# DEMENTIA: What comes to mind?
# An exploration into how the general public understands and responds to dementia

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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, Patricia Mc Parland.

Patricia Mc Parland.

*For my mother, Nan Mc Parland,*
*whose journey with dementia was the inspiration*
*for this work.*

# Acknowledgements

This thesis has brought me on a long and challenging journey with many delights and difficulties along the way.  I don't know that I would ever have found myself in the field of dementia if my mother had not developed Alzheimer's disease, so while I find it difficult to be grateful to the condition I am grateful that in some way I have been able to use my experience positively.

To Frances Mc Mahon for planting the seed and to Dr. Ann O Hanlon for convincing me a PhD was possible, thank you.

I want to acknowledge the support of my family for although a PhD can be an isolating process, it does not happen in isolation.  I am grateful for the times when my family stepped in to ease the pressure of working on this thesis and continuing to care for my mum.  For the countless other ways they offered love, support and encouragement all the way through this process, I want to say thank you.

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# Abstract

This thesis explores how the general public understands and responds to dementia. In the context of this study the word 'understanding' is used to convey the complex co-construction of knowledge and establishing of beliefs that constitutes public understandings of dementia. The study also examines the responses of members of the public to dementia, in the context of their understanding.

Data were collected over a 12 month period and included a module in the Northern Ireland Life and Times (NILT) survey, five focus groups and nine interviews with participants from the focus groups. The survey module included thirty measures examining levels of knowledge and attitudes towards dementia. 1200 participants were targeted and the survey was administered by the Northern Ireland Research & Statistics Agency with a response rate of 58%. The focus groups and interviews provided the mechanism to gather a more nuanced picture, exploring the beliefs behind the attitudes and the self-reported responses of participants to people with dementia.

Findings indicate that the general public has a reasonable knowledge of the symptoms and pathway of dementia in line with a bio medical model. However the findings also indicate that the general public holds a mix of theoretical and empirical knowledge and that this is often contradictory. A complex mix of scientific or medical information, experience, anecdote and assumptions contribute to the discourse. This information is stored and conveyed in the form of stories and a consequence of this interplay is that individual experiences told in the form of stories are generalised to become building blocks in the construction of what the general public understands dementia to be.

The current construction of dementia among the general public is found to be both nihilistic and ageist with clear evidence that dementia is stigmatised. I will argue that that the relationship between dementia and ageing in the minds of the general public is a symbiotic one. Dementia has become a cultural metaphor for unsuccessful ageing marking entry to the fourth age.

The stigmatising response of the general public is the result of a complex interplay of multiple factors. I have expanded on previous ideas of multiple jeopardy and intersectionality, suggesting that the stigma associated with dementia is unique and driven as much by emotional responses as by the social location of the person with dementia. I have borrowed Brooker's (2003) term "Dementia-ism' to describe this stigma.

This thesis argues for a more complex and sophisticated approach to changing public attitudes and reducing stigma. Dementia-ism must be addressed with the same strength of purpose currently applied to sexism, racism and ageism.

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# Chapter 1: Introduction

On a worldwide scale, it is estimated there are currently 44.4 million people with dementia, with the number expected to be 135.5 million by 2050 (Alzheimer's Disease International, 2013). The Alzheimer's Society UK documents 800,000 people currently living with dementia in the UK with an anticipated rise to 1 million by 2021 (Alzheimer's Society UK, 2013). In the Republic of Ireland the number of people living with dementia is over 40,000, rising by approximately 4000 every year (Cahill, O Shea & Peirce, 2012) while in Northern Ireland approximately 19,000 people currently live with dementia with this number estimated to rise to 23,000 by 2017 and around 60,000 by 2051 (Department of Health, Social Services & Public Safety, 2011).

The World Health Organisation (2010) defines dementia 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. This syndrome occurs in Alzheimer disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain"(WHO, 2010).

If the reader were to search for definitions of dementia they would encounter a range of clinical definitions not dissimilar to the one above. While models of care

are now framed within a more social psychological model, the information available to the public on dementia or Alzheimer's disease continues to be framed within a biomedical model. Innes (2009:4) argues, "What such definitions hide is the knowledge generation process that underpins such statements, which is arguably partial, flawed and incomplete". This study aims to explore what the general public understands dementia to be and how they self-report their responses to people living with dementia. It will also consider the factors influencing these understandings and responses.

In this chapter I will describe the professional and personal journey that prompted me to begin this study and identify how I came to my particular set of research questions. While there is no doubt that my personal experience of caring for someone with dementia was the single most significant factor in initially considering this PhD, it has often been the most challenging part of this journey. I have struggled with the emotional aspects of carrying out the research while caring for my mum and later grieving for her when she died as I was writing up my thesis. I have struggled to balance my academic hunger and pleasure in the theoretical with the reality of sitting with someone who is dying with dementia. However, this has also been the factor that tethers my research in an applied sense, forcing me to constantly critique the stance I have taken and the potential for personal bias. I will return to this reflective approach in other parts of the work and in some detail in the methodology section but I will begin by giving the reader some personal and professional history.

I am the oldest child of four born into a small community in Northern Ireland at the height of "The Troubles". I joined the Northern Ireland Fire service at the age of 18

years and spent most of my adult life within this organisation, taking early retirement from the service in 2005. During this time I completed a M.Ed. in Counselling and Guidance. By this time my mother had experienced a series of traumas in her personal life and had struggled emotionally. She had been treated for depression on a number of occasions and since the late 1990s her behaviour had become increasingly unusual. She confided in me that she was worried about her memory. Eventually we attended a local memory clinic but they were unable to confirm what was going on. Everyone except my mum felt it was possibly a result of depression and extreme anxiety. My mother's situation became increasingly difficult for her and us, her family. No words can convey the confusion and fear we experienced as she gradually deteriorated. It was a long time before we received a diagnosis and the support we received both before and after was woefully inadequate. By the time the diagnosis came, as her primary carer, I felt a bizarre sense of relief that at least we now knew what we were dealing with. Now the medical world would help us to manage what was happening. I was exhausted by my role as carer and I longed for some order to be placed on our chaotic world. This relief of course fought for its place alongside grief, fear and sorrow. My mother's biggest fear had always been "losing her mind" and ending up in a home and I had also absorbed notions of the "living dead" and of "the empty shell". These ideas were implicit in the attitudes of the professionals we encountered, who offered no hope and described a process of deterioration, with the inevitable conclusion of total loss of function and death. For my mother the diagnosis was completely devastating. She wept for three days, then forgot that she had been given a diagnosis and when told once again, she grieved afresh. Eventually we stopped telling her. For a woman who had voiced a fear of losing her mind, she was now living her nightmare. I also became acutely aware of the

changing dynamics of everyday relations in my mother's life.  These included her attempts to hide or disguise what was happening and the responses of other family members, some of who denied what was happening and others who simply withdrew.  Friends and acquaintances grew increasingly uncomfortable as her dementia progressed.  Chance meetings in a social context were a complicated process of pretence by both parties.  When this interaction was interrupted with an obvious presentation of my mother's confusion, people either withdrew quickly or tried to ignore what had happened.  My mother entered a care home in 2004 and a few years after leaving the Brigade I went into private practice as a counsellor.  During this time I had received considerable support from the local outreach worker in the Alzheimer's Society and it was Frances who first suggested I begin to study in the field of dementia.  I took an undergraduate module in dementia care with the University of Stirling.  A few years later I began to consider the possibility of a PhD.  Initially I looked at a study examining older people's attitudes to counselling, but I consistently felt drawn to the topic of dementia and eventually submitted a proposal to Stirling that has resulted in this study.

Prior to my mum developing dementia I knew little or nothing about it, beyond the one-liners about forgetfulness and occasional visits to my grandfather, who spent the last few months of his life in a local mental institution as a result of dementia. Stories told by other carers lead me to believe this is not unusual.  For the greater part of my mum's life with dementia I relied heavily on the advice of clinicians, some of which was good and some of which disturbs me still. My mum's experience and mine were set in the context of this information, as it was all we had.

My interest in the topic of dementia clearly has a very personal basis. I am conscious of my sympathies and the potential for bias within the context of this research, and felt it was valid to provide the reader not only with an idea of the understanding and values with which I began the research, but also with some insight to a very personal journey. This research is then "consciously value-laden" (Bryman, 2008:25) and it is hoped that a reflective approach to this personal experience will inform rather than detract from the work. "Mine your experience, there is potential gold there" (Strauss, 1987:11).

My experience suggests that no one really wants to know a lot about dementia unless they work in the field or are affected by it. Yet the statistics indicate that most of us will be affected by it in one way or another. The man on the street, the member of the general public, is the person who will one day develop dementia, or care for someone with dementia, or work in the field. By the time this happens he/she will already have absorbed the cultural understanding of dementia that currently exists and thus his/her journey will be influenced by that particular construction of dementia. I passionately believe that the shift in understanding that needs to take place begins with the ordinary member of the public, and this forms the basis of the study. Before any work is done to change attitudes or understandings we must first know what they are.

**An Introduction to the Thesis**

For the purposes of this research the terms dementia and Alzheimer's disease are used interchangeably. This reflects that Alzheimer's disease is the most common and well known of over fifty types of dementia. The current construction of dementia as disease was established in the early part of the 20th century and I begin the study by considering how dementia is socially constructed. Scientific enquiry is evidenced as only one of the factors contributing to the bio medical classification of dementia with the influence of social and political interaction also evidenced. The scientific and particularly the medical world retain great power in our society, and the current understanding of dementia as a disease ensures the emphasis remains on the individual rather than on social or political factors (Parsons, 1951; Lyman, 1989; Innes, 2009). Other models for understanding dementia have developed; the social-psychological model (Kitwood, 1997; Sabat, 2008; Innes, 2009) is potentially the second most significant model for understanding dementia and places an emphasis on person-centred approaches, particularly in terms of the type of care provided for people with dementia. This approach shifted away from the bio medical model of a diseased brain and the person with dementia as patient, to a view of the person living with a condition – dementia. The emphasis shifted to psychological and social factors directly impacting on the experience of dementia and of caring for someone with dementia. There was also a new emphasis on the importance of interaction. Kitwood (1997) highlighted the potential others have to influence the lived experience of dementia, in either a negative (malignant social psychology) or positive (positive person work) way, according to how they interact with the person who has dementia. Innes (2009) suggests that the most significant contribution of social psychology

has been to place the person with dementia at the centre of both academic and practice endeavours. While there is no doubt that this approach is now an accepted and widely used model within academia and practice, it is not clear to what extent it has influenced the understanding of dementia among the general public.

A social gerontological model placed dementia within the broader study of ageing. There are advantages to this in recognising that factors affecting those who are ageing may also affect those with dementia. However, views of ageing populations as problematic and a burden (Bond, Coleman & Peace, 1993) may reinforce, and be reinforced by notions of dementia as problematic and a burden. The more recent shift to ideas of successful ageing may also impact on the perception of those living with dementia as ageing unsuccessfully. Thus ageism is also a factor in the experience of living with dementia.

While there is a considerable body of literature examining the attitudes of professionals and carers to dementia (Astrom, 1986: Graham, Ballard & Sham, 1997; Cahill, Clarke, O'Connell, Lawlor, Coen & Walsh, 2008; Ayalon, Arean, Bornfield & Beard, 2009), current research into how the general public understands dementia is limited, and where it does exist has focused on knowledge of symptoms and awareness in terms of help seeking behaviour. Until this point a comprehensive study examining knowledge, beliefs, attitudes, and responses has not been carried out. Existing research suggests there is a lack of specific knowledge among the general public (Anderson, Day, Beard, Reed & Wu, 2009) with many people still believing dementia to be a normal part of ageing. While the research documents the existence of stigma, there is some suggestion that people with dementia are viewed in a more positive light than those living with other types of 'mental illness' (Werner & Davidson, 2004). The existing

research identifies the need for more exploration into stigma and the impact of age, referring both to the age of participants, and the age of people with dementia being portrayed in research (Werner, 2005). This study aims to address these gaps.

A focus on improving knowledge and awareness is evidenced in recent policy initiatives. Dementia strategies in Northern Ireland (DHSSPS, 2011), England (Department of Health, 2009) and Scotland (Scottish Government, 2010) specifically address this with the explicit aim of improving early diagnosis rates and reducing stigma. Other studies have challenged the assumption that improving knowledge and awareness will reduce stigma (Crisp, Gelder, Rix, Meltzer & Rowlands, 2000) and this study will consider attitudes in the context of knowledge and awareness.

The overarching question asked by this study is how the general public understands and responds to dementia. In the context of this study, the word 'understanding' is used to convey the complex co-construction of knowledge and establishing of beliefs that constitutes public understandings of dementia. It is not used to imply an in-depth comprehension of this condition.

Taking all of the above into account the research questions I developed are:

1. What does the general public understand (know and believe) about dementia?

2. What factors have contributed to this understanding?

3. How does the general public self-report its responses or potential responses to dementia and people with dementia?

4. What factors impact on the general public's self-reported responses to dementia?

**Thesis Structure**

The thesis is structured as follows. This introduction, including details of the thesis structure, forms Chapter 1. The literature review is contained in Chapter 2. It begins by examining the social construction of dementia, including the establishment of Alzheimer's as a disease, and the later merging of Alzheimer's disease and senile dementia resulting in the arguably dominant bio medical model of Alzheimer's disease. This chapter also includes a review of other models currently used to understand dementia, and of the significance of age and stigma in how dementia is currently understood. Existing literature examining attitudes to dementia is reviewed, and the chapter concludes with a look at the development and impact of current policy relating to dementia, as policy can be seen to reflect and inform the attitudes of the general public. Chapter 3 details the research design of this study. I take a reflective view on my personal motivations and choices, consider the theoretical rationale for my research design, comment on ethical considerations, and detail the methods employed. The findings of this study are reported in Chapters 4 and 5. In Chapter 4, I examine what participants report to know and believe about dementia, and the factors contributing to this. This chapter describes the stories told about dementia and what the general public know about the symptoms and progression of dementia. This chapter also examines evidence of paternalism, perceptions of care and care environments, and evidence of an absence of hope in the way the public understands dementia, with an associated lack of social regard evidenced for people with dementia.

Having considered what the general public knows and believes about dementia, Chapter 5 examines how this impacts on the self-reported responses of the general public to people living with dementia. Specifically this chapter considers the stigmatising response of the public including evidence of ageism, and a desire for social and psychological distance most particularly evident in a view of the person with dementia as 'other'. In Chapter 6, I discuss the implications of what I have found, contextualising it within already existing literature. I highlight any relationship with existing theory and research, and where this study adds to both. I set out three key findings. The first is, that what the general public knows and believes about dementia is a complex mix of the theoretical and the empirical, and is often contradictory. This understanding is gathered and passed on using stories, so that in effect, stories are the building blocks with which the general public constructs its knowledge and understanding of dementia. The second finding relates to the ongoing link between dementia and old age in the minds of the public, and I argue that dementia has become a cultural metaphor for unsuccessful ageing and marks entry to the fourth age. The third confirms that dementia is a stigmatised condition in the minds of the general public, and the public's response continues to stigmatise people with dementia. I conclude by making the argument that the stigma attached to dementia is unique; a complex interplay of the factors explored in this study, and I borrow a term used by Brooker (2003) to describe this response; 'Dementia-ism'. Chapter 6 concludes by considering the limitations and strengths of this study and its implications for policy makers, practitioners, campaigning organisations, and academia. I also make some suggestions for future research.

# Chapter 2: Constructions of Dementia

**A Bio Medical Model**

This chapter begins with an exploration of the establishment of Alzheimer's disease in the form that we understand it today. Alois Alzheimer made the first diagnosis of Alzheimer's disease in 1907. It concerned a 51 year old woman, admitted to the asylum where Alzheimer worked. A biopsy of the patient's brain had confirmed the presence of plaques and fibrils, and it is to this that the condition was attributed. Emil Kraeplin, one of the most influential figures at the time, incorporated Alzheimer's study into his 1910 psychiatric textbook and it was Kraeplin who attached Alzheimer's name to the condition. No account was taken of psychological or social factors, but rather emphasis was given to the patient's behaviour being linked to cellular processes in the brain (Cheston & Bender, 1999). It is important to consider the work of Alzheimer in the political and social context of its time. The German Psychiatric clinic in Prague, run by Arnold Pick of Pick's disease fame, was also looking into similar cases at this time and the establishment of Alzheimer's disease gave Kraepelin's laboratory increased credibility and access to research support. An additional competitive factor was the rise of psychoanalytic thought. Freud and Jung, whose theories lay in direct opposition to Kraepelin's organic psychiatry, were receiving considerable funding. "Kraepelin's push to classify Alzheimer's disease as an organic disorder can be seen in this context as a strategic attempt to gain a foothold in elderly psychosis, a territory that Kraepelin didn't want to lose. His pride, his professional reputation, not to mention his legacy as an academic were at stake" (Whitehouse, 2008:89).

Alzheimer himself later wrote, "There is then, no tenable reason to consider these cases as caused by a specific disease process. They are senile psychoses, atypical forms of senile dementia. Nevertheless, they do assume a certain separate position so that one has to know of their existence" (1911: 376-378) cited in Moller and Graeber (1998). In the same article Alzheimer referred to Kraepelin's uncertainty about these cases. So the picture far from being one of clinical certainty appears to be one influenced by human intrigue and ambition.

For many years scientific fact and exploration were seen to exist outside of the social construction of knowledge. There was a sense of the sacrosanct when it came to medical knowledge. This view has changed to one where scientific facts and medical knowledge are themselves viewed as problematic, and worthy of examination (Bury, 1986). Bury views medical science as something that takes place in the context of social relations, and he argues that "to call an area of experience 'medical' is to place it in a significant relationship to other areas of social life, giving it a definite and powerful shape and meaning" (1986:142). He explores the discovery of disease as something that is not, in fact, the discovery of a natural phenomenon, but rather a social event taking place in the context of conflict and/or agreement in scientific communities. More recently Knorr-Cetina (2005) placed scientific exploration firmly within knowledge that is socially constructed, arguing that scientific discovery takes place in the context of social interaction. Decisions therefore may not be the sole responsibility of an individual, but rather take place in the context of the group they belong to, and involve interaction and negotiation. This is further negotiated in the form of the written word where the scientist's discovery is open to the argument or support of others. "It is within their social location that scientific facts can be seen as selectively

constructed and reconstructed" (Knorr-Cetina, 2005:189). Harré (1990) describes a social world of scientists built on trust and belief. New papers reference those already established and believed in the field, therefore trusted. Others then accept this new work, based on the fact that it is grounded in knowledge already established, trusted and believed. Harré suggests the scientific community is so successful "it represents the most perfect and generally sustained moral order ever created by mankind" (Harré, 1990:98).

**Alzheimer's Disease – Born Again**

Between the period of the First World War and the 1970s little attention was given to dementia, but it is important to note that a clear demarcation continued to exist between senile dementia attributed only to older adults, and Alzheimer's disease, attributed to younger adults. Whether or not Alzheimer's was an actual disease was no longer a debate but it did refer only to the symptoms occurring in younger people, pre-senile dementia (Fox, 1989; Lyman, 1989). Fox (1989) describes the combination of scientific, political and public will leading to the establishment of Alzheimer's and senile dementia as a categorical disease. The work of researchers Katzman and Terry, alongside the establishment of the National Institute of Ageing saw the profile of Alzheimer's disease rise in the United States. Katzman and Terry argued for a shared identity between Alzheimer's disease and senile dementia (Ballenger, 2006). It was the eventual removal of the demarcation between the two that created a single compelling focus, and proved to be the catalyst to achieve research funding. Alzheimer's disease had been transformed from a rare pre-senile dementia to the fourth or fifth leading cause of death in the United States (Fox, 1989).

The reframing of Alzheimer's disease allowed for the repositioning of senile dementia. Old age was now a medical issue. "Bio-medicine refers to medical techniques and 'social actions' (Hindess, 1988) that privilege a biological and psychological understanding of the human condition and rely upon 'scientific assumptions' that position attitudes to ageing in society for their existence and practice" (Powell, 2005:31). Now it could be claimed that this disease was a major cause of death, enhancing the argument for funding to investigate cause and cure (Cheston & Bender, 1999; Fox, 1989; Harding & Palfry, 1997). In Lyman's critique of the biomedicalisation of dementia (1989) she highlights the lack of gerontological interest despite the growing profile of dementia. Acknowledging the usefulness of the biomedical model in attracting research and funding, and perhaps in offering caregivers a sense of order she also reminds us "In reality, the psycho-social experience of a dementing illness often cannot be contained within biomedical concepts of brain disease" (Lyman, 1989:600).

Other factors influencing the Alzheimerisation of dementia are the powerful pharmaceutical and insurance industries, particularly in America. Classification of Alzheimer's as a disease ensured that without diagnosis, there could be no insurance payments in relation to care. It also prompted the creation of a multi-million dollar pharmaceutical industry that continues to grow today (Bender, 2003; Whitehouse, 2008). These now depend on Alzheimer's existing as a disease. "The standard paradigm has pluralistic support from very powerful groups" (Bender, 2003:76).

Alzheimer's disease as the public knows it today was conceived of in the early 1900s and reformed in the 1970s. Harding and Palfry (1997) highlight that once an idea has been agreed upon, as in the case of the classification of Alzheimer's, scientists may, in fact, become deaf to alternative explanations. "This would suggest that once an idea has become dominant, its dominance is perpetuated by this process of selective deafness where those who disagree are robbed of the ability to be heard" (Harding & Palfry 1997:88). Bender cites Kuhn (1962) when he argues "once a paradigm change has gone through, and become accepted, it *rewrites its history*, so that the doubts and puzzles in the previous paradigm(s) are pointers to the inevitable success and correctness of the present one" (Bender, 2003:76).

This new 'certainty' in the understanding of dementia and Alzheimer's disease, supported by the growth of advocacy in the form of the Alzheimer's Association, had implications for the general public. Alzheimer's disease had a new and rising profile, and its new categorisation impacted on public attitudes and public policy (Holstein, 2000). Charles Sanders Peirce (1877) described two methods of fixing belief: tenacity and authority. The former is where an individual determines to hold on to a set of beliefs, as it is more comfortable to feel assured in a belief than to experience doubt. Peirce argues that an individual will attempt to remove or step away from any barriers to this belief, keeping any differing views as far as possible out of sight. However, he argues that this is in fact impossible "Unless we make ourselves hermit, we shall necessarily influence each other's opinions; so the problem becomes how to fix belief, not in the individual merely, but in the community" (1877:6). This is where the latter, and Peirce argues, the more powerful method comes into effect. An aristocracy or powerful group depends on

certain beliefs to maintain their existence and power.  Bender (2003) refers to this in the current framing of dementia within a bio medical model.   Peirce (1877) argues that members of such a group are unlikely to be swayed from their beliefs in the interests of others outside the group.  Peirce's arguments could be applied to the very development of Alzheimer's disease, but also have relevance in terms of public understandings.  The certainty of biomedicine supported by science offers apparently concrete explanations of a very chaotic and complex situation.  This is a tempting if illusory solution when people are unsure.  Further, the medical world remains the place we go to when we cannot explain the behaviour of another; it is where we look for answers.  Berger and Luckmann (1966) in their account of the role of knowledge in society refer to Scheler, an early 20th century philosopher, who described a "relative-natural world view". Such a view suggests that any individual experience is understood only within the human knowledge of a particular socio-historical situation.  It is this situation that gives meaning to the experience, while appearing to the individual as an entirely natural way of looking at, or understanding the world.  Berger and Luckmann, also cite Mannheim writing later that century, who expanded these ideas, suggesting that no human thought, (with the exception of mathematics and some of the natural sciences), is immune to the ideologising influences of its social context.  "Knowledge must always be knowledge from a certain position" (Berger & Luckmann, 1966:21).

There is no doubt that advancements in science and technology have allowed a more detailed picture of dementia and particularly Alzheimer's disease to emerge, but the cause, accurate progression or pathway, and cure remain elusive. Technology allows for examination of the brain and differences are visible, so there is clear evidence, for example, that this brain differs from one previously

documented as normal. However, what then occurs dictates how this difference is understood and classified. Brain scans and cognitive testing supported by social interaction between the person whose brain is being examined, close others e.g. family and professionals, will prompt a classification of Alzheimer's disease or dementia of another type. All of this is interpreted within a social environment where there are already well-established understandings and interpretations of behaviour, based on a now highly publicised model of dementia generally, and Alzheimer's disease in particular. Horwitz (1999) argues that both lay and professionals interpret symptoms and this interpretation is culturally specific. Alzheimer's as a disease of the brain fits well within the Western world's Cartesian philosophy of medicine (Harding & Palfry, 1997), where the mind and the body are seen to be separate from each other with the body viewed as a machine. From a functionalist perspective (Parsons, 1951) the emphasis is on maintaining social order and illness is viewed as deviance, potentially disrupting the social order. The person with a diseased brain, labelled as a patient has responsibilities. Parson described the rights of a sick person as being allowed to give up their normal activities, and as not being accountable for their illness. However, the sick person also has responsibilities, to get well as quickly as possible, and to seek and co-operate with appropriate medical care. People living with dementia sit uncomfortably within this framework; there is no definitive pathway for this condition and no cure.

Dementia and particularly Alzheimer's disease is now viewed "as the most publicised health problem in old age" (Robertson, 1990:430), the disease of the century (Gubrium, 1986). Much of the literature, to be discussed later in this chapter, argues that the dominant biomedical model has failed to adequately

explain dementia, and that ageing and dementia have been incorporated into a "biomedical belief system" based on a Cartesian philosophy. Agbayani-Siewert, Takeuchi and Pangan (1999) suggest "biological explanations of mental illness have found acceptance in the general public's attitudes and beliefs through popular media and literature, along with the popular use of some medications (e.g. Prozac) that have become common household words" (1999:22). Thus the public is accustomed to bio medical explanations of a variety of conditions and this includes dementia.   The medicalisation of dementia, delivered by the experts, medical professionals (Gubrium 1986, Breitner 2006), and marketed accordingly by the media (Johnstone, 2013) is thus accepted by the public.  In a detailed exploration of the construction of Alzheimer's as disease, or as an aspect of ageing, Gubrium argues, "What is concluded is that it cannot yet be determined one way or the other for sure" (1986:65).

The complexity of dementia ensures that there is much still to be answered within the bio medical model and much that is not accounted for therein.  Dementia and Alzheimer's disease are contextualised in a cultural time and space, and as such can be described in terms of social construction and interaction.  In Hacking's consideration of whether madness is biological or constructed he suggests "in the special context of mental illness[1] we have, for the past two centuries been constantly renegotiating our notion of reality." (Hacking, 1999:101).  This section

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[1] Much of the literature examines dementia in the context of or in relation to other conditions defined as 'mental conditions'.  Terms such as 'mental illness' or 'mentally ill' are used often during this review but they are the words used in other literature and do not reflect the views of this author.

has documented the construction of Alzheimer's disease and dementia, and their ongoing renegotiation. The next sections of this chapter will explore a series of other explanatory models of dementia.

**A Social Psychology Model**

It has been argued that the most significant contribution of social psychology to the field of dementia has been to place the person with dementia at the centre of both academic and practice endeavours (Innes, 2009). Drawing on the person-centred ideas of Carl Rogers (1967), Kitwood defined personhood as "a standing or status that is bestowed upon one human being, by others in the context of relationship and social being" (1997:8). Emphasising the priority of experience, Kitwood drew heavily on the work of Martin Buber, who described living in relationship in terms of I-It or I-Thou. Relating in terms of I-It allows for distance, coolness, and avoids risk in relationship. Relating in terms of I-Thou is the path to true relationship and joy (Buber, 1937). Kitwood (1997) argued that it is essential to see personhood in these terms if we are to understand dementia. A meeting of the I-Thou type can occur regardless of the level of cognitive impairment. This acceptance of the reality of personhood in relationship was at the core of Kitwood's work, and does not sit easily within Western ideas of individualism; ideas which were particularly prevalent in Britain at the time of Kitwood's writing. Kitwood is perhaps best known for his conceptualisation of a malignant social psychology. "There seems to be something special about the dementing conditions – almost as if they attract to themselves a particular kind of inhumanity: a social psychology that is malignant in its effects, even when it proceeds from people who are kind and well intentioned" (1997:14). He included in this psychology,

exclusion, outpacing, ignoring and many others, suggesting that our fear is such that we must turn the person with dementia into almost another species to cope. This is in line with the Cartesian model of western medicine, which facilitates the objectification of the person and focuses on the diseased brain.

Kitwood (1997) never disputed that clinical deterioration of the brain in dementia occurred, but rather that it was not the only factor affecting the experience or behaviour of the person with dementia. He described a dialectical interplay between neurological impairment and a malignant social psychology. Kitwood's focus on the individual and the individual in relationship did not perhaps take account of the wider social constructs where Alzheimer's exists as a disease. He did not dispute the existence of the "disease", and to some extent could be considered to have reinforced its existence in his documentation of improvements and treatments, albeit these were more therapeutic than prescriptive. However, his ideas have come to provide a core from which best practice is conceptualised.

Working at the same time as Kitwood but at the other side of the world Sabat and Harré (1992) explored the concept of self within dementia using a constructionist framework. Sabat (2001) describes three manifestations of self. Self 1 relates to the self of personal identity, a person's experience of themselves across time and space, and the self from which we take action. Self 2 is related to our attributes and beliefs, both mental and physical, and Self 3 involves the many personae we present to the world. As individuals we present many different aspects of ourselves, often dependant on who we are relating to, and the context within which the interaction takes place. One of the most crucial factors in relation to Self 3 is that the maintenance of any one of the "selves" we present is, to some extent,

dependant on the co-operation of the other person(s) involved in the interaction. It is difficult, if not impossible to maintain a particular presentation of self without the acceptance of this presentation by other people (Sabat & Harré, 1992; Sabat, 2001). The social positioning of a person with dementia affects how they are related to, which in turn affects their personhood, behaviour, and interactions with others (Sabat, 2001). Goffman (1972) explored social interaction in the context of game participation. He argued that within any interaction there are inhibitory and facilitatory rules that guide what can and cannot be part of the interaction. He described how inappropriate behaviour is viewed as a symptom, first coming to our attention because it breaks the rule of affective restraint in a social encounter. Innes (2002) argues that when we categorise someone as 'demented', it offers society an opportunity to place order on a confusing and difficult to understand situation. In this process the person is labelled "as different and potentially deviant in some way" (Innes, 2002:484). In her 1989 paper critiquing the biomedicalisation of dementia, Lyman reminds us that while dementia is conceptualised in terms of pathology and individual deviance "the impact of power relationships in illness production and disease is not examined" (1989: 602).

