complaints process was established with a local advocacy service which could be accessed independent of the researcher. Research participants could also complain to the School of Applied Social Science, University of Stirling should they need to in accordance with the Code of Good Research Practice (2009).

Participant details

I recruited five dyads and after review sought to include a further dyad, as one of the stories, although rich in detail was relatively short compared to the others. In total I met with eight people living with dementia, however two potential recruits were not included in the final selection. The reasons for this were as follows. One participant was in receipt of palliative care at the time. His physical health had recently changed as he had a cerebral vascular accident. As a result he was unable to raise his head to engage in communication. His wife had been very keen to tell “their story” as a married couple coping with dementia. I was, however, able to provide her with details of a local research initiative seeking carers as an alternative. I also met with another potential participant who declined to participate as she did not feel she had the time needed to take part. All of the participants I recruited agreed to participate from our initial meetings and I was surprised and delighted at the enthusiasm to participate that I encountered. The participants lived in a local authority area with a high percentage of home ownership, car ownership, low unemployment and economically active residents. It has the highest life expectancy in Scotland (Local Authority Area Profile, 2014). These facts are reflected in the ages and economic status of the participants. Four participants were female and two male, which is also representative of the increased population of older women compared to older men in the area in which the research took place. The details of the participants are detailed in Table 3.

Table 3. List of Participants Person with Dementia

Participant	Gender	Age	Living Arrangements
Alan	Male	92	Married, lived with wife Home owner
Beth	Female	89	Divorced, lived alone in sheltered house Council tenant
Charles	Male	86	Married, lived alone wife resides in a care setting Home owner
Dora	Female	89	Widowed, lived in own home with her daughter Home owner
Ellen	Female	81	Widowed, lived alone Home owner
Fay	Female	77	Widowed, lived alone Home owner

I met with as many social workers as I could in advance of the sample recruitment through team meetings and lunch time events to provide information about the research, the recruitment process and potential involvement. I was again surprised at the level of enthusiasm from the social workers to be included and wondered if this was because there was so little social work research in this area (as revealed in my literature review). Each of the social workers that I approached agreed to participate and are detailed in Table 3.1.

Table 3.1. List of Participants Social Workers

Social Work Participants	Details
Social Worker Gwen working with Alan	Female, Hospital Discharge Team, qualified 5 years
Social Worker Helen working with Beth	Female, Older People Team, qualified 10 years+
Social Worker Ian working with Charles	Male, Mental Health Team, qualified 5 years
Social Worker John working with Dora	Male, Older People Team, qualified 2 years
Social Worker Kate working with Ellen	Female, Older People Team, qualified 7 years
Social Worker Lorna working with Fay	Female, Older People Team, qualified 10 years+

All of the social workers were provided with written information about the research (Appendix 4) and written consent was sought in each case. They were advised that information given was confidential and non-identifying. Social work staff were not obliged to participate and could choose not to. Given that the social workers were approached through their place of employment I made it explicitly clear that any decision not to participate would not affect their work or employment with the specified local authority.

The preparatory stages of my engagement with each person also included an exploration of my role as an *intimate insider* (Taylor, 2011, p. 8) within the organisation. At the time of registering for the PhD I was employed as a Team Manager within the specified local authority. In preparation for the research process I negotiated a new non-fieldwork role with my line manager, as well as time out of the work place on an extended study basis to complete the research. This ensured that I had no operational role that would compromise my contact with either the people with dementia or social workers who were participating in the study. Some of the social workers who participated knew me in my previous role, others did not.

An *intimate insider* (Taylor, 2011, p. 8) is where the researcher may also be a social actor within the research locality. As a result previous relationships, reputations and perceived authority or influence have the potential to shape the research process. With reference to the research undertaken by White (2002) it was acknowledged that insider knowledge can open doors to access and knowledge as the researcher is perceived as an informed listener (Woolfit and Clarke, 2008). I was also ideally placed to 'problematize' (Langellier and Peterson, 2004, p. 158) issues of social work practice with people who have dementia as a result of being an informed listener. This meant I could understand where simple phrases and sentences were used to describe, what were in fact, complex or highly skilled practices. Phrases like 'I carried out an assessment' would be one such example. What this intimate insider role did mean, however, was that I had to ensure that the confidentiality of data and

data source(s) was clearly conveyed by me to the participants and that a relationship of trust could be established in my new and very different role as researcher. This was essential in ensuring as open a dialogue as possible was achieved. I took a lot of time and care to talk to potential participants about the research relationship. I also did this where the social workers concerned had not met me before as they were working alongside people who would know me in previous roles.

Data collection

Person with dementia

Having identified each dyad, I met with the person with dementia first. I did this in order to hear the story as told by the person with dementia alone and not to be influenced by the account of their social worker. I used semi-structured interviews (Appendix 5) to elicit the stories of people ageing with dementia which I audio recorded. I also kept written records of thoughts and emerging findings throughout the process through fieldwork notes consisting of ideas, notes and observations from my contact with each person. I met with each person on three separate occasions, first in the pre-research stage, second the main storytelling interview which lasted between 45-60 minutes depending on each person's preference. This meeting was audio recorded. I then met with each person on a third occasion to re-visit the stories that had been shared after transcription. I will discuss transcription later in the chapter.

The people with dementia who participated had varying degrees of memory impairment and it was therefore essential to build time into the process to continue to check that consent was given and to communicate in a meaningful way. Communicating with people who live with dementia is about communicating on their terms. This was confirmed by the Scottish Dementia Working Group, Research Sub-Group in their 2014 paper on this subject who referred to this as respecting "*dementia time*" (p. 684). It involves respecting each person's reality, not imposing the researcher's reality frame onto the

interaction. Environment also plays a pivotal role in either enhancing or detracting from effective communication (Loveday and Kitwood, 1998).

Whilst every care was taken, it was not possible to legislate for the lived experience of telling one's story and the possible distress that this may cause (Elliot, 2006). Ethical practice was therefore dependent on self-regulation by the researcher in judging the mood of the participant and stopping the interview where this was required. Participants were under no obligation to discuss any issues that they do not wish to disclose and they could also stop the interaction with me at any point. Time was also built into the process to respond to emotional disclosures and possible upset. In this respect the researcher is accountable to the participant. This accountability was further demonstrated through ensuring that the participant had choice over the preferred venue, duration and times of the scheduled meetings and the presence of others. This is of particular importance when a person has dementia due to the effects of tiredness on cognition (Robinson, 2002). Appointment schedules were therefore different for each person to maximise optimum participation. Participating in research can be disruptive to families and routines. It can also be physically and emotionally tiring for those participating. Participants and carers required flexibility to cancel and re-arrange appointments, even at short notice.

The relationship status between myself as researcher and the research participant had to be made explicit because the nature of the data collection was dependent on intimate conversation. Elliot (2006) found that this is a particular issue in research that encourages individuals to 'construct and share narratives'. In particular great care had to be taken when asking participants to reflect on areas of their life that they might not have explicitly thought about (Elliot, 2006, p. 136).

Elliot (2006) also highlighted that where the person finds therapeutic benefits as a result of disclosure this also raises ethical dilemma. The relationship boundaries have to be maintained and research is not therapy and cannot be confused as such. Alexander defined this approach as:-

“[negotiating] the borders between identity, difference, detachment and commitment, not only to represent the other but also to re-present the other as a means of continuing a dialogue that seeks understanding” (2008, p. 85).

Reflection and reflexive project management were, therefore, integral to the process as I reflected on each interaction, the nature of disclosures, and the effect on the person participating.

Social work data collection

I used semi-structured interviews (Appendix 6) in my meetings with the social worker participants. I met with each social worker after generating transcriptions of the stories collected from the person with dementia. The purpose of the interview with the social worker was to record their oral accounts as they spoke about their work with people ageing with dementia. This would then form the units for analysis, facilitating an exploration of the themes that could contribute to the public identity ‘person with dementia’. I arranged an appointment time with each person at a venue of their choosing. Each meeting lasted approximately one hour. We met three times and again this consisted of a pre-meeting, a second meeting where the social worker was invited to share their accounts with me of their role, their views on the person with dementia whom I had also met, and their views about people with dementia generally. This meeting was audio recorded. I then met with the social worker to review my transcription of their account.

Although the data collection work with each of the social workers was not considered as intimate or as personally revealing as the narrative approach with the person with dementia, specific issues still had to be addressed. Earlier I addressed the issue of being an intimate insider in relation to being seen as a researcher and not as an employee of the organisation in which the research is

taking place. However there were two additional issues. One was that of accountability to the social work registration body. This research was approached with reference to the SSSC Code of Practice (2009). This meant that I had to build in the possibility that, if in the course of my contact with the social workers concerned I uncovered practice that I was concerned about, or they revealed practice of concern within the organisation more generally, I would have had to refer to the guidance issued by the Scottish Social Services Council (2011) on such matters. The guidance states that where you are concerned that the practice of colleagues may be unsafe or adversely affecting standards of care you must inform your employer, the SSSC and an appropriate authority if relevant e.g. the Care Inspectorate I also had to address my own bias as informed insider. By this I mean that I was aware of my personal and professional interest in promoting the social work role with people who have dementia. I therefore reflected on the ways in which I was interpreting accounts and built in time for reflection as I planned the analysis stage.

The data collection process took place over a two year period. I recruited two dyads at a time, completing my interviews and transcribing before moving onto recruit a further two dyads. I did this to respect the time needed for each person and also so that people were not recruited and then waiting several months to meet with me. The process is summarised in Table 3.2.

Table 3.2. Recruitment and Data Collection Process

Recruitment	Interview	Transcribing	Validation Meeting
Recruit Dyads 1 and 2 Person with dementia. Share information, answer questions and obtain consent.	Interview person with dementia. Data collection through stories	Transcribe audio recorded story for thematic narrative analysis	Meeting to discuss story (stories) and analysis.
Social Worker Share information, clarify researcher role, address issues of intimate insider, and obtain consent.	Interview social worker. Data collection through professional accounts	Transcribe audio recording for thematic analysis of account	Meeting to discuss account and analysis.
Repeat for Dyads 3 and 4. Repeat for Dyads 5 and 6.			

Thoughts on the intimate nature of stories in their translation to narratives

There were a range of issues raised when translating these personal stories and accounts into data for storage, analysis and dissemination. If stories and narrative are considered as representative of the self then there are moral and ethical responsibilities in the life of these data beyond the research participant (Elliot, 2006). Smythe and Murray (2000, p. 318) stated that research in narrative study yields information that “*cannot be disassociated so readily from one’s fundamental human values and meaningful life experiences*”. Personal stories as narratives offer public audiences access to personal experience with the intent of politicising aspects of human experience and social sense-making (Alexander, 2008, p. 91). More importantly the data allows the participant to see the self through another which offers transforming opportunities, but can also be disabling and distressing. Participants were advised of the potential audience for the dissertation. The timescale for keeping research data was also discussed and a date for the destruction of archived material agreed. Post research work to address issues of narrative representation is also required. So, for example, in advance I committed to working with local organisations to ensure there was follow up support to work with those individuals who wished to act on the research findings.

Data analysis

The thematic analysis of narrative text is concerned with the content of stories, and is the most common type of narrative analysis (Reissman, 2008). It focusses on what is said rather than how speech is constructed. This can be considered as a focus on ‘the told’ rather than a focus on ‘the telling of’ (Mishler, 1999). Reissman (2008, p. 54) explained that this approach is not concerned with how narrative is spoken, the structures of speech, who the audience is, what the local context is, nor does it take into account the complexities of transcription. Instead, the researcher extracts categories from the data to reveal the content within the context of the research questions. Emerging themes, developed through the review of the relevant literature, guide the initial exploration of the text. This then reveals new insights about the story (Reissman, 2008). In summary, thematic analysis takes place within specific

pre-defined contexts defined through the unique research questions to be answered. I will now demonstrate this discussing the analysis in more detail.

Creating transcripts.

The first stage of the process was to transfer the audio recordings into written format known as transcribing (Dressing et al., 2012). I started by manually typing out the recorded conversation. The goal was to provide the most accurate representation of the conversation (Skukauskaite, 2012). In order to promote readability I used a simple transcript format. I began by repeatedly listening to the audio recordings to immerse myself in the spoken data to ensure that I was capturing the detail of each story as well as the multiple stories that appeared in each interview. I then produced transcripts. In the final version of the transcript the researcher's voice is removed in order to focus solely on the content of the speaker. I then again immersed myself in the written data, reading and re-reading the transcripts for authenticity and comparison with the audio recordings. I used traditional spellings for words in all cases.

When I decided on this approach with the participants who had dementia I was aware that the stories recorded may appear fragmented, may not follow chronological convention nor have a clear trajectory (Young, 2010) and that the transcripts might then be difficult to read. Despite this the transcripts appeared rich in content and there appeared to be a logical, storytelling flow to all of them. This approach also accommodated different ways of telling stories. For example, one participant Charles used song in his storytelling and I was able to easily reflect this within the transcript and then to type the words verbatim as though he had spoken them. I worked first with the transcript of the person with dementia and then with the account of the social worker, working with two dyads at any given time. I completed the initial analysis on each of the transcripts before then moving on to work with the next two dyads.

Qualitative data software

I used NVivo 10 to support my analysis as this is the software used by the university where I am undertaking my research. NVivo is as a computer aided qualitative data analysis tool (abbreviated as CAQDAS). It is a database with qualitative analysis tools. It supports the research process but does not replace researcher skill and enquiry. I imported all of the transcripts into NVivo in order to deconstruct the transcripts into the specified units for analysis.

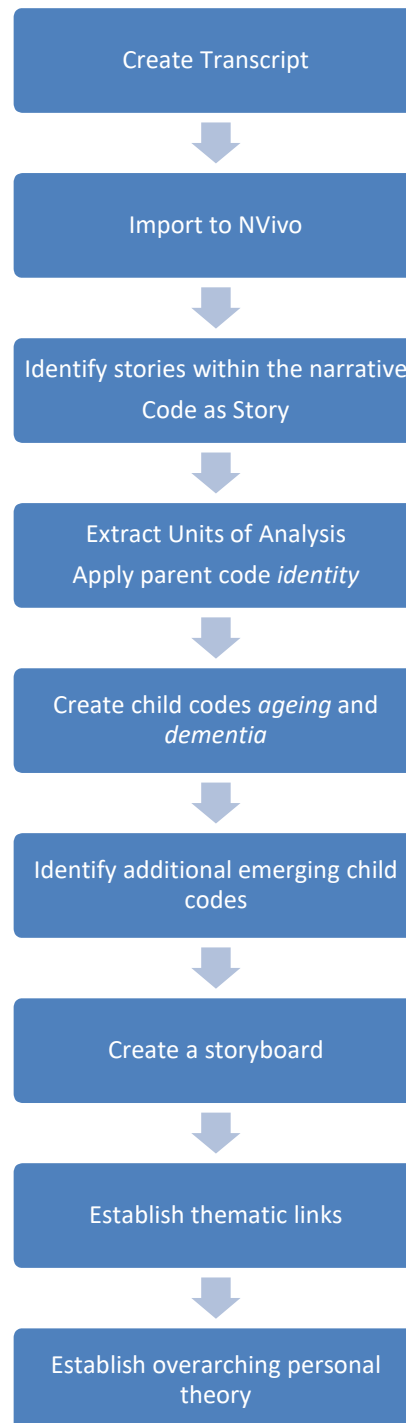
Determining the units of analysis

In determining my units of analysis I referred to the work of Silby and Ewick (2003). In their thematic analysis they examined stories of resistance to legal authority. From a collection of stories, they identified those which met the criteria of demonstrating a reversal of power in order to avoid a negative outcome. They then used thematic analysis to identify how social actors achieved this resistance. Finally, they grouped practices and constructed a typology of resistant practices (Reissman, 2008, p. 61). Resissman (2008, p. 75) uses this work as an exemplar. I was interested in the stories revealed within the overall transcript where the person with dementia actively avoided a negative outcome associated with a possible loss of public identity. The data units selected were therefore clearly defined and related to the research questions. Data reduction was thus achieved as I focussed on selected areas of narrative that might reveal details about resilience. I will provide more details on data units in the following section.

Analysis

I provide an overview of the analysis process used with the person with dementia in Figure 1.

Figure 1. Analysis Process Person with Dementia



Coding: person with dementia

Using NVivo, I took each transcript in turn and looked for evidence of multiple, smaller stories within the whole. I looked for details that appeared connected and content that included people, places and events. I also looked for story introductions and endings that signified the telling of a smaller self-contained stories within the larger whole. I created the code *story* and used this to deconstruct each whole or master narrative into a collection of smaller stories. Miles and Huberman (1994) stated that as well as pooling sections of data, codes also indicate themes that point to the collection of lots of other data, so in effect codes generate more codes. NVivo uses the term *nodes* to house collections of data, however, I will continue to refer to codes as I discuss my analysis. I created a further code called *identity* and reviewed all of the stories captured to identify those where an opportunity to avoid loss of public identity was evident. Inclusion in this category was achieved where the person telling the story revealed content that indicated a challenge to their characteristics, actions, roles or personal qualities yet despite this the story instead preserved or promoted identity. Simply put, the story revealed negative experiences and attitudes yet the person within the story rejected or avoided this. At times the negative attitudes that the participants were reacting to were in fact their own views and not always those of an external party. An example of revealing a negative experience but avoiding a negative outcome within story is provided in this extract from Alan's narrative.

"I was very disappointed I had to give up golf and motoring. I don't know if I really gave it up... I moved here as I had family here, not far from here. ...Well it wasn't about the dementia" (Lines 36-39).

In this example Alan is confronted with the fact that he had to give up both golf and motoring, however, he is able to avoid a negative outcome by explaining this was as result of his house move and not his dementia. I explore this further in the next chapter.

This stage was not as straightforward as it might appear. It required deep listening and re-listening of content as well as reading the transcript to identify where this was happening. The person concerned could also present a version of self that was incongruent with the present. For example, Ellen discussed a very active social life with friends which was not in fact the case. I therefore had to separate my knowledge of the person and their life and instead tried to focus on the identity revealed through the audio record and transcript. There were also many representations of self within stories, which reflected the multiple roles that people have throughout their lives. I gained a sense of those roles and characteristics that were of most importance by reading and re-reading the stories. As a result aspects of personal identity, important to the person, were revealed and, in turn, I began to gain an insight into how each person viewed their own situation. My analysis focussed on the possibilities offered by a resilience lens. I asked the questions, 'What did the inclusion of this story, within the larger story, tell me about this person and their life?' and 'What purpose did this story serve or is it part of the resilience process?' I therefore worked back and forth between the chosen character and characteristics that the person chose to include, considered the character purpose and the specific plotlines or actions that the character was engaged in. I also identified any challenges or threats that the story character was trying to resolve within each story. This phase was heavily influenced by my reading and review of the literature.

I began by moving all of the content that met the criteria of avoiding loss of identity as detailed above into the new code *identity*. I then analysed each of the stories within this code *identity* and identified the content that the person included within this smaller story. I created codes that reflected content topics. These codes were child codes of the original parent code *identity*. I started with the pre-determined child codes of *ageing* and *dementia* but quickly found that the participants included multiple topics that were not easily housed within these two simple code categories. I therefore created new codes to reflect each new topic as it emerged from the data.

I let this stage of the coding flow intuitively and categorised the codes loosely to reflect my interpretation. I stopped at regular intervals to consider my analysis and asked the question 'why was I reading the content in this way'? Having a social work background was very useful for this stage of the process as reflection is integral to the social work role. Reflection included looking at the detail of what I had coded and any potential frames of reference that I was applying to this interpretation from a personal position. This was also a challenge to the research process as it involved building in a process of stopping the coding before progressing further. It also involved a revisiting of codes or allowing a code to decay and be replaced by a more appropriate name or reference. There were also some overlapping topics such as bereavement and loss so I had to spend some time exploring distinctions between codes in order to decide where to place the data. An example of the initial coding of Alan's narrative is provided in Table 4.

Table 4. Initial Coding Example Person with Dementia

Parent Code	Child Codes
Identity	Ageing Dementia Lifestyle Sport Giving things up Family Work Death War Music Marriage

I tried not to be too fixed in my views and allowed myself to consider the option of revised coding through new interpretations. In this way new codes emerged progressively. This was an ongoing process as I continued to think about the coding, revisiting the text and revealing the story meaning through these new codes. NVivo facilitated a good filing structure for this stage which allowed me to retrieve, create, change and compare codes and data as I moved through the process.

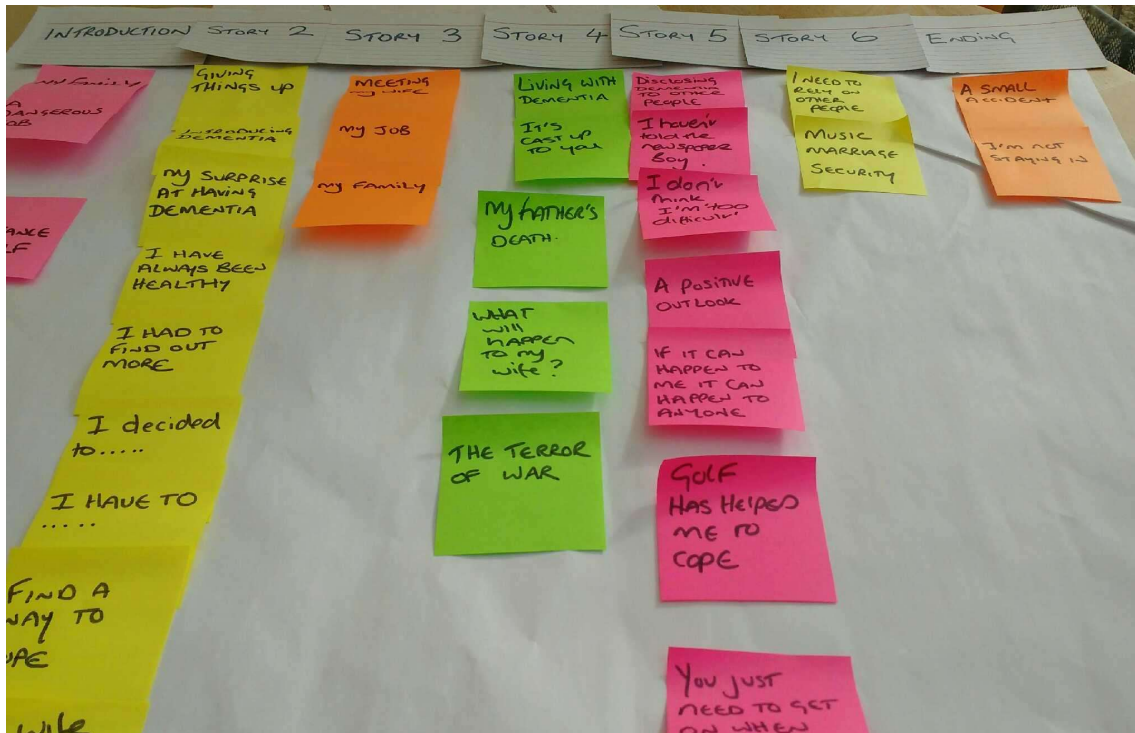
Each person's narrative varied in detail and length, reflecting the individuality of storytelling. For example, I determined that Alan's narrative included seven smaller stories (coded *story*) and of these, five met the inclusion criteria for the *identity* code. By comparison, Beth's narrative consisted of eleven stories (coded *story*) of which seven met the inclusion criteria for the *identity* code. These smaller stories within each master narrative varied in length. As a result, the units for analysis varied in size. Some stories consisted of a few sentences, others were larger blocks of text. Although I initially focussed on those sections of narrative where a threat to identity was potentially avoided, I then re-visited all of the smaller stories in order to better understand how they might work together to both reveal and achieve the story purpose. I considered that this could also reveal important information about the ways in which seemingly everyday stories provide the narrative infrastructure for resilience to emerge. I therefore worked very practically with the printed transcripts and in the next phase of the analysis created storyboards for each person, to both manage each new layer of data as it was revealed, but also to host the re-constructed story as it began to emerge.

Storyboards

Storyboards are traditionally used to plot storytelling in film. Using a combination of images and words storyboards facilitate an impression of the story which is envisioned long before the completed whole (Sova and Sova, 2006). I used this approach in order to build a single visual structure which would house the emerging data. To do this I created a blank wall canvas which named the person and their story. I then identified the key opening and closing story points. From here I added the details of the smaller stories, as revealed through the coding process and, used the storyboard to place these within the larger story to gain a sense of the story trajectory. Below each of these smaller stories I was then able to add layers of story content as revealed by the new codes that were generated using NVivo. This allowed me to see a whole story and story process for each person, which was built layer upon layer in tandem with the NVivo coding process. The initial exploration of the data analyses revealed the surface content of the stories told. I then achieved a deeper understanding as I developed the coding. Alan's initial story board is shown in Figure 2.

A storyboard offers a flexible way of creating levels of understanding. Starting with blank cards I recorded the larger stories revealed through the analysis. I then used coloured notes to record the smaller surface stories contained within each of these. Different colours were used as a visual aid to differentiate between each of the larger stories, so that I could quickly see how many small stories made the building bricks of the larger ones. I then added layers of content below each of these surface notes. So, for example, in Alan's story I could quickly see that story 2 was far more detailed and complex than story 3. The stories were thus revealed as multi-layered and story trajectories became visible. New possibilities were revealed between the content and the potential purpose of each narrative. This approach enabled me to keep the whole story in mind, whilst at the same time paying due attention to the ways in which the layers of content worked together to achieve the narrative purpose.

Figure 2. Storyboard Example (Alan)



I found that this approach helped my creative process and sparked ideas about the relationships between different data segments. I also found that I had more connection with the material through the creation of the story board itself. The tactile nature of handling story cards and notes, and having the flexibility to move story ideas and notes around to try out new visualisations was a means of immersing myself in the data as I physically engaged with the storyboard. I used this process to test the coding process that I had developed through NVivo and it helped me to quickly identify inconsistencies in coding or data inclusion that I could then re-visit and review.

Thematic links

The next stage of the process was to create thematic links between the emerging codes for each person. Thematic links can be used to link or collapse data into new codes to start to make sense of the '*more inclusive, meaningful whole*' (Miles and Huberman, 1994, p. 58). I created themes that reflected the relationships between coded data and collapsed the child codes into these new thematic codes. These thematic codes revealed the possible purpose of the story and I considered that these themes potentially provided evidence of a possible resilience process within the stories told. I again reverted back to the storyboards and tested the themes against the story content. I considered that these themes could be interpreted as hidden plotlines. The themes themselves emerged naturally from the data and were not subject to a lot of revision, unlike the earlier codes. I put this down to having the benefit of the structured storyboard by this stage of the process. I again ensured that I reflected on the categories and relationships. I include a full list of codes, themes and definitions of category inclusion in Appendix 7. The development of the thematic links in Alan's narrative is provided in Table 4.1. The final stage of the process was to consider the master narrative of the overall story. Again, I returned to the storyboard. In effect, my analysis had involved the deconstruction and then reconstruction of the person's story content to reveal resilience processes and story purpose in the preservation of identity. This included consideration of overarching themes to explain the story purpose as a whole.