The acceptance of dementia as a disease of the brain can result in a process of "diagnostic overshadowing" where all behaviour and action is interpreted in the context of the diagnosis (Hughes, Louw & Sabat, 2006). Sabat, Napolitano and Fath (2004) describe the social interactions between a woman with mild-moderate Alzheimer's and significant others in her life. The authors recorded observations of malignant positioning and malignant social psychology, i.e. where family or others in close relationships with the person with dementia can assume a position in interactions based on the diagnosis of dementia, and its associated

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stigmatisation, rather than on the content of the interaction. This is echoed by Sorensen, Waldorff and Waldemar (2008) who, using a series of interviews, explored how people with recent diagnoses of probable Alzheimer's coped with changes in their lives including social relations. The authors concluded that the primary social-psychological problem faced by participants was the awareness of a decline in personal dignity and value. Participants' perceptions were that spouses and relatives responded to them in less meaningful and more critical ways.

"Once persons are positioned socially as nothing more than instantiations of a diagnostic category, their essential humanity, including their intellectual and emotional characteristics, needs and their social personae beyond that of 'demented, burdensome patient' become more and more invisible and ultimately can be erased" (Sabat, 2008:76).

Sabat's recent work (2008, 2012) has explored a bio-psycho-social approach to dementia, arguing that four factors must be taken into account:

1. Brain damage.

2. The person's reaction to the effects of brain damage.

3. The ways the person is treated by healthy others.

4. The reactions of the diagnosed person to the ways others treat him or her.

This approach echoes Kitwood's work where he described a dialectical interplay between "factors that pertain to neuropathology *per se*, and those which are social-psychological" (1997:50).

More recently there have been moves to "broaden the lens" (Bartlett & O'Connor, 2007) for dementia practice and research. Acknowledging the significant benefits in conceptualising dementia in terms of personhood, the authors highlight some limitations. Personhood places emphasis on individual experience and little attention is given to "the impact of social structures related to disability, age, gender, ethnicity and social class on people's experiences of long term care" (Bartlett & O'Connor, 2007:110). The authors also suggest personhood places emphasis on the need for others to value the person with dementia, and this puts the person with dementia in a place of dependency on others to maintain personhood, failing to recognise the person as a social actor with social agency in their own right. Thirdly they argue a personhood lens does not have the language to explore dementia in terms of power relations, potentially overlooking the socio political. The authors explore the benefits of a citizenship lens, specifically the model of citizenship more recently reconceptualised in the literature as something that takes place in practice "through the power dynamics of everyday talk and practice" (2007:112), rather than something that is exclusively rights based and bestowed by others. Bartlett and O'Connor do not make the case to replace the personhood lens with a citizenship one, but rather that the "the lenses of personhood and citizenship need to combine and recognise sociological ideas about agency and structure to create a broader lens for dementia practice and research." (Bartlett & O'Connor, 2007:115). Such a lens results in people living with dementia being "seen simultaneously as both actors constructing their own reality and constructed by prevailing discourses" (Bartlett & O' Connor, 2007:114).

The literature described from a social psychological perspective recognises the importance of interactions with others, and the changing nature of those

interactions where there is a diagnosis of dementia.  More recent developments suggest the benefits of a broader lens that allows consideration of not just individual experience but socio political factors and ideas of agency and power. Both are significant in terms of the aims of this research.  If interactions can influence the experience of dementia, then it is important that the understanding, beliefs and responses of an individual in terms of dementia are explored. However, these beliefs and responses are framed within a broader socio political environment and are influenced by power relations. Thus consideration of individual beliefs about dementia must take account of cultural and social constructions of dementia, including the power relations impacting on such constructions.

It could be argued that cultural understandings and attitudes towards ageing have changed considerably over the last century.  Dementia, as a condition that continues to primarily affect older people is, of necessity, affected by such understandings.  The next section will consider how dementia is framed within a social gerontological model.

**A Social Gerontology Model**

Social gerontology is the study of social dimensions of ageing.  An increasing population of older people has focused the attention of policy makers and researchers alike, so that a wealth of literature now exists on human ageing. However, such attention may have contributed to the view of ageing as a problem, with the dramatic language (burden, rising tide, epidemic) now used in the field of dementia first evidenced in the wider field of social gerontology (Bond, Coleman &

Peace, 1993). There are broader constructs and issues associated with the process of ageing that should be considered when examining dementia and its place in society.

We live in a world where increased longevity has seen dramatic increases in the older population.  This is particularly evident in Western countries and exists within a landscape of constant political and cultural change.  The last century has seen dramatic change in health, types of work, lifestyle, and family structures (Bond, Coleman & Peace, 1993).  The roles and rights of women continue to change with the fact that women are living longer than men having particular significance in terms of dementia; a greater number of women live alone and potentially find themselves in institutional care.

Populations are increasingly migratory and societies continue to grow more affluent.  Peace, Dittmann-Kohli, Westerhof and Bond (2007) highlight some of the issues raised within this landscape, specifically feminism, diversity, and ageism. Victor (1987) reminds us that although often treated as such, ageing is not a homogenous experience.  The diversity of the population requires the recognition of different ethnic, gender, and socio-economic experiences of ageing.  More recently Hulko (2009a) has explored these experiences, in terms of dementia, arguing for an intersectional perspective that takes account of both privilege and oppression to contextualise the experience of dementia.

De Beauvoir's (1977) exploration of old age remains relevant today where she argues that class continues to define the experience of old age. She argues the experience of the wealthy old and the impoverished old are profoundly different,

and that society continues to disregard the majority of older people relegating them to the group of impoverished. She refers to the concept of the old as non-productive and a burden to society. Victor (1987) explored the cultural values influencing the experience of ageing in Britain. These values include independence, and thus the dependant are criticised and regarded with disdain by many. Angus and Reeve (2006) echo this view of value linked to productivity in their review of ageism in the 21st Century. They refer to the different attitudes towards dependency of the young, where the young are seen as future contributors to society, and towards the old, also dependant, but no longer productive in the capitalist sense. Biggs (1993) suggested that the notion sometimes put forth of a healthier ageing population is somewhat optimistic, and that "The major challenge to public health in industrialised societies is how to cope with the problems associated with a high proportion (15 to 25 percent) of people over 65 in the population" (1993:54). While this is an older reference, the notion of the public health burden associated with an ageing population continues to be raised in policy today (DH, 2009; DHSSPS, 2011).

Until the middle part of the twentieth century, dementia was viewed almost exclusively as part of the ageing process, and the ageing process was viewed almost exclusively from a negative point of view. Holstein (2000) cites William Osler (1905), often referred to as the father of modern medicine at the beginning of the 20th century, describing men over the age of 40 as comparatively useless, and those over the age of 60 as absolutely useless. She also refers to the assertion of the neurologist William Krausse that "senility, decline and decay were synonymous to the medical mind" (2000:161). The decline of the mind and body were seen as part of the continuum of ageing, and the view of dementia as part of a

normal ageing process could be seen to have contributed to the negative view of ageing. During the 1940s and 1950s the dominant social theory was structural functionalism, supporting the biomedical approach to ageing, and the view of ageing as a social and medical problem (Phillipson & Baars, 2007). From the 1950s onwards the idea that old age involved inevitable decline was challenged. Researchers began to consider the impact of social and economic factors on ageing with the recognition of ageism as a social problem. Considerable research at this time focused on the link between activity and life satisfaction, although Cumming and Henry (1961) argued that old age was a time of mutual disengagement by individual and society, and that this disengagement facilitated an individual's continued high morale. Thus the loss of role associated with retirement was seen as a natural consequence of growing older and of preparing for the final disengagement from society. This theory influenced policy considerably. "It provided a scientific rationale for the new twentieth century practice of retirement from the labour force" (Coleman, 1993:85). While Coleman (1993) accepts that the theory was a response to the view of ageing as a deteriorative process, he argues that disengagement theory was "peculiarly dangerous" (1993:85) as it risked being a self fulfilling prophecy, where society expected and received little from its older population.

The 1970s and 1980s saw a move away from the view of old age and older people as a social problem. Economic factors contributed to an increase in early retirement, but now there was an emphasis on remaining active during retirement. The re-establishment during this time, of Alzheimer's as a disease, but now incorporating senile dementia was important from a social point of view, impacting as already described on public attitudes and policy (Holstein, 2000).

Biggs (2007) points out that older adults previously viewed as a minority may soon outnumber younger adults, and that this phenomenon influences the field of gerontology itself.  He discusses the positive and negative outcomes of an ageing population living longer and healthier.  The positive impact may be the breaking down of age differences, but on the other hand differing age groups may need to compete for the same things. There is also a growing emphasis on the association between ageing well and continuing to be productive in society.  The move today towards older adults remaining youthful in outlook and engagement is a powerful enticement, but also sets new expectations.   Holstein and Minkler (2003) discuss the "new gerontology" where the old paradigm of loss and decline has been replaced with one that emphasises the potential for a healthy and engaged old age. No one could argue that this is not a positive move, but as the authors point out there is a danger of simply replacing one type of ageism with another.   The suggestion that a person has control of, and responsibility for their own health and well-being potentially ignores the social factors that contribute to this process.  It also ignores the implications for a person with dementia in that the old paradigm referred to above, of loss and decline, continue to be associated with dementia. The return to a more individualistic conception of old age, and a sense of moral responsibility for our own well-being, places a person with dementia in a particularly vulnerable position.

Walker points out that "Rather than being old age itself, it is various social policies which have combined to create, enhance or maintain economic dependency and poverty in old age" (1993:296). The policy discourse on dementia continues to emphasise the financial burden associated with the increasing number of people

living with dementia, and the influence of policy on the discourse around dementia is discussed later in this chapter.

**Ageing and Dementia**

The statistics below (Table 1) evidence the increased prevalence of dementia in older people with the risk increasing as a person ages.

**Table 1: Prevalence of dementia by age group in the U.K. (Knapp, Prince, Albanese, Banerjee, Dhanasiri, Fernandez & Stewart, 2007)**

| Age Range | Prevalence of dementia % |
|---|---|
| 30-34yrs | 0.0094% |
| 35-39yrs | 0.077% |
| 40-44yrs | 0.014% |
| 45-49yrs | 0.0304% |
| 50-54yrs | 0.583% |
| 55-59yrs | 0.1368% |
| 60-64yrs | 0.1557% |
| 65-69yrs | 1.3% |
| 70-74yrs | 2.9% |
| 75-79yrs | 5.9% |
| 80-84yrs | 12.2% |
| 85-89yrs | 20.3% |
| 90-94yrs | 28.6% |
| 95yrs+ | 32.5% |

While taking account of the number of younger people with dementia, the figures above indicate it is likely that the picture of dementia in the minds of most of the

general public will be associated with an older person. De Beauvoir (1977) suggests that status in old age, as in every other stage of life, is imposed on an individual by the society to which he or she belongs. Furthermore individuals are also conditioned by that society's attitudes and responses so that "An analytical description of the various aspects of old age is therefore not enough: each reacts upon all the others and is at the same time affected by them, and it is in the undefined flow of this circular process that old age must be understood" (De Beauvoir 1977:16). Harding and Palfry suggest ageing people are 'socially isolated, as if they have a disease, and indeed they are, in the age of the perfect body, diseased. Old age itself therefore becomes a disease, one which is incurable" (1999:138).

In society today much is made of the idea of successful ageing (Gingold, 1992), linked to ideas of productivity, good health, youthful outlook and appearance. Moves to counteract the negative images of older people in our society have taken the form of aspiring to an eternal youthfulness. The contesting images are of older people maintaining the vigour of youth, with the idea of successful ageing appearing to be linked to remaining youthful, a somewhat contradictory notion. Katz and Peters suggest that "youth oriented, age defying enterprises are guiding our imagination about the future" (2008:348). Featherstone and Hepworth explore the impact of the images of older people in society. They describe images as "a particular type of symbolic medium which we use in interpersonal communication" (1993:251). The authors argue that these images, both verbal and non-verbal, are only available to our understanding within a certain socially constructed range of symbolic language. We may not be aware that our

interpretation of these often, stereotypical images, is restricted and culturally bound.

In a study of personal autonomy as a measure of successful ageing Ford, Haug, Stange, Gaines, Noelker and Jones (2000) refer to numerous different definitions of successful ageing. Common to all of them is the theme of independence. Dependency is viewed as an indicator of unsuccessful ageing. The authors go so far as to include dependency with disability, morbidity, and mortality as negative outcomes (2000:471). Gilleard and Higgs (2010) discuss the "fourth age" of life where the possibility for agency, autonomy and expression now accepted within the third age has disappeared. They suggest that a person moves into the fourth age when they are no longer able to get by in the everyday world "when they become third persons in others' age-based discourse, within others' rules" (2010:122). This age is also inextricably linked to nursing home care, and the authors suggest that nursing homes have become as terrifying as the workhouses or institutions once were, marking the point of entry into this 'fourth age'. Twigg suggests it is "onset of serious infirmity" (2004:64) that marks the point of entry. Gilleard and Higgs make the case that "the fourth age functions as a social imaginary because it represents not so much a particular cohort or state of life but as a kind of terminal destination – a location stripped of the social and cultural capital that is most valued and which allows for the articulation of choice, autonomy, self-expressions and pleasure later in life" (Gilleard & Higgs, 2010:123). In describing how people in the third age respond to this, they talk of "shadows in the mirror that those enjoying the third age half see and half turn away from" (2010:127).

**Ageism**

Ageism was initially defined by Robert Butler as reflecting "a deep seated uneasiness on the part of the young and middle aged- a personal revulsion to and distaste for growing old, disease, disability; and fear of powerlessness, "uselessness" and death" (Butler, 1969:243). Palmore describes ageism as "a social disease much like racism and sexism" (2005:90), but argues that ageism is unique in the sense that other types of prejudice against different groups, for example based on gender, religion or colour are limited to those particular groups in society. Ageism is a prejudice, which, while it exists will affect all of us who survive into old age.

Age as a discriminatory factor has been explored using the notion of jeopardy. The idea of double jeopardy originated in America in the 1960s, when the National Urban League used the term, to describe discrimination based on age and race (Moodley, 2003). The term has since been used to describe other discrimination, such as a consideration of "social, economic and psychological conditions surrounding age and gender" (Rodehaver & Datan, 1998:648). The notion of double jeopardy has also been used to describe discrimination based on age and having a condition such as dementia, and the concept of jeopardy has more recently developed to take account of triple, quadruple, or multiple discriminatory factors such as cognitive decline, ethnicity, gender, and social class (Bowes & Wilkinson, 2003).

Bytheway and Johnson (1990) suggest that biological models of ageing, with the visible changes in the body interpreted as decline, have affected the development of social gerontology and dominated the study of ageing. This echoes the literature

earlier documenting the bio medical model of dementia. They argue that it is in this biological model that ageism is rooted. As with other "isms" this difference allows people to be perceived as other. Hendricks and Hendricks (1977) argue that this view of older people as 'other' occurs when it is believed they do not have the same desires or fears as 'us'. They are thus different to 'us' both in this moment and in our view of our future selves. Jonson (2013) supports this argument suggesting that successful ageing means avoiding "old age as it has been so far" (2013:6). He describes the argument being made today that the new old are not the same as the old of previous generations, as an argument that is, in fact, historically continuous. Jonson suggests that a "temporal construction of old age and older people makes it possible for non-old people to see older people as different from themselves" (Jonson 2013:6).

Angus and Reeve (2006) point out that although we now have a much larger population of older people, this has not significantly impacted on ageism. Rather it is "widespread, generally accepted and largely ignored" (2006:138). The authors explore ageism within the concept of commonsense reality arguing that stereotypes of ageing are an intrinsic part of our cultural practices. "They permeate organisations, inform policy, act as social determinants of health and have the power to shift attention from individual experiences and social conditions" (2006:140). Commonsense reality is defined by the fact that it is constructed from a set of beliefs, which are unquestioned (Angus & Reeve, 2006). Most of those who behave out of this reality are unaware of what it is that informs this reality. It simply 'is'. In relation to ageism, this is not only relevant for younger people's perceptions of older people, but also for how older people interpret and respond to their own ageing.

McHugh (2003) examines ageist scripts embedded in the promotion of successful ageing and argues that "embedded in the ideal of successful ageing is a deep-seated fear of our decline and erasure, projected outward in the form of disdain and disgust for 'old' people who do not 'measure up' and who tumble down the spiral of 'bad' old age" (McHugh, 2003: 180). Brooker (2003) has suggested there is a very particular type of ageism experienced by older people living with dementia. She suggests this double jeopardy of age and cognitive decline should be called 'dementia-ism'.

Greenburg, Schimel and Martens (2002) explore the impact of terror management theory on ageism, and highlight how older people represent the "threat to the young of their own fate: the prospects of diminishing beauty, health, sensation and ultimately death" (2002:29). This is a complex theory but its basic tenets are worthy of mention here. If as the authors argue, the old and dying provoke within us a most primal fear – that of our own demise if we survive into old age, then it is perhaps understandable why people might seek to remove themselves from this stimulus. Martens, Greenberg, Schimel and Landau suggest that older people are "a living symbol of time running out, of faculties fading, of potentially frightening biological facts" (2004:1534). It could be argued that dementia represents the most terrifying prospect of a road to inevitable death, defined by a process of decline and loss. This sense of terror and fear is fuelled by the language used in the literature, media, and policy about dementia with the continued emphasis on burden (Brookmeyer, Johnson, Zeigler-Graham & Arrighi, 2007), cost (DH, 2009; Wimo & Prince, 2010; DHSSPS, 2011 and epidemic (Wilson & Fearnley, 2007). Whitehouse suggests that the very word Alzheimer's can trigger certain neural circuits in our brains accessing inner meanings "loaded with powerful emotions"

(2008: 33). He argues "while every human malady has a biological basis, it is also socially constructed and the latter dimension helps us interpret and behave towards the biological condition" (2008:37). Holstein (2000) argues that terror is created culturally and that the terror associated with a diagnosis of dementia is sourced in the current construction of dementia. She asks if this current construction of dementia as disease is helpful to those with dementia or their carers, pointing to other cultures where this construction is not so prevalent, and dementia is more likely to be "integrated into everyday life as just one of those things that happen to many older people" (2000:176).

**Stigma**

The World Health Organisation define stigma as "as a mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society" (WHO, 2001:16).

How we understand dementia and how a person experiences dementia is further complicated by the stigmatisation associated with mental illness (Goffman, 1972; Curtis & Taket, 1996), and the process of diagnostic overshadowing that takes place when a diagnosis or label has been attached to the person (Hughes, Louw & Sabat, 2006). Goffman suggests that stigma occurs when the anticipated attributes we have assigned to someone in any interaction are not fulfilled. The meeting instead of something outside the norm, of a person with an undesirable attribute, means that this person is "thus reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963:12). Link, Phelan, Bresnahan,

Stuve and Pescosolido (1999) agree that the symptoms of mental illness represent "undesirable personal attributes" (1999:1332), which people want to avoid. Goffman (1963) goes so far as to suggest that we view the person with a stigma as not quite human, an idea later explored by Kitwood (1997) who suggested that to reduce their own anxiety and fear, people "turn those who have dementia into another species, not persons in the full sense" (1997:14).

Since Goffman's original work, an increasing body of research within and across disciplines has contributed to knowledge about stigma. Link and Phelan (2001) suggest a conceptualisation of stigma as one that exists when a number of interrelated components converge. The components include:

1. Noting and labelling human differences.
2. Dominant cultural beliefs link labelled persons to undesirable characteristics (negative stereotypes).
3. Labelled persons are categorised to achieve separation of "us" from "them."
4. Labelled persons lose status and experience discrimination leading to unequal outcomes.

"Finally, stigmatisation is entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination" (Link & Phelan, 2001:367). Jorm and Oh (2009) comment on the multi faceted nature of stigma and the related difficulties in attempting to measure levels of stigma. In a review of literature examining social distance as a component of stigma, they list other

components previously measured in the literature; "personal stigma, stigma perceived in others, internalised self-stigma, perception of mental disorders as due to weakness, reluctance to disclose to others, perceived dangerousness, desire for social control, and goodwill" (2009:183). Link and Phelan (2001) further suggest there are three types of discrimination based on stigma: institutional or structural, individual, and self- discrimination. Structural discrimination can be seen in policy and structural practice, allocation of financial resources such as research funding, and in the interpretation and administration of the law. In a recent study examining government and charity funding for research into cancer, coronary heart disease, dementia, and stroke, Luengo-Fernandez, Leal and Gray (2012) found that research funding into dementia and stroke is "disproportionally small when compared to cancer and coronary heart disease" (Luengo-Fernandez et al., 2012:153). Notably both dementia and stroke impact on cognitive ability.

Deitrich, Beck, Bujantugs, Kenzine, Matschiner and Angermeyer (2004) suggest that individual experience of stigma is most usually in the form of social distance. This is supported by Werner and Davidson (2004) who argue that while studies have suggested that in the case of other 'mental illnesses' the process of stigma is linked primarily to a view of the person as dangerous, in the case of dementia, the feelings of rejection experienced by participants towards people with dementia "may be associated with the distancing, marginalization and discrimination that characterise stigma and its negative consequences" (Werner & Davidson 2004:395). In considering the impact of labelling and stigma on mental health, Link and Phelan (2001) suggest that long before a person becomes mentally ill, they will have internalised ideas and beliefs related to what people think of those who are mentally ill. In general these are negative. When a person becomes

mentally ill these beliefs now relate directly to how he/she may be regarded by others.  This translates into an expectation of rejection, which impacts on their ability to interact with others, and thereby increases the chances of rejection.  In terms of dementia this is closely linked to Sabat's (2001) work on presentation and maintenance of self, discussed earlier.  People living with dementia, or indeed, those who may live with dementia in the future are already very familiar with the negative discourse surrounding this 'disease.'

Research has suggested that people with dementia are not viewed as dangerous or as morally responsible for their condition, and thus are viewed more kindly and sympathetically than those with other types of mental illness (Werner & Davidson, 2004).  There is also a suggestion that the bio-medical classification of dementia as a disease of the brain may reduce stigma (Jorm & Griffiths, 2008).   In this way the person is not viewed as responsible, and the theory is that people will be less likely to seek social distance from this person. However, others have argued that the biological concept of mental illness prompts caution in others, who view people with mental illness as unpredictable, anti-social and dangerous (Read & Harré, 2001). In considering the effect of the disease model on stigma in mental illness, Mehta and Farina (1997) emphasise that this classification triggers fear in others in terms of their own vulnerability to the condition, and results in the situation described earlier where people turn those with the condition almost into another species.  In a survey across Germany, Russia, and Mongolia, Deitrich et al. investigated the nature of the relationship between public causal beliefs and social distance toward people with mental conditions.  While their study examined schizophrenia and depression it has relevance here.  They found a positive

relationship "between biological causal beliefs (i.e. 'brain disease' and 'heredity') and social distance toward people with schizophrenia and depression" (2004:353).

Whether dementia is viewed as the result of old age or as having a biological cause, the label of dementia situates those with the condition among the 'mentally ill'. As such they are subject to the processes used by society to manage mental illness, for example, diagnosis, care, and treatment are generally the responsibility of a psychiatrist, and assessment often takes place in institutions set up to care for those with mental health problems. Curtis and Taket (1996) argue that a diagnosis can be used to maintain particular power relations in society, while Sabat, Johnson, Swarbrick and Keady (2011) suggest that diagnosis and the status of patient limit a person's social identity. The next section will consider the impact of labelling in terms of stigma and the experience of dementia.

**Labelling**

Labelling is identified as "A social process by which individuals or groups classify the social behaviour of other individuals" (Bond, Corner & Graham 2004:229). They refer to dementia as a classic example of primary deviance. It has behavioural, organic and physical components, and those with legitimate authority, medical professionals, have supplied the label. Using a case study they highlight how the label of dementia affects the response of others around them, withdrawal of friends, carers taking control, and in some cases, those receiving the diagnosis taking on the behaviours often ascribed to the condition. Deviance in the form of dementia has been medicalised. The emphasis has shifted from the social

to the individual and the medical world now functions as a form of social control (Lyman, 1989; McKinlay & McKinlay, 2005). McKinlay and McKinlay argue that abnormal behaviour; muddled thinking, and uncomfortable or painful emotions are always present, but that the understanding of these conditions as a disease is culture specific. Horwitz also contends "these individualistic conceptions of mental illness are entrenched in both common sense and in the large and powerful mental health professions" (1999:57). "When people ask and answer the questions "What is mental illness? What are people with mental illnesses like and what should be done about people with mental illnesses? They create and shape social structures that become the realities of everyday experience for people with mental illness" (Link & Phelan, 1999:491).

All of this must, of course, be considered in the context of the positive impact of a label where it may allow access to medication and support, and in some cases insurance cover for care. In the case of the U.K. the issue of insurance is not generally so prevalent. There is however, a great drive at the moment towards early diagnosis (DH, 2009; DHSSPS, 2011). This is promoted by the medical world and indeed other campaigning organisations (Alzheimer's Society, 2013) as the way forward. Questions need to be asked about such an approach. Social Support Services must be seen in the context of an overstretched system with considerable policy documentation of what should occur, but little resources to ensure it does. When a diagnosis is given, somewhere someone will have the opportunity to add another statistic to the growing 'epidemic' of dementia. And having stepped into this process and been labelled by their diagnosis, there is no stepping back for the person living with dementia.

Rather than early diagnosis forming the basis of sound treatment and support, it may reinforce the categorising of a group of people, providing confirmation of their place within the group of those perceived to be 'mentally ill'. Gubrium (1986) argues that carers need a disease label to be applied to help them understand what is happening. Downs et al. (2006) argue that where dementia is viewed as a neuropsychiatric condition the person with dementia is viewed as a patient, a passive victim of disease. This label of psychiatric illness sees the handing over of control to medical experts. The authors assert that the ongoing association between progressive brain diseases and loss of self, negatively impacts on the rights of the person with dementia.

Hulko explores the notion of labelling and categorisation through the concept of social location. This is concerned with the amount of privilege or oppression possessed by individuals on the basis of "specific identity constructs such as race, ethnicity, social class, gender, sexual orientation, age, disability, and faith" (2009b:48). Others can apply such constructs to the detriment or enhancement of an individual's experience. She suggests the social location of an individual is one that is externally imposed, based on "the patterned attribution of positive and negative qualities to perceived social identities" (2009b:48). Specifically Hulko refers to the power to define others as 'invalid' citing Hughes (2002). Hughes explored the invalidation of disabled people using Bauman's sociology of the stranger. He described the modern and post modern struggle with difference, suggesting that "the specific form of strangerhood inscribed upon the bodies of disabled people in modernity requires a particular type of response which is dominated primarily, through the apparatus of non-disabled hegemony as compassion" (Hughes, 2002:577). While post-modern culture has created a space

for the 'stranger' and there is opportunity for the person living with a disability to celebrate their difference, Hughes argues that disabled people are still viewed "as symbols of tragedy, as reminders of the frailty of existence" (Hughes, 2002:581). The process of labelling dementia within a bio medical model of decline, loss, and death provides an example of the attributions described by Hulko (2009b), and people with dementia arguably represent the most emotive 'symbol of tragedy,' and reminder of 'the frailty of existence' (Hughes, 2002).

Thus far, this chapter has reviewed the literature pertaining to relevant models of dementia so that the current construction of dementia might be examined. This has included literature examining the influence of ageism and stigma. In terms of this study, the exploration of how the general public understands and responds to dementia is situated within this social, cultural and theoretical environment. What is yet to be revealed is to what extent the public have accepted, or not, various constructions, and/or models of dementia, or whether there is evidence of stigma in the public response to dementia. The next section of the literature review will thus examine current research specifically exploring public knowledge, attitudes and responses to dementia.

**Knowledge and Attitudes to Dementia Among the General Public**

There is a dearth of research available on the general public's understanding of dementia, and the focus has been on awareness, levels of knowledge, and recognition of signs and symptoms, in line with the political drive towards early diagnosis. This section will begin by examining this body of literature. This will be followed with a review of the smaller body of research that explores the impact

of public understanding on interactions or responses to people with dementia. There is a considerable body of literature examining professional and carer understandings of, and attitudes to dementia. Professional understandings are outside the remit of this study. However, over 40% of participants in the study knew someone with dementia, and a percentage of those had cared for someone living with dementia so that literature on informal carers' understanding, relevant to this study, is reviewed.

Anderson et al. (2009) reviewed research carried out in the U.S. assessing the public perception of Alzheimer's disease and cognitive health. A total of ten surveys were reviewed. The authors documented the difficulties of contrasting findings across the studies due to the variances in age groups surveyed and the questions asked. However, there was evidence across all studies of a lack of specific knowledge. It is worth noting that the authors chose to exclude surveys looking at discrimination and stereotyping that are of particular interest in this thesis.

Low and Anstey (2009) examined the recognition and beliefs relating to dementia among the Australian public. Using vignettes in a cross sectional telephone survey, the authors found that a high number (82%) recognised the symptoms of dementia, and that general beliefs relating to what might contribute to dementia were in line with current scientific thinking. They did however, record an unrealistic optimism about treatment. A survey carried out by Alzheimer's Scotland (2002) across 1000 adults in Scotland found there was a high recognition of the terms Alzheimer's and Dementia, and the majority of respondents associated them both with memory loss and confusion. Approximately one third of those

surveyed believed there was nothing that could be done to help a person with dementia, and a similar number believed dementia to be a normal part of ageing. Some of these findings contrast quite significantly with the results of the Facing Dementia survey (Bond, Stave, Sganga, Vincenzino, O'Connell & Stanley, 2005) carried out in Europe. This survey was carried out across six countries and involved over 2500 people, including the general public, professionals, carers, people with dementia, and policy makers. The findings here indicated that a high percentage of people would not recognise the early signs of dementia. In this survey the questions asked related to what other people might recognise, and Low and Anstey (2009) point out that this may have impacted on the results, as the questions in their survey related to the personal knowledge of the person being surveyed.

The Facing Dementia study (Bond et al., 2005) also documented the tendency to ignore symptoms or to treat them as part of the ageing process. There was an agreement among those participating that fear often prevented people from seeking help. The authors postulated that the combination of fear with a failure to recognise early symptoms, resulted in help seeking being delayed until symptoms were impossible to ignore. A high number of participants felt that government should do more, and that there was an indifference to dementia. The authors argue that this belief in governments' indifference evidences ageism supported in other research, and they refer to the higher value placed on children and working adults by society. "Dementia primarily affects older people, and discrimination against this population is the greatest. For people with dementia, who are too frail to stand up for their rights, discrimination is even greater" (Bond et al., 2005:13). The Australian survey documented a large minority of people who attributed the

risk of developing dementia to personal characteristics of "weakness of character (32%)" and "laziness (22%)" (Low & Anstey 2009:7). The authors suggest that this points to Alzheimer's disease being stigmatised in sections of the community, but they do not indicate which sections or what might contribute to this thinking. In the conclusions of the Facing Dementia survey (Bond et al., 2005), four key barriers are highlighted relating to better treatment and support options for people with dementia. These are:

1. Dementia and Alzheimer's provoke a great deal of anxiety.
2. They result in isolation and an increase in feelings of incompetence.
3. There is a lack of awareness and knowledge.
4. There is a lack of information about treatment and support.