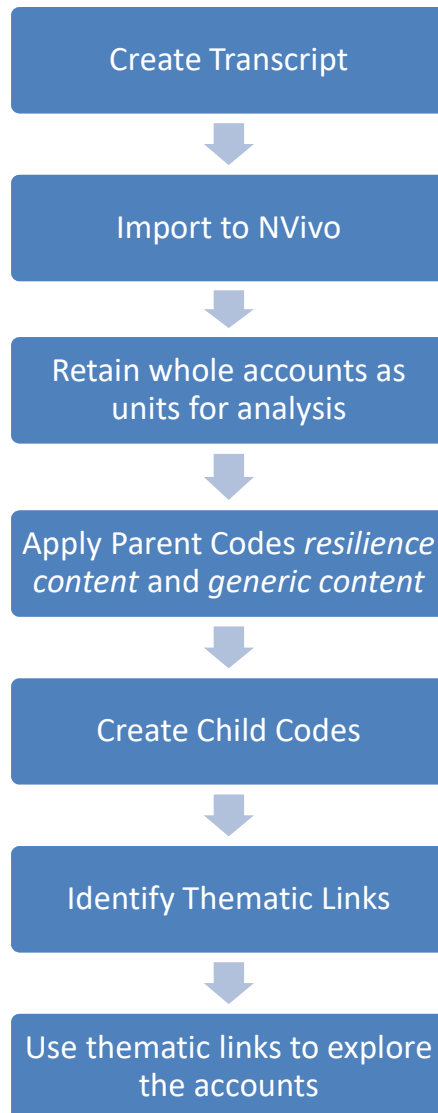
Table 4.1. Thematic Coding Example Person with Dementia

Child Codes	Themes
Ageing Dementia Lifestyle Sport	Self-appraisal
War	Experience of threat
Music Marriage	Self-care Security Caring for others
Family Work Death	Previous experience of adversity and coping
Giving things up	Choosing to disclose Re-interpreting events to gain a sense of control Re-positioning self within story

Analysis of the social work accounts

An overview of the analysis process for the social work participants is provided in Figure 3.

Figure 3. Analysis Process Social Workers



The transcripts of the social work accounts were imported into NVivo. These transcripts did not require deconstruction into smaller stories, as had been the case with the narratives of the person with dementia. I did, however, indicate where a new topic was introduced by each social worker. This improved readability of the document by highlighting each area of new content. This also facilitated a very visible way of seeing which topic areas had more content than others and allowed me to link associated content where it appeared at different points of the social work accounts. I then immersed myself in the transcripts reading and re-reading the accounts line by line, within these content structures. I could quickly see that each account varied considerably and as a result realised that I had held assumptions that the accounts would contain similar content. For example, some participants focussed on their public identity as 'the social worker' in relation to the person who had dementia, whilst others provided more detail on the personal and public identity of the person with dementia. Other accounts focussed on the reporting of social work processes and outcomes. I spent a lot of time reading the transcripts to gain a sense of these different points of emphasis.

I began by extracting the account content that referred explicitly to resilience or that could be indicative of acknowledgement of the person's potential for resilience. This included, for example, references to personal qualities or experiences that could promote resilience. I looked for all content that referred to personal skills, characteristics, knowledge, experience and resources. I coded this content under the parent code *resilience content*. I have described this as applying a resilience lens to the accounts of social workers. This resulted in two categories of material, the first coded under the parent code *resilience content* and the remaining content where resilience was not a feature. I labelled this content under the parent code *generic content*.

I used NVivo for this stage and went through each account individually and tagged data which fell under either the *resilience content* or *generic content* codes. I then went through each parent code and developed child codes to focus the content contained within. An example of the parent and child coding process using Gwen’s account (Alan’s social worker) is provided in Table 4.2.

Table 4.2. Initial Coding Example Social Worker

Parent Codes	Child Codes
Resilience content	Independence Acceptance Experience Personal qualities Support
Generic content	Goal setting The needs of carers Resources (provision of) Defining success Prioritising needs Risks

The next stage of the process was to establish thematic links between the codes that might reveal the deeper meanings within. From here I began to see other links emerge and created new thematic links to represent these new ideas. The final stage involved re-exploring the accounts with these new themes in order to arrive at new overarching themes that could reveal the processes taking place. The thematic links are detailed in Table 4.3. There is a detailed breakdown of each code, theme and category inclusion criteria in Appendix 8.

Table 4.3. Thematic Coding Example Social Worker

Parent Codes	Child Codes	Themes	Overarching Themes
Resilience content	Independence Acceptance Experience Personal qualities Support	Dependent independence Assessment	How I talk about my work.
Generic content	Goal setting Resource (provision of) Defining success Prioritising needs Risks The needs of carers	Reframing acceptance as adjustment Organisational identity versus individual identity	What happened and why

Quality and trustworthiness of data generated through narrative analysis

The intuitive nature of thematic data analysis means that the findings arrived at can be open to question if there is lack of detail about process. I felt it was therefore important to use an exemplar (Silby and Ewick, 2003) as a template for defining data units for analysis and providing a clear outline on the processes applied and reasons for this. Findings also have to be presented in such a way as to preserve sequences of narratives. Long sequences of narrative present the reader with the core unit used for analysis and can provide valuable insights into the researcher process (Reissman, 2008). The very nature of narrative leaves it open to different interpretations by different audiences. I therefore provide large sections of narrative, rich in detail to illustrate my findings in the chapters which follow. I have also identified where themes were shared across narratives although this was not my primary objective.

Validation

From the start of the research I had considered the issue of validation. Using the process consent model as a template I considered that validation with a person who has dementia should also be undertaken using a process model (Usher and Arthur, 1998). I approached validation in the same way through in situ checking of data as narratives were shared; and then meeting with the individual after I had undertaken the initial analysis. I arranged to meet all of the participants individually. This process required careful planning as I was aware that the person might not remember me, or the research project or in fact the interview. I approached each meeting as though it was my first encounter with the person concerned. In anticipation of participants being unable to recall our previous meetings we had at our earlier meetings recorded entries in diaries and calendars as points of reference. In each case I had asked the person what their preferred technique was for dealing with their memory loss and had used this to record our meetings. I had also informed the person's representative where this was indicated of my return and purpose.

Four out of the six participants were able to recall our earlier meetings with prompts. Two participants did not recall earlier meetings with me. Time was built into the process to ensure that the person concerned was happy to speak to me again and for me to explore their original story with me again, or from their perspective as a stranger they were meeting for the first time. Working with people who have dementia involves respecting their reality, not imposing the researcher's reality frame onto the interaction. This means you have to start each interaction from the person's perspective, providing information and other prompts to either confirm a continuous relationship or start with the person as if at the beginning of the research relationship. Another issue in trying to validate content is that the person with dementia might not remember what content was shared in previous meetings. Validation does not then involve factual recall of having told that particular story and can instead be about the person checking the content for recognition of self. In all cases I noted any additional points made by the participant.

One particular issue of concern I had was where Beth had disclosed to me a very painful episode about her son's suicide. She had made clear to me in our previous meetings that this was a painful memory to recall. Ethical practice is dependent on self-regulation by the researcher. I decided in advance that I would not re-visit this story scene with Beth. I was aware that this would mean that I would be unable to validate what was a key element of this person's story. However, Beth did in fact raise this aspect of her story with me unprompted and so we were able to explore this content together to ensure I had accurately reflected her thoughts on the event and the tremendous impact on her. This example highlights the care that is required in validating the analysis of intimate personal narratives. This is not a quick process that can be added to the end of a coding process.

I also carried out a similar exercise with the social work participants. As with the person with dementia, I met again with all of the participants to discuss my analysis. This was an interesting exercise as my analysis had generated data about the personal as well as the professional. Although I had discussed this at the start of the recruitment and interview process discussion required a degree of sensitivity. This process also contained elements of peer validation as we explored together, the personal and the professional aspects of the social work role, as well as the complex relationships that exist within teams and organisations. My insights about the content and purpose of the accounts generated a lot of discussion with each participant. What I found of particular interest was where participants advised that the research process itself had given them new insights into the complexities of their work and the layer of information that social workers process and translate for others through verbal accounts. There were no areas of disagreement with my analysis despite the lengthy discussions on the initial findings.

I will now move on to explore my findings. I will do this over two chapters. The first will discuss how people ageing with dementia manage threats to identity. The second will discuss the competing roles and realities that social workers negotiate in their practice with people ageing with dementia.

Chapter 4: Managing Threats to Identity

I have established through my review of the relevant literature, that both ageing and dementia can be considered as life adversities where individuals may experience a loss of identity (De Beauvoir, 1977; Kitwood, 1997). This can be experienced due to the assumptions of others that personal identity is changed or lost, which could then lead to a loss of public recognition. Loss of identity is a negative outcome for the person ageing with dementia, as described by Sabat in his discussions on malignant positioning (2001). Therefore, the preservation of identity in the face of dementia could be viewed as an outcome of the resilience process.

I have suggested that the resilience process can be understood in terms of a personal resilience reserve; a personal bank of skills, experiences, knowledge, and resources accumulated over a lifetime (Clare et al., 2011; Forstmeier and Maercker, 2008; Hulko, 2009). This reserve acts as a buffer to lessen the impact of adversity and as a repository of resources that facilitate adjustments in situations of risk to self to preserve public identities. I have defined resilience within this context as: “*adjustment in the face of the threats to personal and public identity experienced when ageing with dementia*”. This process must then be interpreted as resilience in action by the other party engaged in communication with the person concerned or the person may remain locked in a cycle of identity loss and misinterpreted responses. I will focus on the social worker as the specified other in the relationship in the next chapter. Here, I will discuss my findings from the individual narratives of people ageing with dementia.

I will present the findings in two sections. First, I will focus on each person's story and discuss the possible personal and public identities that were revealed. I will also discuss the potential challenges to these identities within each story. Second, I will discuss the possible adjustments that the person with dementia made within their story in order to respond to these challenges. I will provide in depth extracts of narrative to support my findings. Each section of narrative is labelled to indicate the story that it belonged to and the specific lines of text that are included. Where extracts contain elements of more than one story this is indicated with a sequence of punctuations (...). In this way I will address the research questions "*What can the concept of resilience bring to our understanding of dementia?*" and "*In what ways do persons ageing with dementia demonstrate resilience in their stories?*"

Revealing identities and threats

In this section I will discuss the ways in which participants used their stories to reveal identities. I will also illustrate the ways in which threats to these identities were revealed within each narrative. I will provide a brief introduction to each person before discussing his or her story.

"See it's my only sort of come back."

Dora was an 89 year old woman who was widowed. She lost a son when he was 9 years old to pneumonia. Dora and her husband were foster parents to many children and adopted a young boy in the years after they lost their own son. Dora was an active member of her church. She had received her diagnosis three years before we met and also had multiple health problems. As a result she was now in receipt of round the clock care.

"I feel that God has been very, very good to me. I've got a home of my own, bought and paid for and I've got a family that come regular to see me and love and take care of me. I've got grandchildren and they'll phone up and they'll say 'Are you alright nana, do you need anything?' but to me that's worth more than all the money you could get. That's the thing, the personal thing that I love and feel that I've got." (Story 2, lines 33-38).

Dora appeared to set the scene for the listener by detailing both her financial and family security. She placed herself at the centre of her family's attention and was able to compare the value of her personal connections versus her material wealth, thus allowing an insight into her personal values. She introduced a performance element where she acted out the part of her grandchildren within her story rather than simply re-telling what they had said. This brought to life the level of concern for her to the listener and, in turn, confirmed her importance within the family. Dora's story communicated that she was loved by others. This could have been the purpose or moral of the story that Dora intended for the listener.

"God's been very good to me. I've had a good long life. I'm over the age of 90. I've travelled the world twice and not everyone can say that but the thing is I've got a book with all the different photographs of where I went, all the different countries that I've been in and, and people that I've met and.... So I can prove what I'm saying, if you know what I mean. You didn't have all the things that perhaps other may have had you know? But we always had plenty love and care and so forth, which to me was the main thing. I had a good childhood, a happy childhood... I feel now that I can't get around the way that I used to be but they say that there is two kinds of old people the 'good old has beens' and the 'good old never was,' well I can say that I'm a 'good old has been' and I can hear people when I say 'I've been around the world'. I can just imagine them saying 'Mm'. As if saying 'and the band played believe it if you like'. But the difference is I've got a book with all the photographs and everything and all the different countries. (Story introduction, lines 1-21).

Dora used autobiographical reasoning (Randall et al., 2015) to weigh up her life and arrive at a decision as to whether, on balance, she had enjoyed a good life. She appeared concerned with the need to prove herself to others, revealed in her discussions of photographs of her travels. Dora's decision to include this content ensured that her story presented the best version of self. This is in keeping with the findings of Hedman et al. (2013) who asserted that people with dementia still make intentional adjustments in the presentation of self to others. This presentation of self, in the best light possible, is a challenge to any unspoken assumptions by the other party in the communication relationship. In this case the other party is unspecified, an unseen audience. It wasn't clear if Dora was recalling a memory of being doubted by others or if this was evidence of the active management of the impression of self by others (Goffman, 1959). This could have been linked to her sense of threat around her ability to recall factual information in the present.

"You'll need to forgive me as I can't remember. My memory is not what it used to be. And even nowadays I have to write in a calendar and they laugh at me and they tell me, if they come in and tell me anything special I put it down in the calendar. That's stood me in good stead many a time because they say 'Mum I told you that already' and I say 'right you are darling, if you told me that it will be down on the calendar' and they go 'Oh mum, I was sure I had told you'. That is my only come back. Because what would get me is they would say 'I told you that already' and I would know that they had not told me. ...Oh and they say you know and say 'Oh I was sure I had told you'. See it's my only sort of come back in a way to keep me right." (Story 5, lines 91-112).

Dora appeared to place her memory loss within a competition narrative: a competition between herself and other members of the family. Having dementia appeared to threaten Dora's identity as a person who could provide factual, accurate information and all this implied about her competence and status in the family. In this way, Dora's story rejected the spoiled identity (Goffman, 1963) of a person with dementia. This could also be considered as an example

of the lived experience of being excluded from citizenship norms (Nedlund and Nordh, 2015). It could also be an insight into Dora's experience of the domestic sphere of citizenship (Bartlett, 2016).

“People might laugh”

Fay was a 77 year old widow who lived alone and she had a son and a daughter. She lost both her mother and father when she was a young girl and grew up in boarding school in Ireland. Fay ran a charity for people affected by drug and alcohol issues which included opening her home to people in need. She had received her diagnosis of dementia the year that we met.

“Some of my friends are in care homes. I would hate that to happen to me. That really would offend me pretty much. I would be down on my knees asking the Lord to intervene. Yes but I would fight against it... The world is not always very hospitable and I think particularly for some people they are trapped in ways and then nobody wants to know them... Absolutely try to get them not to think as themselves as invalids, to act normal, don't get all worried and stressed and think 'what if I wake up tomorrow and I can't do that, what if somebody laughs at me' endless worries really but you don't need to go there. I don't know they don't laugh at me thank God but I think of folk on the street sometimes. They might have a hard time I think but there's not a lot you can do really”. (Story 10, lines 280-283, 286-287, 292-296).

Fay talked about how some of her peers had moved into care homes. She specifically referred to this as being an offence to her and of the need to fight against it. She included content on being trapped, excluded and of being an object of ridicule. Fay could have been concerned about the perceptions of others toward her now that she was a person living with dementia. This could be a reflection on issues of embarrassment and exclusion related to familiar people and known places as identified by Clarke and Bailey (2016). This was, however, expressed by Fay as a general concern about people laughing at

others set within a wider societal context. I considered that this could have been a reflection of her fears around the loss of public recognition and social citizenship. It is possible that Fay used her story to consider a changed future with a diminished public identity. She may then have re-affirmed her preferred personal identity in order to reject this future self. This example from Fay highlighted that the narratives of people with dementia can be complex. These stories could then be important tools used to validate personal identities and challenge reduced public identities through narrative citizenship approaches (Baldwin, 2008; Clarke and Bailey, 2016). Influences, achievements, disappointments, and personal observations of the world around can then be revealed. In essence, stories of lives lived and of lives *being* lived, with in some cases, expressed thoughts and worries about the future. In Fay's example these concerns were projected onto others within her story. This projection could then allow her to distance herself from the personal nature of these worries.

“My wife is really my carer”

Alan was a 92 year old man who lived with his wife. He had two children, one of whom moved to Australia. He worked as a quantity surveyor until his retirement and was a keen golfer. Alan's wife was frail and she needed assistance to get around. Alan considered her welfare to be his main priority. Alan had received his diagnosis of dementia two years before we met.

“We were born, or I was born near the railway and near a golf course, so I spent most of my younger life on the golf course. Of course my father had paid for a, you know, to play there for a year and then he would pay again for the next year. So I could play as much golf as I wanted or that I was capable of... I'm down to now when I go to my eldest daughters, they live near Gleneagles and my son in law likes to play golf. We don't have enough time to play a round but we get buckets of 100 balls and tee up there and knock them as far as we like because you don't have to pick them up.....I then joined a club to get more practice and met people of my own age. So my dad contacted X Golf course to

see if I could join in their competitions and I played there when I could.... I got a prize every year I played...They read out the names of people they wanted to see again and my name was called as well as [famous name]. I won the best score for the 5 holes. Yes I had the best score. And of course being the boy champion I was then approached by other areas to represent them in interarea competitions. So I was then playing with the seniors and I won competitions regularly. To celebrate my 90th birthday the family organised a big do back at the golf club.” (Story introduction, lines 9-30).

Alan’s story revealed an interest in golf which I concluded he used to project a personal identity of a socially active citizen; of being fit and healthy; of being a skilled sportsman; and of someone who had received public recognition to this effect. Golf also appeared to be central to his projections of identity as family man. Using Alan’s storyboard I found that even though he identified himself as a person with dementia throughout his narrative, his story was not focused on having dementia and his story was not presented as an illness narrative (Kleinman, 1988). Illness narratives tend to begin with the illness itself or from the point of diagnosis, often using stories of family or experience to search for answers or lifestyle factors that might have caused the condition (Langellier and Sullivan, 1998). I identified that this could be an example of narrative citizenship (Baldwin, 2008). Alan used this story to influence my views of him as a person managing despite dementia offering an insight into the experience of living with dementia (Clarke and Bailey, 2016).

“I didn’t know about the dementia until last year. I had gone to hospital for some sort of checks. I had lots of, what do you call it when they check all over your body? A scan I was well and truly scanned! So, it was quite a few weeks afterwards that I got information via the doctor that I had a slight tendency to dementia. That was the first I’d heard of it you know? No, not only that but when they told me it was that I never felt any different than I had that day. It was just at the, the surgery, it was a lady doctor who is in charge of the surgery so it was through her that I heard. .. I was a wee bit depressed when I found that as I

always felt so healthy you know? Raring to do anything. So I had to accept that I had dementia so I started to try and get some information about what it was all about. And you know 'you'll have to get a, a carer to look after you for a lot of the time', so my wife is really my carer". (Story 2, lines 40-56).

Alan appeared to use his story of having dementia to demonstrate how unlike a person with dementia he was. In particular, he discussed how his diagnosis had been at odds with his sense of feeling well. Alan also used the storytelling opportunity to describe in detail his experience of the diagnostic process, and he reflected on whether his wife was now his carer. This could be an example of the dichotomy of identity on sameness and selfhood (Ricoeur, 1992) as Alan contemplated what being a person with dementia now meant for him. The fundamental question throughout for Alan appeared to be "Am I the same or now changed?"

With reference to the symbolic interactional perspective of this research (Mead, 1934; Stryker, 1968) threats to identity within stories appeared to be revealed within the context of relationships with others. These relationships were examined for evidence of sameness, offering a mirror in which one could see the self through the eyes of others. Where evidence of change was found in these relationships this appeared to be experienced as a threat. The people in the study appeared therefore to experience threats in relation to changing roles, changing status within families and changing relationships with partners and children. This confirms the role of others in creating and threatening the personal and public self. This is demonstrated in this further example from Alan.

“It’s cast up to you”

“Being told about dementia didn’t affect the family. Well I don’t think it did, at least they never said and they haven’t started avoiding me or anything like that, often though in argument with my wife she’ll raise it she’ll say “well you’ve got dementia!” Well one night there we were both sitting talking... And she said to me ‘what have you done with the coaster, you were the last person using it and I’ve not got dementia’. So sometimes that’s cast up to you. How does this make you feel? Oh not very good.” (Story 4, lines 108-114).

Alan stated that nothing had changed in his relationship with his family but then recalled how dementia now featured in arguments with his wife. This appeared to threaten his perspective on his role and identity within the family. This is an example of malignant social positioning (Sabat, 2006). Alan did not challenge his wife within the context of the story, nor in the present in the telling of the story with the listener. However, his choice of words told the listener that he felt *accused* of having dementia and this then provided an insight into the fact that Alan believed his wife in some way held him to account either for his diagnosis or for his behaviour. This would also appear to be an example of Alan being aware that his interactions with his wife were possibly less meaningful as a result of his changed status or public identity (Johannessen and Moller, 2013; Sorensson et al., 2008). This could therefore be an example of Bartlett’s (2016) reference to the importance of the domestic sphere of citizenship in understanding both the experience of dementia and impact on identity. Alan’s narrative could be considered as an example of a micro-injustice (Bartlett, 2016) within the home and in the context of his relationship with his wife.

“I’m quite under control”

Ellen was an 81 year old woman, who was widowed and lived alone. Her husband retired from the Merchant Navy as he had Parkinson’s disease and Ellen cared for him. Her mother lived with the family and Ellen had cared for both for a period of time. She also had two children, a son and a daughter. Ellen had been given her diagnosis of dementia one year before we met.

Ellen's content focussed on her family and social life. Ellen's story revealed the threats to personal and public identity in interactions with her daughter.

"My daughter organised home helps. And it wasn't as if the place was hanging with cobwebs or whatever. My daughter thought that someone coming in might do me good as she is working, so whether it's needed or not someone comes in. I'm quite under control. I'm very lucky with my neighbours round here and I am not on their doorstep all the time if I were I probably wouldn't be liked No I'm very fortunate if I need someone. Oh my goodness, oh peel me a grape. Yes I've always found company pleasant. No, no it's just the odd. Well I have the girls come in with meals for me and nurses come in. They check that I've taken my medication. What's the medication for? I couldn't tell you. Well... it's I.. See I have memory problems and can't remember everything. That's it! I can't remember that I can't remember! I have memory problems and forget that I have memory problems. No I, I do have sort of lapses of memory. My daughter will say, her mantra is 'mother I told you'. That make you feel annoyed!" (Story 6, lines 88-108).

This example, as told by Ellen, demonstrated how a single scene can summarise the tensions experienced by a person with dementia within the context of the care provided by others. Ellen considered herself to be independent, however being in receipt of support could have been a threat to Ellen's personal identity. Ellen re-asserted herself in this situation by stating that she was 'quite under control'. Ellen also used humour within her narrative to move this difficult section of her story forward.

This scene created a shared emotional experience, generated in that moment, within the storytelling interaction itself. Ellen joked that she was unable to remember the cause of her memory problems. However, I also considered that this statement could in fact be evidence of resilience through intersectional experience (Hulko, 2009). Hulko (2009) found that where a person had

experience of adversity in other spheres of their life, this could mean that they were more resilient to the challenges of dementia. Ellen could then have been communicating to the listener that dementia was not the most important thing in her life when seen within the context of other life experiences.

“In the middle of life we have joy”

Charles was an 86 year old man. He and his wife were living apart due to her admission to a local care home. Both Charles and his wife had dementia. He reluctantly agreed to her move to care as his family believed this to be the best option. Charles was in daily contact with his son and daughter. Charles spent all of his free time with his wife, at the care home, as it was within walking distance of the marital home. Charles had his diagnosis of dementia for over two years.

“My name is Charles X and my father’s name is Charles X, and my grandfather’s name is Charles X. I come from... County Donegal but years and years before my time when I was, well the English were all over Ireland we had an army camp in Donegal. And I think my connections go way back to when the British army were in Donegal I think they must have been as my surname is an English name... Well I’m very interested in music, classical music because I used to do a lot of singing. Concerts and things like that and I was singing with groups you know. Well when I was young, very young, I loved it and I went to a singing teacher, she was an old lady and there used to be pupils and things and I would sing there. I went onto singing in groups and choirs and it felt like I was always singing you know?” (Story introduction, lines 1-7; Story 3, lines 83-89).

Charles’ story focussed on his love of music. Unlike the other people in this study, Charles opened his story in the style of narrator, confident in his chosen topic. He had been a singer in his youth and was used to addressing audiences as a solo performer. Charles appeared to assume the identity of ‘reporter’ (Greatbatch and Dingwall, 2008). He cleared his throat before speaking and

audibly raised the volume of his speaking voice. Charles also provided a political and historical context in which to situate his story. In this way he linked his individual story to a wider series of events and placed both himself and his family within a larger social identity, setting the scene for the listener.

"I can't remember. Ooh she's always been very active until you know. Was she in hospital? Oh not very long just in and out.... Oh I think she could remember things far back and I think that happens with people with this. She could forget wee ordinary things about the house you know? What she has been talking about or people's name or things like that. Yes, oh she still knows the family.... The first verse was just about ordinary life, the second verse was about the joy time when they were dancing about [moves feet in dance steps] and all this. And the last verse was a sad verse about his wife passing away or something. And when it came to the middle verse. Aye the ballad of the poor Irish harper and then in the middle of life we have joy and we're dancing about do you see?"
(Story 4, lines 45- 64; Story 8, lines 137-145).

Charles' sense of threat appeared to be revealed in his story content about his wife and her own health, not with reference to his own experience of dementia. Charles included a song within his story about the stages of life and a final verse where the subject of the song 'the poor Irish harper' loses his wife. The inclusion of this song could be an example of life review (Butler, 1963). Charles' narrative therefore revealed contradictions. He and his wife had experienced her decline into ill-health, hospital care and she had moved to a care home setting. However, Charles stated throughout his story that his wife was 'not that bad'.