In a paper considering the implications of this survey Rimmer, Wojciechowska, Stave, Sganga and O'Connell (2005) highlight the need for improved public education, pointing to the existence of widespread myths, stereotypes and fears among the public. Surveying the Japanese public, Arai, Arai and Zarit (2008) concluded that there was a general lack of knowledge relating to cause, treatment and prognosis. They argued this might in part be linked to a "misunderstanding of dementia as senescence forgetfulness" (Arai et al., 2008:437). This study targeted differing age groups and found that middle-aged women had significantly more knowledge than any other group. The authors suggest this may be linked to a care giving role and to the recent introduction in Japan of a monthly health insurance premium for the over forties.

Sahin, Gurvit, Emre, Hanagasi, Vilgic and Harmanci (2006) examined the attitudes of older lay people in Turkey towards the symptoms of dementia. This was a cross-sectional study of older adults in Istanbul. The authors found that most people saw dementia as a normal part of ageing. However, when asked about specific symptoms of dementia, described for example, as being unable to find their way home, the respondents did not view these as normal. The authors stated that the fact that the prevalence of dementia is age related might contribute to the cultural understanding of dementia as a normal part of ageing. In this survey, women were also found to be more knowledgeable than men, although contrary to Arai et al. (2008) they did not find knowledge to be age related. This research highlighted that socio-cultural and individual factors impact on when a complaint comes to be perceived as a symptom and to be considered within the domain of disease. The authors argue that the threshold for perceiving signs of dementia as abnormal moves according to the circumstances and environment of the individual.

In Greece, Tsolaki, Paraskevi, Degleris and Karamavrou (2009) found community based adults' attitudes towards older people with dementia to be negative. In this survey of attitudes of physicians, caregivers, and the general public towards Alzheimer's disease and other dementias, results showed that the general public perceived Alzheimer's disease as a disease of older people, and that it is associated with negative emotions. Results also indicated that the public had difficulties recognising signs of dementia as they viewed deteriorating physical and mental health as a normal part of ageing. Tsolaki et al. (2009) highlight insufficient information in the public domain resulting in confusion.

## Responses of the General Public to Dementia

In line with the World Health Organisation's call to reduce stigma and discrimination against older people (WHO, 2001), Werner and Davidson (2004) explored the emotional reactions of laypersons to someone with Alzheimer's disease. The study involved 150 Jewish Israeli adults who were interviewed face-to-face using a vignette methodology. The authors document that while research supports the fact that stigma is linked to Alzheimer's disease (Benbow & Reynolds, 2000; Jolly & Benbow, 2000), the body of research examining this area is limited. Werner and Davidson's study examined people's ability to recognise a vignette portrayal of someone with dementia using an open question. They then measured participants' emotional response to the vignette using a Likert scale rating on 16 items. Only a quarter of participants correctly labelled the vignette as portraying someone with Alzheimer's disease or dementia, despite the fact that the vignette depicted someone with Alzheimer's of a fairly advanced stage. The study indicated that participants had a more positive than negative emotional response to the person portrayed in the vignette, with a high percentage expressing a desire to help.

From the 16 items examined, four factors were labelled:

- Factor 1 -Rejection Feelings (disgust, rejection, ridicule, impatience).
- Factor 2- Anxiety Feelings (uneasiness, fear, embarrassment, insecurity, discouragement).
- Factor 3- Prosocial Feelings (sympathy, desire to help, concern, consternation, compassion).
- Factor 4- Aggressive feelings (anger, irritation).

The authors highlight that other studies have found stigma in mental illness to be linked to a view of the person as dangerous (Link & Phelan, 2001) with negative reactions loaded in one factor; aggression. This is not evidenced in the emotional responses to dementia. Rather the authors found that aggression and rejection were regarded independently, suggesting, "feelings of rejection may be associated with the distancing, marginalization and discrimination that characterise stigma and its negative consequences" (Werner & Davidson 2004:395). Werner and Davidson suggest further research is required to examine the "cognitive consequences" (2004:395) of emotional responses to people with dementia.

In 2005 Werner reviewed research in the area of mental health literacy among the general public, paying particular attention to the importance of age in this understanding, and looking specifically into lay understandings of Alzheimer's disease. Mental health literacy was defined as "knowledge and beliefs about mental disorders which aid their recognition, management or prevention" (Jorm, Korten, Jacomb, Christensen, Rodgers & Politt, 1997:182). Werner (2005) reviewed studies examining the ability to correctly identify and label specific disorders (author's words), the knowledge and beliefs about risk factors and causes of disorders, the knowledge and beliefs about professional help available, the knowledge and beliefs about treatments available, and the attitudes and reactions to people with mental disorders. Werner (2005) highlights that most studies had not considered age as a factor in two aspects of their investigations. The first relates to vignettes, where people were not provided with an age of the character in the vignette, so that the influence of age on response could not be established. The second is that the absence of varying age groups among those

surveyed meant it could not be established whether different age groups had different responses or understandings.

Attitudes and reactions were assessed using "two components of stigma: emotional reactions and social distance" (Werner, 2005:374). The findings indicated that negative emotions such as fear and anger are triggered in response to mental disorders, which then leads to social distance. However, personal experience or familiarity with mental illness prompts more positive emotions. Link et al. (1999) while making the link between fear and a desire for social distance, also argued that the symptoms of mental illness represented "undesirable personal attributes" (1999:1332) that people wanted to avoid. Werner comments that despite a widespread belief that people with Alzheimer's disease are stigmatised, her earlier paper referred to above (Werner & Davidson, 2004), suggests that people with Alzheimer's disease were more likely to trigger positive than negative emotions. Wadley and Hayley (2001) also found that the disease label of Alzheimer's triggers a more compassionate response. Although people with Alzheimer's disease may not generate the negative emotions of anger and fear, this does not mean they are free from stigma. If one considers Kitwood's (1997) malignant social psychology, a person is no less stigmatised because they are viewed benevolently. It is rather a benign stigma, which still has the power to facilitate exclusion and discrimination. Hughes (2002) also highlighted compassion as a social response to those we classify as 'strangers', as 'other'.

Crisp et al., in the U.K., (2000) documented a survey exploring public opinion on seven mental disorders, which included dementia. These seven disorders had been established as part of a campaign to target stigma, 'Changing minds; Every

family in the land', and the survey aimed to establish baseline data. Based on the work of Hayward and Bright (1997), they explored themes relating to how people with mental illness are perceived. The themes were; "being dangerous, being unpredictable, being difficult to talk with, having only themselves to blame, being able to pull themselves together, having a poor outcome, and responding poorly to treatment" (Crisp et al., 2000:4). The most negative opinions related to schizophrenia, drug addiction, and alcoholism with 70% of those surveyed viewing people with these conditions as dangerous, and 80% as unpredictable. There was a widespread view that it was difficult to talk to people with any of the conditions. Participants felt that people with dementia would not improve if treated and would never recover. The level of knowledge relating to prognosis and treatment were accurate across the conditions listed and the authors highlight that "Stigmatising opinions are not always closely related to knowledge. It follows that campaigns to reduce stigma have to do more than increase knowledge of the stigmatised condition" (Crisp et al., 2000:6). In relation to the themes explored, the sense of feeling differently to others was scored highest against people with dementia. People with dementia were also scored highly (77.3%) in terms of unpredictability. It is the three themes of being hard to talk to, being unpredictable, and feeling differently from others that the authors highlight as contributing to some of the social distancing and isolation experienced by people with mental illness, and high numbers of people associated all of these with dementia. Crisp et al. (2000) contend that it is social distance that ensures that the reality of the experience of those with a mental illness is not fully understood by the general public or health professionals. They also found that stigmatising attitudes were just as prevalent among younger people, and that people who knew someone with a mental illness were just as likely to hold negative opinions. This

contrasts with Werner (2005), who as discussed earlier suggested that personal experience or familiarity with mental illness prompted a more positive emotional response.

The last two sections have examined the literature relating to public knowledge of and attitudes to dementia. They have also reviewed the literature on public responses to dementia making some comparisons with responses to other types of mental illness. A body of the carer literature also relates to knowledge, attitudes and responses and the next section will examine this literature.

**Informal Carers' Understandings**

A different approach to examining the lay understanding of dementia was taken by Chung in Hong Kong (2000). The author defined the lay sector as families of the person with dementia and their related networks. A grounded theory approach was used to examine the underlying reasons behind how families and carers understood and interpreted dementia. Chung describes lay knowledge as being rooted in the experience of illness, as opposed to professional knowledge rooted in science and theory. The results suggested that caregivers had an inadequate understanding of dementia based on inconsistent and inadequate explanations from health care professionals. This supports research carried out in the UK by Graham et al. (1997), who found that of three groups of carers surveyed, the group that had received support from professionals scored most poorly on rudimentary knowledge about dementia, indicating a problem in the information they were receiving. This group did score highest on aetiological factors such as diet and

infection, which the authors suggest may reflect the interests of professionals rather than the needs of the carers.

Chung (2000) argues that in an attempt to gain some control, carers develop their own understanding based on external events and personal experiences. They create an illness story for the person with dementia, the story of their experience, an idea highlighted by Gubrium (1986). "The illness story places ill health in the context of the individual and his or her life story and relates it to the wider themes of the society and culture in which the individual lives" (Chung, 2000:374). One of the difficulties with the experience of dementia is the fact that it differs from many illnesses, as there is no definitive progression, no certainty in terms of the pathway or what to expect at any particular point in a person's journey with dementia. Chung found that different connections and links formulated different stories ranging from previous medical history, to critical life events, loss of role, and even supernatural beliefs. The study suggests a preference for the use of external events to explain dementia. Perhaps in the absence of information, which seems relevant to the lived experience, people write their own story. It is also worth noting that the stories created by carers form part of the body of knowledge about dementia, which is circulated through networks such as friends, family, and support groups. In many ways this can be beneficial and certainly supportive. However, it can sustain myths and misunderstandings. Chung (2000) argues that a real understanding of the lay perspective can inform health care professionals, resulting in more realistic interventions, and that good care will only be possible when there is mutual respect between professional and lay sectors for their understanding of dementia.

Graham et al. (1997) suggested that while carers with an increased knowledge of causes, symptoms and epidemiology of dementia had lower levels of depression, they had higher levels of anxiety. Proctor, Martin and Hewison (2002) also found an increased association between knowledge and anxiety, but they found this was limited to biomedical knowledge. They consider two possible reasons for these findings. First an increased awareness may heighten anticipation of future losses or difficulties. However, in relation to this, they point out that the biomedical section of the dementia quiz used in the survey focused more on epidemiology and aetiology, than on cause or decline. The second possibility offered is that it is "anxious carers who actively seek out biomedical knowledge in the first place" (2002:1137). Another reason may be that in biomedical knowledge there is a general absence of hope, and of strategies to assist the carer in their role. Rather it is information based on a nihilistic approach to dementia of inevitable decline. Proctor et al. (2002) suggest that in coping with such a difficult long-term condition as dementia, carers may require more than information, they may also require emotional support. They suggest that more research exploring the impact of specific bio-medical knowledge on carer anxiety should be considered, facilitating the development of a more sophisticated theory on the impact of education on the carer experience. This is relevant beyond the carer experience. Current government strategies to inform and educate appear to be linked, in the main, to information relating to signs and symptoms (DHSSPS, 2011), and this will be discussed further below. The idea appears to be the development of a more informed public who recognise signs and symptoms, thus encouraging help seeking behaviour. This does not take account of how people process this additional information or whether it will encourage help seeking or increase

anxiety.  It also does not take account of how or if it will affect their interaction with someone with dementia.

The relationship between knowledge and attitudes is clearly a complex one. Carers of people living with dementia are evidenced to create stories to explain the experience, with further evidence that increased medical knowledge may lead to additional stress.  There are competing agendas, from that of the medical professional to the carer, and the person with dementia.

The experience of dementia and the response of the public to that experience do not exist independently from policy development or implementation.  Innes argues that "Policy decisions cannot be seen in isolation from the political, economic and social concerns of a society, nor can they be easily separated from the dominant theoretical discourses surrounding the applied nature of the dementia world" (2009:135).  With this in mind the chapter will conclude with a review of policy relevant to dementia.

**Dementia Policy**

Having considered the various ways in which society has constructed dementia, it is important for this study to consider how policy has been influenced by, and influenced this construction. Government strategies and policies can be said to reflect and influence societal attitudes and values.  "Policy and economic decisions will reflect social norms and expectations" (Innes, 2009:37). A review of policy associated with dementia is of necessity associated with policy on mental health, old age and community care. Policy reflects the changing attitudes towards age,

ageing, and mental health.  This section documents a shift in policy from the view of older people, even healthy older people as needing to be taken care of, to the current concept of ageing well, with an emphasis on taking responsibility for one's own health.  Attitudes towards mental health and disability have also changed over the last 40 years with the move from institutional to community care, and campaigns aimed at reducing the stigma associated with mental illness. Innes (2009) points to the interplay between policies relating to dementia, mental health, and older people as evidence of policy that continues to struggle with issues around the family and the state, care costs, health and social care boundaries, and the fair provision of services.  Dementia while classified a 'disease' falls within the domain of the bio-medical and most specifically old age psychiatry.  However, much of the support for dementia falls within social care provision; elderly care.  This distinction has significance in terms of health and welfare provision.  Many of the benefits and/or services available to people living with other conditions are not available to people with dementia until much later in the progression of their condition.

**A Global Context**

Policy pertaining to dementia in Northern Ireland can be said to reflect a trend across Europe, America and beyond which sees increasing political attention being given to dementia.  As described earlier, there is now an abundance of research and literature referring to the rising number of people with dementia anticipated in the not so distant future, and this would appear to have focused the minds of governments and policy writers.  While there is evidence of real effort to improve

the situation of people with dementia this is also an issue of cost for government. For a variety of reasons then, we see dementia specific policy and strategy being developed across the world. In Australia the National Framework for Action on Dementia 2006-2010 (Department of Health & Aging, 2006) has led to the development of the Dementia Initiative, which focuses on research, improved care, early intervention, and training. In Europe a number of countries already have a dementia strategy in place. These include the French National Strategy launched in February 2010, the Dutch Dementia Plan launched in 2008 and the Norwegian Dementia plan in 2007 (Alzheimer Europe, 2010).

Closer to home the English Dementia Strategy was released in Feb 2009 (DH, 2009) with the Scottish Government releasing a national strategy in June 2010 (SG, 2010). In Northern Ireland a Dementia strategy was released in 2011 (DHSSPS, 2011). It is entirely positive to see dementia receiving attention at policy level, even while it is difficult to see how the necessary changes can take place in the current economic climate, where the UK government has recently announced the need for departments to cut budgets by 25%, with a requirement for plans to be made available to cut by 40%. I would argue that if governments are to make changes to the way dementia is understood and perceived by society, then this must begin with an exploration of what is actually understood and believed among the general public.

**Dementia policy in Northern Ireland**

Within the context of Northern Ireland, 1974 saw health and welfare services become an integrated health and social services system. The aim was to facilitate a more holistic approach to care and create opportunity for multi-disciplinary practice. Traditionally in Northern Ireland, the care of people with dementia was incorporated within the framework of community care and specifically the care of older people.

There are three main policy documents relevant to the development of dementia specific policy in Northern Ireland. These are the Dementia Policy Scrutiny Report (Department of Health & Social Services (DHSS), 1995), The Bamford Review – Living Fuller Lives (DHSSPS, 2007) and the recently released Dementia Strategy (DHSSPS, 2011). Policy in other fields related to community care, ageing, and mental health are to a lesser extent relevant in the development to date.

The first effort to address dementia in recent policy was during the 1980s with "Past 65- Who Cares" (DHSS, 1995). This report addressed ageing in Northern Ireland and while it identified the need for specialist services for people with dementia, its reference to dementia was limited. The Regional Strategy for Health and Personal Social Services in Northern Ireland 1987-1992 (DHSS, 1987) followed, which again was viewed as having "limited impact on development of coherent dementia services" (DHSS, 1995:2).

1990 saw the release of 'People First – Community Care in Northern Ireland in the 1990s'. It was this document, which was to be fundamental in the approach to

community care right through the 1990s and the beginning of the 21st century. The proposals in this policy originated in the Griffith's report, a result of a major review of the NHS in the U.K. and also outlined how national policy directives within the Government White Paper – Caring For People would be implemented in Northern Ireland.  A significant change as a result of this policy was in the role of the Health Service Boards from provider of services to "co-ordinators, purchasers and quality control" (DHSS, 1991:14).

People First acknowledged that despite the advantage of an integrated structure, progress in the provision of community care in Northern Ireland had been slower and less consistent than anticipated, and that there remained a built in bias in the system towards the use of nursing or residential care, particularly in terms of funding.

The role of the informal carer was recognised and a clear emphasis placed on the need to support the carer within society.  "Most informal carers take on their extra responsibilities willingly but many need help.  Their lives can be made much easier if the right support is there at the right time, and it is one of the Health and Social Services Boards' main responsibilities to do all they can to see that it is" (DHSS, 1991:19).  This is in line with a large volume of literature on caring and carer support, which existed at this time. Further support for the role of the informal carer is evidenced in policy such as Valuing Carers (DHSSPS, 2002), and the Carers and Direct Payments Act of 2002. There is a clear recognition of the extent of the role played by informal carers, and of the potential costs to government should this resource not be available.

*The Dementia Policy Scrutiny Report 1995*

By the early 1990s, it was recognised that a more specific policy and provision relating to dementia was required, and the Department commissioned the Dementia Policy Scrutiny Report in 1994.  The report released in 1995 reflected a person centred approach to the care of people with dementia.  Considerable emphasis was given to empowering people with dementia and to the valuing of a person regardless of their level of cognitive ability.   This report also highlighted the continuing confusion over responsibility for dementia services, suggesting this had hindered the development of a solid and comprehensive service.  The report recommended that dementia care should fall under the elderly care programme within Trusts and resources for dementia should be placed accordingly (DHSS, 1995:32).  For the first time the need for early diagnosis was highlighted.

Direct reference was made to the need to influence the attitudes of the general public arguing that the current attitude of the public was ill informed and negative. "Changing attitudes and confronting ignorance is not an easy task.  However, it is a very necessary one if we are to ensure that people with dementia and their carers receive the care, understanding and support that they need" (DHSS, 1995:39). For the first time a move to educate the public about dementia was recommended "we recommend that the Department, in partnership with the Health Promotion Agency and key professional and voluntary sector interests, launches a comprehensive public awareness campaign to raise awareness of dementia" (DHSS, 1995:39). The report, while covering a broad range of issues pertaining to the experience of dementia and the provision of care stayed away from broader societal issues.  In the main it has a pragmatic tone concerning itself specifically

with issues influencing the experience of dementia for the person diagnosed and the carer.

### *The Bamford Review*

Possibly the most significant policy in relation to dementia until the recent dementia strategy has been the Bamford Review – Living Fuller lives (2007). This was an independent review of mental health and learning disability law, policy and service provision commissioned by the DHSSPS. This was the first policy document to address issues at societal rather than individual level. It recognised the implications of an ageist society, where the additional stigma of a mental illness i.e. dementia, found people with dementia doubly discriminated against. The report has a person centred voice making reference from the outset to dealing with emotional pain and finding imaginative caring approaches. "It is in the fine grain of care that quality is really experienced, the tiny details that show our uniqueness has been recognised" (2007:6). However, the report acknowledges the difficulties of such an approach in a society it describes as ageist and stereotyping people with dementia/mental illness. The document also makes reference to the limitations of the bio medical framing of dementia, citing the Social Care Institute of Excellence (2003) "If we view dementia only as a disease, then we are tempted to abdicate our fundamental responsibility as human beings for the welfare of our fellows, and leave it to scientists in laboratories to discover the pill, potion, gene or magic bullet that will 'treat' or even cure dementia. But if we see dementia as a condition of which degenerative brain disorder is only one part, but which is fuelled by the fear, anxiety, shame and incomprehension of both the person concerned, those who they are in contact with and the wider society – then we can begin to see that we have a role to play for ourselves" (2007:7).

The report can be seen to challenge the bio medical model and acknowledge the implications of fear and stigma in how society responds to dementia. It recognised the changing of attitudes as part of its remit and acknowledged the difficulties associated with this, although the emphasis was on education, and changing attitudes within service provision and organisations providing care. The review stated that its contents should be considered alongside a number of other reports, most specifically, Mental Health Improvement and Well-Being – A Personal, Public and Political Issue (DHSSPS, 2006). This report highlighted the prevalence of mental health disorders in later life, stating that about a third of all admissions to psychiatric care and referrals to community mental health services involved people over the age of 65. Again it is clear that at this point dementia had not yet been identified as a condition with specific service provision, or legislated for in its own right. The Bamford Review acknowledged the inconsistent implementation of the recommendations from the dementia policy scrutiny report, and emphasised the need for mental health needs of older people to be given the same priority as other service groups. It also recognised the need for new legislation, referring specifically to capacity legislation already introduced in Scotland, England and Wales. The Bamford review continues to influence policy and practice direction in Northern Ireland today.

### The Northern Ireland Dementia Strategy

There is little that is new in the recently released Dementia Strategy (DHSSPS, 2011) from the Dementia Policy Scrutiny Report of 1995 or the Bamford Review of Mental Health (2007). There is a continued emphasis on early diagnosis, support for the person with dementia and their carer, and raising awareness. There is however, a change in tone. The promotion of maintaining health, first evidenced in

the Bamford Review has a much stronger emphasis here. There is a clear move to encourage individual responsibility to maintain personal health.

The first section of the strategy includes aims to promote understanding and improve awareness with a view to supporting people to reduce their risk of developing dementia. Section 2 of the strategy addresses the impact of dementia on society, and is entirely made up of projected numbers of people with dementia over the next 5 years including current and projected costs. This section is peppered with phrases like; "meeting the demands", "compound these problems", "significant implications", "increasing pressures", "substantial additional costs", "impact of an ageing society", and "major impact" (2011:11-16). The language is quite catastrophic and continues to evidence the notion of burden while not actually using the word.

In line with the aim referred to above to support people to reduce their risk, section 3 addresses delaying onset or preventing dementia and gives considerable attention to "modifiable risk factors". Almost every major health concern is listed as associated with dementia, most of which are followed with a reference to the lack of firm evidence. For example:

Raised cholesterol "but it is not yet clear whether reducing cholesterol reduces the risk of dementia" (2011:18).

Section four highlights the need to improve awareness and education among organisations and staff in the field, and section five highlights a holistic model for supporting people with dementia where "the individual with dementia is a valued member of society" (2011:33), recognising the raising of awareness as a

fundamental requirement of this. Section 6 addresses raising awareness across three audiences: the general public, those working in services, and those working in health and social care. The targets for the general public are identified as health promotion and disease prevention strategy, recognition of signs and symptoms, and addressing social stigma and fear. The report states "Public awareness of the condition will reduce the stigma of dementia and will promote social inclusion for those who are living with dementia" (2011:41). However, other literature reviewed earlier in this thesis suggests that improving awareness is not necessarily linked to reducing stigma (Crisp et al., 2000).

Innes and Manthorpe (2013) highlight a number of ways the Northern Ireland government demonstrated an engagement with the principles of person-centred care when developing the most recent strategy (DHSSPS, 2011). They commissioned an easy read document for people with dementia and their carers and this document was used as part of a public consultation exercise. Further the consultation document was explicit in advocating a "holistic societal approach to supporting those living with dementia" (DHSSPS, 2010:31). In the context of community, the document targeted three areas - Awareness and acceptance, realise potential to prevent or delay dementia, promote inclusion. In the final document it is interesting to note that the words referenced above (2010:31) had been removed and an additional line under community, "take responsibility for own health" (2011: 33) was added. This might suggest a shift back from original broader societal concerns to individual responsibility, more in keeping with a bio medical model of dementia.

In all of these policy documents there is emphasis on the need to recognise the growing number of older people who will require support from health and social services. The sense of older people and particularly people with dementia as incurring high costs for the rest of the population runs through each policy. The changing attitude to ageing can also be traced through policy. The first documents of the 1980s and 1990s portrayed older people as vulnerable, and they were often referred to in the same sentence as those with mental health issues (DHSS, 1991; DHSS, 1995). This fits with the understanding discussed earlier of senility as an inevitable part of the ageing process. In the more recent strategy document (DHSSPS, 2011), the approach is strongly influenced by the philosophy of ageing well or successfully. The promotion of well-being and of ageing well, while positive in many senses risks further exclusion of people with dementia. If a person is affected by dementia, can this be viewed as ageing unsuccessfully? Cook (2008) argues that dementia does not sit easily in either mental health policy or old age policy, which currently places such emphasis on maintaining health and well-being. The recent attention to dementia in policy could be seen as forcing a fit, with dementia placed, as described above, within a framework of prevention and individual responsibility to reduce risk.

Innes (2009) refers to the emotive language now associated with the projected increase in numbers of people living with dementia. The call for dementia to be considered a priority by governments is a double-edged sword, perpetuating the anticipated high cost incurred as a result, but also one would hope, attracting attention to the need for a new ethos of care and new approaches to dementia. It is problematic that the emphasis remains on costs, and particularly on costs related to care provision. There is no sense of a policy shift from the standard

paradigm (Kitwood, 1997), and Cook (2008) argues that the continued dominance of the medical model, while furthering scientific understanding and the pursuit of a cure has focused on dementia as an "individual tragedy" (2008:15), rather than focusing on the social and interpersonal.  When one considers these three significant policies spanning the last 15 years, it must be said that there is little new thinking or creativity in the most recent strategy.  There has been a consistent emphasis on treating the person with dementia with dignity and respect.  There has also been consistent emphasis on the role of the carer and the associated shift to community care, although Northern Ireland continues to rely more heavily on residential and nursing care than the rest of the U.K. (DHSSPS, 2007:33). However, a new emphasis on prevention and risk modification in the most recent strategy (DHSSPS, 2011) suggests a policy even more in line with the scientific model than its predecessors.

There is a real sense in all of these policies of the need for change in service provision for people with dementia, and all of the documentation acknowledges that the fractured approach to dementia has contributed to a lack of success in developing services.   However, since 1995, while there have been recommendations to address this, there is little evidence of implementation.

With the exception of sections of the Bamford Review the emphasis in these policies has in the main remained on the individual, and there is little sense of addressing dementia in societal terms except in the sense of anticipated burden and costs.  The drive towards prevention and health strategies in the recent Northern Ireland Dementia Strategy (DHSSPS, 2011) does not address how socio economic status might impact on the taking up of preventative strategies, or affect

an individual's ability to stay healthy. There is a sense of moral responsibility, a return to the thinking of the earlier part of the last century in some ways. How will we judge those who are unwilling or unable to take steps such as those outlined? How will we respond to those who will not recover? This individualised approach to dementia care can never fully address the needs of those with dementia, for it does not fully take account of the processes of exclusion that occur. Cook (2008) describes the well documented fears of modern and post modern societies towards age, dementia, disability, and death, which has led to the exclusion of those affected, from the community and the collective consciousness. While the issue of stigma has been raised in policy the emphasis is increasingly on health promotion and disease prevention strategies. The impact of stigma on social well-being or social interactions is, in fact, given much less attention in the recently released strategy than in the previous policies. In contrast, the English Dementia Strategy (DH, 2009) addressed public and professional awareness as one of the first priorities in their implementation plan. This has already resulted in the Living Well Campaign, a joint venture between the NHS and Alzheimer's UK, and the National Audit Report in its interim review of the strategy commented favourably on this aspect of strategy implementation (National Audit Office, 2010:18).

In terms of raising public awareness across the span of these policies, very little has actually taken place. Each policy refers to the need to address the negative discourse around dementia, and the attitudes of both professionals and the general public, but there is no evidence of a campaign. Currently this remit lies with the Department of Health, Social Services and Public Safety. When I contacted the department they advised me that this is being addressed by 'elderly care', and this office confirmed that while a number of items are in the planning stage, no

implementation around public awareness has occurred to date (28/02/2014). The 'Minding Your Head' campaign (Public Health Agency, 2014) in Northern Ireland is a comprehensive campaign targeting mental health issues in society and addressing issues of stigma and exclusion. However, if you access the website, dementia is noticeably absent and the department confirmed that dementia is not regarded as a mental health issue. Information from governmental departments and policy providers is then limited to the sound bite on the news or in the written media. There is a lack of comprehensive understanding in line with the previously referred to aims of Bamford on page 69. Without actually embracing a philosophy such as this, how can policy hope to influence the community it serves?

All of the policy reviewed here is contained within the quite narrow field of elderly and community care, while the experience of dementia takes place within a much broader societal context than simply care provision in old age, and people with dementia are affected by a much wider range of policy (Cantley & Bowes, 2004). Dementia is impacted on by multiple factors, some of which will be explored in later chapters of this thesis, and it is difficult to see how such restrictive policy approaches can hope to address the complexity of the dementia experience.

**Summary**

This chapter has reviewed the literature pertaining to relevant models of dementia from a social constructionist perspective. The significance of interaction in maintaining specific understandings, and in the maintenance of self has been considered. The historical establishment of Alzheimer's disease has been

documented, and the significance of age and ageism explored.  Literature on stigma, labelling, and social location in dementia has also been reviewed.

There are a number of issues that emerge from this review.  It is clear that there remains only a partial understanding of dementia among the general population, and that this understanding is potentially fluid, in line with an individual's personal experience and circumstance.  The information held by the public is both inadequate and incomplete.  Some of the research suggests that the source of this information is the healthcare profession, with biomedical knowledge potentially linked to increased anxiety.  If as Kitwood (1997), Sabat (2008) and others have shown, the psychological and social influence the experience of dementia, as much as the clinical, one might question why the provision of information relating to dementia is primarily clinical.  Improving public awareness of signs and symptoms, while positive, has not been shown to improve help-seeking behaviour or to address stigma (Crisp et al., 2000; Werner, 2005).

The research suggests that negative emotions such as anger and fear are not generally associated with people with Alzheimer's disease.  However, compassion or sympathy does not of necessity preclude stigma.  The malignant social psychology described by Kitwood (1997) need not be driven by negative or malicious feelings, but it nevertheless results in isolation and a diminishing sense of self.  Thus perhaps it is necessary to examine stigma from a different perspective, where it is of a subtle, insidious nature evidenced in the social distancing described by Crisp et al. (2000).  Werner (2005) has suggested the need to examine more closely links between emotional responses to people with dementia and cognitive consequences, and also concluded that more research is

required into the experience of older people, and specifically into the experience of older people with Alzheimer's disease.