Charles used his story to minimise the impact of dementia on himself and in the context of discussion about his wife and his life. He avoided any discussion that sought to challenge his world view and instead contextualised his wife's health as a result of other health needs, despite the major changes in his living

arrangements. However, when he moved on to introduce song to the content he selected a song that would appear to be a reflection on his own life and associated emotions. What was evident was that Charles used his story to maintain that everything in his life was fine. This appeared to be a self-protecting mechanism. As a result this story appeared to be used by Charles to deny that dementia had any impact on him or his life.

“I’m feisty alright!”

Beth was an 89 year old woman who lived alone in a sheltered housing flat. She moved there with social work support as part of an adult protection plan. Beth had her diagnosis of dementia for over four years. She was divorced and had four children with her husband, three sons and a daughter. Her youngest son, Bobby, died by suicide after disclosing that he had been sexually abused by a family friend. Beth’s story began with a focus on her divorce, and then moved on to her son Bobby.

“Yes but wee Bobby he died. Cut his throat after a dirty old man interfered with him. And I went to court. There was a grey headed man. They had to hold me down. I was going to get him and thump him. I know I’m only a wee skinny woman but I was plumper then you know and I was going to get him and you know. But they said ‘you cannie do that, you cannie do that’ and they had a hold of my arm. Well when you have responsibilities you have to cope. So I was thinking about my other children. I also had her [points to dog] and I had to think of her.” (Story 5, lines 96-103).

The story which Beth told was a harrowing story of the abuse and death of her son. Beth chose to include a family pet in this story and used this to reveal her reflections on the events. She questioned why she did not seek revenge on the alleged abuser. Beth didn’t have her dog at that time but discussed that she had been unable to act as she had to think of her dog. I considered that Beth had substituted her dog into the story in the place of other children in the family.

This could then be an example where a person who has dementia uses narrative to clearly express emotion despite the components of the story being incorrect, unconventional or out of sequence, as described by Young (2010). The stories of people with dementia therefore remain valid and powerful testimonies to their experiences and aspirations.

“See if I ever see anyone hit a dog when I’m out. I feel like going over to them. If I see anyone slap a dog and the dog’s not done anything I would go over to them and you know but I’m not tough enough to do anything. Yes I’m feisty alright and I can’t stand injustice of any kind... I can still see the man that done it. You know it’s a wonder my other boys didn’t do anything. They must have tried but they would never have got away with it anyway. Yes, I knew him to see. That’s why I wondered if one of my sons tried to get him. You know to get back at him, but it never happened as far as I know. Well they never told me anything anyway”. (Story 5, lines 103-108; Story 6, lines 123-131).

Beth used her story to assert her preferred public identity of being a person who challenged injustice. Beth also wondered if anyone in the family sought revenge. This again could be an example of the person using the story of a past event to achieve meaning in the present. Typically, when people with dementia tell stories where they include confused details such as this, it is explained simply as a result of cognitive changes (WHO, 1992; Young, 2010). However, a focus on those representations of public identity, even within such apparently confused stories, can still reveal important information about the self in that present moment.

Dementia brings a person’s social competence into question (Cox et al., 1998; Nordh and Nedlund, 2015). However, I argue that there is evidence of the social competence of people with dementia within the stories that they choose to tell. I found evidence of this in Beth’s story where she directed the story,

building story scenes and communicating different versions of self to others, depending on context.

In summary, the analysis of each narrative revealed stories and story content which I considered were rich with expressions of identity. I have presented examples of characteristics, roles, actions and personal qualities within each of the narratives. The use of storyboards helped me to understand the narratives of each person and has further revealed the active nature of the storytelling act. This is an important finding as people living with dementia can be thought of by others as passive or non-contributing in inter-personal exchanges (Sabat, 2001). I concluded that the people with dementia in this study included rich details about their characteristics in order to provide an insight into the type of person that they were or aspired to be. Opportunities for validation by the other party would then appear to have been provided by the person with dementia, through their storied actions and experiences.

The actions of other characters, inserted by the person with dementia within story, and in turn the reactions of the story teller, also provided rich, detailed expressions of identity. In some cases these stories were of the death of a child, divorce, bereavement and abuse. They were not simply surface stories told lightly. Instead they conveyed emotion and I considered that they were evidence of meaning making in the moment, as content was used to reflect on identity and perceptions of self across the life course. This appeared to be reflected in stories of relationships and interactions with others and referred to the threat of loss of recognition in interpersonal exchanges, interpersonal status and societal status. This loss of status was possibly linked to assumptions about the person which in turn had the potential to lead to the further threat of loss of status.

Responding to threats, by way of adjustment is a necessary part of the process of resilience. I will now discuss my findings on the possible adjustments made by people living with dementia in the next section of this chapter.

Adjusting to the threat of loss of identity

I have thus far defined resilience as “*adjustment in the face of the threats to personal and public identity experienced when ageing with dementia.*” I have found evidence that the person with dementia can be active in the construction of self and can be considered as exercising aspects of social citizenship (Nedlund and Nordh, 2015; O’Connor and Nedlund, 2016) within the context of their story. In the first section of this chapter I provided examples of aspects of personal and public identities, and the potential threats to these identities, revealed in the narratives of the research participants. I have proposed that avoiding negative outcomes, associated with threat could be evidence of a resilience process. Within this section I will discuss the possible adjustments revealed within stories in order to achieve this.

Positioning

My review of the literature revealed the central role of positioning (Althusser, 1971) in any discussion about the validation of personal identities and the co-creation of public identities. Positioning involves attributing identities to others (Charon, 1992) and locating oneself in relation to others with reference to pre-assigned identities. Where we already hold an opinion about another person, such as someone with dementia, we can interpret their stories using the meanings that we have assigned (Berger and Luckman, 1996). People with dementia can therefore be positioned by others as passive, incompetent and vulnerable (Cox et al., 1998; Kitwood, 1997; Nedlund and Nordh, 2015; Sabat, 2006). Sabat (2006) stated that this can erase the identity of a person with dementia, where no opportunity arises for the person to challenge this positioning, or challenges are misinterpreted as symptoms of confusion and dementia (Kelly, 2010).

I found some evidence, however, that the people with dementia in this study appeared to use positioning strategies within stories to resist malignant positioning. In this way they could potentially shape new stories in keeping with their sense of personal self and public recognition needs. Clarke and Bailey (2016) discussed the ways in which people with dementia position themselves relative to others using narrative. I have identified a further three distinct positioning strategies that appear to have been employed by the people in this study. These are: rejecting the positioning of self by others within stories; re-positioning of self through stories; and positioning dementia within stories of the relational self with others.

Rejecting the positioning of self within stories

Ellen

“If people are having a conversation the last thing I would want to do is say ‘Oh I am getting old’. No I’m fairly up to date with what’s going on, and as I say I get the paper every morning, the television. I think I’m fairly... So really I’m alright. I vary sometimes I’m quite nice and quite happy but my friends, well one of them died last year, and the other one, well she’s right at the end but she drives and so on. And my neighbours on either side are great. I mean I’m not sitting on their doorstep. I’m quite happy with my own company but I still like to have a chat and a cup of tea. Especially with a fella.” (Story 8, 144-152).

Ellen appeared to use positioning to reject the public identity of the ‘older person’. Ellen’s perception of an *older person* was of someone who was out of touch. Ellen appeared to use positioning within her story to distance herself from this identity by revealing her interest in current affairs. Ellen demonstrated the things that she does to ensure she is not acting like an *old person*. She also used humour throughout her narrative as a tool to deflect from the emotions associated with potentially challenging story content.

I used Ellen's storyboard to reveal the overriding story themes of continued independence, her social network of friends and support from neighbours. These could also be described as resilience resources.

I found that Ellen also included points of reflection within her story. She discussed the changes to her social network brought about, in her view, by the death and ill-health of her friends. I considered that this reflection within stories and the reflections that occur through the telling of the stories could be an integral part of the resilience process. Reflection preserves personal identities (Holstein and Gubrium, 2000) as it facilitates insights and new understandings of personal identity in the moment and supports the creation of new public identities. This example shows that reflection can be deeply embedded within a larger story and as such may remain hidden.

Fay

"And also I have to be very careful that. I have grandchildren and I don't want them to get any sort of vibes that gran is ancient, that I must be ancient. I don't want them to know that. Yes, my own grandmother, she was, she had it hard because she brought up four children and it wasn't easy living in the country. Do things differently." (Story 9, lines 245-251).

Fay's narrative also revealed the rejection of the public identity of older person. Whilst Ellen's narrative referred to unspecified others, Fay was concerned that her grandchildren would position her as an older person. She also referred to her memories of her grandmother in her descriptions of what an older person was. The insidious nature of ageism and in particular the personal revulsion described by Butler (1969) was hinted at as Fay opened her narrative with the admonishment that she has to be careful. I understood this to mean that if she is not careful, Fay's identity as an old person could be revealed resulting in a loss of recognition and diminished public identity.

The inclusion of the word *ancient* to define this state appeared to offer a further insight into her views on the subject. Fay used her previous experiences of old age to reflect on how she wished to be known in the present and then she appeared to plan a different course of action although she did not specify what this was.

Re-positioning of self through stories

There were also examples where the person with dementia re-positioned self, using story, in order to avoid the negative outcomes associated with loss of personal or public identity. This re-positioning can be considered as an active adjustment by the person, in order to present the best version of self (Hedman et al., 2013) both to themselves and also publically, in this case, within the research interaction. Some people in this study appeared to re-position self within the context of their everyday activities. These were often activities which most people would take for granted, but which then take on significance where the person concerned can no longer continue with them.

Alan

“Did I join a club when I moved over here from Edinburgh? No I didn’t bother No. I gave my clubs away to my son in law, but maybe one of these bright days he might want to have a full round with me which I would like. I don’t, I was very disappointed I had to give up golf and motoring. I don’t know if I really gave it up... I moved here as I had family here, not far from here. ...Well it wasn’t about the dementia.” (Story 2, lines 34-39).

Alan told the story of leaving his golf club in Edinburgh. Alan opened by informing the listener that he had not bothered to join a new club and included the story detail that he had given his golf clubs to his son in law. I considered that giving away his clubs was a pivotal part of his story. The golf clubs could have been used as a symbol of Alan’s previous life, and all that golf meant to

him, for example, fitness and public recognition. The story of giving his clubs away might then have been used by Alan to indicate this new period of his life. He also revealed that he is still interested in golf but can only go now if his son in law has the time to go with him, as he owns Alan's clubs. Alan then stated that he had to give up golf and then added that he also had to give up driving. He shared emotional insights into how disappointed he was at giving both activities up. This appears to be an example of narrative openness (Randall et al., 2015) where Alan used his story to provide insights into these recent losses. This story included a point of reflection signalled by the statement 'I don't know if I really gave it up'. Alan then chose to re-position himself within his story as being in control of these decisions. He concluded his story by being clear that he did not *have to* give up golf and driving because of his dementia. Instead, he stated that it was the result of his house move, and conveyed this as fact to the listener.

Dora

"And when I go out a run, I love driving and I passed my advanced driving test. That's my daughter's car. They won't let me drive now...A couple of the parish pastors would say to me at different time 'Dora are you going to church this year?' And right away I knew what was coming. 'Well were you wanting a ride?' 'Well if you don't mind as it means I can leave the car for my wife' So many a time I took the ministers around in my car!... I used to love going a run in my car and that's the thing I miss but in my heart I knew. They asked me to read something and I couldn't see it and I thought 'I'm not driving'. So they didn't stop me I stopped myself. The minute I knew I couldn't read a sign I stopped myself. No way would I put anyone's life in danger but I feel God has been good to me." (Story 7, lines 200-208; Story 10, lines 257-265).

For Dora, driving appeared to be associated with being needed and valued. She was an advanced driver and shared that she was known as such within her family and community. Driving was therefore an important part of her public identity. Dora had used the phrase 'they won't let me drive now'. However, as her story progressed she then re-positioned herself as the person who made the decision about her own competence to drive. Dora did not make reference to dementia in these decisions, instead she was very specific that her driving stopped because of failing eyesight. Her decision not to include dementia could be considered an active act of omission in order to distance herself from the identity of person with dementia. Dora possibly used this story in order to re-position herself from passive to being the active person in control of the situation. She was then able to re-affirm her personal identity as a good, moral person and ended this part of her story with a reference to God. This could be evidence of Dora referring to a resilience reserve within her story in order to preserve her preferred public self.

Fay

"There's nobody comes to the house now. Mind you that is very recent because I did have people coming through this house but they were no trouble. Because my family don't want me bringing people into the house because I'm older, because I'm on my own, because of my memory. And I wouldn't go against that because I would hate to have my family sitting biting their nails because of me! I think that is wrong. I would turn people away but I wouldn't be unpleasant. I would bring them in and explain. I would say 'it's my family's time now, my family need me now'. I've given years of my life to helping others and it's now my family's turn." (Story 10, lines 257-265).

Fay discussed how she had to stop her charity work. She stated that this happened because her family were concerned about her. She revealed that this was because of worries about her age, the fact that she was on her own and that she now had memory problems. However, she then appeared to move herself away from this vulnerable identity by re-framing the scenario. Fay re-positioned herself within the story as taking the decision to stop her work as her family needed her. In this way Fay retained control as the decision maker and remained in her role as providing support to others, in this case her family. This re-positioning appeared to offer the listener an opportunity to validate Fay's preferred identity. This could also be an example of the re-distribution of resources within a resilience context (Sapountzaki, 2007). Fay used her story to focus on personal and family commitments. This offered a positive employment of her skills and resources which would otherwise have been redundant through the cessation of her charity work. Instead, Fay indicated that she would use her person centred values and experiences to now look after herself and her family.

These adjustments in relation to everyday losses and routine activities in order to preserve identities are an important finding, revealing the association between dementia and loss of recognition. In these examples the person did not simply accept the loss, but instead re-interpreted the loss through the act of re-positioning. A sense of mastery over the situation was thus established by moving self from passive to active. In this way loss of recognition could be avoided and identity preserved. In these examples each person could be described as having demonstrated knowledge of their situation and reflection on experiences. Reference to personal, familial and social resources in order to bring the story to life for the listener also appeared to be in evidence.

Positioning dementia within the story of self

Fay

"I think on a day to day basis you can see how things are going, are they going well or is somebody mollycoddling you or are you doing this yourself. And you have the room and the time to do that and to think and choose not to take all of the stuff you don't need and just leave it aside" (Story 9, lines 241-244).

Fay referred to her knowledge, skills and experiences from her counselling work with others and appeared to then apply these to her current circumstances. She positioned dementia as a thing that you can carry with you or choose to leave to one side. This then positioned Fay as having personal control over her dementia, and, in turn, she could then conclude that it does not control her.

Alan

"I try and remember where I left the thing and I try and cope. I decide well I've got it I must cope with it, what else can you do except jump off a bridge or something. Life goes on. Absolutely and I have a wife to worry about, better worrying about her than me...My wife and I go to bed early and put a disc on... and you feel all is right with the world. You know you're together, you're safe. The house is locked up. Cosy...Well, I manage to cope with dementia by going to this place up on the road once a week and talking about it. I don't mind people knowing, well not really until they ask. But, I just told them I had dementia but I haven't told the newspaper boy and he delivers the news every day." (Story 5, lines 139-142; Story 6, lines 210-211; Story 5, lines 135-138).

Alan's story revealed the constant threat and worry he felt about dementia. However, he reported a sense of comfort, security and a release from thinking about having dementia through a focus on his wife and his home. This appeared to provide him with respite from his worries about dementia. His struggle to adjust to his dementia is evident in this section. For example, Alan equated coping with striving to remember. This is of course not a strategy that he can use in the long term as short-term memory loss is inevitable. Alan also discussed telling other people that he had dementia. Alan appeared to retain a sense of control over his dementia by choosing whom to disclose to within his story. Alan again stated that he is managing to cope. Casey and Murphy (2015) found repeated statements from people with dementia in their study about the need to fight their dementia. What is not known is how much the expected public response of being seen to cope contributes to these articulations. Resilience is not however about coping with dementia but rather is about adjusting to the changes to personal and public identity that dementia can bring.

Alan's narrative appeared to reflect his struggle to remain unchanged despite his dementia (Ricoeur, 1992). The importance of the newspaper boy was an interesting story introduction. He was not a central character and this was his only story line, however, he was revealed as significant to Alan because of their daily interactions. He may then have been a barometer for Alan to test whether he was 'doing okay' (Harris, 2008). He could have been representative of the world beyond Alan's immediate family or circle of people that he chose to disclose to. His role in Alan's story could then be re-framed as important daily test for Alan in the preservation of his public self and citizenship status.

Much has been written about the use of positioning by others in their relationships with people who have dementia, however, my findings reveal that positioning is also used by people ageing with dementia in order to achieve positive outcomes in the face of threats to identity. Considering positioning as an aspect of resilience could facilitate a greater understanding as to how people

with dementia respond to malignant positioning (Sabat, 2006). The people in this study appeared to use this as a strategy to reject the positioning of self by others. Stories could also be used to both reveal and test a person's own criteria and self-assessment processes of 'doing okay' (Harris, 2008) or of having a 'good enough' life which I will now discuss.

Developing your own measure of good enough

Several of the participants had developed their own measures of how much being older and/or having dementia had had an impact on them. They then appeared to use this to gauge their own particular situation. This involved elements of self-appraisal and testing the continuation of self.

Ellen

"Getting lost on the bus? No, no I haven't been like that or it could have been I wasn't quite sure where the bus was going. That's easy done...I mean if it came to it if I didn't feel well I would call the doctor to come here or I would make an appointment at the surgery. Well I think if I was in X and couldn't remember where I was, or where I lived that sort of thing. It's one of these things. My daughter will say 'Mother, I told you!' but based on my criteria I don't think I've ever forgotten anything really important." (Story 7, lines 140-141; Story 8, lines 134-143).

Ellen discussed an incident where she had been lost and the police became involved in looking for her. She rejected out of hand that her need for assistance had arisen because she had been lost. She offered an alternative explanation which minimised the extent of the event and the likelihood that it would occur again. By using the phrase 'that's easy done' Ellen suggested that such an incident could easily happen to anyone, and was not any reason to worry about having dementia.

Ellen used her story to take control of the topic of risk and concern. She began by listing her criteria about what would constitute a concern, in her mind this is feeling unwell, not forgetting which bus to take. She then stated what action she would take. She would arrange for a doctor and again was specific about how she would do this. Ellen was clear as to what constituted a concern as far as her dementia was concerned. Her narrative revealed however that her own criteria and those of her daughter might not be in accord. She asserted that her own views carried most weight despite what others said. Ellen did not deflect from the suggestion that her memory was bad but rather defined illness as feeling unwell. Ellen's self-assessment was that she didn't feel unwell, therefore in her opinion she had nothing to worry about. Ellen further asserted her control over this topic when she advised that anything that she had forgotten was not important enough to remember in the first place.

Beth

"Well it was years ago... but I don't really notice it. My memory's not that bad. It's not terrible. I mean I remember my gran and my home in X and I remember the house and all these things... Well say I've got a date to be somewhere....I know I won't remember it so I have to write in on the calendar So If I've got to go to a place. I'll write it down. So I'll not forget! I remember that I forget you know? Yes, yes. It's not that bad. As long as I can remember way back it's only the last few years that I don't remember... There was nothing really to be done about it, if you know what I mean? I know things aren't going to stay there [points to head] you know what I mean". (Story 9, lines 153-167).

Beth gauged how bad her dementia was by how well she remembered important people in her life and her emotional connection to them. She stated that she did not remember day to day appointments but that she wrote these things down.

Beth used the phrase 'I remember that I forget' which appeared to give her a sense of mastery and control over her situation. Beth used a calendar to write things down and used the recall of important memories to appraise whether she was doing okay or not. In Beth's opinion she was doing okay.

Setting criteria for personal decisions about 'doing okay' (Harris, 2008) and assessing self against these criteria revealed that memory and the act of forgetting itself had a central role in some of the participants' stories. However, in the assessment of self it was not the ability to remember that appeared important, rather, it was the person's own interpretation of how important the information was that had been forgotten. So, forgetting was not in itself a primary concern for people when assessing if they were 'good enough'. Instead this was measured through a focus on living with memory loss; accepting that forgetting was now part of life; assuming anything that was forgotten was not important to begin with even where others challenged you on this; a focus on a sense of wellbeing as an indicator of being well or unwell; and finally, a sense of self as unchanged despite short-term memory loss. However, an insistence that you were doing okay despite evidence to the contrary could be evidence of the absence of personal adjustment strategies. In this case, such an insistence could be evidence of low resilience in a specific scenario. This appeared to be the case in Charles' narrative.

Charles

"If I took a notion that I might forget then I would write notes. But I don't forget important things. That's it exactly. I am confident in myself! Well I think if I'm going that way with memory I would leave notes where I would get them. Only important things that I would absolutely need to remember. You don't actually have to remember anything else do you?" (Story 8, 105-110).

Like Ellen, Charles advised that he also remembered the important things in life. The things that he was unable to remember were considered by him to be unimportant and not worth being concerned over. Further, he was confident in his own ability to remember. Charles appeared to project this through story demonstrations of the actions he would take if he needed to. He stated he would take notes if he had important information to recall. Charles was then able to use the fact that he had no notes as evidence that the information was not important enough to write down in the first place. He validated this by inviting his audience to agree with this position.

“I don’t think I’ve got any problems you know, not big problems? Looking after my wife is the most important thing you know? Focussing on someone else”.
(Story 8, lines 111-113).

Charles prioritised his need to look after his wife over any concerns about having dementia. As a result, he did not consider any problems that he might have with dementia as significant in his life. His focus was instead his wife’s wellbeing. He minimised dementia in his own life by focussing on someone else. This focus could be considered as avoidance of dealing with the threats of dementia. This could be an example of denial, which Charles may have been employing as a self-protecting mechanism (Clare and Shakespeare, 2004). This could then be indicative of lower resilience in the face of the threats associated with ageing and dementia. Charles’ story did not reflect the narrative openness (Randall et al., 2015) of the stories that were shared by other participants. A comparison is offered with that of Alan and his focus on the needs of his wife. Instead, Charles focussed on story details which reflected his view that everything in his life was okay. Alan, by comparison, sought the positives in his life that he still had despite dementia.

Alan

“No I don’t feel any different but I didn’t find out very much. But I was talking to a chap the other day at the day care place and I said to him I have dementia and he said so have I. And of course his brother had it and he was worse, it got very, very difficult for his mother to handle him, but he was alright or at least he seemed alright. I don’t think I’m too difficult to handle”. (Story 4, lines 96-102).

Alan appeared to use his story to reject any assumptions I might make about him or his behaviour through role association with the public label of being ‘a person with dementia’. He also cited what he believed to be the attributes of someone with dementia in order that he could demonstrate how different he was from this. This could be an example of ‘the demented other’ (Naue and Kroll, 2008). This is the label that Naue and Kroll (2008) proposed was assigned to a person after they had a diagnosis of dementia. This, they argued, results in the person with dementia being seen to represent difference and otherness (pg. 26). This character could then be the ‘demented other’ within Alan’s narrative although he does not use this language and indeed people with dementia have written about the ways in which the word ‘demented’ can disempower (Sabat et al., 2011). Alan’s word selection reinforced his view that he was ‘ordinary’ therefore rejecting those attributes that would associate him within a dementia frame. He also created characters to validate his preferred picture of self through social comparison with others within his story (Festinger, 1954). There were also elements of self-appraisal within Alan’s narrative.

The inclusion of other people within scenes could act as a means of persuasion, of persuading the self and others of a particular point of view. There appeared to be evidence of this in Alan’s story.

Alan included a person with dementia within this scene, who like him was surprised at his diagnosis, and an 'out of control' other who reflected the issues that Alan associated with dementia. This appeared to achieve several things. One, it confirmed that people with dementia were ordinary, everyday people engaged in conversation, expressing surprise about their circumstances. Two, it revealed Alan's fears about what dementia might mean i.e. to be out of control and three, it created a character that Alan could distance himself from in order that he could demonstrate how different he was from this (Naue and Kroll, 2008). Alan's story could therefore be reframed as a resilience process working to maintain his preferred personal and public selves.

The examples provided could be a reflection of the struggle between sameness and selfhood (Ricoeur, 1992). The person concerned appeared to use their stories to demonstrate sameness of their past and present self. This could be evidence of the extended self, suggested by Caddell and Clare (2011a). At times, through reflection points within stories, the person raised questions of sameness which they then resolved through the storytelling process. Again, this appeared to be an important finding as to the role of stories in questioning what it means to remain the same despite becoming older or having dementia.

Reflections on adversity across the life course

Participants reflected on difficult circumstances in their life within stories and recalled the ways in which they had responded to these. Stories therefore appeared to be used as comparison or as a point of reference. This can be viewed as part of the process of reflection, and used to gain insights into the current situation in which one finds oneself. This could then assist in the preservation of identity (Holstein and Gubrium, 2000). I will now illustrate this with two examples.

Ellen

“Oh yes, I had no health problems or there was a sort of one point I got very depressed but, but then my mother she was living on her own and she became sort of, unwell she came here too, so, so! My husband eventually, the thing with him was that he was having falls he.... I just couldn't cope with it. I couldn't lift him up... Anyway, I eventually I got him into a nursing home. Well the thing is you can't go 'Well to hell with this and just walk out.'...But there was a point when I felt very depressed and I was on anti-depressants. And then I had my mother come she had had a breakdown and the things was I really couldn't go out and leave her with my toddlers. It wasn't that she would be violent but just things would go wrong....I, just didn't want to join in. I wasn't part of anything... I went into myself as it were. Because I really have no commitments now. If I had a lot or I couldn't do certain things or I wouldn't be able to leave family but I don't do a great deal now but I know I can do things if I want to.” (Story 5, lines 53-79, 80-82).

Ellen described her experiences as a carer for her husband, mother and children. She advised that she felt trapped by these responsibilities resulting in an episode of depression. Ellen used this part of the story to convey the realities of caring from her experience. She used narrative openness (Randall et al., 2015) to share with the listener, not only the facts of this period of her life, but also the emotional impact of the situation. This story could be an example of how the experience of adversity in the past can help build resilience in the present. Ellen distilled her experience down into the central issue of feeling trapped. She then compared this to her present experience of living with dementia.

Ellen used her story to reflect on her life and employ autobiographical reasoning (Randall et al., 2015). She used this to determine whether she was experiencing as great an adversity in the present as she had at, what she described as, her lowest point. Ellen's greatest fear was to be trapped, to lose her independence and be unable to come and go at her own discretion. As a result, she did not consider her memory loss as having that great an impact on her. She considered herself well and went out as she pleased.

Alan

"The night my father died I was at the house. What a night that was. He went to the toilet and I went behind him and he started being sick. I had to get a doctor out as soon as I could as he was coughing up blood. That lasted a few minutes and then he sort of went down on his knees and that was that. Well I just had to deal with that as my mother was in the house, you know?... It was an ordeal or an event that I will never forget, you know? Yes it was the worst thing that happened to me although during the war you know I saw some sights there. Some nights you would be going for your dinner and you would smell burning flesh if there had been a crash near the airfield but I coped then and I'm coping now. I have to I have a wife.... Well it was frightening at first being away from home and doing a new job. I, I, I didn't know the area. It was in England but you soon adapt. Maybe that's why I mentioned it because we are talking about my attitude. It was a long time ago. Well, I was frightened. We all were. I didn't know what was going to happen to me. You lived every day as though it might be your last. I got up every morning scared about what might happen or what I might see but I still got up. But everyone did but we never mentioned how we felt. Well, everyone knew, because we all felt it...we just didn't say it.... Well you can't just sit about when there's a war on. I was needed to do a job I couldn't say I can't do that I have dementia? You always think about a war if you've experienced one." (Story 5, lines 120-134, 172-185).

Alan used autobiographical reasoning (Randall et al., 2015) to reflect on his previous experiences of death and war. He recalled the personal and harrowing experiencing of being present when his father died suddenly. This was the worst thing to happen to him. Alan reminded himself that he survived this event and as a result could also survive with dementia. At the time of his father's death he prioritised the needs of his mother over and above his own grief. At this time he prioritised the needs of his wife over and above his own fears about dementia. Alan used the phrase 'there's a war on' in the present tense within his story about living with dementia. His references to coping were revealed as references to survival when the storyboard of his life was reviewed as a whole. Alan's story revealed an association between being at war, and having dementia. This could then be a story about the terror of dementia. Alan's continued reference to coping could be interpreted as surviving when it is observed within this larger narrative. It is the story of the continuation of self in the face of dementia and as such I argue, demonstrates the differences between coping and surviving. The continual nature of *surviving* is conveyed in Alan's statement that every day could be your last.

In Ellen and Alan's stories they appeared to use previous experiences and knowledge to assess threats to self in the present, with each person arriving at a different conclusion. Ellen is re-assured; Alan is afraid. However, both appeared to make the necessary adjustments through their personal resilience resources to live with dementia. What is interesting is that Ellen had taken comfort from being independent and having no responsibilities whilst Alan was re-assured by his responsibilities. This highlights the unique nature of each person's resilience reserve and the dangers in generalising or making assumptions about vulnerability and protective factors. I will continue this discussion about the very personal nature of resilience, life experiences and ageing with dementia in my findings on personal theories.

Making sense: personal theories about ageing and dementia

Personal theories appeared to have an important role in supporting stories of self and constructing public identities which maintain recognition and status. The people in this study had their own personal theories about their present circumstances. For some this included why they had dementia and how to live with dementia. For others the focus was on ageing and health issues. This is congruent with the work of Jacobson (1993) on the way people with mental health issues come to terms with their unique situation. The narrative extracts which I have chosen to include in presenting my findings on personal theories are more detailed than the previous findings. The reason for this is that personal theories were only realised through an understanding of the whole story purpose. As a result they emerged through my storyboard approach of story deconstruction and reconstruction. In order to present this in as rich detail as possible I have brought together important elements of each story. A list of all of the suggested personal theories can be found in Table 5.

Fay

“Well mercifully I don’t get anything too wrong, it’s very rare and I’m not saying that that’s not going to change [laughs loudly] but at the present time it’s no problem for me to recall stuff. I, I don’t know what I will be like again when I’m older but I don’t think I will allow myself to become decrepit and gaga....I have a healthy diet and if someone wants me to do something I tend to do it as I know it will be good for me. The opportunity to do new things. I think you have to be very sensible. ..No, no it’s just part of what to expect. It is part of getting older and I think if you sit and moan and groan about it. I sometimes write things down but my memory is reasonably good, as far as I know. I know the day of the week, as far as I know.... They just mentioned it and told me ‘this is just something that happens in old age’ and I knew that anyway, I know that. Something like that. I assume that it will happen to all of us that’s just life isn’t it? The thing is to make the most of the life you’ve got. I wouldn’t dream of worrying about it. I think if you start to worry about things you exacerbate the

anxiety. No, and I don't intend to worry about it! For goodness sake life is so short." (Story 9, lines 237-240; Story 10, 283-285, 266-269, 271-278).

Fay's personal identity was centred around continuing to be an active member of the community and rejecting those qualities that reflected ageing and ill-health. She considered the effects of dementia to be a lifestyle choice: the choice being between continuing to try new things or to stagnate. Fay stated that dementia was an ordinary part of old age that would affect everyone at some point in their life. As a result, for her, it was not something to worry about as long as you made the right choices to stay active. This appeared to be an example of motivational reserve (Forstmeier and Maercker, 2008) where a person has built a reserve of motivational skills that can then minimise the impact of ageing or dementia, or in some cases both. Fay's narrative revealed that she sees herself as in control of her health and wellbeing. Her resilience reserve possibly acted as a buffer to lessen the impact of dementia and also provided a repository of skills which could then help her to adjust to her new identity. Clare (2003) found evidence of this when exploring threats to self in early stage Alzheimer's disease. This is also covered in detail by Keady et al. (2007). Being a person with dementia appeared to be an unacceptable identity for Fay. Fay's narrative frames dementia as spoiled identity (Goffman, 1963) using derogatory terms such as 'decrepit' and 'ga ga' to clearly convey this to the listener.

Personal theories about ageing and/or dementia were important as they set the context for the master narrative of each person's story. There also appeared to be a complex interplay between personal theories and new experiences that could threaten these. There was a common theme amongst many of the participants, expressed by Fay, that dementia was just something that happened when you were older. This appeared to be a means of normalising the experience and of absolving the person concerned of any responsibility for the condition.

Dora

“My memory is not so good so I can’t remember exact dates or anything but I do know there came a time and I knew that that was the life for me and I gave my heart to the Lord and held him in it... Oh yes! He is with you. The Lord doesn’t say believe in me and I’ll give you a good life. What he does is helps you through all of the bad things and it’s a lifeline. He’s there helping and you know you only need to turn to him and he will give you the grace to do something...I did go and see someone and told them what I did and they said ‘you do the best thing you can do and you’re doing it yourself, you’re writing down important things.’ Oh gosh I’m so used to answering questions it was just another lot of questions. I wasn’t worried about dementia or what they might tell me. I know what like I am in myself and I’m ready to meet the Lord and that was me, and pardon me, and that was me....No never alone, no never alone, promised never to leave me, never to leave me alone. So I always know I was never alone even though here wasn’t another human person here to speak to but I could speak to the Lord. That’s what’s brought me through everything! My faith in him, initially and I feel he brought me through and I have a good family and I really have and that you know.” (Story 6, lines 116-123; Story 9, lines 157-160; Story 10, lines 172-176).

Dora appeared to use her faith to both understand and cope with the changes in her health and her dementia. Dora also revealed that she considered these adversities as life challenges. The role of her faith could then have been to grant her the grace to endure her circumstances. Spiritual or philosophical models of coming to terms with a health crisis viewed identity as in transcendence: the condition viewed as either spiritual crisis or opportunity (Jacobson, 1993). Religion and spirituality can continue to be of importance for some people with Alzheimer’s disease (Stuckey, 2006). Windle et al. (2008) also concluded that spirituality and self-acceptance emerged as important features of resilience in people aged over 50 years. Dora accepted that her health was deteriorating.

Dora's religion was an important part of her motivations, knowledge and experiences. As a result she contextualised her experience of adversity as a test from God. Dora believed that this test was one of her continued faith in the face of adversity. Within her story she balanced her ill-health against the things that she believed have been positive in her life such as her own house, family who care for her, her love of the church and her travels. Dora had not expected God to solve her problems but rather employed self-directed religious coping (Pargament et al., 2000). This was demonstrated where Dora stated that God had given her the strength to deal with negative events and where this was not possible to endure them with dignity. This is defined as *active surrender* (Wong-McDonald and Gorsuch, 2000) where the individual takes actions that relinquish their will to God's will (Allen et al. 2011). Dora appeared to gain control over her circumstances by redefining them as the will of God and contextualising that God does not give you more than you can handle. This personal understanding then allowed Dora to see herself and her circumstances as significant and part of a larger plan and in this way she appeared to achieve meaning.

Beth

"Deaths in the family affected me awful bad. The death of anybody. Wee Bobby, wee Bobby He cut his own throat after a dirty old man interfered with him. And I went to court and the old man was there. I would have loved to have got a hold of him! But what can a woman do? You know what could I do? I would have been jailed as well. No, no really. I can't remember much about it. I don't remember who the man was or where he lived. Bobby was a very young boy but I don't remember. I don't remember much about it. I was at court as well, but I don't remember much about it. But what can a woman do? He was dead anyway. I can't really remember. I don't really know. Someone came up and told me what had happened. Aye the police came up and told me. I can't really remember. The dementia. I don't want to remember. Aye, aye, I don't want to remember and my body knows that... I think if I remember. I think that something bad happened and because of that my memory just went [makes a

whistling noise and uses hand to indicate going over her head]. My body just wanted me to forget it. You know? I think, aye, I think it's something like that. "But If I really want to remember something I have to write it down. I don't want to think about it. My memory is bad because of this terrible thing, you know? My body doesn't want to remember. And I'm very happy really. I'm very happy here... I'm getting laminate flooring." (Story 9, lines 182-185, 189- 194,198-205; Story 11, lines 259-262).

Beth considered that her dementia was a biological response to the trauma of her son's abuse and death. She focussed on the positive impact of memory loss. She believed that she had developed dementia to facilitate a sense of peace or respite from painful memories. Beth discussed her body as creating dementia as a biological defence against bad memories. Beth then framed her dementia as offering respite from remembering her son's abuse and death. Throughout her story she repeatedly asked questions of herself as to why she did not seek revenge for his son's abuse. Abuse and trauma models as defined by Jacobson (2003) could explain Beth's experiences, where the person's difficulties are considered by them to be the result of trauma. They are considered to be a direct result of the experience of physical, psychological and/or emotional pain. There then follows an emphasis on 'pain management' to gain control over the condition. In Beth's case, she appeared to gain control over her dementia through the re-framing of it as a positive or protective factor which she used to achieve pain management. She was then able to focus on the positive things in her life such as getting laminate flooring. This personal theory could position Beth in a survivor discourse, where she was surviving the emotional pain of her previous trauma. This approach could also be an example of intersectional reserve (Hulko, 2009). Beth has had to endure many difficult experiences in her life. Her son Bobby's circumstances, her husband's alcohol use and affair, and her divorce at a time when divorce was not that common. She had also recently been the subject of an Adult Protection Plan due to another son's actions. It is possible that in the context of such experiences, memory loss as a result of dementia may be considered as just one more thing to contend with (Hulko, 2009).

Personal theories appeared to be an essential part of a continual process of adjustment. They appeared to provide a context for each person to manage day to day experiences of ageing, ill-health, or dementia. In turn, each adjustment achieved could be considered as contributing to the resilience reserve where positive personal outcomes were achieved, no matter the size or scale. The accuracy of each person's theory did not seem to have any bearing on effectiveness. For example, we know that dementia is not the necessary result of ageing, and similarly with Beth's example her dementia is unlikely to be a biological response to painful memories. However, what appeared to be important was the level of investment placed in these understandings by the person concerned. Stories then work towards supporting these personal theories, and in turn preserving identity. However, it can also be argued that fixed personal theories could be used to deny threat. It is therefore important within a resilience context to be able to differentiate between those personal theories that support adjustments and those which might make adjustments less likely to occur.

Table 5. Personal Theories

Participant	Personal Theory
Alan	<p>Bad Luck</p> <p><i>"This dementia, it can happen to anyone if it can happen to me".</i></p>
Beth	<p>Biological Defence Mechanism</p> <p><i>"I don't want to remember and my body knows that."</i></p>
Charles	<p>Nothing Wrong/Normal Part of Ageing</p> <p><i>"That's the way of life, that's the way your brain goes as you get older, it's normal."</i></p>
Dora	<p>A Test from God</p> <p><i>"He's there helping and you know you only need to turn to him and he will give you the grace to do something."</i></p>
Ellen	<p>Due to Inactivity</p> <p><i>"I think you become a bit inactive and things just go out of your mind and you don't remember this and remember that but I think things that are important I remember."</i></p>
Fay	<p>Identity of 'person with dementia' as a lifestyle choice.</p> <p><i>"I don't know what I will be like again when I'm older but I don't think I will allow myself to become decrepit and gaga."</i></p>

Summary

Within this chapter I have discussed my findings in relation to resilience and people ageing with dementia. I began by demonstrating evidence from each narrative, of content that revealed the person with dementia as an active agent in the creation of both personal and public identities. I have presented examples of characteristics, roles, actions and personal qualities within each of the narratives. Narrative analysis has, however, revealed that each small detail and story that the person with dementia chose to include was in essence a building block in the creation of a public identity within the research relationship. I found that public identities built on recognition and status, even where this included being seen as 'a person with dementia', continued to be important to each person within this study. There were examples of charity workers, sporting winners, foster parents, church members, friends, as well as more traditional roles such as mother, husband, neighbour etc. presented through the storytelling process. Each person therefore appeared to be an active performer in the story of self. People shared their version of 'who I am' at that moment in time. The review of the relevant literature revealed how the label dementia can call a person's social competence into question (Cox et al., 1998) and in turn result in a loss of public recognition (Sabat, 2006). However, I argue that there is evidence of both the social competence and social citizenship of people with dementia within and through the stories which they choose to tell as he or she communicates different aspects of self to others. This can be understood as a personal resilience reserve which I will return to in the final chapter of this thesis.

An exploration of the challenges to these identities revealed through my analysis highlighted that it was not the bio-medical symptoms of dementia that were considered as threats by the people with dementia in this study. Instead threats appeared to be revealed within the relationships that people had with others, self-reports of the attitudes of close others and the perceived public attitudes of wider society provided the biggest threats.

My findings also revealed the ways in which people with dementia appeared to use stories to reject the positioning of self by others and to re-position self within stories. The positioning of dementia itself in relation to other life events, people and activities appeared to be in evidence. Positioning could then be an important element of preserving self through story (Clarke and Bailey, 2016). In all cases the person with dementia was the narrator of their own story. He or she used story scenes and introduced characters to explain relationships, actions and outcomes. The employment of these positioning strategies appeared to facilitate a sense of mastery and control within stories, where the person was able to talk about changes in life style and their role in making changes within their lives. Mastery was also asserted within stories in relation to present circumstances, future events and even ageing with dementia. In some cases positioning could confirm that the person concerned was able to influence events around them. This was seen, for example, in Dora's account as to why she stopped driving.

Interestingly, dementia was contextualised within stories of family changes and wider social networks, not as an illness within a vacuum. This appeared to reinforce the importance of identity, recognition and reflections of the self through others when a person has dementia. The challenges that people face in holding onto their preferred public self when the views of others were influenced by the label dementia appeared to be keenly felt in these interpersonal relationships. Resilience in responding to these changes could therefore be an important part of living with dementia day to day and maintaining citizenship in the context of domestic and social spaces.

Positioning as a means of rejecting the assumptions and actions of others is important as it confirms Masten's (2001) views that resilience resides in stories of the seemingly ordinary. People with dementia told stories about their lives, their families and the things that were important to them.

Positioning within stories provides an opportunity for each person to make the story their own in demonstrations of narrative citizenship (Baldwin, 2008; Clarke and Bailey, 2016). In effect, stories of the seemingly ordinary were stories of the self. The telling of these stories could be considered as the active process of the preservation of self within the storytelling relationship. In this way stories could be seen as part of this process of resilience. For example, some people used their stories to both reveal and test their own criteria and self-assessment processes of 'doing okay' (Harris, 2008). Challenges to 'doing okay' that arose within stories could then be resolved. This could include scenes where the other characters within the story were proved wrong in their assumptions that the person was likely to forget something important. The person with dementia was then able to position self as they saw fit within their story. The story was their own and the person concerned set the story direction and they were in control of the actors who populated each of their story scenes. In some stories the character who had challenged the views of the participant that they were 'doing okay' admitted that they had been wrong. Positions associated with malignant positioning (Sabat, 2006) and threats to personal and public identity could thus be rejected and redefined by the person concerned in order that their story continued to contribute to the projection of their preferred self. This is possibly a tool in the management of the impression of self by others (Goffman, 1959). Strategies such as these could result in the preservation of preferred public identities by people living with dementia.

I have also discussed other possible strategies which could support adjustments. This included some evidence of developing personal measures of good enough, self-appraisal and testing of the continuation of self. I have also revealed the intricate personal theories that I suggest could be hidden within each narrative and discussed the ways in which these theories could contribute to each person's understanding and response to the threats of ageing with dementia. Each person stated within story that they did not feel any different. However, stories did discuss stresses in relation to experiences with others, where others assumed that the person would not remember or accused them of forgetting. Sense of the continuation of self could then be threatened if the

person did not feel that they had changed but then experienced a loss of recognition to the public self where this was challenged by others. Despite these experiences a sense of continued personal identity appeared to be possible through storytelling. It is important to state, however, that denial about dementia, its impact and/or denial about changed relationships is not evidence of the presence or employment of resilience as I discussed in my review of the work of Clare (2003) and Clare and Shakespeare (2004). Denial would appear to be reflected in rigid stories where the person concerned did not utilise their story for self-assessment, reflection or re-positioning purposes.

I have theorised that personal understandings (Jacobson, 1993) or theories about present circumstances were revealed in these stories. These theories reflected both adjustments and denials. For those people who appeared to have resilient responses, personal theories were an essential part of the continual process of adjusting. They appeared to provide a context for each person to manage day to day experiences. In turn, each adjustment achieved can be considered as a contribution to the person's resilience reserve. Personal theories were also evident in the stories of those who appeared more rigid in their responses to a possible loss of public recognition. For example, some personal theories could support continued denials that threats to identity existed, despite evidence to the contrary. In this way unique, personal understandings could prevent adjustments and promote inflexible responses to dementia. Whilst these can undoubtedly be considered as a self-protecting mechanism (Clare and Shakespeare, 2004) they do not facilitate the act of adjusting in the face of adversity and threat. As a result the person might have been at risk of being overwhelmed by stressful events or becoming increasingly isolated where they withdrew from painful relationships and interactions with others. Resilience is therefore recognisable as positive adjustments under challenging life conditions (Masten, 1994) and distinct from stories of denial and resistance. I will now move on to discuss my findings in relation to the social work participants in this study.

Chapter 5: Negotiating Competing Roles and Realities in Social Work with People Ageing with Dementia.

My review of the literature on social work revealed varied definitions of what social work is, what it sets out to achieve and the extent to which practice can vary (Payne, 2014). Organisational identity and the influence of organisations, politics and policy can further complicate any attempt to define social work in this area (Ferguson and Woodward, 2009; Webb, 2001). Hearing the accounts of social workers about their work with persons living with dementia is therefore essential in understanding this area of practice. It can be argued that although not everyone living with dementia will be resilient, the possibility of resilience could exist despite dementia. However, unless this possibility of resilience is acknowledged and recognised by the social worker, as the other in the interaction relationship, it may not be realised. I have suggested that a symbolic interactionist perspective of social work with a person ageing with dementia could reveal how the public identities of 'persons with dementia' are created through the social work process itself. This could then reveal the factors at play in realising the resilience of the person ageing with dementia in social work practice.

I will begin by presenting my findings on the context in which social workers present their accounts of work with a person who has dementia. This will reveal important information about positioning in practice. I will then discuss what was revealed where a resilience lens was applied to these verbal accounts and will explore how these accounts were influenced by theory, positioning and perspective. I will then move on to explore my findings on the tensions of roles, positioning and values, revealed in the ways that social workers talk about their work with a person who has dementia.

I will provide in depth extracts from the accounts to support my findings. Each section of narrative is labelled to indicate the story that it belonged to and the specific lines of text that are included. Where extracts contain elements of more than one story this is indicated with a sequence of punctuations (...). Table 3.1. (p. 107 of this thesis) provides details of the social work participants and the specific person with dementia that they were engaged with. In this way I will answer the research question: "To what extent do social workers recognise and apply the concept of resilience in their practice with persons ageing with dementia?" I will begin by exploring issues of organisational and individual identity.

Organisational identity versus individual identity

In the UK, social work is typically carried out in organisational employment (Crisp et al., 2007). It is therefore through organisations that policies are interpreted by social workers and that resources are secured. Accordingly, professional values, objectives and decision-making are pursued in an organisational context (Whittington, 2007). Payne discussed the intersection of the identity 'social worker' with the organisations in which they work as the agency-professional arena (Payne, 1990). Tensions can therefore occur where competing priorities are in evidence. So, for example, the social worker may be positioned as 'problem-solver' in their role of local authority representative. However, social workers are often not in positions of autonomy, and utilise assessments to negotiate organisational gatekeeping. The problem-solver role may be incompatible with the social worker's theoretical views, causing tensions where empowerment and social change objectives appear to be minimised. An emphasis on organisational objectives and process could minimise the opportunities to identify and promote resilience in people ageing with dementia. I will now illustrate this.

Gwen

"I am very aware that you need to see people over two or three visits, so they don't tire as well. But you also want to get the services they need in as soon as you can. So it's a constant challenge. I feel under pressure to get the information quickly and generate a paper assessment, but the process of writing is also a reflective exercise where you can revisit what you've been told and think about the emphasis that the person placed on seemingly mundane information." (Lines 80-85).

In this example Gwen spoke of good practice approaches when engaged in an assessment. The account was evidence of Gwen as problem-solver and demonstrated the competing demands of the assessment process and securing resources. Gwen raised the importance of reflection in her analysis process, and in particular, hearing what was emphasised by the person with dementia within the assessment meeting. This practice approach is promoted by Österholm and Hydén (2016) to ensure that the authentic, autobiographical story of the person with dementia is represented within social work assessments. Gwen's account could then be an example of organisational or bureaucratic processes having immediate priority over the use of assessment as a tool to find meaning from the perspective of the person with dementia (Ferguson and Woodward, 2009).

"I identified that he needed total assistance with some personal care and prompting and guidance in other areas. His wife did need to know support was available as she was exhausted. Alan was able to wash and shave, but needed help with dressing so I looked at those areas that could promote his independence...This sounds terrible but and I don't just mean for Alan, you are making the person sound not as good as they are. You don't promote their strengths or you won't get resources. What I mean is you emphasise the things the person can't do and play down the writing around strengths. He is a very independent man, he's been through a lot and has a lot to give but I didn't write

any of that. He has got dementia and can do X, Y and Z but you won't find that written. I did this deliberately to get services. When you look at the assessment you will now think 'hold on that's a bit negative' and you won't find him as bad when you meet him but we have to work in this way. I'm not making anything up about him but I am emphasising the things I know will secure me resources."
(Lines 98-113).

Given the priority afforded to organisational processes Gwen explained what was then included in the assessment, what was omitted and the reasons for this. She explained how she used the assessment report to achieve her own story of Alan's situation. Gwen explained, for example, that an emphasis on need is a requirement to acquire support for people. Her use of the phrase 'you don't promote their strengths' presented this as an organisational understanding of the way in which people who have dementia are reported and not as an individual practitioner's choice. This approach would potentially prevent resilience being realised as to include it would be seen as a risk to securing resources. At worst it perpetuates the social frame of the 'vulnerable person with dementia in need' in both written and verbal social work accounts. This supports the findings of Österholm and Hydén (2016, p. 21) who stated that assessments can undermine the identity of the person with dementia by focussing on the person's shortcomings to meet the needs of the social work organisation. In this way the person can never be realised within social work practice as a citizen with the capacity for resilience. This is an example of the agency-professional arena (Payne, 1990) perpetuating the identity 'vulnerable person with dementia'. However, Gwen demonstrated insight into these tensions and acknowledged the impact that such demands place on the social work task.

Ian

“Doing life history with people is about developing a bit of background. Well you are working with a group who have so much to tell you. The stories that need someone to put them together... People can tell you things that you would otherwise never know... The risk was always that there was only so far that a life story would actually take the process. A lot of the information that is needed is about the here and the now and not so much about what even happened 10 or 20 years ago. I used it as a tool to engage, but it didn’t really bring the clarity that was needed for managers to make decisions about resources and different things.” (Lines 31-45).

Ian discussed the difficulties in implementing different approaches to practice within an organisational context. Ian linked the effectiveness of his chosen approach to its effectiveness in securing resources. Seeing practice tools within this narrow framework can minimise the social work role and affect how social work itself is undertaken. Ian did not associate his use of a life story approach with the opportunity to build information about the person as citizen, nor to the person’s potential resilience reserve. This would appear to be an example of the role of assessor and resource provider being given prominence over empowerment and social model approaches.

Lorna

“It’s about building a relationship, connecting with someone, hearing what’s important to people and combining that with our duties and responsibilities to keep people as safe as they can be. So you are applying principles to her story and her experiences and what we have come up with is an assessment of risk that I have expressed some reservations about at an Adult Protection meeting. I think that we have erred on the side of being risk averse... I do I get that, but it shouldn’t really impinge on her rights...It is to do with culture in terms of risk. We err on the side of caution and I think that comes from not trusting people. I don’t mean that to be critical I think that Social Work is now moving in that

direction....In this situation it was a question of interpretation of part of the risk management plan which was that at the adult protection forum I found it very tackety- booted. They said 'if you find this the police must be informed' etc. So judgements could be made that if staff visiting are concerned about someone they could call the police but that has the potential to take away Fay's civil liberties, decision....And whose judgement is more important staff or Fay? Loss of rights in the moment. The problem is that Fay attended the meeting and was there and agreed to this and to this protection plan. What my issues is, is the lack of clarity... Fay said to me 'I thought I was agreeing if the person was a total stranger and I thought I was at risk'. She was clearer about it than we were!" (Lines 121-129, 148-154, 164-175).

Lorna focussed specifically on the tensions between the roles of safeguarding and enabling as a result of the local authority's adult protection process. She felt this had resulted in more restrictive practice approaches that she was uncomfortable with. This extract provided an insight into the process of reflection, challenge and advocacy, consistent with a social change role of social work. Lorna introduced important topics of risk and trust, and the ways in which she believed the organisation looked after its reputation to the detriment of the person being protected. In this example Lorna described a situation where Fay's potential for resilience was not taken into account in a developing protection plan.

The tensions caused by the competing demands of organisational processes and priorities, and the individual values and practice approaches that social workers strive to implement, are evident from the examples provided. It is important to acknowledge these tensions as the context within which social work practice with people ageing with dementia takes place. This provides important detail as to the context within which both citizenship and resilience are understood, promoted or invalidated which I will now explore.