The concepts of multiple jeopardy (Bowes & Wilkinson, 2003) and intersectionality (Hulko, 2009a, 2009b) have highlighted the complexity of the stigma associated with dementia. Yet this complexity is not reflected in policy aimed at supporting people with dementia to live well. Policy, in general, remains bound up with approaches to care, risking the neglect of multiple other aspects of the experience of dementia. It also continues to reflect an individualistic rather than societal approach. The expressed aim to improve awareness and reduce stigma is consistently linked to notions of recognising symptoms, and modifying risk with a view to prevention.

There is evidence of stories being used to understand and explain the experience of dementia (Chung, 2000). The value of these stories in finding one's way through such a difficult and challenging time should not be underestimated. However, there is a danger that this individual, subjective experience retold by carers can grow to become a 'truth' of dementia. The absence of adequate information allows for the subjective to be treated within a group as the factual and objective. Thus carers can perpetuate ideas of a time such as "the living death" (Woods, 1989) even when thinking has long since developed or even dismissed a theory. Chung (2000) concludes that carers might be better equipped if they had basic medical knowledge alongside a psychosocial understanding of dementia. Information alone is unlikely to create an environment of understanding. Perhaps as Werner (2005) has pointed out it is time to find a more sophisticated approach to education.

# Chapter 3: Research Design

This study aimed to find out what the public understands dementia to be and how members of the public respond to people with dementia. In this chapter, I will discuss the methodological approach I took to the study, the decision to use mixed methods and the rationale behind the specific use of a survey, focus groups and interviews. I will then discuss sampling and access. Details of the data collection process will be covered and the chapter will conclude with a discussion of the analysis process itself.

**Methodological Approach**

The over arching question being asked by this study was what the general public understands about dementia and how members of the general public respond to people with dementia. As discussed in the literature review, the study has been informed primarily by social constructionism. Social constructionism accepts that knowledge and understanding are co-constructed by participants in interaction (Bury, 1986; Harding & Palfry, 1997; Knorr- Cetina, 2005). The methods used and the analytical approaches taken in this study are informed by this theoretical understanding, as discussed below.

The participants in this study, as members of the public had already been exposed to particular constructions of dementia and Alzheimer's disease; "interaction with others in everyday life is therefore, constantly affected by our common participation in the available stock of knowledge" (Berger & Luckmann, 1966:56). The job of this study was to access participants' understandings, explore the

context within which these had been created, and how they might be impacting on the self reported responses of participants to people with dementia.   In keeping with this theoretical understanding, focus groups and interviews offered fitting contexts within which to explore how participants' understanding of dementia had been constructed, and the process of this co-construction with others in interaction.   A survey offered the opportunity to gather initial data on semantic themes that could inform the data collection within focus groups and interviews. Arguably survey responses are also co-constructed in that the role of this researcher and other stakeholders impacted on development and framing of questions, so that responses emerged from within this particular framework.

The aim was to get under the surface of the data, contextualise emerging findings, and through analysis, to identify and interpret the beliefs and ideas behind the findings.  As such while manifest themes would be explored, I was particularly interested in the themes at a latent or interpretive level, and to this end used latent thematic analysis (Boyatzis, 1988; Braun & Clarke, 2006).   Latent thematic analysis "goes beyond the semantic content of the data, and starts to identify or examine the underlying ideas, assumptions, and conceptualisations – and ideologies - that are theorised as shaping or informing the semantic content of the data" (Braun & Clarke, 2006:13). This analytical approach fits well within a constructionist perspective.  There has been some criticism of thematic analysis as an approach that is not clearly defined or explained (Braun & Clarke, 2006), and that is without a clear heritage in terms of analysis (Bryman, 2008).  However, it is a well-recognised approach to data analysis in social science, and this chapter will clearly outline the process of analysis to ensure that rigour and thoroughness are evidenced.   The approach taken was also inductive in that the data were

continuously revisited during analysis, and analysis began while data were still being collected.

**A Mixed Methods Approach**

The questions being asked by this study ranged from establishing what the people of Northern Ireland understand dementia to be, to the more complex processes, which contribute to these understandings (Maxwell, 1996) and how participants report they might respond to people with dementia.

1. What does the general public understand (know and believe) about dementia?
2. What factors have contributed to this understanding?
3. How does the general public self-report its responses or potential responses to dementia and people with dementia?
4. What factors impact on the general public's self-reported responses to dementia?

This range of enquiry and the difference in the type of questions was well suited to a mixed methods approach. The use of mixed methods "reduces the risk that your conclusions will reflect only the systematic biases or limitations of a specific method" (Maxwell, 1990:75). The methods selected for this study were a survey, focus groups and semi-structured interviews. The survey could be used to help answer questions 1 and 3 with focus groups and interviews being used to answer all 4 questions. I anticipated this approach would provide a more complete picture with the opportunity to explore and build on responses to the survey in another

two settings.  This mix of methods also facilitated triangulation of the data "The use of more than one method or source of data in the study of a social phenomenon so that findings may be cross-checked" (Bryman, 2008:700).

Below is a figure outlining the research design.