Using a resilience lens to explore social work accounts

In this section I will reveal the ways in which the social workers in this study talked about their work with people ageing with dementia. Using a resilience lens I explored the content of these every day accounts of social workers. This allowed me to explore the deeper meanings behind social work talk such as: 'person centred' or 'strengths based' approaches and try to reveal the ways in which resilience could have been influencing practice, even where it was not explicitly referred to. It also captures overt references to resilience and resilience frameworks. Equally I included content where concepts similar to resilience, such as recovery were referred to. A resilience lens was used to unpick the ways in which this language was being used and for what purpose. I also included data where the social worker referenced the person with dementia's skills, experiences, knowledge and resources, which I collectively refer to as the 'resilience reserve' (Clare et al., 2011; Forstmeier and Maercker, 2008; Hulko, 2009).

The social work accounts provided unique insights into positioning (Althusser, 1971); the positioning of self and that of people, and persons with dementia. As discussed in the earlier literature review, positioning is a combination of individual, attitudinal and institutional views that one party holds about 'the other' within interactional relations. Positioning affects the perspective from which the actions of others are then interpreted and understood. With respect to ageing and dementia, this can mean that actions are only considered within the restricted frameworks of frailty, vulnerability and decreased mental capacity (Kane, 2008). Positioning can also be influenced by organisational roles and responsibilities (Ferguson and Woodward, 2009; Pane, 1990; Webb, 2001). Payne (2014) has discussed perspective as a means of consistently applying values and principles in social work, but that perspective can also be a way of flexibly seeing different points of view. I have found three distinct ways in which social workers revealed positioning and perspective which I have called *person in theory*; *person in assessment*; *person in situation*. Some of the accounts contained examples of more than one approach. I will now discuss each in turn.

Person in theory

In some accounts, positioning was revealed in the way social workers talked about theory. Theory is an integral part of social work as it defines what social work is and how it is undertaken (Payne, 2014). The use of theory within accounts demonstrated that the social worker was knowledgeable in their field, and that they were applying this knowledge within a practice framework. Use of theory within accounts is also a way in which social workers can communicate to others that they are both accountable and self-disciplined (Payne, 2014) in the exercise of their duties and functions. This, in turn, explains what the practitioner is doing and why. Within the following examples there were theories of what social work is, how social work is practiced and theories of the social world.

Ian

"I think our role is to work with the individual, see how their life is for them, how are they identifying what recovery is, and work towards that, whether that is helping them to find resource or by being someone who can be there to support them whilst they are figuring out what they need in order to move forward...I think a lot of people think recovery is 'you are going to get better', 'you are going to reach this point where you were before', but recovery can be about just the kind of the small day to day things about helping someone to maintain a level of knowing how to do a task, even stuff like living day to day, personal care and if they need more help to do that then that's still about recovery and coming to terms and you know, not losing those personal things...Social work on the outside is very much a medical model we are just there and very often we are only brought in at the end when someone needs a resource which is how the medical model sees it. Whereas, we can actually be there helping to shape relationships and talking about recovery and goals that mean something to the person not just the medical goals." (Lines 54-58, 59-62, 71-76).

In this extract from the account of Ian he made specific reference to identifying the social work role from an empowerment approach (Dominelli, 2009). There was specific reference made to identifying recovery as an integral part of the social work role. I have addressed the differences in recovery and resilience within my review of the literature. Recovery is considered as a new life vision for oneself (Leamy et al., 2011). Resilience, instead, is the process of continual adjustments in the face of smaller interruptions to wellbeing (Bonnano, 2004; Norris et al., 2009). Although Ian does not use the term *resilience*, his description of recovery in the context of dementia does in fact refer to the person coming to terms or adjusting to their present circumstances. He also cited smaller, day to day adjustments, which is more in keeping with resilience than recovery. Application of a resilience lens to this account raised the question of the conflation of related terms such as recovery and resilience which I explored within the literature.

Ian also discussed how the social work role can be defined by others and how this can then position the social worker in inter-professional relationships. His description reflected the views of Golightly (2010) on the social work role with people who have dementia. Ian used his account as an opportunity to challenge this and instead articulated his views on both the value and purpose of social work in people's lives. This positioning of social work, and social workers, by others could also diminish opportunities to promote resilience with a person living with dementia. This could occur where the work of the social worker is only equated with the acquisition of practical resources, such as homecare, by others.

John

“Part of the role is definitely realising their potential that is certainly part of it. Obviously safe, keeping them safe, making sure they feel safe and asking them how their new diagnosis, how this feels and if it’s affecting them? Or provide some kind of support in, you know and do the things that they were able to do before. And sometimes they will need that extra, well sometimes people with dementia are physically well and could do those tasks but perhaps lack or need the encouragement or added supervision to do the tasks....Realising their potential, they just need a little bit of support to do them things. Well it’s just it’s something like, you know, if you sometimes work with people who, they maybe, used to play golf for example. Quite a lot of the time... they are physically very well and could still physically do it. Obviously, there are practical issues of getting to the actual place, of doing the activity but all these things, you know, that’s where I can help.” (Lines 42-61).

In this example John discussed the social work role with people who have dementia. His account positioned the social work role within both empowerment and problem-solving approaches (Payne, 2014). This was an interesting mix and revealed the tensions that appear to exist between each of these roles in work with people who have dementia. For example, John used the phrase ‘keep them safe’. This implied a paternalistic approach that would seem incongruent with empowerment models. ‘Keep them safe’ would also appear to position the person as ‘a risky person’ (Bailey et al., 2013) which could in turn undermine the opportunity for resilience enabling practice to emerge. This highlighted the tensions between risk enabling and risk management that many social workers face in their work with people living with dementia (Barry, 2007; Manthorpe, 2004). Such an approach would also limit the approach which Clarke and Bailey (2016) advocate of attempting to re-frame risk from the perspective of the person with dementia. John did not refer to resilience directly but did discuss ‘realising their potential’ throughout his account and provided an example of how he could do this. John referred to people with dementia using pronouns ‘they, them, their’ which would indicate both the distinction between

himself and those with dementia, but also could potentially homogenise persons with dementia into one group with shared needs and risks. I will return to this issue in the next part of this chapter.

Kate

“Your own life history... makes you think about working in other people’s lives...I often look at their identity and where they are and what influences they have had within their life and their home, their attachments. I think with older people there’s a high percentage have lost their spouse. They are living on their own. They are often experiencing low mood and can be quite stuck as well because they have not kind of moved and obviously... attachment issues around where they are and where they are going....And it’s the same with theories. We talk about person centred but this means coming at things from the person’s perspective and what they have lived through. What’s important to them and their kind of quality of life and I’ve always thought that way and I think it’s come from my personal experience... knowing when you are struggling with ‘self’ and I think, probably, in the older generation it’s much harder to move on with the loss of a spouse or sometimes we are moving people out of their house.” (Lines 239-250, 232-238).

Kate referred both to practice theory and theories of the social world within her account. She included issues of grief and loss and the impact of these on identity. For example, she explored how loss can lead to people feeling stuck, in turn preventing them from moving on or adjusting to their present situation. Attachment theory (Bowlby, 1969, 1980) is presented as a means of understanding this. These can be considered as examples of vulnerabilities that Kate had identified within the context of resilience. Vulnerabilities refer to those things that make a negative outcome more likely for the person concerned. This is an important part of understanding the resilience process from a social work perspective. Attachments can also be resilience enabling in the lives of people with dementia (Clarke and Bailey, 2016), however this issue is not developed

within this account. Kate does, however, reflect resilience as a complex interaction of vulnerability and protective factors, within context specific situations.

The importance of recognising vulnerabilities as well as assets is continued. Kate discussed the importance of perspective in the application of practice theory. She suggested that ageing could make it harder to adjust to loss. Kate also suggested that the social work role might add to the losses of old age with her final sentence 'we are moving people out of their house'. However, she did not reach any conclusions to her questions on identity, loss and adjusting to change. Instead, this section of her account offered an insight into the process of reflection as she tried to integrate practice theory and theories of the social world in understanding the perspective of the person ageing with dementia. These frameworks need to address the complexity of resilience, taking account of vulnerabilities as well as protective factors, in the employment of resilience by people ageing with dementia.

In summary, I have used the term *person in theory*, to describe those accounts, or sections within accounts, where the social worker appeared to use theory to establish positioning. The use of theory within accounts can be used to demonstrate that the social worker is knowledgeable in their field, and that they are applying this knowledge within a practice framework (White, 2002). Use of theory within accounts also communicated that the speaker was both accountable and self-disciplined in their practice (Payne, 2014). This then placed the speaker in a position of authority. Theory was at times discussed in general terms, and did not always translate into practice examples with the specific person with dementia that the social worker had been engaged with.

Person in assessment

Some of the accounts used the assessment itself as a vehicle for discussing the person who had dementia. The accounts provided varying degrees of detail and did include information about each person's characteristics, roles, experiences and resources, without necessarily linking these things to resilience. Assessment is central to social work practice (Crisp et al., 2007). Within the literature review I have discussed the role that assessment plays in determining meaning (O'Connor et al., 2006). Sullivan (2009) highlighted that finding meaning is seen as the role of the social work assessor and as such social workers can be uncomfortable with ambiguity and unanswered questions.

Kate

"I guess she well, her view was she didn't need support...A lot of our cases have a lot of support going in and... she didn't have a lot of supports. I thought of social work as... social support network services, and she seemed to be coping....Initially I thought 'I don't know how much social work she needs' because she presents very well. And actually she is quite happy with her lifestyle and after meeting with the daughter she... talked about direct payments and things but within a couple of weeks there was one incident...She'd been out and kind of got a bit lost. She'd got on a wrong bus and...had to get a taxi back but obviously was still able to get home. Obviously it kind of highlighted some concerns." (Lines 62-65, 44-52).

This appeared to be an example of the application of professional experience in the assessment of a person with dementia. Sullivan (2009) stated that professional knowledge and meaning are constructed and confirmed through practice situations. In this case, Kate compared Ellen's needs and level of formal supports to that of other people with dementia that she had worked with.

As Ellen had a good social support network, and little input from formal supports, Kate interpreted this as Ellen being independent, despite her dementia. Given that Ellen appeared independent Kate had then been taken by surprise when it was reported that she had been lost. Adopting Brannelly's (2016) view of society as consisting of people who are interdependent and not independent of each other, may have provided Kate with a citizenship framework from which to address these practice dilemmas and reach an understanding of Ellen's situation.

This section of Kate's account revealed her attempts to find meaning in Ellen's situation. Ellen is described as 'presenting' well within the assessment interaction, with a plan at that time to progress a direct payment. However the issue of risk then appeared to complicate the original assessment outcome that Kate had reached. Issues of risk and protection are a feature of social work practice with people living with dementia (Barry, 2007; Clarke and Bailey, 2016; Manthorpe, 2004). Kate, however, did not automatically assume that Ellen was a 'risky person' (Bailey et al., 2013) instead she considered how Ellen had responded to the situation and what the outcome had been. Although resilience is not mentioned by Kate within this section there is a clear focus on trying to understand how Ellen found her own solutions to her predicament, which could be considered as an attempt to realise the identity 'resilient person with dementia'. This placed Ellen as a person in a risky situation rather than as a risky person. This supports the findings of Clarke and Bailey (2016) on understanding risk from the perspective of the person and their story. This change of focus is essential if the resilient person with dementia is to emerge in practice.

Gwen

“He is a 90yr old man and for his age, looking at his strengths he is an able man and apart from his dementia he is well, good health, mobility wise. He gets around. He is still independent with aspects of daily living you know like washing shaving but his wife prompts him but he’s still able. You know he still has a lot of sort of strengths there, you know and it was important to him to keep a hold of. Lovely family, had a good job, which he loved, travels a lot and was a keen golfer. He doesn’t tend to do this now I don’t know why...What I established early on is that his wife who is the main carer has various different health problems which result in chronic exhaustion and she is quite a frail lady. So in the morning she struggles and as part of the assessment I identify what areas are difficult for people. In the morning Mrs. A wants to rest however couldn’t as Alan is up early wanting his breakfast and she prepared all the meals... “We felt that if she had a direct payment. She needed someone to make sure he was up, washed, dressed, had his medication and had his breakfast. So that was the official thing regarding direct payments.” (Lines 55-61, 35-39, 40-42).

Gwen structured her account as a verbal assessment report. White (2002) identified that social workers can structure their accounts in such a way as to persuade others of the attribution of causality. This occurs through the sharing of details about people in a recognisable format. This account was delivered using such a format. It contained recognised information categories that asserted the details as facts borne from a professional assessment of the person i.e. biographical data, medical information and social issues. Gwen referred to Alan’s strengths, skills and interests, however, in the telling of the account a point of reflection occurred where Gwen asked why Alan had given up golf. Within the assessment report Alan’s identity of golfer is presented as a detail from his past. However, in the sharing of the account Gwen was able to pause and consider why Alan no longer golfs, although, no explanations were presented.

This account could be considered as prioritising the social worker's narrative over that of the individual. It could also be a reflection on the scope to look at the person's narrative afresh out with the boundaries that the assessment process can impose. For example, Österholm and Hydén (2016) discussed the ways in which the autobiographical story told by the person with dementia can get lost within assessments in order to focus on the details required by the social work organisation.

White (2002) also identified that social workers use details about risks to individuals, within their accounts, as motivating factors around timescales for intervention and resource provision. In this account Gwen focussed on the risks to Alan's wife. As a result, Alan is positioned as the source of the risk, which in turn could reduce the opportunity to realise resilience and resilient responses to the situation. This can invalidate the resilience of the person with dementia. The solution is then provided in what is an example of a problem-solving approach to social work.

The positioning of Alan, by Gwen, within this account appeared to support the findings of Österholm and Samuelsson (2014). They found that social workers can engage in 'elderspeak' (2014, p. 16) which was signalled by phrases such as the one used by Gwen where she stated "we felt that". This, they advised, implies that prior discussions and decisions have been made by others in the person's best interests. This practice placed the person as passive, and the problem-solving approach focussed on solving the problem of the person, rather than the areas of conflict caused by competing realities. Such practice is considered by Österholm and Samuelsson (2014) to deny the citizenship of the person with dementia, with reference to resilience, this could perpetuate a loss of recognition and reduce the person with dementia's opportunity to be seen within the context of resilience, or as a citizen with the potential for resilience.

In summary, I have used the term *person in assessment*, to refer to those accounts which used the assessment itself as a vehicle for presenting the person who had dementia. The accounts provided information about the person, their health and social care needs as well as referring to characteristics, roles, experiences and resources. In the same way that the inclusion of theory was used in order to establish the professional identity of the social worker, it appeared using assessment as the structure for verbal accounts also achieved this outcome. Moreover, the role of assessor give legitimacy to the views and opinions that are aired. Solutions to the issues that were identified by the assessment appeared to be driven by the views of others on need and risk, and organisational processes and restrictions. This reflected the views of Clarke et al. (2010) on the contested areas of risk that people with dementia experience. Such approaches could be considered as promoting the professional narrative over the narrative citizenship of the person with dementia.

Person in situation

The phrase '*person in situation*' was first used by Coulshed and Orme (1998: 134) to describe psychosocial approaches to social work practice. I have used person in situation to describe those accounts where there was some evidence of the person with dementia's perspective and meaning making. This is compatible with a narrative approach (Young, 2010) where the person is the central character and promotes social and narrative citizenship approaches. This then facilitates an interpretation of events and circumstances in the context of that particular person, within their particular story, using social work knowledge to achieve this. Lorna and Helen, who worked with Fay and Beth used this approach although neither referred to narrative as the vehicle for their interaction or their analysis. They also used the term resilience, explicitly linked characteristics, roles, and experiences to the process of resilience and included a definition of resilience within this context. Each account provided detailed information about the person, their life, the challenges that they faced and their resilient responses.

Lorna

“Her whole persona and her whole approach is very much person centred. It’s very much very trusting of people, that’s her starting point... She’s actually much, more savvy, than that, she is quite street wise. She hasn’t worked with drug users all these years and not learned that people aren’t always as good as they appear. She is aware of that. And she has always taken that chance with people because if she loses that, she loses everything, who she is, so she has to trust everyone and sometimes they prove her wrong and in her world they haven’t proven her wrong often and certainly not often enough to rethink her whole value base. It’s crucial to her sense of who she is. Crucial to who she is....How I experience Fay is as someone who has lost their short term memory significantly... She doesn’t remember my name. She probably doesn’t remember where I work but I think she remembers that I’m helpful to her and I listen to her and we seem to be able to start where we left off. I don’t think she has lost memory emotionally, I don’t know what the word is for that, possibly resilience although I’ve always had a different way of thinking about resilience, but she trusts people and we seem to be able to pick up where we left off....She is resilient in that she still experiences the here and now. What I would mean by resilience is an ability to absorb things that are difficult. And not to personalise those. To find the strength to let those things go and remain intact and I mean emotionally intact. Yes, retaining a sense of identity. I suppose every interaction we have challenges us and our sense of self. If that sense of self is healthy for want of a better word, fairly intact but not rigid, open to ideas then we can absorb as well as let go. We interact gently with the world, with our own world but with flexibility to change.” (Lines 136-147, 178-196).

Lorna’s account included an in depth analysis of Fay and of the things that mattered to her and why. She also identified past experiences and skills that continued to contribute to Fay’s personal resilience reserve (Clare et al., 2011; Forstmeier and Maercker, 2008; Hulko, 2009). Fay had been considered vulnerable by the local authority adult protection process because of her contact with drug users. However, Lorna instead stated the case that it was

exactly this experience that empowered Fay. Crucially, Lorna also pinpointed the potential threat to Fay's personal identity if she was denied the opportunity to assess risks for herself. This is an example of a social change approach to social work (Payne, 2014). Lorna challenged the taken for granted narrative of the 'vulnerable person with dementia' and instead re-framed Fay as 'streetwise' and informed in the management of these specific risks due to her unique knowledge and experiences. This is an example of the context specific application of resilience by Lorna in her consideration of Fay's circumstances.

Lorna reflected on how Fay maintained an emotional connection with others despite her memory impairment. Lorna also discussed resilience within the context of relationships and interactions with others, situating the resilience of people with dementia in the present or within the moment of contact with others. This would then appear to be an example of the use of symbolic interactionism to both define and understand resilience. Caddigan and Pozzuto (2008) stated that although social workers discuss use of self they can fail to realise the impact of others on their own identity. Lorna did, however, reflect on the fluidity of all of our identities within the context of interaction with others. This account appeared to reflect my view, established through the review of the literature, that using symbolic interactionism to understand the social work process with a person ageing with dementia, could reveal the construction of a public identity which realises the resilience of the person with dementia.

Helen

“She appeared to be a very independent woman, who knows her own mind, who could state her case, enjoyed the fact that she saw herself as quite a tough cookie who could deal with things. Didn't really need other people's help...Well she has a great sense of humour, she's a great laugh. She's a very hard working woman. Has been all her days. Parents' deaths were difficult and the death of her grandmother hit her hard... She had a very difficult marriage and she's happy to talk about these things openly. She wants to impress upon you

that she's had difficulties in her life but she's coping. She's come out the other end and that's all part of her resilience. These traumatic incidents have, she advises, made her very strong and I would agree with that. Well, all these things could have broken other people... And her youngest son killed himself... Beth often talks about this and how she feels about seeing this man in court and watching him be defended... She has had huge upset and trauma in her family life and she talks about it openly. Her family is very important to her and she's worked, very, very hard to bring her kids up and do her best by them. She had an abusive husband and she had to leave him and take the kids to stay with a friend and start all over again. So she's had huge crosses to bear... Beth has her inner strengths and qualities, she has a strong character and personality and most of those things have remained intact". (Lines 41-46, 54-61, 71-74, 77-81, 85-86).

Helen structured her account to portray Beth within the story of her life. She did this by building the character of Beth for the listener. Helen's account facilitated a direct link for the listener between Beth the person, Beth's skills, experiences, roles and resources, and resilience. Helen placed the adversities that Beth had faced within the context of her life and relationships with others. Although Beth had experienced a very traumatic incident with the abuse and death of her son, Helen did not build her account around this, nor does she define Beth by this incident. Instead, Helen focussed on aspects of Beth's identity that helped her cope with adverse events and also those which have been strengthened as a result of adversity. This would appear to be an example of Helen recognising the value of Beth's intersectional experiences i.e. the experience of divorce, hardship and coping with abuse, and the role that these can play in helping people to adjust to the changes that dementia can bring, as described by Hulko (2009).

In summary, I have used the phrase *person in situation* to describe accounts where the relationship with the person with dementia appeared to drive the social work process. These accounts reflected a narrative approach where the person with dementia was the central character within the story. Adversities that the person had experienced over their life were discussed as well as the ways in which skills, experiences and resources contributed to adjustments to different circumstances in their life. Central to these accounts were reflections of the person's personal and public identities within situation.

All of these accounts revealed the variations in definitions as to what social work is and what it sets out to achieve (Payne, 2014). The influence of organisations and policy also influenced issues of professional identity and practice. The accounts given by the social workers in this study revealed the ways in which resilience is applied, or dismissed, within a practice context. I have demonstrated that this could be influenced by theoretical understandings and practice approaches, viewed from the perspective of the knowledgeable social worker within interaction with a person ageing with dementia. There was no consistent understanding of the concept of resilience nor a consistent definition of resilience within the context of dementia. Neither did there appear to be a consistent approach that identified and analysed the different components of resilience or their application to specific situations.

The social work accounts in the study provided unique insights into the complexities of the social work role with people who have dementia. The accounts also revealed the positioning of self and that of people, and persons with dementia. This provided insights into the individual, societal and institutional views that those social workers held about persons ageing with dementia.

I have suggested that the accounts contained evidence of three distinct ways in which social workers approach discussions about social work practice with a person ageing with dementia. I have labelled these as person in theory, person in assessment, person in situation. Some of the accounts contained examples of more than one approach.

Some of the social workers appeared to use their accounts in order to reflect on the application of theory. For some social workers in this study there appeared to be a dichotomy between theory and practice and realising resilience within the context of dementia. For example, all of the social work accounts contained examples of empowerment or problem-solving theoretical approaches to social work. Some accounts contained both approaches. However, the practical application of the preferred theoretical approach, in order to realise resilience and resilient responses, was not clearly demonstrated within the accounts. What was evident in my analysis of the accounts was that there appeared to be tensions between positioning of the professional self, prescribed roles assigned by organisations, the expectations of others, and social work values. In the next section I will explore these tensions in more detail.

Tensions between positioning, roles and values

This section highlights the tensions around roles and positioning within social work practice, as revealed within the accounts of the people in this study. This information is important if a symbolic interactionist approach to social work is to be understood. I will discuss my findings under the following topics: knowledge about people with dementia versus the individual person with dementia that the social worker was engaged with; the expectation that people with dementia will accept the support decisions being made on their behalf through a reframing of resignation as acceptance; and finally the importance placed on independence, by social workers even within the context of decline, where a person is living with dementia.

Person with dementia versus people with dementia

The social workers' accounts contained examples of content that differentiated between the homogenous group 'people with dementia' and the individual presentation of the 'person with dementia' that the social worker was engaged with. As discussed earlier in this chapter, positioning is a combination of individual, attitudinal and institutional views that one party holds about 'the other' within interaction. Positioning affects the perspective from which the actions of others are then interpreted and understood. These accounts provided some evidence that social workers can find it difficult to use resilience based frameworks where they apply generalised understandings of dementia in their practice. Such frames of reference focus on risk, issues of safety, and the need for protection (Manthorpe, 2004) and do not support individual citizenship approaches.

John

"So her short term memory was very poor. So that stuck out for me I thought she has very poor short term memory and she was frail and a high risk of falls. She had a community alarm in and I asked whether she was going out of her house and things like that, you know the more serious risks for people with dementia 'Are they going out of their house?' and things like that and, touch wood, she hasn't and I don't think she ever will do anything like that. There's a sign on the door that says 'please do not go out' and certainly I don't think she is ever going to do this... Her memory is the number one thing that is very much impaired and her cognitive ability is such that she can't carry out certain tasks but in terms of where she is and keeping safe she's got that ability. In that initial visit I didn't know that and when I saw that her memory was very poor and when I saw the note on the door I did ask, but knowing her now I know she wouldn't do that." (Lines 167-181).

In this example, John emphasised Dora's short term memory and frailty. He then translated this into risk categories and in particular risk of falls and risk of going out. John stressed that for people with dementia, the risk of 'them' going out was a major safety concern. However, he was able to differentiate Dora, the individual, from the more generic approach to risk management in this area. The solution is one of containment and Dora is not discussed as being supported to socialise or go out of the house, but rather to re-assure the social worker that she would stay in the house.

Helen

"For me... it's about not how somebody is functioning just now but it's about their history, who they were, and painting that picture and finding out about who they were, and how they functioned and what they did in their life and what their interests were. I think this is really important because what are assessments used for? Often in our business it's about providing information to other service providers so that they can work with the person. So it's important that they see that person and not just as 'that's a tuck call' or that's 'day care 2 days a week'. To actually see the person so I provide points of reference in their personal history so that others can link in and engage with...It's about helping people to maintain the skills they already have and supporting them to come to terms with skills they have lost either emotionally or through practical support. It's about working with the person to fill some of these gaps and maintain a preferred way of life. Now some people want to be looked after and that's fine it's not about what I think is good for someone. It's about helping people find the path for their life. Now the problem with dementia is that this isn't always clear or there might be difficulty understanding what a person feels or want. But through use of self, spending time, respecting a person's need for time and space and also privacy...but we have to also keep them safe and independent. Well is not just the bread and butter things like homecare. I think social life is very important and engagement with the wider world, continued opportunities if you like."
(Lines 107-116, 167-176).

Some accounts, such as this example from Helen, contained a detailed exploration and rejection of generic understandings of dementia, consistent with social change approaches to social work. Challenges to these assumptions could be found within accounts. Helen explained the importance of seeing the assessment as more than a report of circumstances. Helen detailed how people with dementia can be defined by the help they need or the services that support them. Such approaches can de-personalise the individual concerned. Instead, Helen focussed on how assessments which contain detailed information about important events in people's lives can be used to engage and see the person as an individual.

The social work role in promoting resilience with people who have dementia is described by Helen. She did not make assumptions about what people with dementia need. Instead she described an individual approach. Time, space and use of self were seen as integral to a resilience based approach with a person with dementia. Helen also reflected on the issues that can arise when dementia affects communication. Factors such as time for therapeutic practice are dependent on organisations supporting social workers in their empowerment and social change objectives. Helen concluded this section with a statement that people who have dementia have continued opportunities in life.

In summary, I have discussed the ways in which the social work participants in this study talked about people with dementia. This happened in two ways. The first was where people were discussed generically with reference to 'what people with dementia do'. The second approach was where a specific person with dementia was referred to. As a result a different picture often emerged where the person was described as an individual who had life experiences and access to resources that could be employed in their day to day lives. Both of these approaches could be seen in accounts, with the social worker at times moving back and forth between these frames of understanding. This revealed the competing nature of such frames that both exist and influence practice.

Reframing resignation and acceptance as adjustment

All of the social workers' accounts described the social work process and the outcomes achieved. In many cases support was implemented when the person with dementia was seen to come to terms with their present circumstances. The solutions arrived at were often practical and problem-solving in nature (as opposed to empowerment or resilience based options) and were presented as the preferred outcome. There were examples of the needs of others being prioritised in the goal setting and care planning process. There was an expectation that the person with dementia would accept their new reality, whether that was related to age, dementia or disability, and how this provided problems for those around the person. This was a critical point in the accounts. It was linked by each social worker to his or her effectiveness in providing solutions within situation.

Gwen

"He does take in that he's having problems with certain things and he'll say things like 'oh my memory' and he does recognise that his wife has to do things and she'll say 'remember that you have problems making something to eat' or do simple things like pick out his clothes. So, it's a case of trying to discuss that with him to say that 'you are struggling there'. You know, helping him take that on board. You know, 'this is what your wife's doing for you and she needs a break in the morning'... His involvement was about him coming to terms with what his wife actually does for him" (Lines 43-54).

Gwen stated that Alan's involvement in his support planning was to come to terms with what his wife actually did in caring for him. Gwen used several phrases to emphasise this such as 'he does take in' and 'he does recognise'. The account did not however reveal how the process of 'coming to terms' would occur or what it would look like. Neither did Gwen discuss other aspects of Alan's involvement. This would appear to be an example of denying Alan's citizenship within his domestic situation (Bartlett, 2016).

John

“A person with dementia who had a power of attorney, but the person doesn’t realise how much the attorney is having to do or how much assistance she needs. They were going on holiday and she had to go to respite for a week as because of safety it was definitely worthwhile. So I did speak with her and write details in her diary and she was fine about it but on the day she didn’t remember and she didn’t want to go when the day came. She came round and I drove her there in my car and I could tell she wasn’t herself and I didn’t feel comfortable. But she couldn’t be on her own, it was only for a week and I knew she would be looked after. I knew she didn’t want to be there. So people with dementia can’t always understand but for needs to be fully met ...but I wasn’t happy.” (Lines 97-110).

In this example from John, we can see that where the person with dementia appeared not to accept the picture of self framed by the social worker, that this could be presented as the person being unrealistic. Österholm and Samuelsson (2014) identified that the social workers in their study positioned people with dementia as less competent than the other people present within the assessment interaction. There is then a risk of invalidating the person with dementia’s opinion where the person does not agree with the assessment findings or the proposed support. This can be explained as a continued failure to recognise citizenship status and, as a result of this loss of recognition, the person concerned can be disempowered, even where like John, the practitioner had tried to practise in an inclusive manner.

Ian

“He would limit what he did to ensure his wife’s needs were met. He did articulate this to me but was very clear that was his role as a husband and was clear that he didn’t want to change it too much. He didn’t want to upset his wife and he didn’t want her to say that he wasn’t there for her...He was never resistant but was always quite clear that he had a role and he wasn’t going to, kind of, be forced to take a back seat and that was very good to see that he could advocate for himself, advocate for his wife and had a clear idea about what he wanted....I think, the one thing that did come of this one, this assessment, although we recognised his commitment, his loyalty we actually had to work with him to move him away from some of those qualities because they were detrimental to him in that he would have went with his wife to a day service that wasn’t suitable. He would have not, gained no benefit for himself. No rest from his caring role because he was quite definite about his need to be there and be the carer for his wife. For me it’s about prioritising those needs and then being quite open with the client and saying ‘This is what I’m thinking. This is what I propose. This is what I think I can do and this is how I see it working for you.’ We all practice in a way that’s unique to us. That’s the way I practice as it’s something that I would want.” (Lines 93-110, 164-172).

Ian referred to Charles’ public identities of both husband and carer. He used his account to present the situation from Charles’ perspective. However, Ian’s account then went on to explain how the importance Charles placed on being his wife’s carer, was considered detrimental to Charles by the other people in the assessment relationship. Social work intervention was then focussed on how Charles could relinquish this role. There was no discussion about how public identities such as husband or carer might be supported through a resilience framework. This intervention had the potential to result in further loss of identity for Charles and could be considered as increasing the likelihood of a negative outcome. This provided an opportunity for me to consider competing outcomes in social work practice and the role that resilience could play in aligning outcomes that preserve identity, including those identities that

contribute to the domestic sphere of citizenship (Bartlett, 2016) as a core component.

In summary, I have discussed the ways in which social workers discussed the person as coming to terms with their dementia. This is discussed as the person accepting changes as to what they are able to do, and changes in their relationships with others. However, I found that what is in fact being discussed could be interpreted as being an expectation that the person will accept support arrangements or limited life opportunities.

Dependent independence

Within the social work accounts there appeared to be recognised language cues to reflect the implementation of social work values in action. Use of the word independence is one such example. Independence featured in the social work accounts as an aspiration of the practitioner; as an indicator of how well the person was coping with their dementia; as an indicator of how much support was required and as an outcome of the social worker's intervention. According to the Oxford dictionary, independence or the state of being independent is where *one is free from outside control and not subject to another's authority*. However, this word was frequently used in situations that implied outside influence on the person and or the actions undertaken. This definition of independence was applied by social workers to people with dementia. In essence this was a dependent independence. The phrase 'supported independence' (Hale et al., 2010, p. 2) has been used to denote the specific care work or support services that enable older people to continue to live at home. However, the social workers in this study used this notion of dependent independence in a far broader sense as highlighted in the examples below.

Gwen

“He is still independent with aspects of daily living you know like washing shaving but his wife prompts him but he’s still able. You know he still has a lot of sort of strengths there, you know and it was important to him to keep a hold of his independence. What I did notice was, the smaller things that is probably prone to people with dementia. He was getting a bit disorientated around familiar places and in the house he was losing his bank card, his glasses and things like that. But his daughter is quite good in that she is coming up with solutions like putting a chain on his glasses and different things and on his wallet he has a thing to attach it to his belt and that’s so he doesn’t misplace his wallet, so practical things to enable him to manage better.” (Lines 26-34).

Gwen’s account described independence and dependence in terms of day to day activities. Practical solutions to problems that arose were provided by Alan’s daughter. This account reflected a resilience approach based around small adjustments to the changes that dementia can bring. Independence is discussed as something which can be lost and the focus of practice is one of helping the person to hold on to levels of independence.

Helen

“I think some of the outcomes we talked about jointly together were about Beth maintaining her independence. She wanted to do that, and it was about finding ways for that to work for her. She needed more formal support to maintain friendships and make new friends and she decided to try day care. We also managed to support her with a personal support worker three times a week to meet her social needs. She needed practical help with housekeeping, shopping, budgeting. Day to day things. Well there’s levels and levels of dependence and independence. We were and are able to support Beth to be independent by offering appropriate help which she accepts to maximise her opportunities to be social on her own terms. But it is also about how help is given. You know she is worried about being considered round the twist or a

charity case as she calls it. She will be incredulous at times saying ‘Why I am getting all this attention?’. You know support is stigmatising.” (Lines 140-148, 155-160).

Hale et al. (2010, p. 2) suggested that independence is achieved through the control and autonomy that an older person can exert over the support they receive. Helen discussed independence from an empowerment perspective. Her account reflected Beth’s perspective and provided a resilience based approach to maintaining independence on the person’s terms. Helen highlighted that support can further stigmatise people who have dementia, adding to a loss of recognition publically within the person’s community and social network; and could contribute to self-stigma where the person’s sense of personal identity is challenged. In this example, however, the word independence appeared to be used in place of the words resilience or resilient.

Kate

“I think like that initially I’m not challenging her views or anything and trying to explain if there is a difference between parties that we are just trying to help and just saying ‘we are here to help’. And she doesn’t really acknowledge that she has a memory problem and it’s just about getting a wee bit more support. And one of the actual incidents that happened was the fall then she seemed to be very accepting of everything because they wanted to take her independence away.” (Lines 136-140).

Kate discussed independence as a status that was granted by others and more importantly that could be removed by others. This is similar to the way in which Kitwood (1997) discussed personhood and could reveal that Kate was making an association between being independent and being seen as ‘a person’.

Barnes (2012) commented that independence is supported through autonomy and control and that dependence is managed through care and protection. The language of being independent is therefore loaded with citizenship rights that can be denied to those deemed dependent (Brannelly, 2016). This could then be an example of Kate exploring the wider implications for Ellen of being labelled as dependent by others. This example also demonstrated the role of power in care planning with people with dementia, where people are dependent on others to facilitate or allow their continued independence. Kate described how Ellen agreed to the support that was offered as the alternative was that 'they would take her independence away'. It is not explained why or how this would take place. She also positioned herself as passive or external to this, where she referred to 'they' but did not define who 'they' were. This may have been a reflection that Kate herself felt powerless in this situation. This could then impact on the social worker's ability to promote the resilience of others.

In summary, within this section I have discussed my findings in relation to independence and the important role that this appears to have in social work practice. References to independence featured in all of the accounts given by the social workers in this study. This included defining people as independent within the context of decline and describing people as having a dependent independence.

Summary of findings

Within this chapter I have discussed the content of the accounts of social workers. I began by explaining that social workers' practice takes place within the context of competing organisational and individual identities. This is important as it demonstrates the different influences that social workers have to take into consideration when undertaking their work with a person ageing with dementia. The context within which practice occurs has the potential to influence practice priorities and approaches. This, in turn, can influence potential to realise resilience through social work practice.

I then discussed my findings in relation to the application of a resilience lens to the verbal accounts of social workers as they described their work with a person ageing with dementia. The accounts contained some evidence of the ways in which social workers could approach discussions about practice with a person ageing with dementia. I have called these 'person in theory', 'person in assessment' and 'person in situation'. This is an important finding as it revealed the different ways that the social workers in this study could position self and others within accounts, using theory, practice knowledge and organisational process to achieve this. Important information about citizenship and the ways in which this can be recognised and invalidated through these different approaches used in verbal accounts was also revealed.

The accounts contained detail of generic understandings of dementia. Some accounts contained a detailed exploration and rejection of these consistent with social change approaches to social work. Challenges to assumptions could be found within accounts. The tensions between established knowledge of how people with dementia are or were, alongside attempts to work in a person centred way with individuals, appeared to be in evidence.

All of the social workers' accounts described the social work process and the outcomes achieved within practice. There did however appear to be an expectation that in order to move forward, the person with dementia would have to accept their new reality. Independence also featured in the social work accounts as an aspiration of the practitioner; as an indicator of how well the person was coping with their dementia; as an indicator of how much support was required and as an outcome of the social worker's intervention. Independence was however also discussed as a status to be granted or removed by others.

My analysis revealed unique insights into the complexities of the social work role with people who have dementia. Competing roles and priorities can affect how social work is undertaken with people ageing with dementia. An emphasis on organisational objectives, process and resource provision can minimise opportunities to identify and promote resilience through empowering social work practice. My analysis of the accounts revealed content that could be interpreted as the management of tensions between how social workers talk about their role and values, and the realities of day to day social work. Social work principles of empowerment and social change were not easily reflected in accounts where the citizenship of the person with dementia appeared not to be recognised by or recognisable to the practitioner.

Although I found some evidence of strengths focussed talk, reflective practice and thoughtful considerations of what resilience might look like in the context of dementia, I did not find a consistent definition of resilience. Neither did there appear to be a consistent approach that identified the potential for/or absence of resilience. Although resilience was discussed both explicitly and implicitly there was no evidence of the practical application of preferred theoretical approaches in order to realise resilience and resilient responses although other theory was in evidence. However, application of a resilience lens to these accounts revealed opportunities to embed resilience in social work practice with people ageing with dementia. I will now discuss all of the findings, their implications and the contributions to knowledge made by this research in the final chapter.

Chapter 6: Realising the Resilience of the Person Ageing with Dementia in Social Work Practice

I will now bring together all of the work contained in the thesis thus far. In order to explore resilience within the context of ageing with dementia I began with a review of literature on the subjects of dementia, resilience and social work practice. Approaching this subject from a symbolic interactionist perspective (Blumer, 1969; Mead, 1934; Stryker, 1968) identity can be understood as a co-creation. Personal identity is influenced by those we interact with at a micro and macro level; and the realisation of public identities made possible through the validation of others. The thesis has so far addressed the questions “*in what ways do persons ageing with dementia demonstrate resilience in their stories?*” and “*to what extent do social workers recognise and apply the concept of resilience in their practice with persons ageing with dementia?*”. Within this chapter I will answer the underpinning research question as to “*what the concept of resilience brings to our understanding of dementia?*”

Overview of findings, their importance and contributions to knowledge

This research has contributed to the existing knowledge of work in this field by: proposing a definition of resilience within the context of dementia; through an exploration of how the stories told by people ageing with dementia could be reframed to reveal the possible adjustments made to sustain identities; and finally, by exploring social workers’ accounts through a resilience lens to reveal how these contribute to the public identity of ‘person with dementia’. My analysis of the narratives of people ageing with dementia supports the possibility that cognitive (Clare et al. 2011), motivational (Forstemeir and Marcker, 2008) and intersectional (Hulko, 2009) reserves contribute to resilience. My research has built on this work by identifying domains that could contribute to resilience. I refer to these domains collectively as the ‘resilience reserve’ (see Figure 5). I argue that the content of this unique resilience reserve can lessen the impact of threats and facilitate adjustments in the face of adversity.

I have theorised that a resilience reserve could consist of those skills, resources, experiences, roles and personal qualities that people acquire over their life. These might then mitigate the threats of ageing and dementia that lead to the potential for loss of recognition and contribute to the preservation of identity. Further, this research has suggested the ways in which stories unfold could be an expression of resilience strategies in the preservation of identity. Placing these stories within a continuum of protective and vulnerability factors might enable social workers to plot story themes and details alongside other important assessment data to reveal resilience and promote critical analysis in practice (see Figure 4). Problem-solving, empowerment and social change models of social work theory could then evolve to facilitate resilience focussed outcomes (see Figure 6).

The original contributions to knowledge made by this research are that a resilience discourse can facilitate a re-conceptualisation of social work with people ageing with dementia and as a result, offer new opportunities to realise resilient identities through social work practice, education and research.

In summary my key findings are that:-

- Applying a resilience discourse to the subject of identity and dementia can reveal new insights and, in turn, offer alternative perspectives on both dementia and the nature of resilience itself.
- The stories told by people ageing with dementia can be demonstrations of resilience in action performed by social citizens.
- The application of social work theory, which is informed by resilience focussed research in the context of ageing with dementia, will realise resilience in practice.

I therefore suggest that new opportunities to realise resilient identities will occur through defining resilience in the context of ageing with dementia; visualising the possibility of a resilience reserve; and developing, and testing, a resilience framework for practice, education and research settings. I will outline a proposed model (see Figure 7) and provide practical examples of how this model could be operationalised in social work practice with a person ageing with dementia.

A resilience framework for social work practice in the context of dementia

Although not everyone living with dementia can be considered as resilient, my findings raise the possibility of resilience despite, or perhaps because of, the condition dementia. However, unlike other people, those with dementia can find their resilient responses misinterpreted or re-labelled by others (Hughes et al., 2006). If the resilience of the person with dementia is to be realised it must first be recognised by those engaged in interaction with the individual concerned. I therefore argue that the co-creation of a public identity that recognises the resilience of the person ageing with dementia can be realised through relationships. This is dependent on three factors. Firstly, that social workers recognise reflections of identity within the stories told by people with dementia. Second, that social workers understand the significance of these reflections within a resilience context, and finally that the concept of the resilience of the person with dementia is incorporated into a wider social understanding of every person unique to their individual situation. This hypothesis reflects the personal, political, theoretical and ideological aspects of the social work role referred to in the literature.

The different approaches to describing practice, revealed within the social work accounts is an important finding. Positioning in social work practice with people who have dementia has been addressed in small scale studies looking at attitudes (Sullivan, 2009) and assessment interactions (Österholm and Hydén, 2016; Österholm and Samuelsson, 2014). I also suggest that the negative positioning of people with dementia can occur through the ways in which social

workers use theory, practice and knowledge, including knowledge of organisational process, within their verbal accounts.

This is important as these verbal accounts or stories of social work, then contribute to practice knowledge. They also contribute to the citizenship (or lack of citizenship) of people living with dementia by providing a prominent narrative about dementia and living with dementia. This reflects White's findings (2002) on the role of professional accounts in discussing the needs of children. These accounts were considered by White to be structured to persuade the listener of the social workers' authority and to seek agreement on decisions reached and plans implemented. An awareness of the ways in which practice is described and how these descriptions are used as a means of persuasion could reveal potential opportunities and challenges to realising citizenship and resilience in everyday interaction and practice with people ageing with dementia.

This focus on the person being seen to come to terms with their situation, whilst at the same time living in the context of *dependent independence* appears to be an important finding. Independence featured in the social work accounts as an aspiration of the practitioner; as an indicator of how well the person was coping with their dementia; as an indicator of how much support was required and, as an outcome of the social worker's intervention. The presence of independence was discussed even where the person concerned was also defined as being dependent. There are several possible explanations. First, this implies that there are lower standards of expectation about what is possible for those living with dementia and verbal accounts of practice could be seen as supporting new categories of graded independence for those with dementia. It could, however, also reflect the social worker's search for new ways of understanding independence in the context of decline. These findings then reveal the importance placed on the value of independence by social workers as a measure of the success of their intervention and of the important place that independence has within social work values.

My analysis of these accounts of practice suggested that by using a 'dependent independence' frame social workers could assure themselves and others that independence goals had been achieved. This could be evidence as to how practitioners manage tensions between realism versus idealism (Whittington, 2007). This then differs from the similar concept of supported independence (Hale et al., 2010) which is an open dialogue about physical decline and the acceptance of limitations. Instead, dependent independence appeared to redefine independence as something different in the context of dementia. In doing so this could legitimise social work actions and outcomes as detailed within the verbal accounts. This could be linked to my earlier finding on reframing resignation as acceptance. Redefining independence as something less than the standard applied to the rest of the population could possibly facilitate a different mode of practice for those with dementia. This might then be evidence of conflict in the social work task around independence as the ideal and the unspoken worry of people with dementia as 'risky people'. This could be because, unlike physical health problems, insightful communication with a person who has dementia about risk is perceived to be impossible. A resilience framework could then help to facilitate such discussions by providing a written representation of resilience within specific contexts and situations of risk.

This conflict around the need to promote independence and at the same time address risks for people living with dementia could also be seen where independence was discussed as a status that is granted to people living with dementia. This then implies that independence is not a right that people with dementia can exert. Instead, the person concerned must demonstrate their worth or entitlement. As a result it was also discussed as a status that could be removed where the person did not engage with the recommended support. Although social work has a duty to protect adults considered to be vulnerable to risk (Adult Support and Protection (Scotland) Act, 2007) the starting point for practice engagement must be the recognition of a person's rights in accordance with the Human Rights Act (1998). Practice must then address risky situations and consider what support the person with dementia needs in order to promote

independence in those areas or it must evidence where freedoms have to be restricted in accordance with the appropriate legislation.

A resilience framework is a useful tool in such necessary discussions, and can serve to assure the practitioner that every option to promote resilience focussed lifestyles has been explored, even within the context of dependent independence. This approach would be compatible with citizenship models of dementia; as to approach independence as something to be earned would represent a challenge to realising the resilience of the person with dementia in practice. Re-framing all of our lives within the context of society as consisting of interdependent citizens could be a useful approach. This is recommended by Brannelly (2016) as offering a new ethics of care for people with dementia. This approach opens up opportunities for support relationships to be defined by those involved, rather than simply referring to 'the dependent person with dementia' and 'their carer'. Instead, both parties can be considered as contributing in different ways within interdependent relationships. Opportunities to realise resilience could then be promoted.

This finding also confirms that social work with people who have dementia is a complex area of work. These accounts have shown that people can still be considered as inherently 'risky people' rather than people in situations of risk (Bailey et al., 2013). A balance must be found between promoting social justice and implementing duties in respect of support and protection (Gilmour et al., 2003). To focus on the person as the embodiment of risk could lead to paternalistic practice, where the whole interaction focusses on the need for the person to be 'kept safe' even at the price of their independence. The social work accounts therefore contained important information about the preservation of the public identity of *social worker* in the face of these tensions between seeing the 'vulnerable person with dementia', addressing issues of risk and protection, promoting social work values where the preservation of independence is paramount and realising the potential for resilience.

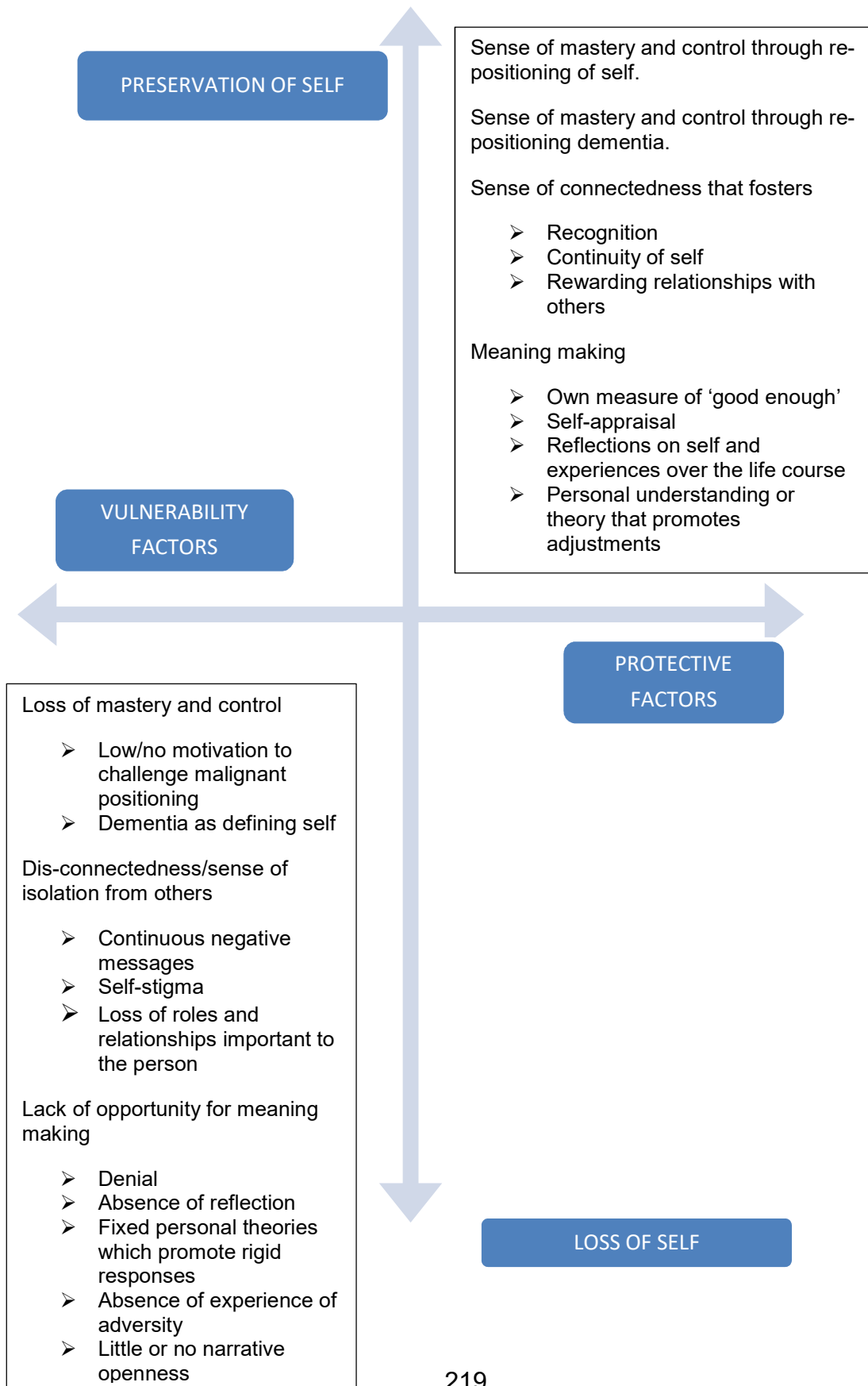
Adopting citizenship models that are inclusive of people with dementia does not negate the social work role in assessing and responding to situations of risk. Instead, it could promote responses to risk that consider the role of the person themselves in mitigating situations of harm (Clarke and Bailey, 2016) and where formal intervention is required to ensure that the rights of individuals are recognised and upheld. This is important in ensuring assessments of risk are based on informed, critical social work assessments, the informed promotion of risk enablement from the perspective of the person with dementia, and not based on assumptions about dementia and/or inherently risky people (Bailey et al., 2013; Sherwood-Johnston, 2016).

Positioning techniques can help to validate the social worker as expert through an assertion of knowledge and theory. I argue that this could work as follows. First, the accounts confirmed that dementia is known, can be recognised and has care trajectories, risks and needs that can be predicted. Second, they validated the social work role as offering a solution to the known problem of dementia. Third, the accounts facilitated the social work role as *sense maker*, where the social worker was able to state whether behaviours were common to others with the condition or constituted serious risk; and finally, they provided justification that those outcomes which were restrictive, and/or where the person with dementia had not been in agreement, were inevitable. This can then lead to explanations that the lack of resilience based practice is because resilience is not possible with a person who has dementia; or that the current practice undertaken by social workers is resilience based despite no evidence to support this. This research then has the potential to disrupt such assumptions and to support social work practice that challenges such social frames. I argue that resilience based frameworks that address resilience in the context of decline (Clare et al., 2011a) or that challenge traditional definitions of thriving (Luthar et al., 2000; Masten, 1994) could resolve these apparent tensions within practice, resulting in more honest accounts of the processes at play.

Stories, within the context of narrative social work practice, can help us to understand the complex interaction of vulnerability and protective factors that are at play within the context of adversity and resilience (Mitchell, 2011). They do this by providing the context for these interacting factors, and placing the person within situation. Narrative social work practice, such as that suggested by Roscoe et al. (2011), advocates a three stage process of: engagement with the person concerned, story deconstruction and then story re-authoring (p. 51). Deconstruction is the process of critical analysis, where the social worker applies theory, knowledge and values to the raw story details. Re-authoring then occurs to locate the social and cultural position of the story teller. This provides a basis from which social workers can realise resilience in action as well as supporting narrative citizenship for people with dementia (Baldwin, 2008; Clarke and Bailey, 2016).