**Figure 1 – Research design**

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┌─────────────────────────────────────┐
│         Stage 1 – Survey            │
│  Themes emerging from the survey    │
│             inform…                 │
└─────────────────────────────────────┘
                  │
                  ▼
┌─────────────────────────────────────┐
│       Stage 2 – Focus Groups        │
│   Themes emerging from both the     │
│   survey and the focus groups       │
│             inform…                 │
└─────────────────────────────────────┘
                  │
                  ▼
┌─────────────────────────────────────┐
│        Stage 3 – Interviews         │
└─────────────────────────────────────┘
```
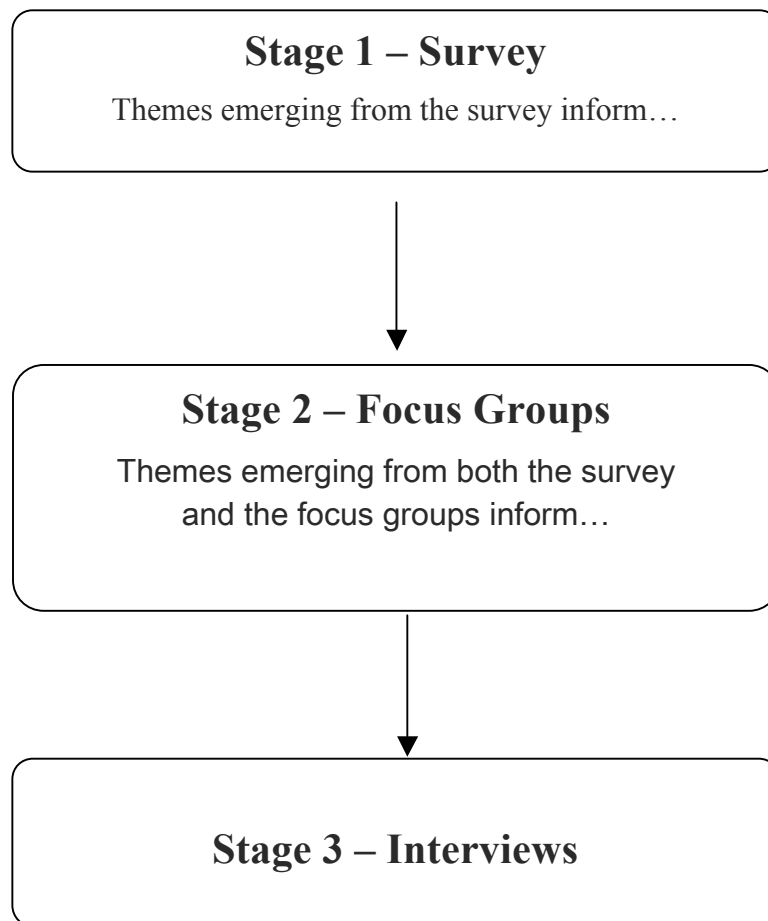
The order of data collection should not be taken to imply primacy of one method of data collection over another.  The initial collection of survey data provided semantic themes that contributed to the focus groups and interviews. The themes were explored within these settings to reveal what assumptions, beliefs and constructions contributed to them.  As these more latent themes emerged, they

then were used to once again examine the quantitative data. Bryman (2008) suggests that in mixed methods research, quantitative and qualitative data should be "mutually illuminating" (Bryman, 2008:603), and this was the aim here. In practice these stages did not occur in the linear fashion planned in Figure 1, but instead the focus groups took place while survey data were still being analysed, and the interviews began after the first two focus groups. This helped to foster a very inductive approach to the data with the opportunity to constantly and reflectively allow one dataset to inform and contribute to another.

**Methods Rationale**

This section will discuss the rationale behind each of the methods employed to collect data, including the use of vignettes.

**Survey**

While attending a seminar in Belfast, I had the opportunity to gather information on the Northern Ireland Life and Times (NILT) Survey. I realised that if I could somehow use this survey I would have access to a much greater proportion of the population than I could hope to target as a PhD student. The NILT Survey is a social attitudes survey that has been carried out annually in Northern Ireland since 1998. The survey has a modular format with two core modules repeated annually: political attitudes and community relations. The remaining modules vary annually and are designed to be repeated in years to come. The survey is one of a number run by Access, Research, Knowledge (ARK). ARK is a joint resource managed by Queens University Belfast and the University of Ulster that aims to make social

science data on Northern Ireland accessible and available to a wide audience. Approximately 1200 people are surveyed and the data collection is carried out by the Northern Ireland Statistics and Research Agency.   I approached the team at ARK with a proposal to include a module on dementia in the 2010 NILT survey. The Northern Ireland Dementia Strategy was out for consultation at this time and ARK had included modules on attitudes to older people in 2008, and attitudes to disability in 2009.  The 2010 survey was to include a module on attitudes to social care, and on attitudes to informal carers so I argued that the dementia module would be timely, relevant, and fit well with the other modules planned for 2010. The Dementia Services Development Centre (DSDC), Stirling had funded my PhD and were able to support my approach to ARK.  The team at DSDC, Belfast and Stirling supported me through a process of negotiation that resulted in the inclusion of a half module, with funding provided by Atlantic Philanthropies.

The survey allowed for the collection of data on the knowledge of dementia among the general public.   It also created an opportunity to explore the attitudes of the general public to dementia and people with dementia.  Further, attitudes could be explored in the context of knowledge held, and this contextualisation was something that had not yet been done in the field.  The survey could provide, what might be described as, surface data on attitudes and this quite broad picture could be used to inform the ideas explored in the next stage of data collection.  In terms of demographics it could provide data on a much greater scale than could be hoped for in focus groups or interviews, and create the opportunity to test the significance of a series of variables on attitudes.    An additional benefit of this particular survey is that it is a well-established social attitudes survey in Northern Ireland that is completed annually.  Depending on funding there is a good chance

that the module on dementia will run again in a few years creating the opportunity to observe any changes in knowledge and attitudes.

While this static picture of understandings and attitudes would be of great value (Bryman, 2008), I anticipated it would not provide answers as to how these understandings had been constructed, or how they might affect the way someone responds to a person with dementia. Stroh (2000:198) highlights the limitations of questionnaires: "They lack the sensitivity to be able to explore difference, inconsistency and often, meaning and argument". Thus, in addition to the survey data on expressed beliefs and attitudes, I needed to gather data on the subjective experience and responses of participants in relation to dementia.

**Focus Groups and Individual Interviews**

Focus groups and interviews provide a mechanism to explore the processes and factors contributing to the development of attitudes or beliefs. "It is a very good way of accessing people's perceptions, meanings, definitions of situations and constructions of reality" (Punch, 2005:168). This study also hoped to illuminate any links between "personal experience and how it is socially constructed, both within one's immediate environment and within a broader societal context" (O'Connor, Phinney, Smith, Small, Purves, Perry, Drance, Donnelly, Chaudhury & Beattie, 2007:134). Focus groups and one to one interviews are methods that align closely with theories of social constructionism that have informed this thesis. Both types of interviews were semi-structured. The focus groups opened with a series of questions, but in the main used vignettes to explore the topic while the

individual interviews contained a series of open-ended questions, and reflected on the vignettes used in the focus groups. Both were informed by the themes identified in the survey and later in focus groups, but were also flexible in that they allowed me to respond to new directions taken by participants.

*Focus Groups*

Punch (2005) highlights the usefulness of focus groups in stimulating people to "make explicit their views, perceptions, motives and reasons" and "in bringing to the surface aspects of a situation which might not otherwise be exposed" (Punch, 2005:171). The literature has highlighted the importance of interaction in the world of someone with dementia (Sabat & Harré, 1992; Kitwood, 1997; Sabat et al., 2004; Hughes et al., 2006; Sorensen et al., 2008), and the significance of interaction at a societal level in how people are included or excluded, and in the ways care is provided (Downs et al., 2008). In focus groups "The accent is upon interaction within the group and the joint construction of meaning" (Bryman, 2008:474). They allow the researcher to access this process of interaction, to "elicit a multiplicity of views and emotional processes within a group context" (Gibbs, 1997). There is an argument that participants may not disclose more uncomfortable or less socially acceptable views in a group environment (Bryman, 2008), and this is dependant to some extent on the particular skills that group interviews require (Punch, 2005). My particular skills as a trained counsellor served me well in the facilitation of these groups and the level of disclosure among participants sometimes surprised me. Morgan (1988) concludes that the strength of focus groups are in providing an opportunity to collect data on topics of interest to the researcher, being more controlled than participant observation and less

controlled than individual interviews.

*Interviews*

May (2001) suggests that semi structured interviews are useful when the researcher has a specific focus and is also using other methods. They allow the researcher an opportunity to probe the responses given, taking account of the cultural context. The inclusion of one to one interviews allowed for another perhaps more personal encounter to explore a potentially sensitive subject, addressing the potential limitation, that in a group situation participants might express more culturally accepted views (Bryman, 2008). As interview participants were selected from those attending the focus group, it was likely that those agreeing to be interviewed would have developed some element of trust with me. Interviews are argued to be a joint construction of the interviewer and interviewee (Rapley, 2004). Rapley suggests, "interview-talk speaks to and emerges from the contemporary ways of understanding, experiencing and talking about the specific interview topic" (Rapley, 2004:15), but that analysis must take account of the "specific local interactional context". Interviews also allowed the opportunity to explore some of the issues raised during the focus groups from a participant's personal perspective. As already stated, I chose to use a semi-structured interview. I felt this was a legitimate approach, as it would allow me to ensure I covered issues that had emerged in the survey and focus groups as significant, but would also allow the interviewee flexibility in how he/she responded.

**Vignettes**

Research exploring public understanding of 'mental illness' and dementia has used vignettes (Werner & Davidson, 2004; Low and Anstey, 2009), and these are increasingly recognised as a valuable tool in qualitative studies within the social sciences, and in particular to explore attitudes, perceptions and beliefs (Hughes, 2002). Vignettes in this study were short scenarios, read aloud and designed to elicit participant responses to the situation and characters being described. Barter and Renold (1999) suggest vignettes serve three purposes:

- To allow actions in context to be explored.
- To clarify people's judgements.
- To provide a less personal and therefore less threatening way of exploring sensitive topics.

Using vignettes means that participants do not need to have a particular knowledge of the topic in question and they can "elicit participants' automatically generated meanings" (Hughes & Huby, 2002:384). Hughes and Huby (2002) suggest that vignettes reduce the risk that participants will provide a socially desirable response; the vignette and characters in it offer the participant a way of responding within a fictional situation, creating distance from their own life. Vignettes often use moral and ethical dilemmas, and Wilks (2004) suggests this may reflect a belief that "dilemmas act in some way as a key to our conceptual world". This study aimed to access the conceptual world of participants and to avoid as far as possible socially desirable responses, rather hoping to access a more instinctive response that might offer insight to the values and beliefs behind attitudes to dementia. Thus from an ideological perspective, vignettes were a good

fit for this study. They were also a pragmatic choice, offering a way to stimulate discussion on a topic that participants may not have particular knowledge about.

Themes from the survey informed the development of vignettes (Appendix 6), but having considered the results of the survey I was also able to use vignettes to explore other issues that it had not been possible to include in the survey, and to probe further on ideas emerging from it. Vignettes were designed to reflect accurate portrayals of situations that might involve people with dementia. The ideas were primarily sourced in my experience of caring for my mother and the reported experiences of other carers and professionals working in the field. The question of validity is key when using vignettes and these vignettes were initially submitted to my lead supervisor Professor Innes, a recognised leader in the field of dementia. A pilot focus group of 8 locally recruited participants also took place. No amendments were suggested at this time but a number of amendments were made as fieldwork progressed. During the first two focus groups, participants drew attention to a situation that they felt was unrealistic and I amended this vignette prior to the next focus group[2]. Another two vignettes covered a progressive story of a situation with a work colleague (Vignettes 4 and 5). This tended to divert the participants away from the dilemma being portrayed to a discussion on the nature of relationships with work colleagues, so I changed this vignette to portray the character as "a friend". Vignette 11 initially portrayed the character as being 75 years old. Participants reflected that they thought it unlikely that anyone of this age would be even considered for transplant so the character age was changed to 62 years. It is worth noting that many participants commented

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[2] Vignette 3 described a person becoming confused after admission to hospital with a broken wrist. Participants thought this unlikely based on the injury and the vignette was amended to suggest the character had broken their leg.

on how useful they found the vignettes, and how for some of the participants, elements of these fictional situations reflected their experience.

A further methodological issue in the use of vignettes is the nature of the relationship between the behaviour participants report and their actual behaviour. Wilks (2004) suggests this is more problematic in quantitative studies where limited response options are available, and that qualitative use of vignettes "reorients research towards the meanings respondents ascribe to situations" (Wilks, 2004: 83). Werner also highlighted the limitations of vignettes in her review of lay perceptions of mental health "as such, their conclusions are limited to the responses given to the cases presented and cannot be assumed to be identical to the responses in actual situations" (2005:373). While recognising that the responses in this study are limited to being the self-reported potential responses of participants, the complexity of the data gathered and the confirmation by participants of the meaningfulness of the vignettes, suggests that the data gathered reflected the beliefs and values of participants.

**Ethical Approval**

Overall ethical approval was sought and approved by the ethics committee at the School of Applied Social Science, University of Stirling. Specific ethical approval for the survey was sought by the research team at ARK and approved by the Ethics Committee in the School of Sociology, Social Policy and Social Work, Queen's University Belfast, where the survey coordinator is based.

This study involved members of the general public, and while 'vulnerable' adults, such as those living with dementia were not specifically targeted, it was possible that individual participants might have vulnerabilities not known to the researcher. All efforts were made to ensure that the information provided to participants was clear and unambiguous, and that any risk to participant and researcher was minimised. A copy of the risk assessment can be seen in Appendix 1. As stated earlier, participants in the survey were asked if they would be willing to participate in further research about dementia. When I made the initial contact with a potential participant, I explained the research I hoped to do and what taking part would mean. I developed a phone script (Appendix 2) to ensure I provided all the information the caller would need to make an informed choice and also to ensure consistency. Information sheets were provided to all potential volunteers (Appendix 3). Information sheets were provided again on the day of focus group or interview, and consent forms (Appendix 4) were explained and completed at the same time. At the focus group, participants were asked to consider taking part in individual interviews. A sheet was provided for potential interview participants to enter their contact details (Appendix 5). Their willingness to continue was confirmed by phone or email prior to the scheduling of interviews. The information sheet was issued again at this time, and participants were asked to complete a second consent form (Appendix 4). These measures ensured informed consent (Punch, 1998; Seidman, 2013).

It was possible that the matters under discussion in the focus group or interview could cause some distress. The decision to use vignettes was in part to ensure that participants could gain distance from potentially uncomfortable or distressing emotions. I am a trained counsellor and was confident that should a member of

the group become distressed, I could employ my counselling skills to return the discussion to a less distressing level. I informed participants that should they wish to discuss how they were feeling, I would be available to talk immediately after the focus group or interview. Details of the local outreach services of the Alzheimer's Society were also provided. All of the measures outlined above were taken to ensure that participants were fully informed before making a choice to take part in this research. There was no instance where participants became distressed, although there were participants who had personal and sometimes distressing experiences with relatives who had dementia. There were also a number of older people who were clearly concerned about the possibility that they had dementia. The most difficult part of the process, in terms of ethics for me, was that participants wanted information about dementia and I felt there was a balance to be found between providing some information, and not influencing the process. This is reflected on later in this chapter (page 117).

To ensure confidentiality, scripts were anonymised and quotes used only for illustration. No record of the participants' details appear in the final research documentation. All records pertaining to participants are held in a password protected computer file. Any contact details or consent forms held in paper format are stored in a locked cupboard within my personal office. I also registered with Data Protection for research purposes.

Transcription services were accessed through approved university sources. Any data that I wish to retain post-viva will be transferred to CD and submitted for SASS archiving.

**Methods**

This section of the chapter will detail the methods employed in this study, from sampling through to data collection and analysis. Sampling rationale is followed with details of planning and implementation. The process of planning and collecting data is discussed, and the chapter concludes with details of data management and analysis.

**Sampling Rationale**

In the early stages of this study, I had considered targeting specific groups such as paid carers, unpaid carers, social care professionals, and medical professionals, defining these as different groups within the larger group of the general public. However, as the work progressed I was increasingly aware of the considerable body of research examining attitudes of professionals and carers to dementia. These groups would provide potentially specific understandings when the purpose of the study was to establish what the greater group of the general public understood dementia to be, and how they might respond to dementia. I was more interested in the voice of the person whose views on dementia are much less frequently sought. These are also the group of people who interact with a person living with dementia on a daily basis: the shopkeeper, the bus driver, and the bank official. I decided to focus on this group of people, and to exclude as far as possible professionals who may have worked with people who have dementia. I did consider excluding people who know someone with dementia, but decided against this as my experience suggested that a considerable number of people will know someone who has dementia even where they have not been in a caring role, and I also felt that logistically this would have been difficult to apply.

For the purposes of this study the general public was thus defined as ordinary people living in Northern Ireland, not belonging to the group of health and welfare professionals.  People with dementia were excluded from the study, as the purpose of enquiry was not how people with dementia understand or respond to dementia, but rather how other people respond to them.

### Sampling Stage 1 – NILT Survey

As explained earlier the survey is managed by Access, Research, Knowledge (ARK) and collected by the Northern Ireland Statistics and Research Agency (NISRA). Sampling decisions pertaining to the survey are part of an existing strategy at ARK. A brief summary is provided here but full details can be found at http://www.ark.ac.uk/.

A stratified random sampling strategy was employed using addresses from the Land and Property Services Agency to ensure correct geographical coverage, standard practice in Northern Ireland social surveys (Devine, 2004). People living in institutions (though not in private households in such institutions) were excluded from the survey.  The Land and Property Services Agency provides a good sampling frame of addresses, but does not contain information about the number of people living at an address. Further selection stages were therefore required to convert the listing of addresses to a listing of individuals from which one person is chosen to complete the questionnaire.  The NISRA interviewers listed all members of the household eligible for inclusion in the sample: that is, all persons aged 18 or over living at the address. From this listing of eligible adults, the interviewer's computer randomly selected one adult. This person was then

asked to complete the interview.

*Sampling Stage 2 - Focus Groups*

Northern Ireland covers a geographical area of 5,452 square miles with a population of 1,799,4001 (NISRA, 2010).  In 2007, a major restructuring of the health system took place and four Health Boards responsible for health and welfare provision became five Health Trusts.  These Health Trusts are responsible for health and social care services. Any provision for care in dementia is the responsibility of these Trusts.  2007 Population figures for the trusts are detailed below (NISRA 2007)

**Table 2: Northern Ireland population figures by Trust**

| Trust Name | Population 2007 |
|---|---|
| Belfast Trust | 335 150 |
| South Eastern Trust | 338 482 |
| Northern Trust | 449 628 |
| Western Trust | 295 192 |
| Southern Trust | 342 754 |

At the time of study design, figures were not available for dementia prevalence by the new Trust areas. The Table below indicates the prevalence of dementia by the pre-existing Boards in 2007 (Knapp, Prince et al., 2007).

**Table 3 – Prevalence of Dementia by Board Area**

| Board | 30-64 | 65-74 | 75+ | Total | % of people 65+ with dementia | % of all people with dementia |
|---|---|---|---|---|---|---|
| Eastern | 154 | 994 | 5842 | 6991 | 6.90 | 1.05 |
| Northern | 105 | 642 | 3293 | 4040 | 6.38 | 0.92 |
| Southern | 73 | 425 | 2038 | 2536 | 5.96 | 0.77 |
| Western | 64 | 397 | 1742 | 2203 | 6.27 | 0.76 |

Statistically there is not a significant difference in prevalence across Northern Ireland.   More recent figures became available in 2011 detailing the total number of people in each Trust area with dementia, both diagnosed and undiagnosed. These figures reflect the change in structure to five Trust areas and confirm there is little variance in prevalence across the different Trust areas (Alzheimer's Society, 2011; NISRA, 2010).

**Table 4 – Prevalence of Dementia by Trust Area**

| Trust Name | Number of people with dementia (diagnosed and undiagnosed, 2010) | Population figures 2010 | % of population with dementia |
|---|---|---|---|
| Western | 2522 | 299 431 | 0.84% |
| Southern | 3102 | 358 647 | 0.86% |
| Northern | 4674 | 458 746 | 1.02% |
| South Eastern | 3694 | 346 794 | 1.07% |
| Belfast | 3773 | 335 774 | 1.12% |

However, I was conscious that different experiences of service or care provision across the Trusts might influence how participants respond, and as a result decided to plan a focus group within each Trust area.

A question included in the survey was whether or not participants were willing to take part in further research relating to dementia.  This provided a list of potential participants.   In the event that the list proved insufficient, the following recruitment options were agreed:

- Advertisements in local newspaper
- Leaflets and posters distributed in local health centres, leisure centres and community centres

- Contact with local volunteering organisations to seek assistance in recruiting volunteers

On completion of the survey, the team at ARK provided me with the list of participants who had agreed to consider taking part in a further piece of dementia related research. The first step was to eliminate, as far as possible, professionals working with people living with dementia. The Standard Occupational Classification (SOC, 2000) system[3] had been used to establish occupation among survey participants, and Table 5 details the codes and occupations omitted from the list of potential participants in the focus groups and interviews.

**Table 5: Occupations excluded from focus groups and interviews**

| Code | Occupation |
|------|------------|
| 1184 | Social services managers |
| 1185 | Residential and day care managers |
| 2211 | Medical practitioners |
| 2212 | Psychologists |
| 2442 | Social workers |
| 3211 | Nurses |
| 6111 | Nursing auxiliaries and assistants |
| 6115 | Care assistants and home carers |

The list of potential participants provided by ARK was across Northern Ireland and not by Trust area. To ensure that I had access to groups within each Trust area, I needed to group potential participants by Trust area. Trust information is not gathered as part of the survey data but the District Council area of each participant is included. I attached each of the District Council areas associated with a participant to the relevant Trust area and was then in a position to group volunteers by Trust. Details are presented in Table 6 below.

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[3] SOC 2000 is the current occupation classification system operated by the Office for National Statistics.

**Table 6: District Council Areas within Trust Areas**

| Trust Name | District Council Areas | Volunteer Numbers |
|---|---|---|
| Belfast | Belfast, Castlereagh | 138 |
| South Eastern | Newtownards, Down, North Down, Lisburn | 147 |
| Northern | Antrim, Ballymena, Ballymoney, Carrickfergus, Coleraine, Cookstown, Larne, Magherafelt, Moyle, Newtownabbey | 142 |
| Western | Derry, Limavady, Strabane, Omagh, Fermanagh | 74 |
| Southern | Armagh, Banbridge, Craigavon, Dungannon, Newry & Mourne | 98 |

*Sampling Stage 3 – Interviews*

Interview participants had previously participated in focus groups. During each focus group, I explained to participants that I would like to have a one to one interview with two participants from the group. I advised them that anyone interested could complete the form I had prepared (Appendix 5), leaving their name and preferred method of contact. In four of the groups two or more participants volunteered but in the Western Trust there was only one volunteer. Where there were more than two volunteers the interview participant was selected based on creating balance of gender and age as far as possible. I had initially anticipated a total of ten interviews, two from each Trust area. Where there was only one volunteer in the Western Trust area, it would have been possible to hold an interview with a participant from another Trust. However,

initial analysis of data did not indicate a marked difference in the content of responses from different Trusts and as a result I calculated that the additional interview was not necessary. A total of nine interviews took place.

**Fieldwork**

In this section I will detail the planning for each stage of the fieldwork, details of access and actual data collection. In the case of the survey, details of question development are included, but as data collection was carried out by the Northern Ireland Statistics Research Agency, only summary details are provided here. Full details can be found at [www.ark.ac.uk](www.ark.ac.uk). Data collection during the focus groups and interviews proved a challenging and sometimes difficult process for me. Some of the attitudes expressed by participants were more negative than I had expected and this is discussed in reflections on page 117.

**Survey**

The measures for inclusion on the dementia module were developed in consultation with the team at ARK. A number of other stakeholders (Carers N. I. and DSDC) were also consulted, resulting in two further questions beyond those I developed. Table 7 below provides a summary of the type of questions included in the module.

**Table 7: Survey Question Classification**

| Type of Question | Number of Questions | Range of Responses |
|---|---|---|
| Knowledge of someone living with dementia | 1 | 'Yes ', 'no', 'myself, 'family member', 'friend', 'acquaintance'. |
| Knowledge and beliefs about dementia | 8 | True, false or don't know |
| Characteristics associated with someone who has dementia | 1 | Unlimited selection of words from a list of 15 |
| A series of attitudinal measures on attitudes to people with dementia | 5 | Likert scale from 'strongly agree' to 'strongly disagree', including the option 'can't choose'. |
| Attitudes to risk and safety | 8 | Likert scale from 'definitely' to 'definitely not' including the option 'don't know'. |
| A further series of measures on attitudes to people living with dementia | 5 | Likert scale from 'strongly agree' to 'strongly disagree', including the option 'can't choose'. |

Established tests, such as the Alzheimer's Disease Knowledge Scale were not appropriate for this study. The inclusion of a 30-item knowledge scale would have placed an unreasonable burden on the survey respondents. A total of six modules were included on the 2010 survey and the average time to complete was over 2 hours. Therefore only 8 questions tested knowledge and beliefs. The remaining questions asked respondents to identify which of a set of positive and negative personality characteristics and emotions they would ascribe to someone with dementia, and then explored respondents' attitudes towards people with dementia, specifically examining attitudes towards interaction and participation.

A final series of questions examined attitudes towards levels of independence for people with dementia, and specifically if these varied according to length of time since diagnosis. A total of 29 questions and measures were included on the survey.

Funding for the module had only been agreed at a very late stage and the consequence of this was a very limited timeframe to develop the questions. Great care was taken to avoid specialist and medical terminology, and considerable effort was made to avoid ambiguity. The response options for the knowledge questions were true, false, or don't know, and the majority of attitudes questions were measured on a standard 5-point Likert scale. For all questions, respondents were able to answer that they didn't know. A pilot survey was carried out with 60 respondents and positive feedback was received on the dementia module. One question was considered ambiguous by these respondents and was therefore removed. Details of questions can be found at http://www.ark.ac.uk/nilt/quests/. In hindsight, some of the questions would have benefited from more time to perfect their form and I had concerns that despite the team's best efforts, some questions might be ambiguous. However, analysis of the survey data suggested little evidence to support my concerns. A consistently low percentage of respondents selected "don't know" across the dementia module.

*Access*

Data collection was carried out by the Northern Ireland Research and Statistics Agency between September and December 2010, and involved 1205 face-to-face interviews with adults aged 18 years or over. As already stated, participants were selected from the Land and Property Services Agency sampling frame of addresses.

If more than one eligible adult was living at the address, the computer would randomly select a person to participate. A combination of Computer Assisted Personal Interviewing (CAPI) and Computer Assisted Self Interviewing (CASI) were used. Full details on the fieldwork can be found at www.ark.uk. The data were made available to me in April 2011 in SPSS format.

**Focus groups**

A series of five focus groups were held: one in each of the five Trust areas. When considering the questions and data emerging from the survey, I sometimes recognised limitations in either the way some questions had been phrased or simply in the nature of responses to a survey. I attempted to address this in the focus groups, sometimes in the form of a general question, or more usually by developing a vignette that would allow further exploration of a specific issue. Details of questions and vignettes are included in Appendix 6.

*Access*

As described in the sampling detailed above, I had contact details for a number of potential participants, now grouped by Trust area. Initially I selected a major town in each of the Trust areas and searched for convenient locations that might facilitate a focus group. I began with Belfast Trust, and having provisionally selected a suitable location I began working my way through the contact numbers. I prepared a script to guide the conversation with a potential participant (Appendix 2) and in the first instance I established if the person I was contacting was interested. When I had enough interested participants, I then contacted

people again with a possible date. This proved a lengthy and unnecessary process. I realised I would get a better response by stating the date of the focus group on the first contact and allowing people the opportunity to confirm availability. This was the process I used from that point onwards. I then took their address and sent out an information sheet, with details of the focus group location and time. Having allowed a week or 10 days to go by, I contacted the person again to confirm their attendance. Nine participants took part in the Belfast Trust group, 6 male and 3 female.

The second focus group was scheduled to take place in Newry[4] (Southern Trust). I had difficulty getting enough participants and was forced to cancel this group. I began to realise that I had scheduled the remaining focus groups too closely together. The time expended in the recruitment process was restricting the time available to reflect on the implications of the prior focus group(s), thwarting the aim to allow future groups to be informed by those that had already taken place. With this in mind, I rescheduled the remaining groups allowing much more time between each one. Although the Southern Trust had not gone ahead, I was able to recruit sufficient participants for the South Eastern Trust group. This went ahead in Lisburn with 6 participants, 5 male and 1 female.

When the Southern Trust group had to be cancelled for a second time I decided to review my strategy. I established where the greatest concentrations of participants were living within each Trust area and choose a location in this area. As I didn't have address details, I checked all available landline numbers and then

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[4] Town names have not been anonymised as participants were recruited by Trust rather than town. Trusts cover a large geographic area and neither town nor Trust details could be used to identify participants.

compared this with BT prefixes thus establishing what area people were living in. I then used Google maps to check distances between locations with the greatest number of participants, and selected the location likely to be most accessible. An example of this in recruitment for the Northern Trust is detailed below.

**Table 8: Participant locations**

| BT Prefix | Area | Potential Participants |
|-----------|------|------------------------|
| 02879 | Magherafelt | 6 |
| 02885 | Ballymena | 18 |
| 02827 | Ballymoney | 5 |
| 02829 | Kilrea | 4 |
| 02821 | Martinstown | 1 |
| 02894 | Antrim | 16 |
| 02820 | Ballycastle | 2 |
| 02893 | Ballyclare | 12 |
| 02886 | Cookstown | 2 |
| 02870 | Coleraine | 5 |
| 02828 | Larne | 6 |
| 02891 | Bangor | 2 |

The greatest concentration of numbers in this Trust occurred in Ballymena, Antrim and Ballyclare. Based on the fact that Ballymena and Ballyclare are both approximately the same distance from Antrim, I selected Antrim as the best location and booked a room in the Civic Centre. The Northern Trust focus group took place with 5 participants, 1 male and 4 female.

I used the same strategy in the Southern Trust, and the best location remained the town I had initially selected. On the third attempt I did get enough volunteers to hold the group with 4 participants, 1 male and 3 female.

My first attempt to hold a group in the Western Trust had not been successful. Based on the new criteria detailed above, I changed the location but was still unable to get enough volunteers. At this point I had 200 flyers printed up and I posted these to health centres and community pharmacies in the Trust area, seeking volunteers to take part in a focus group. There were no responses to this, so I then contacted a local volunteering centre that was able to access enough volunteers to facilitate the group. The Western Trust group involved 8 participants, 4 male and 4 female.

The process of recruitment was much more time consuming than I had imagined, running from April to October 2011. The alternative recruitment in the Western Trust meant that this group of people would not have participated in the survey; as described earlier I was unable to recruit sufficient participants from among survey participants so this group were recruited through a volunteer agency. While I would have liked continuity across all Trusts, the recruitment of people from within a volunteering centre could be examined to establish whether there were significant differences in the way these participants responded.

In total 33 people took part in the focus groups and interviews. Background information on participants' characteristics is detailed in Table 9 below.

**Table 9: Background information on participants**

| Gender | Male | 18 | 55% |
|---|---|---|---|
| | Female | 15 | 45% |
| *Age* | 18-30 | 4 | 12% |
| | 31-50 | 9 | 27% |
| | 51-65 | 10 | 30% |
| | 66-80 | 9 | 27% |
| | 80+ | 1 | 3% |
| *Educational level* | Primary | 1 | 3% |
| | Secondary/Grammar | 12 | 36% |
| | Third level | 20 | 60% |
| *Working Status* | Unemployed | 2 | 6% |
| | Training Course | 4 | 12% |
| | Working | 12 | 36% |
| | Semi-retired | 3 | 9% |
| | Retired | 11 | 33% |
| *Know someone with dementia* | Yes | 14 | 42% |
| | No | 19 | 58% |
| *Health* | Not so good | 2 | 6% |
| | OK | 6 | 18% |
| | Good | 12 | 36% |
| | Very good | 13 | 39% |
| *Socio Economic Status* | In difficulty | 1 | 3% |
| | Struggling | 3 | 9% |
| | Doing OK | 28 | 85% |
| | Doing very well | 1 | 3% |

At each focus group, I distributed the information sheets again, answering any queries. Participants were asked to complete a demographic questionnaire (Appendix 8) and a consent form (Appendix 4). I clarified issues relating to any of these, as they arose.

*Data Collection*

Focus groups proved particularly challenging at a logistical and personal level. The process was incredibly time consuming and frustrating. Having a pool of almost 600 participants I had naively believed it would be relatively easy to set up 5 focus groups when, in fact, as detailed above it proved difficult. Each focus group was challenging and interesting. At the beginning of the groups I asked participants to be as frank as they felt comfortable with, and explained that my aim was to explore what they thought without censorship or judgement. I was surprised at the level

of frankness. Participants were unaware of my personal situation, and there is no doubt that on occasion it was difficult to hear some of the things being said. The day after the first focus group I was visiting with my mum and found myself simply crying for the entire visit. It was only in supervision that I became truly aware of the personal impact and at this point I sought the support of my counselling supervisor as planned. More detail on this process can be found on page 117.

As would be expected in a focus group, some voices were stronger and more strident than others. I managed this to the best of my ability making a conscious effort to offer the opportunity for participation to more reticent members of the group. This met with varying degrees of success. Most groups commented on the value of the vignettes as a way of stimulating discussion although I did decide to remove some of the vignettes after the first two focus groups. The first group in Belfast lasted over 2 hours. On reflection I realised that this was too demanding on the group. I looked at the data and removed vignette 1 (Appendix 6). This vignette had triggered a discussion that moved away from dementia and instead prompted participants to hypothesise about what might be wrong with the character under discussion. The second group was still long and demanding on participants so at this point I removed vignette 2 (Appendix 6), that had not stimulated a great deal of discussion. At this point I also made a number of adjustments to the vignettes based on feedback from participants.

While it had been difficult to recruit participants, when they took part they were very interested in the topic and this provided its own challenge. Many participants were seeking information about dementia and regarded me as the expert. In the first focus group I found myself answering more questions than I felt comfortable

with, and in the groups after this I was careful to remind participants that I was not an expert and had no medical knowledge. However, I felt there was a balance to be struck. It was not unreasonable for participants to expect some information in exchange for their time so I carefully explained that my aim in the focus groups was to gather information, but that if they had any questions I was happy to answer these at the end of the session. This worked well although naturally there were still instances of participants asking questions during the process. I grew more confident in managing these as the process continued.

**Interviews**

*Access*

At the beginning of each focus group I advised participants that I hoped to facilitate two interviews with members of the group. I had prepared a sheet for potential volunteers to add their name and preferred method of contact (Appendix 5). I suggested they decide at the end of the focus group if they were interested in taking part in an interview, and when the focus group was over I reminded them again. In four of the focus groups at least two people volunteered and for one group only one volunteer came forward.

*Data Collection*

Setting up the interviews was a much less complicated process. For the most part, interviews took place in the participants' homes. In the Western Trust they took place in the same volunteer centre as the focus group, and one other participant from the South Eastern Trust asked that it take place outside his home. This interview took place in a local civic centre.

Initially I had hoped to complete all focus groups before beginning the interviews. The delays in setting up focus groups forced me to rethink this approach. In consultation with my supervisors it was agreed that I had enough data from the first two groups to inform the interviews from within these groups. This resulted in interviews and focus groups taking place within the same timeframe. Some interviews were lengthy, but others quite short, and I had some anxiety that I was creating adequate opportunity for the participant to talk about the topic. On analysis there was nothing to suggest that I inhibited the process. In one interview the participant was rushing as she had another appointment and I was influenced by her need. In hindsight it might have been better to have rearranged this interview for another time.

**Data Management and Analysis**

This section will discuss how different datasets were managed and analysed.

**Survey Data**

Survey data were analysed using SPSS (Version 19). Descriptive and summary statistics were produced. A series of categorical bivariate relationships were tested (Chi-square) and tests of association (Cramer's V) were completed. Details on all variables tested are provided in Table 10, page 140 but the variables that proved significant across datasets were gender, age, education, and knowing someone with dementia. For further comment on all variables see Mc Parland, Devine, Innes & Gayle (2012). Initial analysis of the survey data was useful in developing vignettes and later in guiding the early development of themes from focus groups

and interviews. Early descriptive statistics highlighted the significance of certain attitudinal statements; for example relating to the notions of a disappearing self. Vignettes 5 and 6 (Appendix 6) took account of this by creating a story of a person finding out they had dementia, then moving into care and needing help with all daily living activities. Early analysis also highlighted questions or statements that warranted further exploration through interview. For example, survey data suggested that a large minority of participants believed people with dementia could be best cared for in a residential or nursing home, but the reasons were unclear, so questions about where people with dementia live and should live were included to explore this in the focus groups (Appendix 6).

**Focus Group and Interview Data**

The early work to begin analysis of focus group and interview data began while data collection was still in progress and while the survey data were still being analysed. I made the decision to send the focus group audio recordings to a transcription service. This was a pragmatic choice based on making best use of my time, but I transcribed the one to one interviews. The transcription process itself provided the first glimpse of emerging themes in the qualitative data and this work coincided with the return of some focus group transcriptions. I read and reread the transcriptions, often playing the audio while I worked. This process allowed me to get a better sense of the data, taking account not just of the talk taking place, but also of the tone and the context. The result of data collection continuing to take place during the early stages of data analysis was a total immersion in the process. The interplay created the opportunity to develop emerging themes across

different sources and to inform the ongoing data collection e.g. through amendments to vignettes. The result was a much more organic analysis with no dataset being analysed in isolation.

The choice to use NVivo to manage qualitative analysis was based on it being the programme recommended by the University, and that it is arguably the most popular computer aided data analysis system in use today. NVivo is a complex software analysis system and I received two different types of NVivo training that I will reflect on further, later in this chapter (page 117).

NVivo proved very useful for managing a large and quite complex set of data, and Bazeley (2007) suggests if computer programmes can be used to record, sort, match etc., then this enhances the data analysis process. Bryman (2008) reminds us that the attraction of rich qualitative data also brings the difficulty of a large cumbersome database. Transcribed focus groups and interviews were imported into NVivo 9 (QSR, 2013), and at this point I was faced with the reality of Bryman's caution when I considered the scale of the analysis process both within NVivo and across the survey dataset. NVivo supports the organisation of data in a number of forms. These include sources and nodes. Sources in this instance included all primary sources of data such as interview and focus group transcriptions. Nodes are used to store, manage and categorise themes, and are in effect a coding system. Case nodes hold all participant related information from any source. A case node was created for each participant and a table of participant demographics (Appendix 8) was created and imported. This demographic information was then linked to the case nodes. Creating this link to demographics allowed for limited quantitative analysis of variables on qualitative data.

*NVivo – A Relational Database*

NVivo is a relational database facilitating the linking and analysis of information prompting the identification of themes.  Links can be made between different types of information and in this thesis the following data types were linked

- Sources

- Classifications

- Memos

- Journal Articles

Memos were used to make notes on identified codes (nodes), to record analytical strategies and to give context to sources where applicable.


**Coding Framework**

Nodes hold data that have been coded from a primary source against a specific theme or code.  All of the nodes were created and defined by the researcher and as suggested by Bryman (2008) I began to code early, beginning with early ideas of general themes and then reviewing and developing these as detailed in Figure 2 below.  A full list of NVivo coding can be found in Appendix 11.

**Figure 2 – NVivo Coding Process**

**Phase 1- Open Coding**

Themes derived from survey data

Further development of broad, participant driven, descriptive coding]

**Phase 2- Re-evaluation of open coding**

Codes re-ordered, renamed and merged as appropriate.

Categorised under emerging broader themes

**Phase 3 - Selective Coding**

Deeper analysis of emerging themes and categories.

Creation of sub categories e.g. positive/negative

**Phase 4- Consolidation**

Consolidation of existing codes and elimination of less significant codes

Organised under significant codes with attached sub-categories

**Phase 5- Summary statements and Analytical memos**

Production of summary statements relating to lower level codes

Production of analytical memos at thematic level

**Phase 6- Findings**

Run querys to test findings

Analytical memos cross checked against data

Synthesis of all phases to produce findings

An example of this process can be seen in the figure below.

Figure 3 details a selection of open codes being re-evaluated and re-categorised under Deviance and Stigma as selective codes:

**Figure 3: Coding Example**

| Living Shell | Euthanasia | Fear | Labelling | Quality of Life | Infantilisation |
|---|---|---|---|---|---|

**DEVIANCE**

| Living Shell | Embarrassment | Social Distance | Labelling | Sadness | Infantilisation and role reversal |
|---|---|---|---|---|---|

| Value | **STIGMA** | Views of late stage dementia |
|---|---|---|

| Aggression | Dignity | 'Other' | Unpredictability |
|---|---|---|---|
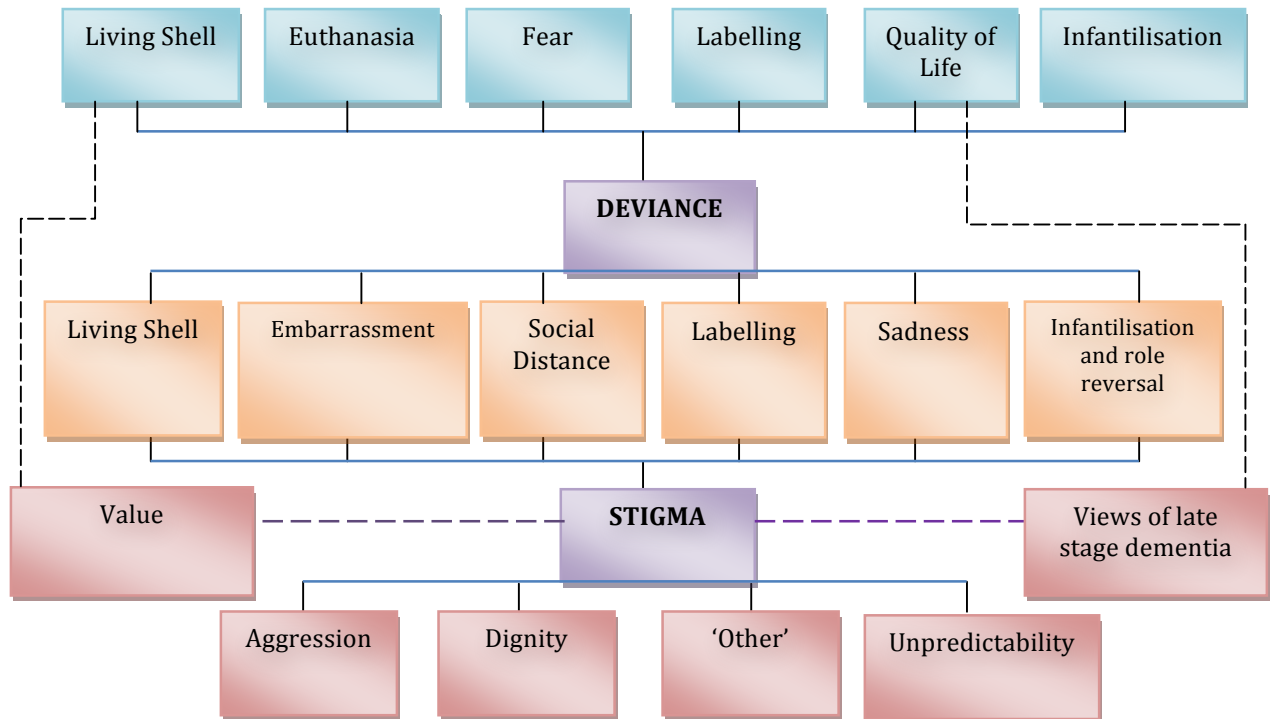
At the point of consolidated coding (Figure 2), the codes that were to drive the early drafts of the findings chapter had emerged: age and ageism, knowledge and understanding, nihilism and stigma. Full details of open, selected, and consolidated coding can be seen in Appendix 11. The process detailed in Figure 2 is not as discrete as it might appear, but is in fact more inductive in nature. Quite often these stages ran alongside one another or the generation, for example, of a summary statement or analytical memo in phase 5, may have prompted me to revisit phase 4 and so on.

Additionally the analysis of qualitative data often returned me to the survey data for further analysis and comparison, and vice versa. This process of cross checking was an intrinsic part of analysis; I wanted to minimise the risk of bias and ensure rigour in the process. I also wanted to take advantage of having different data sets, checking for difference, or validation, and taking account of the setting within which the data emerged.

**A More Complete Analysis**

While NVivo was extremely useful for the management and analysis of the data, it is a data management tool, and cannot replace the personal engagement with the data that is required from the researcher. The process is only as robust as the researcher. "It is important that researchers recognise the value of both manual and electronic tools in qualitative data analysis and management and do not reify one over the other but instead remain open to, and make use of, the advantages of each" (Welsh, 2002:5). In addition to the process described in Figure 2 within NVivo, I also used more visual processes reverting to pen, paper, coloured cards, and a large floor space to organise my thinking. This was particularly useful after the initial round of coding, and again as part of a mapping process after major themes had been identified. This process involved creating cards for all of the themes and sub themes I had identified. I used colour coding to group themes and ideas. I then placed these out over a large space and initially just looked at them regularly. I then began to organise the cards, grouping together themes and shifting sub themes around. I also created paper links between themes where I saw potential relationships, and by the end of the process I had rejected a number

of themes that no longer seemed relevant or had been subsumed within another theme. On the occasions where I used this process it had the result of freshening my relationship with the data, and I returned to NVivo to translate these ideas into the database.

Further caution was required in ensuring the contextualisation of data. Sections of transcript attached to a particular node could have been easily misinterpreted unless they were checked within the original source for context. There was also no substitute for listening to the audio and placing a particular piece of text in the context of the actual interaction. This allowed for consideration of tone and pace, which often changed the interpretation of a piece of narrative. While NVivo, as described above, provided a structure to examine the data, the most useful feature of the system for me was the easy access to the transcript, so that I could consistently return to the participants' talk. Having created a code, I would return to the transcripts associated with this code and create appropriate sub codes. This iterative process took place throughout analysis. This process is perhaps less easily quantified within data management tools, but is essential in terms of analysis. Throughout analysis I used all of these methods to ensure data, while analysed thematically, took account of context and interaction.

I was mindful of the need to consider the dynamics of the focus groups and interviews throughout analysis. These were not groups who had already established connections so there was no sense of a previous shared identity. Rather these individuals had come together as a group to discuss the topic of dementia. Given that 4 out of 5 groups had already participated in the survey and agreed to consider participating in further dementia research, it was likely, but not

certain, that the topic was what prompted their participation. Thus from the point of view of analysis this was a group of individuals sharing a momentary common focus. "Focus groups like dyadic interviews should be regarded as interactive and communicative events" (Hyden & Bulow, 2003:319). In line with Smithson's (2000) suggestion that focus groups should be viewed as a performance, I did not assume that the opinions voiced during the process were necessarily views they had formed prior to attending the group, but rather that these emerged during interaction as discourse in the context of the group. This does not detract from the issues and themes arising, as the theoretical framework of this thesis is one of social constructionism.

Data analysis was a lengthy and often complex process as the emerging data were rich and multi-layered. The multiple sources of data did, as hoped, allow opportunity for triangulation, and also provided a more complete picture of what the general public know and believe about dementia. A survey alone would have provided valuable information, but would not have allowed this study to delve into the beliefs and values informing the attitudes expressed. The focus groups and interviews provided rich and detailed data, but could not alone have provided the demographic strength of a large-scale survey. As such the methods employed served their purpose in the exploration of how the general public understand and respond to dementia.

**Reflections**

This was a mixed methods study involving the collection and analysis of both quantitative and qualitative data. The survey data were collected by the Northern

Ireland Statistics and Research Agency and passed to me in SPSS format for analysis. It was the collection of qualitative data that proved challenging at a personal level. While my experience suggested that the attitudes of the general public were generally negative, I was not prepared for just how negative they proved to be. As described earlier in this chapter, the first focus group proved particularly challenging, and I found myself crying through my next visit with my mum who was living in care. My mother at this point personified many of the images being discussed by participants. When I realised the impact the data collection was having, I raised this in discussion with my supervisors, as I was aware this could impact on the process. As I am a qualified counsellor I had a counselling supervisor already in place and I accessed her support to work through any issues arising for me. This work did not entirely negate my response to participant attitudes, but it allowed me to take advantage of my existing skills and knowledge to place some distance between what was being said and my personal experience.

This study is informed by social constructionism and as such acknowledges that both participants and researcher create the knowledge gathered here. In the early stages of data collection it was obvious that participants viewed me as 'expert' and certainly initially as 'medical expert'. I addressed this explicitly in ensuing groups, but I doubt that I dispelled this perception entirely. The questions asked were often medical referring to how dementia is classified, what drugs are available, and the possibility of cure. This could be argued to evidence the ongoing dominance of the bio medical model, with participant expectations of 'expert' clearly linked to medical expertise and/or knowledge. To some extent the perception of the

researcher as 'expert' is a natural occurrence during a staged interaction where the researcher is the person introducing the topic of discussion.

I was also aware that I could be perceived as sympathetic and while I made every effort to communicate a neutral stance, this sympathy may still have been communicated at some level. I believe my skills as a counsellor may have gone some way towards balancing this affect. In a therapeutic environment my role is to create a space where a person can explore difficult and often uncomfortable issues without fear of judgement. Thus despite my personal sympathies, the data suggest that participants were willing to reveal potentially unsympathetic and less socially acceptable views.

During analysis I was perhaps overly anxious that my personal situation or sympathies would not 'interfere' with data analysis, and this prompted a very robust approach to analysis detailed in this chapter. These cautions around the influence of my personal situation do not negate the positive affect they may also have had. The ongoing relationship with my mother before she died kept me grounded in the lived reality of the impact of dementia. I was reminded daily of the importance of completing a piece of work that was relevant and timely. This delicate balance was something I negotiated throughout the process.

There are a number of issues outside of the impact of my personal journey worth reflecting on here. One of the focus groups (Western) was recruited through a volunteer agency as already detailed in this chapter. These participants did not take part in the survey. There was no notable difference in the type of responses evidenced in this group. There were a greater number of younger people in this

group and their opinions were in line with that of younger people in other groups and in the survey.

In terms of analysis, I used NVivo 9 for data management and analysis. I found this a very useful tool but it is also a complex tool. I had initially received training at the university but the training occurred some time before my data were ready and it concentrated on the mechanisms of the programme rather than its overall place within qualitative analysis. When I initially began to use the programme, I really struggled to work out how to make best use of this tool in terms of my analysis. I made the decision to purchase a one to one training programme, and I am confident that without this level of training I would not have been able to take best advantage of such a software programme.

**Summary**

In this chapter I have outlined how the theory of social constructionism has influenced the methods I chose to complete the study and the data analysis process. Ethical issues pertaining to the study and the process of gaining ethical approval have been documented. I have discussed the rationale behind each of the methods, including sampling, access, recruitment and data collection. Data analysis decisions and process have been described, and the chapter concludes with some personal reflections on the process.

The thesis thus far has described my journey to undertake and work through this study, documented the literature I believed relevant to the topic, outlined research design decisions and the process of data collection and analysis. In the next 2

chapters, I will outline my findings.  While the study has employed three different methods of data collection, the findings will be presented thematically, referencing the different sources of data.  This allows each theme to be explored discretely with supporting evidence. However, what emerged in analysis was the interwoven and complex nature of how the public understands and responds to dementia.  The themes both contribute to, and are driven by each other, and the final section of chapter 5 will consider evidence of this complexity.

# Chapter 4: Public Understandings

The data within this study on how the general public understands and responds to dementia is both complex and intricate. Multiple themes weave through the findings and I will outline the decisions I have made to present these discretely while acknowledging the relationships between them.

Table 10 below, introduces the chapter, providing detail on respondents' knowledge and beliefs gathered during the survey. This is followed with detail on how the chapter will be structured.

**Table 10: Respondents' knowledge and beliefs about dementia** (adapted from Mc Parland et al., 2012)

| | % reporting 'true' | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Dementia is a disease of the brain | Dementia is a mental illness | Dementia is part of the normal process of ageing | Dementia is another term for Alzheimer's | People who eat healthily and exercise regularly are less likely to get dementia | There are drug treatments that help with dementia | There are many different kinds of dementia | Dementia can be cured |
| **All** | 94 | 54 | 28 | 58 | 29 | 75 | 72 | 6 |
| | | | | | | | | |
| **Sex** | *(V=.078) | **(V=.112) | | *(V=.073) | ***(V=.124) | | | *(V=.085) |
| Male | 92 | 60 | 29 | 55 | 35 | 75 | 70 | 8 |
| Female | 96 | 49 | 27 | 61 | 24 | 76 | 73 | 4 |
| | | | | | | | | |
| **Age** | **(V=.108) | ***(V=.143) | ***(V=.143) | ***(V=.176) | ***(V=.161) | ***(V=.127) | *(V=.095) | |
| 18-24 | 90 | 74 | 16 | 35 | 16 | 67 | 68 | 6 |
| 25-34 | 95 | 59 | 23 | 52 | 24 | 65 | 78 | 7 |
| 35-44 | 96 | 56 | 23 | 59 | 24 | 75 | 77 | 6 |
| 45-54 | 96 | 47 | 24 | 60 | 32 | 84 | 71 | 4 |
| 55-64 | 94 | 41 | 36 | 60 | 31 | 82 | 69 | 4 |
| 65-74 | 94 | 50 | 42 | 71 | 41 | 79 | 66 | 3 |
| 75+ | 87 | 63 | 42 | 74 | 53 | 68 | 65 | 12 |
| | | | | | | | | |
| **Marital status** | *(V=.076) | ***(V=.107) | *(V=.081) | ***(V=.108) | | *(V=.075) | | |
| Single | 93 | 67 | 24 | 51 | 24 | 68 | 67 | 7 |
| Married/ civil partner/ cohabiting | 95 | 50 | 28 | 58 | 32 | 78 | 74 | 5 |
| Separated/ divorced | 93 | 52 | 37 | 68 | 24 | 76 | 67 | 4 |
| Widowed | 89 | 54 | 36 | 71 | 32 | 84 | 66 | 8 |
| | | | | | | | | |
| | | | | | | | | |
| **Occupation** | | **(V=.104) | | | | | **(V=.104) | **(V=.110) |
| Non manual | 94 | 51 | 26 | 56 | 30 | 77 | 75 | 3 |
| Manual | 94 | 57 | 30 | 59 | 27 | 73 | 66 | 8 |

| | Dementia is a disease of the brain | Dementia is a mental illness | Dementia is part of the normal process of ageing | Dementia is another term for Alzheimer's | People who eat healthily and exercise regularly are less likely to get dementia | There are drug treatments that help with dementia | There are many different kinds of dementia | Dementia can be cured |
|---|---|---|---|---|---|---|---|---|
| **Educational qualification** | *(V=.094) | *(V=.088) | ***(V=.163) | ***(V=.165) | | **(V=.107) | ***(V=.13) | *(V=.092) |
| Degree | 97 | 48 | 26 | 51 | 30 | 85 | 79 | 4 |
| Higher education | 95 | 51 | 16 | 53 | 25 | 77 | 76 | 4 |
| A level | 94 | 58 | 23 | 50 | 28 | 73 | 79 | 6 |
| GCSE A-C | 94 | 59 | 22 | 57 | 29 | 70 | 74 | 2 |
| GCSE D-G | 91 | 56 | 30 | 64 | 29 | 82 | 61 | 7 |
| No quals | 92 | 55 | 42 | 69 | 33 | 83 | 62 | 9 |
| | | | | | | | | |
| **Know someone with dementia** | | **(V=.092) | | **(V=.107) | | ***(V=.134) | *(V=.087) | *(V=.083) |
| Yes | 94 | 50 | 28 | 63 | 28 | 82 | 76 | 4 |
| No | 94 | 57 | 28 | 54 | 30 | 70 | 68 | 7 |
| | | | | | | | | |
| **Carer** | | | | | | | | |
| Yes | 94 | 54 | 28 | 58 | 30 | 74 | 71 | 6 |
| No | 93 | 54 | 28 | 59 | 27 | 80 | 73 | 4 |
| | | | | | | | | |
| **Religious Denomination** | | | | ***(V=.097) | | | | |
| Catholic | 94 | 53 | 30 | 64 | 27 | 74 | 77 | 6 |
| Protestant | 93 | 55 | 27 | 58 | 29 | 76 | 68 | 5 |
| No religion | 96 | 55 | 24 | 44 | 32 | 79 | 72 | 4 |

*: p<0.05, **: p<0.01, ***: p<0.001
(Cramer's V in brackets)

This chapter will begin by covering a number of sections that address the first research question:

1. What does the general public understand dementia to be?

These sections are; seeking information, sources of information and what the general public understands dementia to be. Also included in this chapter are a number of sections more closely aligned with question 2:

2. What factors influence this understanding?

These are public perceptions of dementia and growing old, public perceptions of care, shame and secrecy, and dementia as a hopeless condition.

A complex mix of empirical and theoretical knowledge will be evidenced, and I will explore how the general public often holds apparently contradictory beliefs.

The ongoing complex discourse around dementia evidenced in the literature review was also evidenced in this study. The narrative of the focus groups represents a microcosm of the narrative taking place among the general public; the telling and retelling of stories that are placed in the context of individual and group experience, and then incorporated into or disregarded from a belief system. This fixing of beliefs (Peirce, 1877) takes place within the already well-established, almost exclusively nihilistic, bio-medical model of dementia. It is this model that

has been legitimised (Berger & Luckmann, 1966), and forms the framework within which the general public understands and responds to dementia.

The fist section below will examine the sources of information that have informed participants' understanding about dementia. Participants confirmed that they have not sought out information on dementia, but the first section of this chapter documents their responses to where they might seek information if they needed or wanted to know more. This section then goes on to document the sources participants suggest have influenced their current understanding of dementia. This includes the media, anecdotes of other people's experiences, and personal experience. These experiences are usually communicated in the form of stories.

**Seeking Information**

There is no evidence to suggest that participants seek out information about dementia until it becomes a personal concern or a concern for someone close to them:

*SEFD: "It's one of those big almost taboo areas in society, it's like cancer. No one actively seeks it out unless there is a reason needed, or you absorb it without really thinking about it, watching a TV programme or magazine article or newspaper article, but its em people go blissfully along and not really seeking it out until there is some."*

When participants did consider looking for information, the sources of information differed according to context. The most commonly reported source was the

Internet. This was closely followed by the GP although participants made the point that they would not seek information about someone else, such as a family member or friend, from their GP:

*NFA: "I don't know where I would go, we don't use the Internet. Probably ask the doctor's advice."*

*SFJ: "I think it would have to probably be, in my case it would have to be someone related to you before you go to the GP, I don't know."*

*BFF: "The doctor would probably give you a booklet on it, cause he's not gonna tell you anything else about anybody else's condition, cause usually in a GPs there's brochures on it."*

*SFG: "And you would feel you were taking up the GP's time if you were going to them, if it wasn't an issue for yourself."*

Participants reported they would visit the GP if the concern were personal:

*BFJO: "You tend to go to the GP with your own issues, rather than with somebody else's issues."*

Other sources mentioned were the Alzheimer's Society, the health centre, community centres, and a small percentage reported they would use the phone book as they did not feel confident about using the internet.

Having asked participants to consider where they might gather information about dementia in a general, quite abstract sense, participants were then asked to consider what they might do in the event that dementia became a personal possibility.

**When Dementia Becomes Personal**

Two questions explored participants' responses if dementia were to become a personal possibility. These revealed something of the more instinctive response of participants and what they associate with dementia:

1. Imagine you have recently found yourself forgetting things and sometimes feeling quite confused. You are worried that something might be wrong. What do you think you might be feeling and what might you do?

2. Imagine you have been given a diagnosis of Alzheimer's disease.
   What are the words that come to mind when you hear this? What are the
   feelings?

Almost without exception participants focused on the feeling aspect of the first question, but in terms of what they might do, they referred again to the GP:

*NFJ: "But I think I would go for medical help at that stage. Go and talk about it with the GP or something like that."*

*SFG: "Be fearful what the future held for you, and you would at that stage, I would say you would be going to talk to your GP".*

Some participants expressed concern about going to the GP:

SEFJ: *"But you feel maybe I'm stupid going to the doctors, maybe just the age process that you are in."*

SEFJ indicates a concern that the doctor will associate the symptoms with ageing and this discussion goes on to highlight a concern that nothing will be done:

SEFER: *"The other thing you know, if you, say you turn round as you're sitting in the early stages you're finding that you're forgetful, that sort of thing, you go to the average doctor and say eh I'm starting to forget things here. What's the, what's the chances of anything being done?"*

SEFD: *"I would say very little."*

And that the limits on a GP's time might also impact on getting an accurate diagnosis:

SEFER: *"No I don't, I would think at the moment you have ten minutes with your doctor. That's it, he wants you in and now right enough the ones that we are with now at this point, they are very good, but I wonder if you came with the situation like that and you said look I'm starting to forget things."*

SEFE: *"I don't think they would pick up on."*

The evidence supports existing literature (Milne, Woodford, Mason & Hatzidimitriadou, 2000) in suggesting the GP's role is vital, but also indicates that participants were unsure how helpful the GP would be. Some participants reported they would seek support from family and friends before contacting a GP. This support was sometimes described in terms of checking out the validity of their concerns:

*SEFE "Probably talk to family who had experience of it."*

WFV: "*I would talk to my friends and tell them to take me to the doctor or, you know, just these wonderful people, just.*"

SFJ: "*Well I might maybe talk to some family members and see, did they notice anything in my behaviour or whether they thought I was forgetful as well, and did they think I need to pursue it as SFG said, going to see your GP or whatever, just something.*"

The second question focused on what participants might feel and the words that came to mind. Below are a selection of key words and phrases that featured in the responses to both questions across focus groups:

*Scared, panic, worry, angry, frustrated, concerned, frightened, devastated, preparing for the future, gutted, focus on other things, denial, go out with somebody a lot younger than myself, act the goat* (fool around)*, worst feeling in the world, find out what help there is, sad, talk to friends, see the GP, see a counsellor, tell your mum, confused, embarrassed, nothing you can do, look for solutions, worry, suffering.*

These responses cover the actions participants reported they might take and the way they reported they might feel.  There is significant evidence of fear and other distressing emotions – devastation, sadness, and panic.  There is no evidence of hope or optimism, and the two humorous references "go out with somebody a lot younger than myself", "act the goat" (fool around) were made by older people, who indicated during the group that they sometimes worried that they might have dementia.  These could be viewed as a way of distracting from the very real sense of fear being described by other participants.

During the interviews, I developed this further by asking participants what words or images came to mind when they heard the words dementia, demented or Alzheimer's.  Below is a summary of the key words and phrases used:

*Forgetfulness, loss of memory, driving round and round in the car, not knowing where to go home, not knowing anyone around you, forgetting names, you lose yourself, fear, sadness, they stop worrying, you can be OK for a while, finds everything funny, repeating yourself, wandering, needing to be fed, shouting, not responding, no concept of time, violent, agitated, lost in yourself, not even knowing really who they are.*

The words and phrases used here are again overwhelmingly negative.  The phrase "finds everything funny" could be argued to be less negative, but when considered in the context of the story being told the picture remains an overwhelmingly negative one:

*WIH: "After this lady's husband's accident it really seemed to take over, losing her purse, taking things from her cutlery drawer and saying people had stolen them, and she found them up in her dressing table in her room… (Goes on to describe the lady going into care). Whatever sort of dementia she had **everything was very funny**. But for my friend it was soul destroying, because she couldn't take her home and because her mother no longer knew her."*

Below are other quotes to give context to the words and phrases used above:

*SIG:" **People who can't feed themselves**, who can't… **who don't know who they are**, who if they get out of the house **they wander away**, things like that."*

*SEIT: "They remember certain things, but very little of I suppose the intimate relationships they would have had eh, with their wives, their children or whatever. **They just don't remember those things**, it's gone **and yes they can function to a certain degree, but it just gradually gets worse and then they can't function."***

*WIR: "When **you say demented and connect it with dementia its, well its sounds horrible doesn't it, obviously demented, not of right mind**, I suppose is how you would think of linking those two words together. It's not really how I would link them, but I would think **confusion, and then loss of faculties and not being able to look after self or be independent and live an independent full life."***

SIG conjures up an image of total helplessness and both SEIT and WIR focus on loss and inevitable decline.

In these last two quotes, the participants talk about how the words dementia and Alzheimer's trigger fear for them. Both of these participants were over 65yrs:

BIC: *"Well I think **as you get older it puts fear into your mind**. That's the first thing. All of us are **frightened of getting Alzheimer's or dementia** and that is usually it puts a sort of a fear into you, you know, and then wee (common word for little or small) **things you do and you forget things and you think, Oh God, is this gonna start this, you know that type of thing."***

SEIE: **"It could affect me, that's what comes to mind**, *immediately. How would I react,* **who's going to look after me, who's going to help me, how are my family, how are my three children going to respond to it? Am I going to be a burden on people, you know, where am I going to go,** *you know, that sort of thing."*

On reflecting over all of the words, phrases and stories shared in this section, they present a confusing, frightening picture of dementia associated with tragedy and loss. In responding to these questions, participants revealed much of what they instinctively associate with dementia, and in the next part of this chapter I will consider some of the sources of participant understandings of dementia.

**Sources of Knowledge**

Although as detailed above most participants had not actively sought out information about dementia, the early questions in the focus group suggest participants do make particular associations with dementia. There is already evidence of particular negative beliefs associated with Alzheimer's disease and

dementia. Participants report the sources of this knowledge as personal experience, anecdotal evidence in the form of other people's stories, and the media. On occasion participants communicate knowledge and beliefs about dementia that are contradictory. This is most evident in participants awareness that dementia is a condition that can affect younger people while they consistently discuss it as something that happens to older people. While many participants began by saying they knew very little about dementia, almost everyone had a story to tell about someone they knew, or someone they had heard about with dementia. The next section in this chapter will detail evidence of the media as a source of knowledge on dementia, and will then document the use of stories to both understand and communicate about dementia.

**Media**

Participants indicated that the television was a source of information and while general references were made to newspaper articles, more frequent references were made to television programmes or personalities:

*NFP: "I think it does yes, because I think when you don't have any personal*

*experience of your own you can watch it on the TV."*

Over twice as many negative as positive references were associated with the media. These more negative associations were inclined to be dramatic. They included references to programmes highlighting poor care in nursing homes and

this will be explored later. The programmes referred to did not necessarily relate directly to dementia care, but clearly triggered associations with dementia care:

*BFJ: "But they could put you in a nursing home, that's really iffy, like there's been a lot about that in the news in the last couple of days."*

*Patricia: "There has"*

*BFJ: "It's quite scary."*

*BFP: "The one in Bristol."*

*BFJ: "Oh the one that was on the news the other day, that was for the young people."*
(Murmured agreement about how awful it was).

Participants also drew on stories about TV personalities:

*SEFJ: "Because I remember Peter Suchet said it, Peter you call him, it was a newsreader and he was saying that his wife Bonnie or someone, that when she started putting dirty dishes back into the cupboard and things again, he knew then that it was really serious."*

Some participants referred to the documentary on Terry Pratchett:

*BFC: "Well we mentioned Pratchett, what is it Pratchett (other people give the name – Terry), Terry Pratchett, and he's still able to read and so on and so forth."*

*BFJ: "Terry Pratchett seems to be, you know that author? He seems to be quite vocal about it all, so maybe, it sounds awful, but maybe a high profile sufferer can highlight it."* (Nervous laughter while talking).

Participants also referred to storylines in television soaps:

*BFJ: "They nearly tried to make, I don't really watch Coronation street, but do you remember when Mike Baldwin was in it and he had dementia and they tried to make it quite funny, you know. Leanne, the girl he was going with, you know they tried to make it quite funny. I suppose it was funny to an extent, but it wasn't. I mean it's not really funny, but they tried to bring you know more light heartedness to it."*

*BFP:" I suppose it's quite good sometimes. Is it Jim in Eastenders, is he?"*

References were also made to new drugs or treatments referred to in the media, but participants were often unclear on the details:

*WFR "I'm just aware that recently I heard something on it; they're going to do research on it, on curing it, just recently, wasn't it? Or is that maybe just hoping?"*

*SEFT: "Well I read in the paper, the daily mail, that, maybe a few days ago, that there's a pill there which will keep you feeling younger, but you won't look any younger. But it will keep you feeling healthier shall we say, and you will get older without maybe getting Alzheimer's or maybe getting any other diseases so."*

Apart from the more emotive media presentations of dementia, participants reflected that television reports on dementia are unlikely to register with them unless they have a specific interest in the topic:

*SFJ: "And even if there is something in the media, it goes over your head unless you know someone that has it. Really that information means nothing to you unless you know someone."*

After an interview with one participant (SIM), she commented that there had been something about Alzheimer's on television that she simply would not have heard before the focus group. She felt it caught her attention as a result of having attended the group. This particular participant had relatives with dementia but was not in a direct caring role.

In summary the knowledge or information that participants reported from the media included frightening care situations, stories of confusion or loss, humorous stories, and vague recollections of drug treatments. The sources included documentaries, soaps, and newspapers.

**Stories**

The primary source of information for participants is stories, and almost all participants in focus groups and interviews used stories to contextualise their understanding of dementia. Sometimes this was a story of personal experience and sometimes it was one that had been passed on by a relative, friend or colleague. These stories sit at the core of the narrative during focus groups and

interviews; they are the medium used by participants to convey what dementia means to them.  As participants told their stories, others frequently accepted these as validation of their own experiences or as supporting stories they had heard before.  Occasionally others in the group challenged a story, but this was the exception rather than the rule.

Below are three stories I am including as examples.  The first quote is from a participant who tells two consecutive stories of people living with dementia.  The first prompted much laughter among the group but when examined it portrays quite bizarre behaviour, and the second story conveys a picture of a very distressed person also behaving bizarrely.  The participant also highlights the immediate availability of stories on dementia  *"within minutes these stories were coming out of my colleagues"*:

*BFP: "At lunchtime today at work, I was saying I was coming here this evening and within minutes these stories were coming out from my colleagues.  One of them was saying that their aunt was fixated on this Christmas dinner that one of the cousins ate, and then when she saw the cousin – where's my Christmas dinner?  It's in there* (pointing to his stomach). *I want it back,  and everyone starts laughing so it reminds me, and there's a French teacher who's Nan got dementia, and at a wedding she started screaming all these things out so."*

The next story told below also prompted laughter among the group, but again the subtext to the story is danger and confusion:

*SEFT: "Yeah I think the worry could vary, from country to country and this is the story, and it's apparently true and some years ago I was in South Africa and knew some people, and they told us this story that this lady went to the supermarket in her car. Parked the car and went in, got her stuff, came back out, car was gone! So she starts walking home carrying the bags and she's stopped at a pedestrian crossing, they call them robots, eh, and a car drove off and she saw two black guys in it, and she says that's my car! So she had a gun in her bag as some of them do in South Africa, that's just the way it is. She took the gun out, and went up to the car and says get out. The two black guys got out; she got into the car and drove home. And she got in and she told her husband, and he looked at her and he said you didn't take the car! And she said ooh, and went to the police station and told the police this story, and when they went to the police station the two black guys were in the police station reporting what had happened. Now that apparently, now it sounds funny."*

In this final story the participant is clearly moved by the situation a relative found himself in when his mother developed dementia. The story conveys a frightening and sad situation:

*SFM: "Just myself, my brother-in-law's mother was diagnosed just there at Christmas and she just seemed to have gone downhill, now she was 82, but she went downhill very quick and she was a sprightly woman, very fresh, and she just went from being diagnosed, and out on the street, couldn't be left alone. He was in an awful predicament, he was over here and he only had one sister over there, and she basically had to go into care, and she was only in about a month and died. Just really drastically from seeing her at Christmas chatting away and then the lady is dead.*

*It was such a shock to realise that someone could go downhill from being having a normal conversation with you, to not be able to dress, screaming in the street, didn't even know where she was, and her neighbours had to go out, it must have been very frightening for that person, awful."*

Other stories told were much more general, less a description of an actual event and more in the form of reminiscence. Participants referred to older people in days gone by, when what is now understood to be dementia might have been referred to as 'doting'. The first quote below evidences the participant's memory of people being cared for *"they are fed and looked after and cared for,"* but also that there was no expectation of much more *"and nobody bothering very much with them"*:

*NFA: "I think when you're growing up you do remember old people in people's houses, sitting in the corner, and nobody bothering very much with them, because they are fed and looked after and cared for, but they don't talk any more. I do remember people like that in their homes."*

The next quote from WFH reminisces about a time when she feels people with dementia were more accepted and there was less fear:

*WFH: "I mean when I think of it now, as a child growing up we had quite a few people doting, but they were nobody to be afraid of or embarrassed about or anything else, and somewhere along the way we have lost that".*

There was an undercurrent of nostalgia attached to these descriptions, but when examined these are less comforting images than participants were perhaps trying to convey.  As can be seen from the quotes above, the 'acceptance' being described is of people with dementia being there, but *"being in the corner".*

Of all the stories used in the focus groups and interviews, none could be described as presenting a positive image of dementia.  Some might be argued to be neutral in terms of dementia, representing nostalgia for a different time and a different approach to care, but when examined more closely they suggest an acceptance of people with dementia as being somehow outside of our world, there, but not there. Some stories such as the ones told above by BFP or SEFT were humorous, but it could be argued the humour is a tool to create distance between the person and the story itself, as the story is in fact a picture of confusion and fear. Overwhelmingly the stories told were of tragedy, loss, confusion, and sadness. The retelling of the stories to other participants often stimulated agreement with the picture portrayed, and thus consolidated the views held in the group.  They also served to contextualise responses to vignettes or direct questions, allowing insight to the beliefs lying behind participant responses.

In summary there is no indication that participants have sought information about dementia but when asked where they would look for information most people would use the Internet.  When they were considering where to go for help or advice the most common response was the GP.  However, there were concerns, particularly among older people, that the GP would link symptoms to ageing and that the limits on a GP's time might negatively impact on provision of good support.  When asked to consider where the knowledge they have comes from,

participants identified stories told by other people, personal experience, and the media. The stories told and the language used by participants evidences an overwhelmingly negative and nihilistic understanding of dementia, in line with the current bio medical model. While the media has clearly influenced understanding, it is the experience of participants, and the stories of others' experiences that seem to have had the greatest impact on how participants understand dementia, and this empirical knowledge is perpetuated in interaction. The next section of this chapter will examine in more detail what participants know and believe about dementia.

**What The General Public Understands (knows and believes) Dementia To Be**

I will begin by considering the evidence of knowledge and beliefs gathered in the survey, and then explore the data relating to this gathered in focus groups and interviews. As already described, the first stage of this study was a survey of 1200 adults across Northern Ireland. In terms of knowledge, the survey was used to explore basic knowledge of dementia. While knowledge of dementia symptoms or progression was not explicitly explored in the focus groups or interviews, this did come up in discussion and will be explored here. The survey began with a series of statements that aimed to elicit what participants know and believe to be true about dementia. Participants were asked to respond 'true', 'false' or 'don't know' (see Table 10, page 121).