In order to put the findings from this research into a practice context I have referred to the work of Daniel and Wassell (2002a, 2002b, 2002c) on the use of resilience with children and young adults. Resilience is explained using a resilience matrix and this matrix is an integral part of the Getting it Right for Every Child policy in Scotland (GIRFEC, Scottish Government, 2008). I have used this recognisable practice design in the development of this model (see Figure 4). However, unlike the GIRFEC matrix which uses all four quadrants to address resilience in many different areas of a child's life, this matrix is focussed around resilience in the process of identity preservation. The way in which the matrix is applied is therefore quite different and this is reflected in the design which is focussed on only two of the quadrants rather than four. I provide an example of the matrix application in the following section. I have used the term support planning to describe the process of developing a personal plan for the person concerned. This is a term that has developed alongside personalised approaches to care such as the self-directed support agenda and replaces older terminology such as care plan (For example, Scottish Government, 2010b).

Figure 4. Dementia Resilience Matrix



I will now demonstrate how this model works in practice using Fay’s story. Fay’s narrative was developed by deconstructing the original story elements through the application of theory and critical analysis, reconstructing this as narrative. To recap, Fay was a 77year old widow who lived alone. She had a son and a daughter. Her father died when she was a baby and her mother when she was a young girl. She grew up in boarding school in Ireland. Fay moved to Scotland as a young woman and later ran a charity for people affected by drug and alcohol issues. This included opening her home to people in need. In order to understand Fay’s potential for resilience it is necessary to visualise the vulnerability and protective factors revealed within her story using the resilience matrix (Figure 4). The protective factors are presented in Table 6 and the vulnerability factors in Table 6.1.

Table 6. Resilience Protective Factors (Fay)

Protective Factors	Details
Sense of mastery and control through re-positioning of self	Fay discussed how she had to stop her charity work. Fay re-positioned herself within the story as taking the decision to stop her work as her family needed her. In this way Fay retained control as the decision maker and remained in her role as providing support to others, in this case her family. Fay used her story to focus on personal and family commitments. This offered a positive employment of her skills and resources which would otherwise have been redundant through the cessation of her charity work

<p>Sense of mastery and control through re-positioning of dementia</p>	<p>Fay employed her knowledge, skills and experiences from her counselling work with others and appeared to apply these to her own situation. She positioned dementia as a thing that you can carry with you or choose to leave to one side. This then positioned Fay as having personal control over her dementia.</p>
<p>Sense of connectedness- Recognition Continuity of Self Rewarding relationships with others</p>	<p>Fay situated herself within a community of neighbours, friends and family. She identified most with her role in helping others through her charity work, but being a mother was also important.</p>
<p>Meaning making – Own measure of good enough Self-appraisal Reflections on self across life course Personal theory that facilitates adjustments</p>	<p>Fay's personal understanding of dementia was that it was a lifestyle choice. The choice being between continuing to try new things or to stagnate. She used reflection to make sense of her current situation and to contextualise events.</p>

Table 6.1. Resilience Vulnerability Factors (Fay)

Vulnerability Factors	Details
Self-stigma	Fay's narrative frames dementia as spoiled identity (Goffman, 1963) using derogatory terms such as 'decrepit' and 'ga ga' to clearly convey this.
Potential for loss of role/recognition	Fay's personal identity centred around continuing to be an active member of the community and rejecting those qualities that reflected ageing and ill-health.

It is clear from this representation that the protective factors in Fay's case outweighed the vulnerability factors. Fay was able to make adjustments in the face of the threats of dementia. This process also revealed the importance to Fay of recognition, continuity of self and continuing to have rewarding relationships with others. These points could then be prioritised within the support planning process. Fay was able to make sense of her situation by defining dementia as a lifestyle choice. In this way her personal theory facilitated adjustments and promoted her resilience in this context. Such insights into personal understandings of dementia could then provide a shared basis for discussion about living with dementia between the social worker and the person with dementia.

The detail provided through the application of this matrix on vulnerability factors could provide social workers with specific risk areas to address. For example, during the research process Fay's social worker had expressed frustration that the adult protection process had not taken account the importance of Fay's charity work to her. Instead, this was positioned as the risk activity that had to be managed (see p. 181/182 of this thesis). Use of the resilience matrix within practice could have evidenced how cessation of such activities might contribute to vulnerability. This could then provide a valuable tool for social workers in evidencing contributors and detractors to resilience in discussions with others, and as part of organisational processes, built on social work theory, knowledge and skills. The next step in the proposed model is to identify the individual resilience reserve that Fay might have access to. This is where the resilience reserve is used (Figure 5).

Figure 5. Resilience Reserve Model



Taking each domain in turn the social worker records any relevant data in each domain. The results of Fay's resilience reserve are recorded below in Tables 6.2 to 6.7.

Table 6.2. Resilience Reserve Experience Domain (Fay)

Resilience Reserve Domain - Experience
Previous experience of coping with adversity –Death of parents
Adapting to change
Managing on own – moving to Scotland
Positive experience of education and learning
Strong female role models
Supporting others in need
Organisation and management of a charity
Happy family life and marriage
Being part of a community

Table 6.3. Resilience Reserve Knowledge and Skills Domain (Fay)

Resilience Reserve Domain – Knowledge and Skills
Good listener/communication skills
Organisation
Approachable
Person centred/value based interactions
Educated
Supporting others
Articulate
Knowledge of adversity in other people’s lives through charity work

Table 6.4. Resilience Reserve Motivation Domain (Fay)

Resilience Reserve Domain - Motivation
To try new things
To look after self
To stay socially active
To not be a source of ridicule
To not move into a care setting
To not be viewed as a ‘frail’ older person or as a dependent person with dementia

Table 6.5. Resilience Reserve Assets and Resources Domain (Fay)

Resilience Reserve Domain – Assets and Resources
Home
Family
Dog
Friends and neighbours
Financial security
Social support
Support to manage dementia where it is defined by Fay

Table 6.6. Resilience Reserve Roles Domain (Fay)

Resilience Reserve Domain - Roles
Mother
Counsellor /supports others
Manager
Student
Wife
Friend

Table 6.7. Resilience Reserve Personal Qualities Domain (Fay)

Resilience Reserve Domain – Personal Qualities
Reflective
Available for others
Self-reliant
Supportive
Empathic
Determined
Caring
Educated
Sense of humour
Sociable

Categorising Fay's narrative within these domains instantly begins to build a picture of the person's potential capacity for resilience. The content of each of the resilience reserve domains can then be considered as either buffers to lessen the impact of the threats that were determined through the resilience matrix or as resources to facilitate protective factors. The social worker concerned can then apply their preferred social work theoretical perspective to facilitate resilience focussed practice. I will now explore this final part of the process.

Social work theory which is resilience informed could realise resilience in practice.

Through this research I have identified the processes that could contribute to the current understanding of social work knowledge about dementia and resilience. These frames must be disrupted if practice in this area is to utilise new knowledge about resilience and dementia that can be realised in support planning processes. I have built on the model of social work practice theories developed by Payne (2006, 2014) to demonstrate how social workers could potentially use their own understanding of what social work is in order to realise the resilience of the person with dementia. Payne (2014) presented three main objectives of social work to represent the different discourses that the profession is engaged in. These were problem-solving, empowerment and social change approaches. I explored these perspectives in my review of the literature on social work practice. In summary, problem-solving approaches support people in times of difficulty, within existing structures and support systems. Empowerment approaches promote the personal power of individuals in order to overcome disadvantage. This involves learning about self and building resources. Finally, social change approaches seek co-operation in society as a means of breaking down institutional power in order to benefit those who are most oppressed.

Payne represented these three approaches as the corners of a triangle with each competing for dominance (2014). My analysis of the social work accounts revealed that there is the potential for social workers to use a default problem-solving approach in their work with people who have dementia. As I have already discussed this can often include the person with dementia being viewed as the problem to be resolved. In the context of dementia this can mean existing social work theories can in fact negate the possibility of recognising and building resilience based interventions. I therefore argue that practice theories can be re-framed in order to realise the resilience of the person with dementia in social work practice (Figure 6). I will now discuss how each theoretical approach could use the data generated from the resilience matrix (Figure 4) and the resilience reserve model (Figure 5).

I will begin with problem-solving approaches. I have previously argued that living with dementia day to day involves the process of continual or continuing adjustments to threats to identity. I have theorised how small adjustments within stories achieve and communicate preferred identities within interactions. I also referred to the work of Norris et al. (2009) who define the act of resilience as one of continual adjustments in response to subtle changes. The person concerned cannot then be defined as 'adjusted' as adjustments may be required in each interaction that the person is engaged in. The continual process of 'adjusting' to problems rather than 'solving' problems may therefore be a more appropriate approach. This would then result in re-framing the person concerned as active in the preservation of self, in the face of threats, opening up the possibilities of practice engagement. I provide examples of this within this section. This could then facilitate a broader understanding of the person with dementia within relationships with others, locating problems as co-produced within situations. The stories told by people with dementia can then be re-framed using symbolic interactionism to reveal both the act of adjusting and aspects of the resilience reserve employed in this process.

This approach could also redefine what constitutes *a problem* for those living with dementia, placing issues of identity and loss of recognition for each person at the centre of practice responses. In the case of Fay, the problem to be addressed could be re-framed as to how Fay could continue to contribute to her charity interests, whilst at the same time addressing her family's need to know she is not taking unnecessary risks. This utilises information from Fay's resilience reserve as to her preferred roles and motivations. In this way the relationship between Fay, her family and her vocational work could be viewed as relational, with changes occurring as Fay experiences new challenges as a result of living with dementia. Removing her vocational work does not therefore resolve the problems that Fay may experience as this absence impacts negatively on her personal ecosystem. Using such a visualisation would have provided Fay's social worker with a platform on which to help Fay negotiate between competing risk perspectives. Instead, the social worker reported that the reputation of the organisation appeared to have priority within the adult

protection process which then legitimised what she referred to as restrictive practice (see p. 181/182 of this thesis). The role of the social worker could instead have been to demonstrate Fay's resilience potential and to arrive at a professional consideration as to how Fay could be supported in developing resilience strategies to self-manage elements of risk and lifestyle within her personal network.

Problem-solving approaches to the daily challenges of living with dementia can also be employed. For example, although Fay was reluctant to speak about any problems as a result of dementia, support could focus on the experiences day to day of adjusting to her changing roles. Reference to the content of Fay's potential resilience reserve in addressing problems could then take place. For example, Fay's social worker described how Fay had retained emotional memory (see p. 194/195 of this thesis). A focus on the challenges of adjusting to living with memory loss through practical support could be approached alongside the emotional impact. This approach could then make use of elements of the resilience reserve to respond to feelings of self-stigma that such perceived losses could generate.

With reference to empowerment, approaches that focus on the stories told by people living with dementia could realise resilience in practice. Empowerment practice in the context of dementia could then be re-framed as promoting the preservation of identity. A focus on identity, threats to identity and responses would then follow. A resilience focussed approach would then involve working with the person with dementia to recognise resilience reserve, building on those areas that can contribute to adjusting to loss of recognition. Stories can therefore provide the context for empowering social work approaches, placing each person within situation, and providing a basis from which social workers can realise resilience in action. An understanding of these factors can then empower the individual concerned, promoting practice responses which mitigate vulnerability factors and promote protective factors. This can then contribute to a dynamic model of resilience based social work practice with

people ageing with dementia. For example, Fay's resilience reserve content revealed her experience and knowledge as a leader in her charity work, supporting others and making day to day decisions. Being considered as the person in need of support could potentially be difficult for Fay to accept. However, Fay had a wealth of knowledge, revealed through her resilience reserve, that her social worker could access in order to help Fay explore experiences of living with dementia. Using Fay's knowledge of the charity sector could reveal alternative roles within her area of interest. Instead of visitors arriving at Fay's home could Fay instead provide support by mail, phone or social media with assistance? By recognising Fay's knowledge she could be empowered to continue to support other people, and in this way maintain her vocational interests, social networks and community recognition.

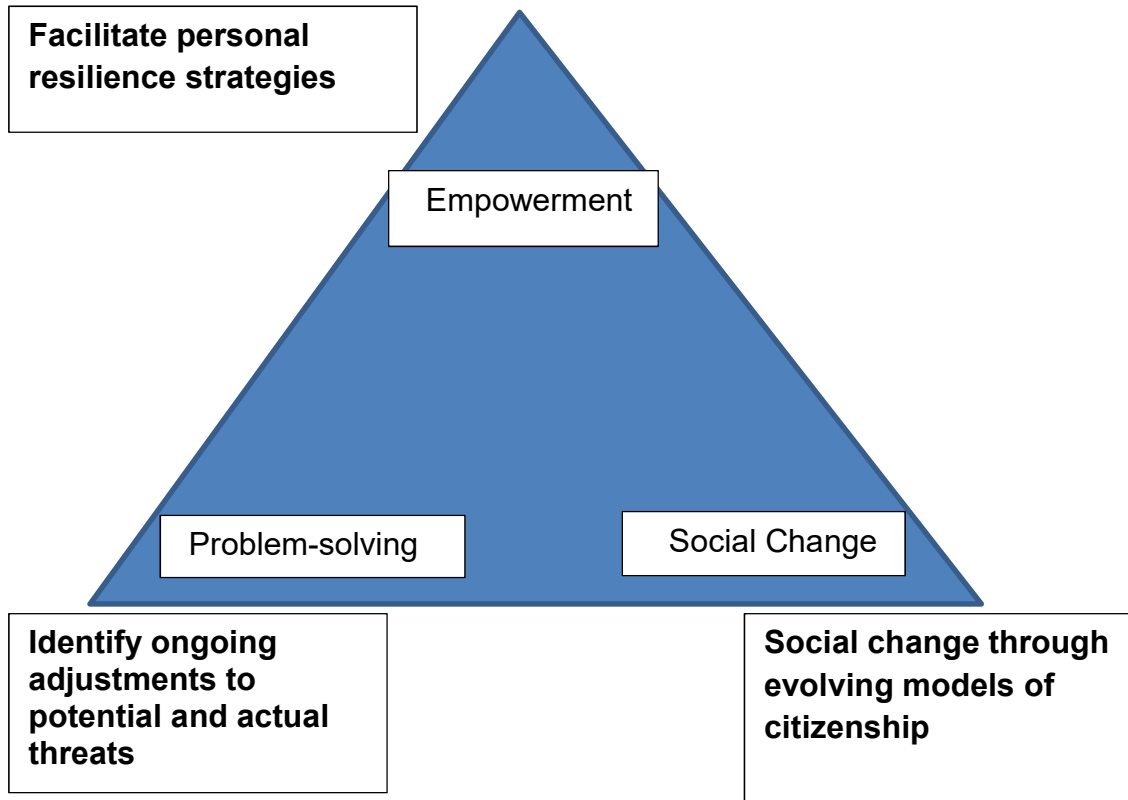
Empowerment can also be achieved through the creation and sharing of the resilience reserve data itself. Creating a visual record of resilience for the person to refer to and to share with others could potentially be very powerful for the person concerned. Empowerment focussed practice could also look at those areas where a person's resilience could be strengthened through targeted interventions. For example, Fay's social worker stated that the process of resilience relied on a person absorbing ideas but also letting them go (see p.194/195 of this thesis). Fay would appear to be at risk from negative messages about ageing which could contribute to self-stigma. This was reflected in the motivational reserve content where she expressed that she did not want to be seen as either "ancient" or "gaga". Empowerment practice could then focus on addressing the source of these opinions and fears, in order to lessen the potential impact on Fay as she continues to age, achieving what her social worker described as letting go.

Social change approaches to social work are focussed on power inequalities within society (Payne, 2014). However, as I have discussed within my review of the literature, the issues that affect those ageing with dementia can still be a hidden problem (Batsch and Mittelman, 2012). The complex interplay of ageing, ageism, stigma and self-stigma can result in exclusion and loss of recognition for people within their most personal relationships, as well as within wider society (Sabat, 2001). The language of dementia which refers to 'sufferers' and economic burden further contributes to potential loss of status (Innes, 2009). Social change approaches to social work therefore offer an opportunity to first recognise the ways in which structures and institutions can work to contribute to and maintain loss of recognition where a person has dementia; and where, in fact, social work practice in and of itself perpetuates loss of status. With reference to Fay, the adult protection process was identified by the social worker as contributing to perceived power inequalities for Fay (see p. 181/182 of this thesis). She had observed that Fay was included to the extent of being present at discussions but stated that the outcomes of those discussions did not reflect Fay's preferences. Social change models would therefore focus on a challenge to the blanket assumptions of risk associated with those with dementia and the rights that people have to make lifestyle choices. The resilience matrix findings could be used to reflect both protective and risk factors in the context of organisational protection processes and decision making, facilitating recognition of Fay's citizenship in doing so.

Similarly, social change models could challenge the assumptions made about the nature of Fay's work, demonstrating the knowledge, skills and experience that Fay still has access to in order to manage interactions in her day to day life. Further, using Fay's knowledge of her particular charity sector, new roles could be explored within her area of interest. Fay could be supported to play a role in changing social attitudes to either those individuals that she dedicated her working life to, or indeed people who are living with dementia. Although Fay did not want to be recognised as a person with dementia publically, and this is important, her influence through other community roles could change the perceptions of other people about what a person with dementia can continue to

do. For example, Fay could be encouraged to record her achievements over her life, her ongoing work and importantly her unrealised ambitions or future plans in a continued citizenship role.

Figure 6. Social Work Theory (Resilience and Dementia)

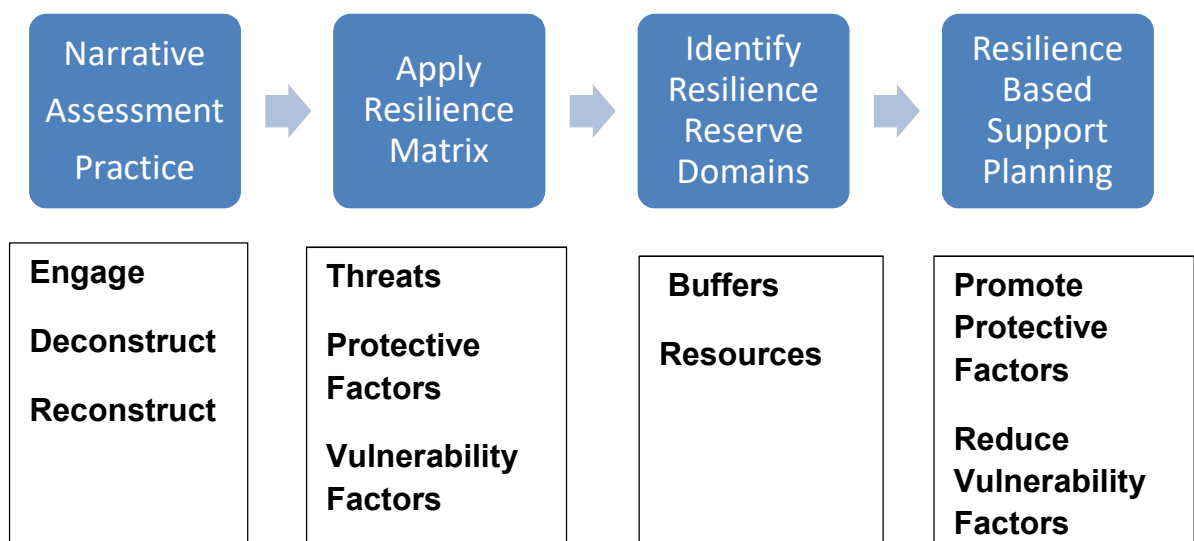


[Adapted from Payne (2014)]

In summary, social change approaches can also create a new discourse such as that promoted by Nedlund and Nordh, where all persons with dementia are regarded as “*capable citizens*” (2015, p. 131). Social work is ideally placed to recognise persons with dementia as citizens, through theory, knowledge and practice and, consequent verbal and written accounts. This affords a unique role from which to challenge the accepted discourse on what it means to be a citizen. Where a person has been referred to social services they can be defined solely with reference to their dementia. However, challenging assumptions about what it means to have dementia can sometimes be

achieved simply by living well despite the condition. Practice interventions could begin by finding the ways in which those with dementia exercise power to influence their own lives, the lives of others but also the content of their citizenship. In this way problems and situations can be re-framed to focus on resilience responses and adjustments, which may previously have been misunderstood. Nedlund and Nordh (2015) argue that in order to think differently about those with dementia creative thinking about the nature of citizenship itself is required. I contend that social workers can provide leadership in this area through new approaches to social change theories of social work with people ageing with dementia. The practical application of this resilience model is outlined in Figure 7.

Figure 7. Social Work Model of Resilience Based Practice in Dementia



[With reference to Roscoe et al., (2011)]

Study strengths and limitations

This study was undertaken using a symbolic interactionist perspective. The interpretations, analysis and findings were therefore unique in relation to each participant. The processes that generated the stories told and the meanings given to the story details were also unique to the researcher and participant in that space and at that time. This is both a strength and limitation of using this approach. The strength is that it captures unique interactions, records them for posterity and reveals the processes at play, and suggests the reasons for them. However, studies of this nature tend to have a relatively small sample size due to the level of detail recorded. Using a narrative methodology can also have limitations. For example, although the stories which form the narratives for analysis were co-created through the research process, the deconstruction and reconstruction stages were undertaken separately by the researcher. The views of the person concerned were then sought after the analysis had taken place. This methodology closely mirrors narrative approaches used in practice by social workers (Roscoe et al., 2011). This is therefore a strength in research that seeks to make recommendations for practice. This study of six dyads of person with dementia and social worker is rich in detail, reflecting the in-depth interactions with the twelve participants concerned. I have made every effort to clearly convey the conclusions I have reached and the ways in which I have done this.

Another strength of this study is that I did not confine participation to people in the early stage of dementia, instead, participants discussed how long they had been living with their dementia diagnosis. Participants had different types of dementia and were at different stages of the condition. This variety across the sample provided rich details of different experiences under the umbrella term 'dementia'. The social work participants were recruited from across the host authority, including hospital social work, mental health and older people teams. The social workers who participated had a variety of work experiences and interests. The participants also varied as to when they had undertaken their social work training. The accounts shared were therefore shaped by these differing experiences of culture and learning.

It is possible that the fact that I was an 'intimate insider' (Taylor, 2011) may have impacted on the accounts shared with me by the social work participants, although, this is hard to gauge. However, there did not appear to be a great deal of variation between the accounts of the participants, some of whom had known me in previous roles, and some of whom had not. All of the accounts could be described as open, rich in detail and consisting of both positive and negative messages on the subjects concerned.

With regards to resilience, the proposed model that I have developed has a focus on revealing adjustments within stories which appear to preserve identity within interactions. This model defines resilience *in the moment* with an emphasis on the continual nature of adjusting to threats as they are experienced by each individual. I am, therefore, not making any claims as to the future resilience of any of the participants but rather offering a window on the possible processes at play, during the moment of my interaction. In this way, I propose that my methodology can be replicated in practice, in order that social workers can also identify resilience within the stories of people with dementia, through narrative approaches in practice.

Implications for people ageing with dementia

This research has several implications for people ageing with dementia. The first is that this work could contribute to evolving models of citizenship for persons living with dementia. The importance of identity and mitigating loss of recognition that this research has revealed could contribute to new ways of understanding the active citizenship of people ageing with dementia as they interact with others, and use their own stories to preserve self in the face of threat. This work could then both contribute to and provide a bridge between current understandings of narrative citizenship (Baldwin, 2008; Clarke and Bailey, 2016) and social citizenship (O'Conner and Nedlund, 2016) in understanding resilience in the moment of interaction.

The promotion of resilience in social work interactions could result in more rewarding social work encounters for those living with dementia, where stories are valued as reflections of citizenship and the preservation of identity is central to measures of interventions success. Through this research I have referred to the resilience reserve that a person ageing with dementia could develop over their life. Use of such a model could re-frame people with dementia as having the potential for resilience, and to be supported in the development of resilience strategies. This changes the current discourse on dementia and decline offering positive, personalised choices to people with dementia in new ways.

The opportunity to visualise resilience and resilience reserve could be a powerful tool for people with dementia to use to communicate their own needs in interaction with others. One such opportunity could be to facilitate a specific resource such as Talking Mats (Murphy and Oliver, 2013). Talking Mats is a communication tool that uses picture communication symbols to reflect a person's views or story as a visual record. Picture symbols could be developed to represent different aspects of the resilience reserve using such a tool. This then brings the data to life in real world interactions with others. This approach can also be used with people ageing with dementia where there are communication difficulties to support the storytelling process. There are also opportunities to promote visualisations of resilience using new technologies and applications (apps), which could be more responsive to changing reflections of resilience due to their accessibility. This is a developing field (see for example, Smith, 2015) and the promotion and support of resilience could be a part of this technology. Bennett (2015) identified the importance of technology in enhancing resilience and that the current technological landscape for resilience looked promising. This research could contribute to this field.

Implications for social work

Social work training and education

With regard to social work training and education, this research could facilitate an exploration of how we define people ageing with dementia, and stimulate an examination of the purpose and impact of social work practice in this field. A focus on what social work is, and the social work theories that support our current discourse can then be explored from the perspectives of those ageing with dementia. The importance of identity, recognition and citizenship for those experiencing ageing and dementia can then start to shape discussions in this area.

Practice and continuing professional development

There are several implications for social work practice and continuing professional development as a result of this research. The first is that there will now be a practice theory for the application of resilience within the context of people ageing with dementia which social workers can utilise in their work. Second, this theory has been developed into a practice model, grounded in narrative approaches, and consisting of a resilience matrix and model of resilience reserve. This can now form an integral part of the social work toolkit in working with people who have dementia in the same way that children and families practice routinely use resilience frameworks (Scottish Government, 2008). This framework could assist social workers to critically analyse their assessments and possibly arrive at new decisions which focus on the facilitation of resilience. Interventions which focus on promoting protective factors and identifying vulnerabilities in the preservation of identity may then be realised. A focus on the stories of people living with dementia could promote narrative based practice as an alternative to care management models. This could result in more creative practice which keeps the person with dementia at the heart of the process; providing support in such a way that it attends to the threat of loss of recognition and the promotion of citizenship.

This work could facilitate a re-focus on theories of what social work is, in the context of older people with dementia, where social workers could approach their work with the confidence that resilience can be at the centre of different discourses within the profession. Using a resilience tool which can evidence threats to identity, vulnerabilities and protective factors could also assist in dealing with organisational discussions and processes to access support, or provide protection, without losing sight of the citizenship of the person with dementia. This could then result in more authentic assessment content which resolves practice tensions around issues of realism versus idealism (Whittington, 2007).

Resilience frameworks can be used within a number of practice situations under different policy briefs. For example, the implication of the pillars of support models for people living with dementia (Kinnaird, 2013; Scottish Government, 2013) would be informed through a definition of resilience, and a model which realises the resilience of people with dementia through social work practice. This could assist in the delivery of the pillars in a meaningful way, informed through social work practice and providing a framework to assess ongoing success in the preservation of identity. The report of the Scottish Government's Focus on Dementia partnership improvement programme (2015, p. 5), stated that it would build resilience for people with dementia. The quality criteria to measure whether personal resilience has been addressed in planning outcomes for a person with dementia are stated in the document appendix as: recording important relationships, networks and community connections; strengths and abilities; information about how the person will have control in their life and finally; how each person can build on their strengths (p. 36). The addition of a practice model, such as the one that I propose, which focusses on identifying the complexity of person in situation, vulnerability and protective factors; and recognising the impact of different domains of resilience could provide a more informed and detailed data set with which to work. This could facilitate the important role of social work knowledge within the Focus on Dementia agenda, and highlight the unique contribution of social work to the

national dementia conversation. Social workers could then have an opportunity to assert an expert status in work which focusses on resilience and dementia.

Another key area is in adult support and protection practice. Reference to resilience frameworks could deliver a dimension currently missing, from social work practice in this area. Again this could assist social workers to talk knowledgably about resilience within situation, with reference to a recognised framework, as is the case with colleagues who work in the support and protection of children (Scottish Government, 2008). The work of Daniel and Wassell (2002a, 2002b, 2002c) on features of resilience in children and adolescents is standard reading for social workers in this field. This review demonstrates the need for resilience related materials to be developed for social workers in their work with people ageing with dementia. Resilience based frameworks are required to meet demands for increased professional capacity and improved evidence based practice for social workers in their work with people who have dementia. I therefore posit that the development of this approach could enhance social workers' professional judgement in this complex area of practice. I suggest that there is a lack of empirical evidence on the social work role when working with a person ageing with dementia and that this research will provide an important contribution to this area of work.

Finally the Vision and Strategy 2015-2020 for Social Services in Scotland stated that:

"Our vision is a socially just Scotland with excellent social services delivered by a skilled and valued workforce which works with others to empower, support and protect people, with a focus on prevention, early intervention and enablement." (Social Work Services Strategic Forum, 2015, p. 7).

This research contributes to the aims of this document through describing a model of social work practice which is both citizenship and resilience focussed, and grounded in the values, ethics and principles of modern social services in Scotland. It recognises the unique contribution of social work in people's lives

and contributes to the aims of the profession in using research to both understand and inform practice.

Implications for academia and future research

This research could extend the '*citizenship turn*' (O'Conner and Nedlund, 2016, p. 287) as it addresses domestic and socio-political spheres of understanding citizenship. This research has revealed the ways in which the micro-experiences of people living with dementia can be experienced as threats to their identity. Importantly, it also offers insights into how people with dementia potentially respond to such experiences. Social work practice is undertaken within the context of people's lives, operating at the intersection of the personal and the political. An examination of the ways in which social workers reflect the everyday experiences of the person with dementia and afford narrative citizenship to those people that they work with is therefore an important contribution to this field.

A focus for both social work and dementia academics on resilience within the context of assumed decline could provide a new approach to understanding evolving models of citizenship. This could build on my proposed model of resilience opening up new opportunities for teaching and research. It could also provide the means with which to challenge previously held assumptions about people ageing with dementia. Bartlett (2016, p. 459) advised that research which is focussed on citizenship can "*help to advance the social justice agenda in relation to people with dementia.*" This research could then help to develop new ways of understanding the experiences of people with dementia and new methods of interacting with and responding to those with dementia. This research has also contributed to the current body of work on identity in dementia and could provide a new perspective on this subject through the application of resilience.

The methods employed in this research could also be tested with other groups of people for whom resilience has been assumed as absent or not applicable. They can also be used to explore other aspects of resilience, such as resilience in the context of technology and social media for people ageing with dementia, as I have previously referred to. Research opportunities also exist to explore the responses of people ageing with dementia within the context of adult support and protection, from a resilience perspective. Finally, there is scope to apply the learning from this research in other practice areas within health and social care, and consider development of the models for use by other professional groups. For example, within residential care settings in the promotion of resilience, within advocacy organisations and across other disciplines such as nursing.

Reflections on the research process and findings

This PhD has been conducted over a six year period and looking back on my early work to the point of this completed thesis I can plot the evolution of my developing ideas. Initially when I outlined my potential research questions I was focussed on the applicability of research in the context of dementia and definitions which could support this work. However, over the course of the literature review I began to realise that what was important was what resilience contributed to my understanding of dementia. This occurred in part through my reading on narrative identity and the importance of storytelling within interaction with others. My research design using symbolic interactionism therefore emerged organically from my reading. Using a micro-level theory facilitated the amplification of the person with dementia's voice within the research process and this was at the heart of my research purpose and planning.

I was struck by the depth of the stories shared by the people with dementia in this study. I was also humbled by the intimate nature of stories about self, society and observations on life. The stories told by people with dementia can be dismissed as non-factual or superficial, assumed to have no substance or purpose (Sabat, 2006; Young, 2010). However, I found that the stories told by

people ageing with dementia can in fact be rich repositories of information. In particular, stories can reveal insights into what might constitute a better than expected outcome for that particular individual, and without that story, these important aspects of life can remain hidden from view. They are therefore powerful and at the same time sensitive and must be treated with respect. This applies to the act of generating stories together, but also in handling stories as they are transformed into narratives for analysis. Stories offered points of reflection and re-positioning for the people in this study. The active nature of these aspects of story revealed the ways in which people with dementia could possibly regain power within interactions. Reflecting on this research as whole I would then argue that the act of storytelling in and of itself provided an opportunity for resilience to be realised. This has led me to believe that invitations to tell the story of self can in itself be a catalyst for resilience to be realised, in the moment, for people with dementia.

The same is true of my interactions with the social work contributors who appeared to use the research process as an opportunity to reflect on their practice. This occurred not just in relation to the person they were working with but in relation to practice in a wider context. Reflections were provided on social work, its purpose and the person's individual role as a professional social worker with people with dementia. Opportunities for reflection about the experience of practice through storytelling could possibly offer something new that would benefit both the social worker in their ongoing professional development and ultimately the person they are engaged in practice with.

Reflecting on the research process I found that the use of storyboards offered a new dynamic in understanding layers of potentially hidden narrative. This could also be a very accessible practice tool with which to engage with the stories of people with dementia and/or as part of the assessment process. Surface stories could be built upon and critically analysed through the application of social work theory, knowledge, skills and values. Additional layers which represent associated policy and legislation could also be applied. My experience of using

storyboards in this study has led me to believe that this is an under used resource that could be of interest to social workers both in their practice and in the communication of their practice with others.

Reflecting on the choices that I made as to how to present this work, and retain the centrality of the voices of both the person with dementia and the social work participants, I can see that the decisions I have made about the thesis content and structure have been influenced by my social work values and principles. This thesis as an output of the research process could then demonstrate the unique perspective that social work researchers can make to the academic world.

These findings could be considered to be contributing to new practice models for working with people who have dementia; to new research methods which utilise the stories of people with dementia to reveal both citizenship and resilience in action; to practice methods, and to supervision and professional development which not only supports resilience focussed practitioners but promotes reflection on practice.

Concluding comments

In conclusion, I have addressed the underpinning questions posed at the outset of this research, as to what the concept of resilience could bring to our understanding of dementia. I have provided both a definition of resilience and a proposed model. Resilience can be defined as ‘adjustments in the face of the threats to personal and public identity experienced when ageing with dementia’. It is context specific and, I suggest, is an important aspect in the preservation of identity for people with dementia in relationships with others. Resilience is not static and is influenced by the complex interaction of vulnerability and protective factors in a person’s life. Through my review of the literature and analysis of descriptions of practice, I have found that social workers do not have a current framework that facilitates their use of resilience in work with people ageing with dementia. However, I suggest that a re-framing of theories of what social work is, and what it sets out to do, could promote opportunities to use social work knowledge and practice to realise the resilience of the person ageing with dementia. I have therefore developed a resilience focussed approach that facilitates the learning from this research in order to achieve these aims. Social work practice and research, with people ageing with dementia, can then take place within a new model of citizenship that recognises the contributions that people with dementia make to their own lives and to those of other people.

I therefore conclude that the concept of resilience can contribute to our understanding of dementia. However, how people experience dementia and respond to the challenges of living with dementia, can also reveal much about the nature of resilience. This research has contributed to the existing knowledge in this field by proposing a new model of resilience in the context of people ageing with dementia, social work practice and social work research. Further, this knowledge has the potential to be developed across different disciplines to support developing policy and practice within an integrated health and social care future.

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Appendices

Appendix 1: Information for Organisations



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Research Project Information Sheet 1: Information for Organisations

How do we understand resilience in the context of a person with dementia and what are the implications for social work practice?

Research Aims

The purpose of the study is to consider the way in which social workers approach their work with a person who has dementia. The study is particularly concerned with how social workers recognise strengths and coping mechanisms. The findings of this research will be used to develop a range of materials for social workers, in their work with people with dementia, that enable more positive, individual responses to the condition to be achieved.

This study will consider the concept of resilience in the context of a person with dementia. There will be a particular focus on the views of social workers on the subjects of resilience and dementia. The implications for social work practice of employing resilience models when working with people with dementia will be explored. The anticipated outcome of this research is to re conceptualise the relationship between the social worker and the person with dementia. This will be achieved through an examination of views currently held by social workers, and the development of a resilience framework to support social work practice and professional judgement. This will facilitate a strengths based approach for social workers in their work with a person with dementia.

Research Questions

1. Is the concept of resilience applicable to people with dementia?
2. If so how do people with dementia define it?
3. How do social workers define and identify resilience in their work with people who have dementia?
4. How do these factors interact and what are the implications for social work practice?

Research Design

Three methods of data collection are proposed: interviews with people with dementia, interviews with social workers and consideration of the written reports generated by social workers about people who have dementia. A minimum of five people over the age of 65 years who are referred to the Social Work Department in the specified local authority between January 2011 and December 2013 will be selected. The sample will include both men and women who have been identified by the Social Work Screening service as having dementia and requiring an assessment of need. Inclusion will be determined by the person's willingness to disclose aspects of their life and condition to the researcher. There will have to be a shared communication approach and understanding of the information between both parties. This issue will be addressed prior to the commencement of the research by meeting with the person and their representative to explore how this might be achieved.

There is no identified risk of harm to the individual through either participation or cessation of involvement with the researcher. Written information about the project will be developed alongside an independent advocacy project. All of the potential research participants will be provided with written information about the project and consent sought. All participants will be advised that their decision either to be involved or to opt out of the project (at any stage) will in no way influence the service or support that they receive from the Social Work Department.

All participants will be advised that any information that they give will be confidential and non-identifying. Written consent will be sought from participants, in the presence of an independent advocate or named other, where this is the person's choice. I will develop information in individual formats where written information is not the preferred medium of the potential participant. Where there is a designated welfare proxy I will approach this individual for consent in relation to inclusion as well as engaging with the person who has dementia. This is in accordance with the Adult with Incapacity Scotland (2000) Act part V principles about researching adults who lack capacity. A welfare proxy can consent on behalf of the person they are representing however engagement with the individual remains essential. I will also employ process consent (Usher and Arthur, 1998) and will re-visit the subject of consent on each interaction with the research participant.

Contact details of independent advocacy will be provided in the event that the person would like to discuss the project. Participants can withdraw at any time. A complaints process will be established with Ceartas advocacy service which can be accessed independent of the researcher. Research participants can also complain to the University of Stirling during the process should they so wish in accordance with the Code of Good Research Practice (2009).

If you or your organisation would like further information about this research project or wish to make any comment on the proposed design then please contact me at the address below. The PhD is funded by my employer.

Julie Christie
PhD Student
School of Applied Social Science
University of Stirling
julie.christie@stir.ac.uk Tel: 0141 355 2200

Appendix 2: Information for Participants (including Consent Forms)



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Research Project Information Sheet 2: Information for Potential Participants

This information is available in audio and large print formats on request.

My name is Julie Christie and I am a PhD Student at the University of Stirling, School of Applied Social Science.



How do we understand resilience in the context of a person with dementia and what are the implications for social work practice?

I would like you to consider taking part in a research study.

The purpose of the study is to consider how people respond to having dementia and to explore the way in which Social Workers approach their work with a person who has dementia. This study is particularly concerned with how Social Workers recognise the strengths or coping skills that people have.

I hope that this research will encourage social workers to have a positive, individual approach in their work with people who have dementia. This information will then assist in the development of materials for Social Workers.

I am a Social Work Manager with the specified local authority who are funding this research. If you decide to participate your services will not be affected in any way. I will not be involved in the delivery of your care if you take part in this research.

What is involved?

If you agree to participate I would like to meet with you to discuss your life story. You can decide what you tell me and you can edit the story as you would like. I would need to meet with you on more than one occasion and you can decide how long these meetings last. With your permission I will audio record these meetings. If you would like someone else to be present such as a friend or relative during these meetings this can be arranged. I can also meet with you in the venue of your choice.

As well as meeting with you I would also talk to your Social Worker. I will ask your Social Worker about their work with you and talk to them about the subject of dementia. I will not share your story with your Social Worker as this is confidential. The last stage of this research would be for me to read the Assessment Report that your Social Worker has written about you.

What Will I Do with this Information?

- All of the information that I generate will be anonymous and will not identify you.
- I will compare the story that you tell me with the conversations that I have with your Social Worker. I am interested in areas of agreement and difference about your strengths or coping skills that might arise.
- I will then look for this information in your Assessment Report.
- This information will be stored securely and I will be the only person who will have access to it.
- You can see my findings and edit your story before I submit my work.

Next Steps

If you are interested in finding out more you can get independent advice and information from Ceartas, a local advocacy service in East Dunbartonshire. Ceartas can be contacted in person, by phone or by email:

McGregor House

10 Donaldson Crescent

Kirkintilloch

G66 1XF

Tel: 0141 775 0433

Email: www.ceartas.org.uk



Or call me, Julie Christie at **0141 355 2200 (local contact no)**.
PhD student at the School of Applied Social Science University of
Stirling. Thank you



Please read or listen to the statements on the attached form, before signing to indicate your consent.

- I understand that my participation is voluntary and that I may withdraw my consent to participate at any time, without any consequences to me.

- I understand that this information may be used to assist in the development of future services for people who have dementia.

- I understand that there are no foreseeable risks to me.

- I understand that all information collected will be confidential. Any information used will not include any material that could identify me.

- I understand that I may ask questions at any time.

- I understand that I can seek advice or complain to an independent party at any time. Details are provided.

- This research is subject to the scrutiny of the University of Stirling. I understand that if I have concerns about this research or the conduct of the researcher I can contact the university to complain.

Should you have any questions or concerns you can contact:-

Gordon Thomson at Ceartas Advocacy Project

10 Donaldson Crescent

McGregor House

Kirkintilloch

G66 1XF

Tel 0141 775 0433

Email: www.ceartas.org.uk

Or my supervisor-

Professor Anthea Innes

The University of Stirling

School of Applied Social Science

Rm 3S10 Colin Bell Building

Stirling

FK9 4LA

Tel 01786 467710

I have read the above and give my consent to participate in this process.

Signature of Participant:

Date

Signature of Witness (where appropriate):

Date

Appendix 3: Independent Advocacy Support



The name Ceartas (pronounced Kier-tis) is a Gaelic Word for equity, fairness, justice and right.

Ceartas provide advocacy and information services for people in the specified local authority. We have a responsibility to provide this service, ensuring the rights of individuals are always central, in compliance with national advocacy standards.

If you would like to meet with someone to discuss participating in this research project then we can give you free, impartial advice about

- what the research is about
- what your participation would involve
- what your rights would be as a participant

Ceartas can also offer you practical support by

- being present when you consider the research information
- being present if you choose to sign the consent form

Should you choose to participate in this research Ceartas can

- be present when you meet with the researcher
- speak to you in confidence should you have any concerns or complaints about the process

Please contact Ceartas at
McGregor House
10 Donaldson Crescent
Kirkintilloch
G66 1XF
Tel 0141 775 0433
Email: www.ceartas.org.uk



Appendix 4: Information for Social Work Participants (including Consent Forms)



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Research Project Information Sheet 3: Information for Potential Social Work Participants

How do we understand resilience in the context of a person with dementia and what are the implications for social work practice?

Research Aims

The purpose of the study is to consider the way in which social workers approach their work with a person who has dementia. The study is particularly concerned with how social workers recognise strengths and coping mechanisms. The findings of this research will be used to develop a range of materials for social workers, in their work with people with dementia, that enable more positive, individual responses to the condition to be achieved. This study will consider the concept of resilience in the context of a person with dementia. There will be a particular focus on the views of social workers on the subjects of resilience and dementia. The implications for social work practice of employing resilience models when working with people with dementia will be explored. The anticipated outcome of this research is to re conceptualise the relationship between the social worker and the person with dementia. This will be achieved through an examination of views currently held by social workers, and the development of a resilience framework to support social work practice and professional judgement. This will facilitate a strengths based approach for social workers in their work with a person with dementia.

Research Questions

1. Is the concept of resilience applicable to people with dementia?
2. If so how do people with dementia define it?
3. How do social workers define and identify resilience in their work with people who have dementia?
4. How do these factors interact and what are the implications for social work practice?

What is involved?

If you wish to participate I would meet with you to conduct a one to one interview. I will audio record this interview. The information will be anonymous and will be stored securely. I will be the only person who has access to the data. I will also read the Assessment Report that you have written. I will also meet with the subject of your report and speak to them about their life. I will then compare all of these accounts.

Please note

This Research is funded by my employer.

Your conditions of employment are in no way affected by your decision to participate or opt out of this research project.

If you would like more information please contact me-

Julie Christie

PhD Student

School of Applied Social Science

University of Stirling

julie.christie@stir.ac.uk Tel: 0141 355 2200 (local telephone no.)



Please read or listen to the statements on the attached form, before signing to indicate your consent.

- I understand that my participation is voluntary and that I may withdraw my consent to participate at any time, without any consequences to me.

- I understand that this information may be used to assist in the development of future services for people who have dementia.

- I understand that there are no foreseeable risks to me.

- I understand that all information collected will be confidential. Any information used will not include any material that could identify me.

- I understand that I may ask questions at any time.

- I understand that I can seek advice or complain to an independent party at any time. Details are provided below.

- This research is subject to the scrutiny of the University of Stirling. I understand that if I have concerns about this research or the conduct of the researcher I can contact the university to complain.

- The research will be undertaken with reference to the SSSC Code of Practice (2009).

Should you have any questions or concerns you can contact:-

Gordon Thomson at Ceartas Advocacy Project

10 Donaldson Crescent

McGregor House

Kirkintilloch

G66 1XF

Tel 0141 775 0433

Email: www.ceartas.org.uk

Or my PhD supervisor

Professor Anthea Innes

The University of Stirling

School of Applied Social Science

Rm 3S10 Colin Bell Building

Stirling

FK9 4LA

Tel 01786 467710

I have read the above and give my consent to participate in this process.

Signature of Participant:

Date

Signature of Witness (where appropriate):

Date

Appendix 5: Interview Prompts for Use with the Person with Dementia

Opening sentence: Tell me about yourself

Further prompts

Tell me about your life

Are there people or places that are important to you and why?

Tell me about the important events in your life

Tell me about the significant people in your life.

Why were these things important?

What happened?

What did you do?

How did you feel?

What did other people do?

How would you like other people to describe you?

How do you think they would describe you?

What is important to you now and why?

Do you think about the future? What are your plans?

Appendix 6: Interview Prompts for use with Social Workers

What was the purpose of your contact with the person?

Please describe the person you were/ are working with to me?

How did you go about your assessment?

How would you describe your interaction with the person?

What did you expect your assessment findings to be?

What were your assessment findings?

Tell me your views about the role of social workers with people who have dementia?

Do you want to tell me anything else about your work with this person?

What are your views on social work with people who have dementia?

Appendix 7: Coding person with dementia

Pre-selected Codes	Inclusion Criteria
Identity (Parent Code)	<p>Details of characteristics, personal qualities, roles, skills.</p> <p>Stories told where the person represented themselves as a character.</p>
Ageing	<p>Details of the self as older person.</p> <p>Stories of ageing or of older people.</p>
Dementia	<p>Details of the self as a person with dementia.</p> <p>Stories about dementia.</p>

Open Codes	Inclusion Criteria
Lifestyle	<p>Stories and story content about preferred lifestyle choices, past, present and future. Including aspirational lifestyle choices.</p>
Sport	<p>References to sport interests and hobbies.</p>
Giving things up	<p>Details within stories where the person describes giving things up, letting go of previously cherished roles, hobbies, items and activities.</p>
Family	<p>Any references to family, family unit, family members, past and present.</p>
Work	<p>Any references to work, work roles, past and present.</p>
Bereavement and Death	<p>Stories and story details which include loss, bereavement and death.</p>

War	References and stories to war and war experiences.
Music	Stories about and references to music, music related activities and memories associated with music and song. Singing within stories
Marriage	References to marriage, including references to spouses.
Alcohol	Stories about drink, alcohol use, living with a person with alcohol dependency.
Losing contact	Stories which include storylines where the person loses contact with people and places.
Suicide	Stories where suicide featured.
Abuse	Stories which contained details of abuse or abusive situations.
Injustice	Details within stories where the teller expressed an injustice had taken place.
Pets	References to pets past and present. Stories of pets and their impact on the person or others in their life.
Health	Stories which discuss health and feeling healthy or the importance of health.

God	References to God or a higher power. This also included religion and religious activities.
Feeling trapped	Stories where the person expressed feeling trapped.
Joy/happiness	Stories and story details of happiness and wellbeing past and present.
Change	Details of change and transition in space, place, roles. Feelings of change related to the self and identity.
Depression	Explicit mention of depression.
Socialising/Friends	Stories of and references to friends, social networks and friends. Past and present.
Vocation	Details within stories of vocation or purpose in life or related to specific activities such as work or charitable contributions.
Ridicule	Expressions of ridicule, of being the object of fun, of others being the object of fun.

Themes	Inclusion Criteria
Self-appraisal	Setting criteria to test the self against Testing the self within stories against these criteria. Asking questions about self. References to the self through the eyes of other characters within stories.
Choosing to disclose	Stories where the person discusses telling others people about their dementia.
Re-interpreting events	Stories where the person re-interprets the story events for the listener, after presenting the initial story details.
Re-positioning	Where the person changes their role, motivations and actions within stories.
Previous experience of adversity and surviving adversity	Stories of adversity, trauma, abuse, bereavement, loss and hardship. Stories which detail what the person did, and why. References to these stories in resolving issues in the present.
Security	References to safety, security and comfort.
Role Models	Story characters that are referenced as having an influence on the person past and present.

Focus on the positive	<p>Details of the good things in the person's life and statements about focussing on these.</p> <p>Minimising problems through a focus on the positive</p>
Rejecting stereotypes	<p>Descriptions of groups of people or group identity such as older people and story details which then show the person concerned to be different from the earlier description.</p>
Having Fun	<p>Stories of having fun past and present.</p>
Previous experience of adversity and feeling events were out of control	<p>Stories where the person described a traumatic event and then detailed their anxiety or lack of control over what happened.</p>

Appendix 8: Coding social worker accounts

Pre-selected Codes	Inclusion Criteria
Resilience Content (Parent Code)	References to resilience, strengths, hardiness, coping. References to the person's characteristics, personal qualities, roles, skills and experiences. Related concepts used to refer to resilience
Generic Content (Parent Code)	Any content which was not included in the resilience code. Awaiting further open coding of content.

Open Codes	Inclusion Criteria
Independence	References to the independence of the person concerned or discussion about the concept of independence.
Acceptance	Any content that was used to describe where the person came to terms with their situation or accepted the views of others including the social worker.
Experience	Experiences of trauma or adversity and explanations of how the person overcame them. Life experiences used to explain current situation.

	References to the person in the context of their life experiences
Personal qualities	Any content where the social worker referred to the personal qualities of the person that they were working with. References to personal qualities within the context of living with adversity/ and or dementia.
Support	Content which focussed on the need for support or types of support for the person with dementia.
Goal Setting	Discussions which referred to the setting of goals with or without the involvement of the person with dementia.
The needs of carers	Any references to carers needs, including carers assessments.
Resources (provision of)	Inclusion of support within a resource context including budgets, staff and time.
Defining success	Content which discussed successful intervention by the social worker or that discussed outcomes and then detailed the ways in which they achieved the care planning goals.
Prioritising needs	Content which discussed needs, competing needs and then prioritised needs for the listener.

Risks	<p>Content which focussed on risks to the person or other people as a result of their dementia.</p> <p>Risks associated with the person in a general sense.</p> <p>Risk assessment and risk management activities</p>
Organisation/ Organisational Process	<p>Content which described the organisation that the social worker was employed by.</p> <p>Reference to organisational processes.</p>
Gatekeeping	<p>References to gatekeeping of resources and/or people.</p>
Identity/ Roles	<p>Content which explored identity of the person with dementia and/or the social worker. Including references to roles, past and present.</p>
Vulnerability	<p>Content which described the person as vulnerable or referred to details to evidence vulnerabilities.</p>
Power	<p>Content which highlighted issues of power and inequalities within a person's situation or as a result of social work intervention.</p>
Stigma	<p>Content which referred to stigma or that highlighted examples of stigma.</p> <p>Details within the accounts where the</p>

	social worker revealed the ways in which events could be stigmatising.
Recovery	References to recovery and recovery – focussed interventions
Strengths	Content which highlighted or described the strengths of the person or within the person's network.
Practice interventions	Reference to social work practice interventions.
Relationships	Descriptions of relationships or discussions on the nature of relationships.
Reflection	Use of reflection within accounts or discussions about the use of reflection within practice

Themes	Inclusion Criteria
Assessment	A focus on references to the process of assessment. The use of assessment in arriving at decisions.
Dependent independence	Use of the word independence within the context of account content about decline or dependence on others.
Re-framing acceptance as adjustment	Content which described the person as adjusting to a situation, where the solutions was provided by another party, including the social worker.

Organisational identity vs individual identity	Conflicting elements within accounts where organisational identity and individual identity appeared to create tensions for the person involved.
Theory	References to theory.
Seeing the person within situation	Account content which located the person within situation, referring to their life, the context of any issues experienced within their life story.
People with dementia Vs person with dementia	Account content which featured both generalisations about people with dementia and specific information about the unique person with dementia. Challenges to generalisations about dementia.