Survey data indicated a fairly widespread understanding of the features of dementia in line with current clinical definitions. Ninety four percent of those surveyed recognised dementia as a disease of the brain, and 91% that it cannot be cured. However, 54% also selected as true "dementia is a mental illness". Thus a

considerable number of participants recorded dementia as a disease and also as a mental illness. This was reiterated in the focus groups and interviews where participants referred to these and other related terms in the context of discussing dementia. Participants referred to madness, mental health, mental illness, loss of mind, and loss of mental faculties more frequently than to brain disease. In the first quote below, SEFE evidences his uncertainty about what dementia is:

SEFE: *"But, this is a disease of the mind, is it really?"*

But later he indicates knowledge of Alzheimer's as a brain disease when he describes the use of a scan for diagnosis:

SEFE: *"There's an early brain scan that they do now."*

BFT also queries the use of scans indicating an awareness of dementia as a disease:

BFT: "*How do they diagnose it, what type of dementia you have, is it just a brain scan?*"

In the next quote a younger participant (18-24yrs) is talking about whether or not someone should be told their diagnosis and refers to not telling him *"he's going like mental":*

WFB: *"Maybe just tell him he was sick, kind of thing, and not tell him, you know, he's going, like, mental, kind of thing."*

And in the following quote NFJ refers to 'them' as being *"mad."* Responsibility for this opinion is passed to *"people"*, allowing the speaker to distance herself from what is being said. This is something that occurs throughout the focus groups and interviews and will be discussed in more detail later:

*NFJ: "And people's ignorance of dementia. I mean I'm like you I don't really know an awful lot about it, but people say they are all mad."*

The next set of quotes evidence references to mental health and mental illness. BFP suggests that some people repeat themselves as a result of their mental health or age, highlighting not just the association between dementia and mental illness, but also with age and this will be discussed later in this chapter:

*BFP: "Some people do go on and on about things whether it's their age or mental health."*

*BFJ: "It's maybe easier with a broken arm or whatever which is a much more clinical situation whereas issues of mental health."*

In a discussion about the potential placement of a volunteer with a diagnosis of dementia NFJA describes people with "mental illness":

*NFJA: "It's reasonable if the degree of dementia isn't severe at this stage. Usually in those situations the workers are supervised. The ones with mental illness and that who go out to work, but they are all well supervised, so why wouldn't it work?"*

During her interview BIC refers to losing mental capacity making the link with losing her 'self':

BIC: *"I think a lot of people fear, you know if you lose a leg or something like that you can still go about, but if you lose your mental capacity you're not you anymore, what do you do then, you know?"*

The evidence suggests that participants do not differentiate between brain disease and mental illness reflecting a general ambiguity about not just the nature of dementia, but also the nature of brain disease and mental illness.

The survey also explored participants' awareness of risk factors for dementia. Only 29% of survey participants recorded as true that "people who eat healthily and exercise are less likely to get dementia". Categorical bivariate analysis indicated the influence of age and gender on this variable. The pattern in terms of age was not clear (p<.001, Cramer's V=.161), although only 16% of those in the 18-24yrs age groups recorded this as true compared with 46% of those over 65yrs. Men were significantly more likely than women to record this as true (p<.001, Cramer's V=.073). There was no question relating directly to this in the focus groups or interviews, but it is worth noting that no participant raised this in any context during the collection of qualitative data. Participants did make references to potential causes of dementia, but these had no link to diet or exercise; rather they were anecdotal. For example the quotes below demonstrate a belief that the brain will not work properly if it is not stimulated and active. This is not surprising given recent media advertising for brain training and games, and the often quoted 'use it or lose it':

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*WFT: "Well I believe there's pretty much doubt with those who are pretty much in - because if they don't have any social activities or anything like that, their mind starts to go, and then...that's why I believe that Alzheimer's kicks in."*

*SEFI: "I was going to say that I think someone who lives alone and is lonely, and hasn't got very much contact with other people, then I would think they would suffer at an earlier age, because of that they don't have the stimulation to, eh, move on."*

Another participant in an interview indicates his surprise that someone who he regards as *"bright and intelligent"* can get dementia:

*SEFE: "You get it from that programme last night; it was on there saying who is it, Pratchett? He's a very bright and intelligent guy you know, but he has written books and he is writing books, and he keeps on going and he's a super mind, and he's got Alzheimer's and you'd think it wouldn't that type of guy at all for he's a very eh agile brain, that he wouldn't get it, but it does come to someone like him you know?"*

Another participant indicates a belief that mobile phones have an impact:

*NFJA: "It's these phones burning the ear off them."*

In his interview BIF suggests that dementia exists in us all to some extent. His understanding is the instances of forgetfulness experienced by most people are dementia that may or may not develop fully:

*BIF: "Nobody knows what happens, down the line. Everybody's got a wee bit of dementia in them anyway cause it's not the first time I've put, where'd I put them keys?"*

So while participants mused on who or why people may get dementia, there was no reference made to the potentially increased risk as a result of unhealthy diet or lack of exercise.

Three quarters of those surveyed knew that there were drug treatments available to help with dementia, and those who know someone with dementia were significantly more likely to know this, 82% compared with 70% ($p<.001$, $V=.134$). There were a number of references to drugs and treatments of dementia in the focus groups and interviews and some of these have already been referred to in the earlier piece on media sources of information. As with earlier references, participants referred to drugs or treatments in a vague and often confused way. There was no indication of a clear understanding of the current use of drugs in the care of someone with dementia. Rather there was a sense of the existence of drugs that could be used with little understanding of what the drugs could actually do:

*SFM: "But the early diagnosis, if you have an early diagnosis of it isn't there some drug now they can give?"*

*SEFJ: "I can't remember whether I looked at the leaflet in the doctors or it was in some book, and there if the early symptoms, if you go to your doctor they can sort of work out and start you on these tablets, and it sort of puts it on the backburner type of thing."*

The following section is taken from a focus group discussion that developed when participants were considering how they might feel and what they might do, if they were concerned about symptoms that might indicate a dementia. BFJO asks about possible treatments, but also refers to an awareness that as people age they will deteriorate:

BFJO: *"I suppose you would, I mean is there a medical treatment that would stay the progress or help out through drugs or whatever, again I just don't know, I mean I'd like to find that out. I'm not saying* (pauses) *progression of life is that we all deteriorate. I'm not closing my eyes to that."*

BFT: *"I think there are certain drugs that slow it for a while, there's no cure."*

BFC: *"No cure."*

Patricia: *"No."*

BFJ: *"Wasn't there one that was supposed to be very cheap, only a pound a day or something?"*

Participants comment on there being no cure for dementia, supporting the survey where only 6% of participants thought there was a cure, but also indicating very little understanding of pharmaceutical interventions for dementia beyond the fact that some drugs help slow the progression. In an interview with BIC who was a participant in the same focus group, she again refers vaguely to "various tablets" and voices her wish that a cure would be found quickly:

*BIC: "If they could hurry up, and I know they're working on various tablets and various things for it. I wish they would hurry up quick before I* (laughs)*. I think I'm still alright so far, hurry up* (sings this), *you know that type of thing."*

72% of survey participants recorded as true that there are many different kinds of dementia, and 58% recorded as true "Dementia is another term for Alzheimer's". While there was evidence of awareness that dementia and Alzheimer's are linked, there was no evidence in the qualitative data that people understood there were many different types of dementia. Comments pertaining to the different types of dementia were limited to Alzheimer's disease and dementia specifically and indicated confusion rather than clarity.

While the first quote below reflects how the merging of Alzheimer's and dementia described in the literature review was experienced by this participant, it does not suggest an understanding of what this means, and the other quotes below evidence ongoing confusion:

*SEFP: "I think eh, my mother had in the eighties through to nineties, and, but at that stage the dementia and Alzheimer's were two separate things, now everything's lumped under Alzheimer's."*

*BIF: "He finished up, started up with dementia, went into Alzheimer's that's what he died of, Alzheimer's, didn't know* (unclear), *didn't remember anybody, didn't know anybody, it was sad you know."*

*BFD: "I'm not really sure if dementia is the same as Alzheimer's."*

*BFJ: "Dementia and Alzheimer's aren't the same thing necessarily, are they?"*

*SFG: "Just on that there, we talk about dementia and we talk about Alzheimer's, are they one and the same?"*

Participants sometimes asked about the difference between Alzheimer's disease and dementia and where this occurred I provided the information. One of the vignettes included a character with vascular dementia and this also sometimes prompted a request for clarification. However, outside of these examples no specific reference was made to different types of dementia.

Categorical bivariate analysis on survey knowledge statements indicated the significance of a number of variables. Respondent age emerged as significant in terms of all knowledge statements, but in the main this was not a linear progression. Exceptions to this were in response to the statements in Table 11 below.

**Table 11: Knowledge statements by age by where linear progression is evidenced.**

| Statement | % recording true | |
|---|---|---|
| | **18-24 yrs** | **65yrs+** |
| Dementia is part of the normal process of ageing | 16% | 42% |
| Dementia is another term for Alzheimer's disease | 35% | 72% |
| People who eat healthily and exercise regularly are less likely to get dementia | 16% | 46% |

Cramer's V indicated a weak association in all cases.

Gender was significant against some but not all knowledge statements and again when tested using Cramer's V the association proved weak. Education proved

significant against almost all knowledge statements with a general pattern indicating that those with lower qualifications had a different understanding to those with higher-level qualifications. Cramer's V indicated weak associations. For a full overview of initial survey data analysis, see Mc Parland et al. (2012).

In considering survey data specifically, most respondents were able to answer 5 or 6 of the knowledge questions correctly but only 3% answered all 7 correctly. This was examined in more detail (Dowds, Devine & Mc Parland, 2012) by categorising participant responses as low (four or less correct answers), medium (5 correct answers) and high (6 or 7 correct answers). A number of variables are worth mentioning here; people age 65yrs or over were much less likely to score highly than those in the 18-24yrs group; 32% of those aged 18-24yrs had a high score compared with 19% in the 65+ group. 34% of those educated to degree level or higher scored highly compared with 14% of those with no qualifications. There is correlation between these results as older people are more likely to have left school with no qualifications.

While it could be said that the survey indicated participants have a reasonable knowledge of dementia, this is not borne out in the qualitative data. This may in part be down to the survey only offering the opportunity to record true, false or don't know. In the context of a discussion in the focus groups or a conversation during interviews it was possible to get a more nuanced picture of participants' understandings.

In summary participants are unclear about the distinction between mental illness and dementia specifically, and mental illness and brain disease in general. There is limited understanding that the risk of developing dementia may be modified through diet and exercise. The survey indicated that participants are aware of drug treatments to help with dementia, but the focus groups and interviews suggest that participants have little understanding of what these treatments might be or how they might be used. While the survey suggested that participants are aware that there are many different kinds of dementia, participants in the focus group did not refer to any type of dementia except Alzheimer's disease and were confused about the difference between Alzheimer's disease and dementia.

While most of the knowledge statements in the survey and related data from focus groups and interviews have been explored above, the statement related to dementia as a normal part of ageing was excluded so far. The link between dementia and ageing in the minds of participants demanded a more detailed analysis as it is a thread running through the data. In the next part of this chapter I consider this link as participants have conveyed it.

**Participants' Understanding of Dementia and Ageing**

The theme of age emerged as significant in all data sources. The data suggest there remains a great deal of confusion about ageing and dementia, with the general public remaining unsure whether dementia is simply a part of growing older or something entirely different. Participants' understandings of dementia were consistently placed within the framework of an older population, with the stories told of dementia almost exclusively involving older people.

The association between dementia and ageing was initially explored in a survey knowledge statement. Twenty eight percent of survey respondents recorded as true "dementia is part of the normal process of ageing" with 69% recognising this as false. Bivariate analysis suggested a number of variables were significant for this statement; the most notable being age with the figure recording this statement as true rising to 42% among the over 65s.

**Table 12:** *"Dementia is part of the normal process of ageing"* **by age**.

| Dementia is part of the normal process of ageing | |
| --- | --- |
| **Age** | **% recording true** |
| 18-24 | 16 |
| 25-34 | 23 |
| 35-44 | 23 |
| 45-54 | 24 |
| 55-64 | 36 |
| 65-74 | 42 |
| 75+ | 42 |

Education also proved significant with 42% of those with no qualifications recording dementia as a normal part of ageing compared to 26% of those educated to degree level or higher.

While Alzheimer's is now classified as a condition that can occur in younger people, the risk of developing this or another type of dementia increases with age. Table 1, page 38 detailed the increasing prevalence of dementia according to age. This risk moves from 0.0094% in the 30-34yrs age group to 5.9% in those aged 75-79yrs, and 20.3% in the 85-89yrs group. Thus while the message to members of the public is that dementia is a disease of the brain and not a normal aspect of

ageing, the public are much more likely to have met someone with dementia who is older.

While almost a third of survey respondents regarded dementia as part of the normal process of ageing, ninety four percent of respondents recorded as true that *"dementia is a disease of the brain".* Thus a percentage of those surveyed have recorded dementia as a disease and as a normal part of ageing. There was evidence of confusion in this area in all focus groups and interviews. The excerpt below is an example of how participants "know" that dementia can happen to anyone, but "think" of it as something that happens to older people. This contradiction is an undercurrent throughout the narrative, with the knowledge held in an abstract form that does not impact significantly on the experiences people have:

*NFP: "You probably do I think and I'm not really sure why, I think age is a major factor, and I think that's probably because we are of a generation that think Alzheimer's and dementia only happen to old people."*

*NFS: "And it's part of growing old anyway."*

*NFP: "I don't know whether that's what everybody thinks, but I do think we are of a generation where we think Alzheimer's and dementia only happens to old people, I know it doesn't."*

In the next quote, a participant indicates a developing awareness that dementia is not just something that happens to older people, but something that can happen to anyone at any age, as she describes it " like any disease":

NFJ: "At one stage I would never have thought anybody under seventy could have had, but now you realise it can strike at any age, it's like any disease."

The next quote takes place during an interview where the participant is talking of his own worries about getting dementia, as he grows older.  The participant is unclear about whether or not this is normal as he ages, or a symptom of dementia:

SEIE: "It's so unknown, and I don't know a lot about it, but it's so debilitating, and really, you seem to lose all control, and, you know, what's going to happen to you? I suppose you'd be like that, as you get older, anyway, I don't know."

In the next quote, a participant evidences how strongly the notion of dementia as something that happens to older people is ingrained.  She is describing a situation involving her friend's mother:

NFP: "I don't know, because recently one of my friend's mother, she is getting older, you know, this is the perception of mine, **she is getting older, she was starting to forget things**, I just thought well she has stopped working now and has no focus in life, and she footers about and she makes tea and all the rest of it.  **That will come to us all**.  That's possibly not the right attitude to life, and then very recently someone said to me, but did you not know she had dementia and I went what?  I didn't, I genuinely didn't, it had never crossed my mind, not in a million years and then I

*thought, so what exactly is this dementia because I didn't even really know what it was.* **Yes, okay, she is getting forgetful, she doesn't do much in a day, but I just thought that was an age and stage in life,** *and I was really quite like, oh my goodness, really I was quite shocked when they said did you not know?  I didn't see it; I didn't know what I was looking for."*

The participant indicates how until very recently she completely accepted some of the symptoms of dementia as a normal part of ageing.  Another participant in the same focus group also evidences an understanding of dementia as part of ageing:

NFS: *"And it's part of growing old anyway."*

In another focus group, a participant makes an association between the ageing body and dementia:

BFT: *"You must remember people with dementia; their body is usually pretty old too."*

However, the same participant later points out to other members of the group that dementia can occur in younger people:

BFT: *"Did you ever hear of Rita Hayworth, she died of dementia in her fifties?"*

While the vignettes I used included examples of younger people with dementia, the stories told by participants were almost exclusively about older people.  I examined the data for examples of where the narrative indicated an association with ageing, and also for where this was not the case and participants indicated an

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understanding of dementia as something that could happen to younger people.

The pie chart in Figure 4 below details the weight of the referencing:

**Figure 4: Narrative associating dementia with ageing.**
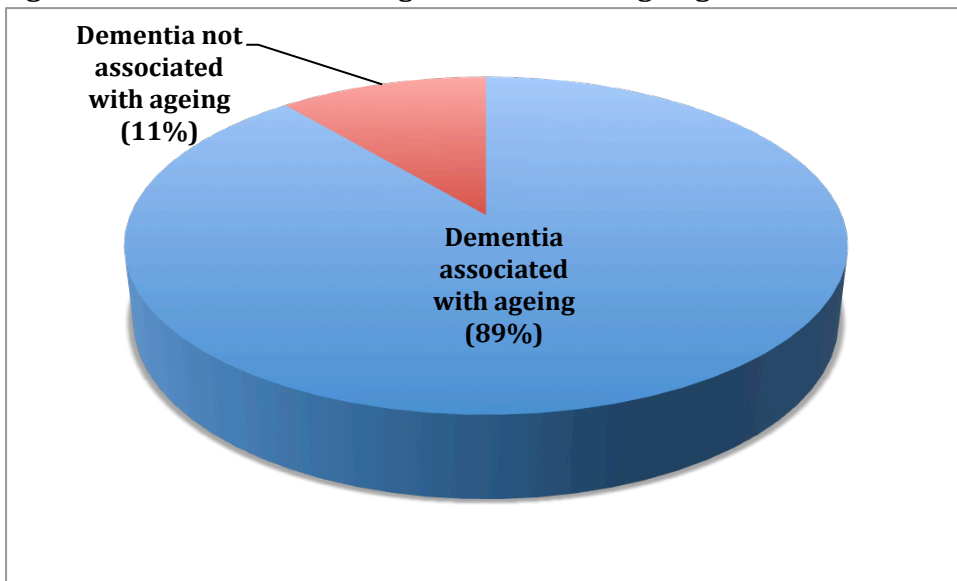


Table 13 below shows that the age of the participant emerged as significant with 51% of the references associating dementia with ageing being made by those in the 66-80yrs groups, compared with 21% in the 51-65yrs groups, and 28% in the 31-50yrs group.

**Table 13: Dementia as a normal part of ageing by age group.**
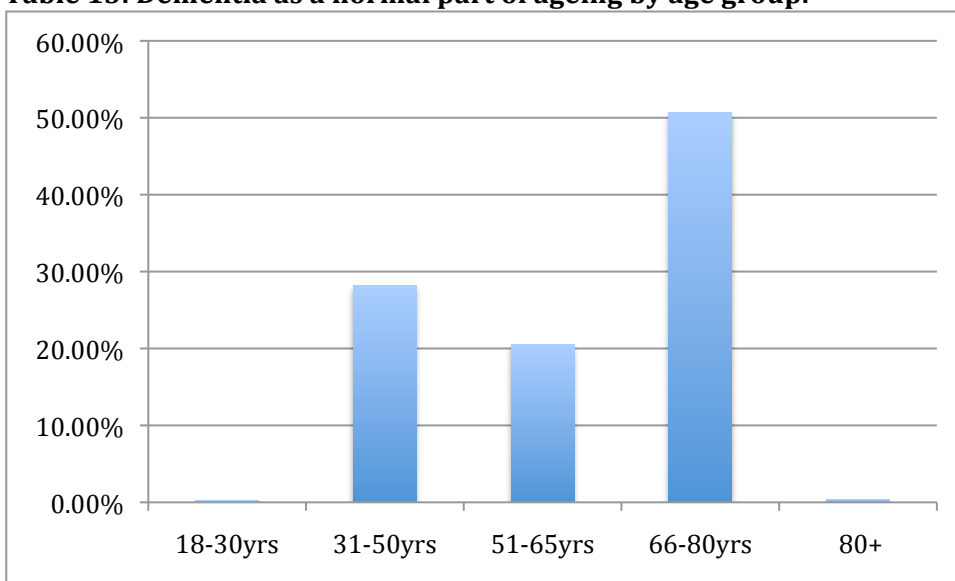
This supports the data from the survey detailed earlier, where the number responding true to the statement *"dementia is a part of the normal ageing process"* rose to 42% among those over 65yrs.

As already described, some of the narrative was explicit in associating dementia with ageing, but more often it was implicit. The following two quotes from focus groups are examples of the implicit association with older people:

*WFDE: "Aye, because I remember my **granddad**, he more or less forgot everybody near the end." (Participant age - 18-30yrs).*

*BIF: "Aye, my eh, my eh, **brother's wife's father** had, he had dementia." (Participant age 51-65yrs).*

It became clear that when people think about dementia, the images they access to contextualise their understanding are overwhelmingly of older people:

*BFJ: "She used to accuse me of stealing her teeth, and I'd say **granny** I've got my own teeth, what would I want with yours."*

*BFD: "Yet I've seen another couple went to (name),....**older** folks, both in a similar situation, when the wife died, they had to put the **daddy** into a home."*

*SEFJ: "Some people if they can't accept it. There's a man in the church and he, he has it, but his wife will say you know he's got Alzheimer's, but he doesn't know it, but she says we just have to keep an eye on him. He's quite **elderly,** but he ..."*

There are some references to younger people, but these are notable because they are unusual in the narrative. In the quote below NFA speaks about knowing that younger people get dementia, but she sets this in the context of her concerns about dementia as she grows older. She talks of getting to that stage, associating dementia with an age and stage rather than a disease. She is also expressing her personal fear:

NFA: *"Well we would be the oldest here and it's all sort of in the back of your head as you're getting older, because you hear of other people getting to that stage and being in that stage, and I would be relying on the tablet, apparently there is some medication you can get that delays it or can help to delay it, well we would be coming up to that. But I do know other people who are a lot younger than we are who have dementia. I know people who are in their very early, or late fifties, early sixties who have dementia and very badly, they're just not with it now, and it's the saddest thing."*

The next quote indicates that the participant was prompted to remember the younger person with dementia as the discussion developed. It was not an immediate response, but one that was a triggered by this quite in-depth discussion on dementia. The group was discussing whether or not someone should be told their diagnosis and I had asked if the age of the person made a difference:

SFG: *"The more we talk here the more things I remember, there was a guy I knew about 10 years ago had Alzheimer's, and he took it when he was about 50, and he was really aggressive and he died when he was 60."*

The link between the images of dementia in the minds of the participants and ageing is clearly well established. There is a further complexity to these images in that they are associated with older people who have had dementia for a long time or whom some would describe as being in the later stages of dementia:

WFR: *"You just feel somebody gets dementia, they get old, slowly or quickly but the mind goes, no longer able to look after themselves. Family can't or don't look after them."*

This suggests that the vulnerability and lack of agency associated with dementia are associated with a period in life rather than the impact of disease. Another participant whose grandmother had dementia describes below what her mother says about growing old:

BFJ: *"You know I don't want to live to be too old because I can remember my mum being very forgetful and if you live to be too old, that's how people remember you."*

Below, an interview participant responds to a question about what are the images that come to her mind when she thinks about dementia:

NIP: *"I just, I didn't really know, I mean I think I've only ever been in a nursing home once in my life, you know to have a look around and I was with a friend visiting a friend, and I couldn't have pinpointed in there the people who had dementia and the people that didn't so I couldn't have, because the people all just looked old to me and what is the difference from being really old to having dementia or Alzheimer's or*

*whatever. There obviously is a big, big difference, but you know I just don't know, I think it must be something very difficult to have to deal with."*

This represents the continuing tension between what participants know (dementia is a disease of the brain that can affect anyone) and what they believe (dementia is part of growing older). NIP acknowledges there must be a big difference between being old and having Alzheimer's but points to her experience that she couldn't tell the difference. It is also worth noting that her response immediately set dementia within the context of a nursing home. In another focus group, the participant below was responding to a vignette about visiting someone with dementia in a nursing home. The vignette concerned a person with dementia who now needed help with all of their daily living activities:

*SEFJ: "It's the loneliest place. I've visited elderly neighbours where I was when I was young and they were all neighbours when I was young when I lived in the house then, and I had gone to different homes and everybody's just sitting. I had an elderly aunt in, and I had a neighbour of mine who was ninety nine coming at the end of this month and she's in a home and eh they all just sit, it's the loneliest place, and it's either they are just sitting now like zombies, they are comfortable enough, but there's no real conversation between them you know?"*

While SEFJ is referring to older people and not necessarily people with dementia, the comment is made in response to a vignette about a person with dementia living in a nursing home. She describes them as comfortable enough, but also like zombies. The fact that she refers to older people as "zombies" in response to a question about someone with dementia suggests she may be attaching the

characteristics she associates with dementia, to older people living in care. This characterisation is consistent with the idea of creating an image of the old and in this case specifically people with dementia as different from us (Bytheway & Jonson, 1990; Jonson, 2013). The link between images of care and images of people with dementia will be considered later in this chapter, and the association between zombies and dementia (Behuniak, 2010) later in the thesis.

In summary the link between ageing and dementia is well established in the minds of participants. Participants associate dementia with older people. To some extent this is to be expected as the risk of developing dementia increases with age, and the experiences people have had with dementia generally involved older people. However, there is some merging of the characteristics people attach to those living with dementia and to older people in general. This stereotypical view of a person with dementia has implications in terms of the day to day interactions people have with someone living with dementia, and in the way we provide support and care for people living with dementia. The next section will focus on how participants talk about the provision of care and care environments.

**Public Perceptions of Care**

This section will explore perceptions of care among participants. The decision-making and actions described in participant stories of support and care also serve to highlight attitudes to safety and risk for people with dementia. This will be discussed in chapter 5. This section serves to highlight the link between participants' negative perceptions of care environments, and understandings of dementia. It also suggests that participants more easily identify with carers than a

person living with dementia.

The evidence discussed earlier indicates that the images participants have of people with dementia are of older, frail people with very advanced dementia and generally living in a formal care environment. Dementia related policy in Northern Ireland has acknowledged a built in bias towards the use of nursing and residential care here (DHSS, 1991; DHSSPS, 2007). This may go some way to explaining why many participants refer to experiences of people with dementia within care environments.

When asked to consider where people with dementia should live, participants suggested that people with dementia should be supported to live at home, but they also believed that this was not always a realistic possibility:

*NFP: "We don't live in that ideal world."*

There was also reference to experiences of inadequate support or services and the perceived lack of choice in terms of care:

*SEFJ: "Where he lived in xxxxxx he couldn't get a package for to bring the wife home and in the end he had to put her in a nursing home."*

In another group there was considerable discussion about where people with dementia live with many of the group pointing out that it depended on what 'stage' the person was at. The participant below suggests that choices are more limited when dementia is advanced. It is also worth noting that the participant refers to

support in a medical context "different types of nursing care":

*BFC: "I suppose it kind of depends how far along the line you are. There's different types of nursing care offered at different stages. When it gets near the end, you know it's not so good then. You don't have a great lot of choices about where people go."*

There was a general sense that while people should be cared for at home, this could only happen up to a certain point in terms of the 'stage' of dementia:

*SEFJ: "Until they actually become a danger to themselves."*
*SEFE: "Until you can't go on."* ('You' refers to the carer).

*SEFD: "If it had reached the stage where eh you couldn't, they got aggressive or they couldn't be kept you know by normal means, in their home."*

It is unclear what SEFD understands by *"normal means"* but the implication is the decision is related to the carer's ability to manage the situation. In another group the theme of carer burden is articulated:

*BFT: "I know a bloke did that for ages and ages, but at the end of the day he just couldn't do it anymore. She was turning violent as well. He couldn't handle it anymore."*

BFD describes a younger man who had dementia and became aggressive:

*BFD: "It was for his own safety because he was smashing doors down and everything*

*to try and get out. If you stood between him and the door you were going to get hit.*
*That's what she told me. So they just had to put him in."*

Participants are empathising with the carers in the situation more readily than the person with dementia. This empathy is evident in discussion where participants suggest that dementia is often worse for the family, and people around the person with dementia than for the person themselves, particularly where dementia is more advanced:

*BFJO: "Yes well I've seen the spouse take the biggest end of the load often to the detriment of their own health."*

*BFD: "I don't really know I'm just throwing this out, that it's nearly, it's nearly worse for the family."*

*NFJ: "It's one of those things it's probably harder to watch someone maybe than actually be the sufferer, once you get to that stage. The beginning will be harder on the sufferer."*

*SFG: "I think the people who are watching it, those are the people who are suffering."*

The following excerpt raises the question of quality of care suggesting that care environments are task driven:

*WFR: "But it's not a life with the condition he's going through, wherever he is, but I think even in a residential – this sounds terrible, but he'll be just...well, maybe a bit*

*more than a number, but do you know what I mean, the people coming in and doing what's needed to be done and away again. Well no love, certainly, even if there is care, there'll be no love for him in wherever he's living."*

*WFD: "Aye, just a job."*

*WFH: "And I don't think he would have a quality, really......there would be no quality of life there, even though they are caring and probably doing their best for..."*

*WFR: "But what is the best, if you're just running from one to another and doing duties; stripping beds, changing people, feeding people, and that's, you know."*

When it came to images of care environments participants' perceptions were overwhelmingly negative. The following conversation was triggered by a comment about a relative who *"had to be put into a home because he was getting sort of agitated"*. This reminded participants of a television programme and the excerpt below illuminates many of the fears expressed about care environments, from the overuse of drugs to the association with a zombie like existence:

*SEFER: "He was and then the other thing is too, now I can't remember whether it was, it was on the television, and there was a person there who I think had something like that, and he was put into a home and whatever drugs they'd given him."*

*SEFJ: "Aye that was on the television, he was like a zombie."*

*SEFER: "Before he went in he could walk, he could more or less look after himself."*

The group goes on to talk of the overuse of drugs to control patients generally:

*SEFJ: "That's what they said, most of the homes, 90 percent of the people don't need those drugs, but then for the staff they give them a good night's, they get them all like that, they are like zombies."*

In another group BFD tells the story of a lady he knew who had dementia.  He describes a woman who occasionally got mixed up:

*BFD: "Her only problem was that she would have turned up for a hairdressing appointment on the wrong day."*

He goes on to describe how the family was worried and she was placed in a nursing home:

*BFD: "I never seen anybody go downhill so quickly in my life."*
*…………………… "and I've just seen other people so distressed in nursing homes."*

This lady's deterioration is linked in the mind of the participant to her entry into a nursing home, as are the images of distressed people.  A similar story emerged during a participant interview where a friend's mother had started to behave strangely, *"getting up to dance by herself and sometimes wearing odd shoes or two watches".*  WIH describes the family intervention and the lady's admittance to hospital:

*WIR: "She went from being a little bit odd to being put straight into xxxxx and inside*

*a week she hadn't a clue where she was."*

SEIT describes how a relative was sent to an institution for assessment when she had dementia:

*SEIT: "You've heard of Chris Rea, the road to hell, that's what xxxxxx called the road to xxxxxxx................she went in there and she came out worse than she went in"*

Below SEFI describes how he visits an elderly lady living in care:

*SEFI: "But she has no life whatsoever. And the ladies sitting beside her have no life either. As you say she is just sitting, they're just sitting there with their heads down. It's depressing."*

During interview WIR describes visiting someone in a nursing home and seeing:

*WIR: "Somebody stuck at a window, and when I left several hours later they were still stuck at that same window, in a wheelchair, head down, nobody, you know. It's like other people have given up on them and then they give up on themselves, but you're living there like, you're just, well it's not quality of life."*

A participant who had a family member living with dementia describes visiting her in a care home:

*SEFT: "My xxxx's in a home right and she recognises us from when we go and see her, but when I sit there with her and I look around me, and I say to myself, this is not a*

*life because it isn't, especially with the people that are there and the condition that they are in as well."*

He later suggests that entry to a home can accelerate deterioration:

*SEFT: "Yeah probably going into a home would lessen the risk of having an accident, but probably accelerate the dementia."*

One participant during interview starts to talk about supporting independence among people living in care, and how much of the work currently done is tokenistic. She begins with general reference to nursing or care homes and goes on to tell the story of a friend working in such an environment. The same participant later tells another story of an elderly lady who was left sitting on a toilet for hours as the carer forgot to return.

*WIR: "You know treating them like a pathetic child or cause they've wet themselves, leaving them sitting there because they'll not know any better.*

The participant goes on to tell a story of someone working in a care home:

*"She was following the nurse round and they were feeding her* (the resident) *the spoon, and putting the spoon to her mouth, and it would go down round her chin, and the next mouthful, they just kept putting it in, hardly wiped it at all, just kept putting it in and away she went. This wee woman she hasn't talked in years and they're just chatting away to my friend and doing what she had to do, feed her and in fact she didn't wipe her."*

A few days later her friend was feeding the same lady:

*"She give her a spoonful of her food and it spilt, and she took a tissue and wiped it just gently and the wee lady said thank you" …… "she said I thought you couldn't speak xxxx. Well she said, if you were treated like that would you speak and she hadn't spoken in years."*

There were few references to care environments that could be considered positive:

*BFT: "I saw a programme once, they had this home where people with dementia, they actually had their own wee apartment, that looked great so it did, they had carers there but they seemed to be happy there in that situation. I thought that was terrific that."*

*SEFP: "Maybe homes aren't all that bad."*

*SEFE: "Yeah I'm sure there are some homes that are great, there's no doubt about that, some people, it works out well for them. Other people it doesn't."*

*WIH: "And I have been in some of the homes and some of them are very nice but some of them I think, they don't deal with them as individuals, that would be my feeling on it."*

*WFV: "I only visited one two weeks ago in xxxxxxx and it's really a beautiful place, there are big gardens, electronic doors to go in."*

In summary, the data indicate that negative perceptions of care environments are a significant factor in participants' experiences and associations with dementia. Moving into care is considered something people do when there are no choices left, through lack of support and services, and where carers are unable to live with the person who has dementia anymore for a variety of reasons, but particularly where the person behaves in an apparently aggressive way. It is as one participant phrased it *"the last resort".* The final separation of the person with dementia represented via entry to care appears to represent the most hopeless picture of a life with dementia. This hopelessness will be explored further in the final section of this chapter.

**Shame and Secrecy**

Participants suggested that the stigma associated with dementia is much less significant than they believed it would have been a number of years ago. They referred to the public being better informed, and more likely to seek answers or reasons than to simply accept dementia as a part of ageing. In general they did not feel it was a condition that had a stigma attached to it. However, the stories they told, and the comments they made during the course of focus groups and interviews often belied this.

During her interview, BIC explicitly stated she felt there was nothing to be ashamed of and that she doesn't believe there is a stigma attached to dementia, but her personal response to a potential diagnosis contradicts this:

*BIC: "I don't know if I would or not, I have to be honest with you.  Being somebody that always prided themselves on being a bit – not brainy, but bright, I think that would be an awful thing you know to have to tell people you were losing it, dunno, I might, dunno."*

SIG in interview also says that he does not believe there is a stigma attached to dementia but later comments:

*SIG: "You know you don't want to be remembered for that person who didn't know their own name."*

SIM felt she wouldn't want to know her diagnosis and also that she would be embarrassed telling anyone:

*SIM: "I would hate to think I ended up, I've seen other people, I would hate to think I ended up like that you know."*

NIP stated that she would not want to tell people as she feels there is a certain stigma attached to dementia that is different to being old and forgetful:

*NIP: "Cause when you talk about Alzheimer's, you do have these visions of people sitting in the corner talking to themselves and counting their fingers so you do."*

These quotes suggest that despite being sympathetic to people living with dementia and expressing the belief that there is not a stigma attached to dementia, participants' talk indicates they believe dementia is something to be embarrassed

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about.  There is a sense of shame in such a diagnosis.

**Hopelessness and Social Death**

Analysis of the data so far has documented the current understanding about dementia among the general public including the ongoing association with old age, negative perceptions of care and the sense of shame that continues to be associated with dementia.  In the literature review, I documented the currently dominant bio medical model and its nihilistic nature, featuring an absence of hope and the futility of treatment.  People with dementia do not fulfil the role of patient; they are unable to meet the criterion of getting better (Parsons, 1951).  Berger and Luckman (1966) describe legitimation as the way a socially constructed universe is maintained and nihilation as the denial of any phenomena that fail to fit in to this construction.  It could be argued that dementia is just such a phenomenon; people with dementia threaten the social definition of reality and the threat is conceptually destroyed, nihilated by assigning people with dementia an inferior ontological status; they are regarded as less than human.  This section will explore the nihilism and hopelessness evidenced in the data, and a response to people with dementia as 'socially dead' (Sweeting & Gilhooley, 1997).

The survey data provide some early indicators of the social regard participants have for people with dementia (Table 14).

**Table 14: Attitudes indicative of social regard.**

| Statement | Strongly agree | Agree | Neither Agree nor disagree | Disagree | Strongly disagree |
|---|---|---|---|---|---|
| There comes a time when all you can do for someone with dementia is keep them clean, healthy and safe | 24% | 59% | 5% | 8% | 3% |
| Once they have dementia, the person you knew eventually disappears | 18% | 57% | 11% | 11% | 2% |
| For people with really bad dementia, I don't think life is worth living | 4% | 23% | 19% | 39% | 14% |

Eighty three percent of those surveyed either agreed or strongly agreed *"there comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe".* The concept of the ultimate erasure of the person is evidenced in the response to the next survey statement *"once they have dementia the person you knew eventually disappears".* Seventy five percent of survey participants agreed with this. Age and marital status proved most significant for this statement. The relationship with age was linear until the age of 75yrs or over where it dropped slightly again. Those in the youngest age group were significantly less likely to agree (42%) than those in the older age group of 65-74yrs (85%, p<.001, V=.187). Single participants were also significantly less likely to agree (62%, p<.001, v=.101). In this instance knowing someone with dementia was also significant with 78% agreeing, *"once they have dementia the person you knew eventually disappears"* compared to 72% of respondents who did not know someone with dementia, (p<.05, v=.088). A significant minority (27%) of survey participants agreed, *"For people with really bad dementia, I don't think life is worth living",* with a further 19% selecting 'neither agree nor disagree'. Age was again significant with those in the 65-74yrs group significantly more inclined to agree (36%) than those in the 18-24yrs group (9%), (p<.001, v=.117). People who knew someone

with dementia were also more likely to agree with this (30% compared with 24%), (p<.05, v=.086) suggesting that it is older people and people with direct experience of dementia who are more likely to hold what might be described as nihilistic views. There were no instances in the focus groups or interviews of participants describing someone with dementia living a good life. The following quotes were made during a conversation about visiting someone in a nursing care environment. Participants describe it as follows:

*SEFI: "They are waiting for God aren't they?"*

*SEFJ: "Exactly."*

*SEFE: "Aw that's what they say about xxxxx (a local psychiatric hospital) God's waiting room down there."*

In referring to *"God's waiting room"* participants situate people with dementia in a state of living death, simply waiting for God to catch up. Below are some quotes from the discussion about a friend who is now living in a nursing home and needing help with all daily living activities (Vignette 5, Appendix 6):

*SEFER: "You wouldn't, you wouldn't. I wouldn't fancy trying to exist in that sort of situation."*

SEFE refers to existing rather than living and below BFT questions why the person remains alive:

*BFT: "Just why, just why, why are they still alive cause they don't have a life really other than they're breathing."*

BFT makes a number of similar references during the focus group, demonstrating strength of feeling about this. He has also known a number of people with dementia, which may suggest, as described above, that people who know someone with dementia hold the most nihilistic views. SEFT, in a description of visiting a family member living in care, already described in the previous section, suggests her life *"is not a life".* The next two quotes also suggest that the life under discussion (in a nursing home with dementia) is not a real life or a life worth living. As with the quote above, the participant refers to existing rather than living:

*WFD: "Just not doing nothing, need help with everything, it's not a life at all."*

*NFJ: "It's existing rather than living. It's an existence."*

Once again it is clear that the most provocative images are linked to care environments and that little value is attached to such a life. As in the survey there was support for the idea that life was not worth living with *"really bad dementia"* in the focus groups and interviews. These references confirm the notion of a life with dementia as one without value, hope or purpose. The regular use of the word 'existence' reinforces the dehumanising of the person with dementia, suggesting this life is not a life, as participants understand a life to be. It suggests that people with dementia, as described in vignette 5 (Appendix 6), needing help with every day living, are socially dead (Sweeting & Gilhooly, 1997). This can also be linked to the concept of 'othering' to be discussed later in chapter 5. The quotes above also

serve to demonstrate how people with dementia are referred to and spoken of in group interaction. The nihilistic interpretation of dementia is communicated regularly throughout the narrative and thus these ideas are reinforced. The participants who knew someone with dementia are evidenced above to hold some of the most nihilistic views, and there is weight attached to their description by other participants, as they are in some senses the experts.

In the survey 38% of respondents agreed or strongly agreed that *"There is little or no benefit to be gained from telling someone they have a diagnosis of dementia,"* suggesting that knowing a diagnosis may be pointless and confirming the notion of an inevitable decline. Focus group and interview participants were more divided on the issue of diagnosis, with the decision being related in the minds of participants to the age of the person. This is discussed in the section on ageism in chapter 5.

In terms of personal fears (should they receive a diagnosis of dementia) of telling other people, participants described fear of the total loss of control, of other people taking over, and of embarrassment. Below a participant responds to a question asking where they would rank dementia alongside other conditions such as cancer or heart disease in terms of personal fear:

*SIM: "I would place it quite high,………………I would hate to think that I ended up, I've seen other people, I would hate to think that I ended up like that, you know."*

*Patricia: "What does "like that" mean to you?"*

*SIM: "Not able to relate to other people, not able to go to the toilet by yourself, fear of letting someone down, and making, embarrassing yourself, embarrassing your family, you know putting their lives on hold to look after you and that type of thing."*

SIM has on other occasions in the focus group and interview expressed a sympathetic attitude towards people with dementia, but in reflecting on what such a diagnosis would mean for her, she indicates revulsion of how people with dementia appear to her. The perceived loss of control and dignity, coupled with a sense of shame *"embarrassing yourself, embarrassing your family"* are what defines SIM's understanding of "ending up like that".

**Summary**

This chapter has presented findings related to what the general public understand dementia to be, taking account of the sources of this understanding, from the Internet to the media, and most specifically the stories told by participants. Stories are the primary mechanism used to communicate about dementia. The data suggests the general public have a limited understanding of dementia; an understanding that appears to include clinical information, anecdotal evidence, assumptions and personal experience. The findings indicate that more knowledge is not necessarily linked to more positive attitudes towards dementia, with people who know someone with dementia expressing more negative attitudes. There is a continued link between old age and dementia in the minds of the general public, and a sense of shame associated with the condition. Participants see dementia as a condition without hope, and linked to inevitable decline and death. People with dementia are stereotyped, and there is no real sense of an understanding of the progressive and individual nature of dementia. Rather it is viewed in terms of the

more advanced presentation of dementia, and in the context of old age and care environments. This stereotypical view results in participants ascribing certain characteristics to someone with dementia regardless of the point in their personal journey with dementia. What the general public knows and believes about dementia, as explored in this chapter, has an inevitable impact on how participants respond to people living with dementia, and it is to these responses we turn in the next chapter.

# Chapter 5: A Stigmatising Response

The previous chapter has examined what the general public understand dementia to be; taking account of how this understanding has been constructed and how it is communicated. This has included detail on the associations participants make between dementia and old age, dementia and poor care, notions of shame and secrecy, and the view of dementia as a hopeless condition. In this chapter, the self reported responses or potential responses of participants to dementia are explored. As highlighted at the beginning of chapter 4, multiple themes weave through participants' stories, but they will be documented here under the following headings: risk, safety and paternalism; ageism; social distancing; psychological distancing, and euthanasia. The chapter will conclude with a section evidencing how the multiple themes are woven into participants' talk. This chapter thus addresses the last two research questions; asking how the general public respond to dementia and what factors impact on these responses.

As discussed in the literature review, stigma has long been a factor in the way people respond to those perceived to have mental health problems. The literature has debated the extent to which people living with dementia experience stigma. However, this study suggests that people with dementia are seen to possess undesirable attributes (Goffman 1963; Link et al., 1999), perhaps the most undesirable attribute in our hyper-cognitive society, that of 'losing one's mind'. The chapter begins by considering participant responses to issues of safety and risk for people with dementia, and the evidence of paternalistic responses to such situations.

**Risk, Safety and Paternalism**

This section will examine paternalism as evidenced in the data, including evidence of infantilisation.  Infantilisation could be described as an extension of paternalism in that it facilitates beneficent decision making such as that made by a father for a child, the very root of paternalism (Beauchamp & Childress, 2001).  It is not within the remit of this study to debate the moral implications of paternalism in dementia or to debate the tension between beneficence and autonomy.  However, this tension exists and paternalism is evident in the care of people with dementia.  The type of paternalism we are discussing has been described in the literature as 'weak' or 'justified' paternalism (Breeze, 1998).  "An agent intervenes on grounds of beneficence or nonmaleficence only to prevent substantially non voluntary conduct – that is to protect persons against their own substantially nonautonomous action(s).  Substantially nonvoluntary or nonautonomous actions include cases of consent or refusal that is not adequately informed, severe depression that precludes rational deliberation, and addiction that prevents free choice and action.  In weak paternalism, then, a person's ability must be compromised in some way" (Beauchamp & Childress, 2001:181).

The themes of paternalism and infantilisation were initially explored using the survey. In response to the statement "Other people take over making decisions for people with dementia far too much", 43% of those surveyed agreed.  This suggests that participants were aware of the existence of paternalism and not convinced of its appropriateness.  This is also supported in the level of agreement in response to the statement  "As soon as someone is diagnosed with dementia they are not treated like a thinking human being any more" (46%).  However, 73% of respondents agreed, "People with dementia are like children and need cared for as

you would a child", a significant indication of the infantilisation of people with dementia. This was supported in the focus group and interview data where participants made direct reference to infantilisation:

*SEIE: "Yeah, to think and function, and operate for yourself, and that you can't be left, you can't be trusted, you're like a child, really, you're going back to childhood, aren't you?"*

SEIE also raises trust as an issue and this supports the idea of people with dementia being unpredictable, a trait associated with the desire for social distance (Crisp et al., 2000):

*BFC: "Well who used to be your mother, you have to turn around and become her mother, they're like a child."*

BFC describes above a situation often referred to by carers where the child finds themselves in a parenting role and this is again referred to in the quote below where SFJ describes the situation her mother finds herself in with her father *"she has to watch him like a child":*

*SFJ: "Now at the moment my mother does think he is starting to suffer a wee bit from dementia, that he is very, very, forgetful, and she doesn't know whether that's because of his medication or his radio treatment, all of that, so she really has to watch him like a child."*

All of the above indicate a view of the person with dementia as someone who needs cared for and looked after as a child. These are responses referred to by Kitwood (1997) and others in the context of disempowerment for the person with dementia. The responsibility for communication remaining on more equal terms is often placed with the other person in the relationship (Davis, 2004); that is, the carer or family member. However, infantilisation can be a situational response as indicated by WFH below:

*WFH: "But for my friend it was soul destroying, because she couldn't take her home and because her mother no longer knew her. Now she did know, J would say to her mammy, who am I, what's my name and the lady would say you're my mammy."*

This suggests it is often difficult to resist responding to the person as a child, and also raises the question of which is more appropriate in the context described above. I had expected to find a greater number of occasions in the qualitative data evidencing the process of infantilisation than actually occurred. This may be as a result of my experience in a caring role where I encountered this response frequently. Given that these findings were not specifically about care or seeking to explore carer responses it is perhaps not surprising that there were less references. However, coupled with the responses to the survey, the data suggest that the process of infantilisation does take place with people who have dementia.

The survey also explored attitudes to decision-making capacity among people with dementia. Fifty two percent of people disagreed with the statement "People who have just been diagnosed with dementia are unable to make decisions about their own care." The term "just diagnosed" was intended to imply mild or moderate

cognitive impairment. The response to this statement indicates that over half of the respondent population believed that people just diagnosed were capable of making decisions about their care, but this result, particularly in terms of an awareness of the progressive nature of dementia, was not supported in other parts of the data and is discussed in more detail below.

The most paternalistic attitudes were held by older people with the percentage agreeing that *"People with dementia are like children and need cared for as you would a child",* rising from 51% among 18-24yr olds to 83% in those over 65 years. A similar increase occurred in response to *"People who have just been diagnosed with dementia are unable to make decisions about their own care"* (22% of 18-24yrs compared with 52% of 65+). Older people were more likely to view nursing or residential care as the best option for people with dementia and they were also the most likely to think *"there is no pointing in trying to talk to people with dementia as they won't be able to understand".* When it came to considering the benefits of telling someone their diagnosis, 51% of those over 65yrs felt there was no benefit compared with only 19% of the 18-24yrs group. A matrix query of qualitative data confirmed that older people in the focus groups and interviews also held more paternalistic attitudes.

Table 15 below indicates the influence of education with more paternalistic attitudes evidenced among those with no qualifications or lower level qualifications.

**Table 15: Paternalistic attitudes by education.**

| | % responding agree or strongly agree | | | | | |
|---|---|---|---|---|---|---|
| | As soon as someone is diagnosed with dementia they are not treated like a thinking human being anymore | People with dementia are like children and need cared for as you would a child. | It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home | There is little or no benefit to be gained from telling someone they have dementia | People who have just been diagnosed with dementia are unable to make decisions about their own care | There is no point in trying to talk to people with dementia as they won't be able to understand |
| Degree | 35 | 62 | 32 | 25 | 15 | 8 |
| Higher Education | 39 | 68 | 26 | 27 | 21 | 7 |
| A Level | 49 | 66 | 36 | 31 | 25 | 11 |
| GCSE A-C | 51 | 74 | 25 | 34 | 22 | 9 |
| GCSE D-G | 51 | 79 | 44 | 56 | 40 | 17 |
| No Quals | 50 | 85 | 43 | 48 | 46 | 27 |

Two measures in the survey examined issues of independence for people with dementia.  The first asked a series of questions in the context of someone who has just been diagnosed with dementia.  The second asked the same questions in the context of someone who has been living with dementia for a long time.  *"Just diagnosed"* was intended to reflect people who had relatively minor cognitive decline, while *"diagnosed a long time"* was intended to reflect those with greater cognitive challenges.  While this is perhaps a rather crude classification, in the context of the data uncovered in this study it does appear to have been an adequate definition.   Table 16 below records the percentages responding 'probably not' or 'definitely not' in both instances.

**Table 16: Attitudes towards independence**

| % reporting 'probably not' or 'definitely not' | | |
|---|---|---|
| Do you think in most cases they should | Just diagnosed | Diagnosed a long time |
| Continue to live alone | 46 | 81 |
| Continue to manage their own medication | 63 | 87 |
| Continue to drive | 80 | 93 |
| Have an electronic device fitted so they can be located if they wander | 15 | 16 |

Almost half of participants do not support people who have just been diagnosed living alone and this figure rises to 81% for those who have been diagnosed a long time. Only 7% of 18–24 year olds and 10% of those over 75 years old felt that people with dementia should continue to live alone. The percentage across other age groups ranged from 16% to 24%. In response to the other three statements, little difference is made between the two groups, with the majority of survey respondents supporting people with dementia having an electronic device fitted, if they should "wander". The results indicate a lack of awareness of the progressive nature of dementia and the stereotyping of people with dementia. There was also evidence of this stereotyping in the focus groups and interviews:

*WFV: "Once the doctor tells you, you have it, you are not aware of the situation anyway, so whether you live at home or in a home, safety element and......"*

While the focus group responses to the question of where people with dementia should live suggested that participants had some awareness of the complexity of individual situations and of the progressive nature of dementia, this series of questions suggests a much more generalised view. This reflects the findings in the section on participants understanding of dementia and ageing, that the images of

dementia are associated with those living with more advanced dementia. The responses to this section of the survey are further evidence of a paternalistic attitude towards people with dementia. Clearly real issues of risk and safety exist for people with dementia, but the lack of support for any form of independent living among those surveyed is striking; people diagnosed for a long time should not drive, live alone, be responsible for their own medication and should wear a tagging device. When the issue of tagging was raised again during interviews, participants voiced their support for some form of electronic tag with caveats such as discrete appearance, and that the aim should be to support independence. Only one participant was firmly opposed to the idea and this was based on the association between tagging and criminality. The same participant later points out that it would be useful to identify people with dementia:

*BIF: "Will they be alright on their own and even going out, even going out, even going out into the town. Do they know how to get back home again? That kind of way it would worry me too. You know it happened to her, it happened to his; he was getting up in the middle of night. They'd to lock doors to keep him in cause they go wanders, something like, it's a wee bit different from sleep walking I suppose but it's in the same category near enough, the same category."*

BIF uses *"they"* when actually referring to someone he knows. *"They'd to lock doors to keep him in cause they go wanders".* This places the person being referred to among 'them', the people with dementia. This is an example of a paternalistic attitude set in the context of psychological distancing.

Another participant expressed reluctant support for the use of tags while suggesting that initially *"it sounds terrible".* It is also worth noting how BIC objectifies the person saying, *"if they had been tagged"* rather than wearing a tag. This type of objectification further facilitates paternalistic decision-making:

*BIC: "Yes, I, yes. I'm sorry, I know it sounds terrible but I actually agree with that cause that wee woman, back to her again, if she had of been, they would have known where she was. And when I looked in her bag it said xxxxx and I was trying to figure out did she come all the way from xxxxx to here, you know and I couldn't and I didn't know and I thought to myself if, and I know different ones who have had people who have had Alzheimer's and have wandered away off in their nightdresses and things in the middle of winter. Well quite obviously if they had been tagged they wouldn't have been put through such distress and the people would have been able to have found them right and sharp you know, and I know it sounds terrible, you know tagging somebody but I think well it's a sort of technology that might help to find, you know that sort of a way."*

SEIE expresses doubt that people with Alzheimer's can be left alone at all:

*SEIE: "I don't know whether they can or not. I think, maybe, they would need to be taken into care, or helped in some way. I don't think they can be left, at all, if they've got Alzheimer's, because they could walk off, and endanger themselves, and, as you say, if they do that, they'd need the tag, but as far as I can see, they couldn't live on their own."*

In another interview SIG reflects on the moral and ethical dilemmas posed by consideration of tagging:

SIG: "Sometimes I think there's too much of that [laughs]. You know… I don't know, sometimes I think we're too… There's people lobby for things and get things, and at the end of the day, 20 years down the line, you sort of wonder, is it the right thing that we've done? So… I know people have rights, but then it's for their own good. You know, what's the harm in knowing that if such and such… Say Joe has got Alzheimer's and he lives on the edge of a town and there's a river, and there's mountains, and he's sixty percent down his path in Alzheimer's, and I don't know how bad you would be with that level, but I'm assuming you would be quite, maybe still able to look after yourself to a certain extent, maybe with help, in your own environment but you might wander (stroll) off a little. If Joe wandered off up into the mountain or wandered off down to the river, it would be a good thing maybe to know somebody that would keep an eye. I don't know whether that's the thinking on it. But no, I don't think that's a violation of anybody, that's part of the treatment, part of the cure."

This excerpt clearly evidences a paternalistic approach set within a framework of care and safety *"I know people have rights but then it's for their own good"*:

Safety, risk and management emerged as particularly significant in the way participants spoke about people with dementia. Vignette 6 (Appendix 6) triggered much of this discussion:

*NFS: "I think he probably is a risk to his own health and safety. Could he wander off and fall, fall into, I don't know, a lake, a river, stumble into traffic."*

*NFA: "Aye well (pause) I think he should be allowed to do what he wants to do, too many people looking after everybody. You're trying to save him from himself and I don't know how you go about that. As you say, I agree with you, he would go downhill once he is taken into care or anything like that, well he's not in his environment any more, he's not free any more so I would let him fall into the shuch (ditch) or whatever if he wanted to, there would be somebody around that would pick him up."*

The contrasting opinions expressed here were voiced across all focus groups. NFS refers to the health and safety aspect while NFA suggests that the risk of deterioration, if Joe is placed in care, is just as relevant. The suggestion that a care situation could potentially be more damaging formed a thread that ran through the data as discussed in chapter 4. In another focus group the discussion centred around risk, although once again a participant (SEFT) comments on the potential to make Joe's situation worse by calling in social services. SEFT had a close family relation with dementia so his comments are likely to have been influenced by his experiences with social services:

*SEFP: "I think he is a risk."*

*Patricia: "You think he is a risk?"*

*SEFP: "Just takes a few minutes and you could be run over or something."*

*SEFT: "I think the danger would be eventually he might not come back. And when do you make that decision to, you don't know."*

*SEFER: "It's a slippery slope."*

*SEFT: "And if you do make the decision to call social services, and they come in and say he is to go into a home, and he goes into a home, and that could make him worse right away."*

Below BFF also refers to Joe's safety while BFJO comments on the need for control:

*BFJO: "There has to be some control of the situation. You can't have someone like that."*

*BFF: "For his own safety he should be put into the home."*

Safety is also discussed in the Southern Focus group where participants expressed concern for Joe's safety. In this instance the burden this worry would place on people caring for Joe is also raised:

*SFG: "Joe possibly doesn't know, maybe Joe should be, this maybe is a time that he should be taken into care, because Joe could wander away somewhere or fall into a hole or lie in a ditch or whatever, die of the cold, soaking, so for his own good I think that might be a time for his self-esteem, he's not able to look after himself."*

*SFMA: "I don't know, like Joe, is Joe fit to be asked how he would feel about getting into care and I feel if he is totally against it he should be left at home, but try and organise some care or 24 hour care for him, but that's a lot of money then."*

*SFJ: "But then too, you know, it would, I agree with what everyone is saying, but just as SFG said, if he was lying in a ditch somewhere, or even in your own house, if you were living in a town and he got out and got run over or somebody came into your house because the door was open, like you wouldn't get any rest yourself or sleep. You don't know if he is going to turn the cooker, the gas, forget about that, or smoking in bed, 50 million things that would be worrying you if you had him at home for yourself too. I don't think you would really get a peaceful night sleep, so I agree with what SFG is saying, I do think some type of carer or shared housing would be the only option."*

This section highlights the perceived unaffordability of supporting Joe to remain in the community, but there is clear evidence of paternalism in *"this maybe is a time that he should be taken into care"* and *"so for his own good".* SFJ lists a catalogue of possible dangerous situations for Joe and the worry this would create for the person caring for Joe *"50 million things that would be worrying you."* In the Western group WFT believes the decision lies with the children, a clear example of paternalism. He also refers to the concern around involving social services:

*WFT: "I'd say it's pretty much up to the kids, really, because do they want to see their dad in that situation, with the homecare and all that, you know. Because I personally wouldn't want mum or dad, even if he is wandering around, getting lost or whatever, I still wouldn't want the social services getting involved."*

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The responses to this vignette indicate that participants struggled to conceive of the best way to address this situation. While there was clear evidence of an awareness of risk and a paternalistic desire to make decisions to protect Joe, there was also an awareness that this might not be in Joe's best interest. This ethical dilemma is one that occurs often in the lived experience of dementia and participants' responses reflected the complexity of such a situation. Participants consistently raised the issues of risk and safety. In the quotes below the first participant suggests that *"some people"* (referring to people with dementia) need to be in a secure environment, and that there comes a time when you must think about security and safety, suggesting that a care situation might be better for *'them':*

SFG: *"So people that are in specialist places they tend to be better monitored, I know you talk about them being locked up 24/7, but some people need to be in a secure environment for their own good really."*

SIG: *"Well I think holding on to their independence as long as they can is good but then, as it progresses, I'm talking about Alzheimer's and whatever, people start wandering away and becoming a danger to themselves, then you have to start to think about do they need to be in a more secure environment?"*

This theme is continued in the story below:

BFD; *"I know another situation where I live and this lady lived in a fold, one of those places where visitors have to punch in the house number, but this lady was shocking for walking about the place, but there was a whole maze of corridors so she was safe.*

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*But over the winter this year the sisters realised, what happens if she goes out, cause it was just a push door, you know those round disabled buttons and they realised that if she went out she wouldn't be able to get back in again, and they had to move then and say we're gonna have to look into this, and they had to put her into another place, just for her own safety."*

*Patricia: "So they took the step even before she did it."*

*BFD: "They had to, they saw the potential that if she had gone out that winter she would have been dead. She wouldn't have got back in again, you know, and that was in a sort of a sheltered place with I assume it was a sort of live in warden, but I'm not 100% sure, there was a warden there during the day. But they just thought what happens if she gets out at night, you know the bad snow that time in January. They had to move her."*

In this instance BFD is describing decisions being made as a precaution. He indicates his support for this approach *"they had to"*, *"they had to move her"* and suggests they had no other choice. This did stimulate some discussion in the group where other participants wanted to know if other possibilities had been considered indicating that some participants were not convinced by the approach taken:

*BFC: "Could they maybe not have changed the doors is what I was thinking, you know really?"*

*BFT: "That would mean anybody else could come in that's the problem."*

*BFC: "No well I mean there's a whole lot of different ways they can operate doors and that now."*

*BFT: "Well she can get out and she can get in easy, then somebody else can get in easy. That's the problem."*

*BFC: "The point about it is, it seemed like an awful heavy-handed thing to do for what it was, that's all I'm thinking, you know."*

This story perhaps indicates that the vignettes allowed participants to consider this dilemma in an abstract form, stimulating more consideration of the implications for the person with dementia while BFD's story indicates a more defined paternalism in this 'real life' situation. The excerpt below supports this:

*SEFJ: "Because 'F' your brother he had to go into a home because 'F' your brother."*

*SEFER: "That's right."*

*SEFJ: "He had to be put into a home because he was getting sort of agitated."*

As with the earlier excerpt it is notable that the participants suggest a lack of choice *"he had to go into a home."* This may also be a way for participants to distance themselves from the consequences of their choices for the person concerned. These are difficult and often emotionally laden decisions, where families try to balance the autonomy of the person concerned, with safety and

practical issues. In the following excerpts participants evidence the desire for good care and the notion of handing over care to 'experts':

*BFJO: "Or take them to the next stage, where they're cared for under supervision or in the right environment. I feel you'd want to see they were sort of handed over to a responsible care situation."*

BFJO describes wanting to be sure the person is cared for, using words like *"cared for under supervision",* and *"a responsible care situation".* His comments reflect the sense of the person with dementia no longer being part of his world anymore. Their status has changed, and the priority now is to ensure their safety and care by *"handing them over"* to *"the right environment".* SFJ (below) also seeks reassurance that the person will be well cared for, reinforcing the idea that care is now handed over to professional others:

*SFJ: "You would like to know they were being well cared for, that they weren't getting really bad treatment."*

This paternalistic approach also serves as a way of creating distance. In the role of beneficent caretaker it is possible to ensure 'the right care' is taken while psychologically distancing oneself from the person with dementia's reality. The next quote indicates a rationalisation of a situation; something I have often heard carers express:

*SFG: "If they are in a situation where they don't really know where they are, possibly being in care is not a bad thing for them."*

Faced with increasingly chaotic situations and perhaps unable to continue in a caring situation, part of this paternalistic decision making process may involve convincing oneself that this is the best solution for the person with dementia, when sometimes it is the only solution the carer can find. Thus a paternalistic approach may be used to help justify difficult decisions.

The next quote from the Western group demonstrates a sense of paternalism facilitating the greater good of the family or the community. It is worth noting that this participant was not a native of Ireland and her comments might be influenced by different cultural understandings. As with many other instances the language used creates distance *"dished out to places".* While there may have been cultural influences at play, WFV's statement is supported by WFD who adds, *"it's to look after them too":*

WFV: *"None of us want to see our families dished out to places but again, come back to the safety; our safety and other people's safety, sometimes we have to sacrifice for the best of everybody. Our wish is different, but sometimes, again, as I said, for the wellbeing of everybody."*

WFD: *"You know it's for their own good, though. It's to look after them too."*

In summary this section has documented significant evidence of paternalistic attitudes among participants. This is often framed within a landscape of managing risk and ensuring the safety of a more vulnerable group of people (people living with dementia). There is evidence of an awareness that the choices being made; particularly in terms of institutional care may not always be the best choice for the

person with dementia. However, participants indicate a lack of other available choices and appear to accept the choice that provides physical safety over emotional safety.

As already described in chapter 4, there is considerable evidence that the images participants have of this group of vulnerable people are almost exclusively associated with older people. The next section will consider the impact this understanding of dementia and old age has on their responses to people with dementia, specifically an ageist response.

**Ageism**

Ageism is defined as "Discrimination, or the holding of irrational and prejudicial views about individuals or groups, based on their age. It involves stereotypical assumptions about a person or groups' physical or mental capacities and is often associated with derogatory language. Most commonly these are applied to the elderly" (Scott & Marshall, 2009:11). There is evidence of ageism in the attitudes of the public to people living with dementia. This ageism presents in many forms, from that discussed earlier, where the symptoms of dementia are so consistently associated with older people, to assumptions about the abilities, needs and desires of older people, and specifically in this instance older people with dementia.

The following is an excerpt from a focus group where participants were discussing whether someone should be told their diagnosis. There were two vignettes on this issue, one with a younger person and the other with an older person. Focus group participants were generally supportive of people being told their diagnosis but

there were differences in attitude according to the age of the character in the vignette. I asked participants about this and below are some excerpts from the discussion:

*BFC: "Oh I would think so, if you're 84 you're sort of going, you know it's not gonna ruin your life to the same extent cause your life is more or less grinding to a halt anyway but if you're young it would be, wouldn't it. It'd be a shock for you a terrible, you know thinking that's a long distance into the future."*

*BFJ: "An 84yr old might not take it in to the same extent."* (As the younger person).

*BFC: "Probably not."*

BFC suggests that at 84 your life is grinding to a halt and that dementia might be less of a shock and BFJ suggests that older people may not take in the information in the same way.

However, other people in this group challenged this view. Also notable in this quote is that the participant indicates an awareness of the progressive nature of dementia; *"it's just early Alzheimer's":*

*BFT: "Well at 84 people can be very bright, it's just early Alzheimer's, they're still very bright."*

*BFC: "Well my mother was 86 and she was very bright but then as I say when she had, I can't remember the name of it, she just sort of went gaga overnight practically and it happened so quickly."*

*BFJ: "Yes, my mum's 86 now and she's really bright."*

The same discussion in another focus group prompted:

*SFM: "I do think, I don't know, you do get like say it's an 80 year old, they're getting on anyway and if it's not that it would be something or other else and you know, that's probably why I think the older they are the more they shouldn't be told really, because they have had enough, and they've lived long enough, and why put them through this when they're older."*

*Patricia: "You're nodding SFJ, you think the same?"*

*SFJ: "I do think, I'm agreeing with what SFM is saying, I do think that too, and plus I think they might go downhill maybe quicker to a degree when they're older; what SFM is saying they have had their life, but then they can say, well I have this and there is no hope for me, and they might start maybe not taking their medication, or not feeding themselves properly and their general health might go down quickly, because they might go downhill as well, you know."*

There are underlying assumptions being made about older people, that they are less able to understand what is happening, less able to process the diagnosis emotionally, that they will feel as if they have lived long enough, and will be more

at risk of giving up. The suggestion that older people will be less able to understand what is happening may be linked to an assumed level of cognitive decline as people age, discussed earlier.

The quote below took place during an interview and at first glance could be regarded as a positive statement of the participant's view of older people. However, the fact that she separates older people from others and also states, *"no matter how bad they would be,"* suggests a benign but none-the-less ageist attitude. It is also worth noting that this quote comes immediately after the participant had been talking about *"Alzheimer's patients"* suggesting a conceptual link between the two:

*WIH: "I must say I adore old people myself, I really enjoy them, I enjoy their company, I enjoy their stories. I enjoy just old people and no matter how bad they would be and I must say in the home that this lady was in, this friend of mines mother, they were very good but..."*

Another vignette (3, Appendix 6), asked participants about a situation where a person has become confused during a hospital stay. Social services have become involved and are suggesting this person may need residential care. Participants were shocked at the response of social services, but again drew attention to the age of the person concerned as relevant and attached specific characteristics to the older person, as can be seen in the following quotes from three of the groups:

*SEFE: "But it's very upsetting for older people especially to be anywhere else."*

*SFM: "Most old people get confused."*

*BFT: "You have to remember shock affects people, especially older people."*

In response to another vignette (8, Appendix 6), discussing the potential building of a dementia specific unit in their street, participants again attached specific characteristics to older people:

*BFC: "Elderly people are not for running about too much and chasing you or anything, would they love.  No I don't think I would mind."*

Age became a real issue across the focus groups in response to vignette 11.  The discussion was about whether someone with dementia should be eligible for a kidney transplant.   In the first focus group the vignette was about a 75 year old lady and the responses immediately centred on age:

*BFT: "What age is she, 75?  Would they put somebody of that age on the list?"*

*BFC: "No."*

*BFT: "No, not at the age.  I wouldn't expect to go on the list whether I'd dementia or not at 75yrs of age for renal transplant."*

And later in the same discussion:

*BFF: "Would that be discriminating, are you discriminating between certain ages?"*

*BFC: "But we have to be realistic here and if you've got a shortage of donor organs, it should be younger people that get them and you know if I was 75, and had senile dementia, and was like that, I don't think I would say I demand or my family should say we demand she gets it."*

*BFJ: "Well like if you were giving a kidney would you rather give it to a 20 year old or some old codger with dementia* (draws in breath sharply and giggles). *Do you know what I mean; you'd rather give it to somebody who had most of their life ahead of them."*

*BFP: "It's really about age and not*" (pauses.)

Participants are suggesting that older people should be discriminated against in this process and in the final quote the participant draws a negative comparison between *"a 20 year old"* and *"some old codger with dementia".*

In later focus groups I changed the age of the person in the vignette to 62. In all discussions, after discussing the original scenario I asked people how they would respond if the person was in their forties or fifties. It was clear, and in some focus groups explicitly stated, that the issue was less about dementia and more about age, although there were concerns raised about the quality of life that could be expected for a person with dementia. In a group where the age of the vignette character had been changed to 62, I then asked the group how they would feel if the character was 79. I wanted to test that what I thought was occurring was consistent. Below are some of the responses:

*Patricia: "I suppose the other thing I'm going to ask you now is difficult, let's say that instead of being 62 this lady is 79?"*

*SFJ: "Then I would say no, give the kidney to somebody more deserving, a child or somebody starting off their life."*

*SFMA: "I would probably still be the same."*

*SFM: "Well 79 I think I would be…"*

*SFMA: "If it was me I would be wanting to go on."*

*Patricia: "Go on?"*

*SFMA: "Pass on* (reference to dying), *79."*

Similar debates were stimulated in all groups about this scenario and the issues that continued to come to the fore were the age of the character, the potential for additional years, and quality of life for the person:

*SEFJ: "Even if you didn't have Alzheimer's and you were elderly they wouldn't put you on the list."*

*SEFE: "You know she would never get the transplant or she shouldn't go on the list, cause they would assess her physical ability to put up an operation of that size and the assessment would be that she couldn't cope with it, I would think."*

*SEFI: "On the other hand as happens in the hospital they face reality and they say well we can treat a younger person or two younger people for the same money, so we will treat the two younger people."*

*Patricia: "And what's younger, where do you fall into that younger bracket, do you think in your mind's eye?  If she was in her fifties or forties?"*

*SEFI:  "As against seventy five.  I think the forties, it's much clearer cut then."*

*SEFE: "Over fifties the medical profession will think you are old now and if you're over seventy, they just don't want to know! You're over the hill."*

And in another group:

*NFJ: "You think if there is one kidney and as a 16 year old or a 60 year old with dementia, who is the more deserving case, if you look on it that way too."*

In another scenario, where a person living in care has had a hip replacement, the same participant wants to know the age of the person in the vignette before she frames her response:

*NFJ: "What age is he?"*

The association made by participants between ageing and dementia has already been discussed, but there is also evidence that participants are attaching characteristics to older people that are in fact symptoms of a condition such as

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dementia. In the next quote the participant suggests that previously symptoms were regarded as part of ageing, but now we have begun to define and label dementia. However, it is a 'stage of ageing' she is describing as being defined, rather than a specific condition or brain disease.

*NFP: "Is this because in the past when people have got older we have put it down to an age and stage and you just say, oh they have become forgetful they are old, and now they are starting to define it and label it."*

In another group SFJ suggests people are less likely to accept this as part of ageing and more likely to look for reasons:

*SFJ: "But I think also that people, we're all getting older and we are now more informed now than our parents' generation and as you said, looking up the internet, and we are learning more things about our own health and how to live longer and different things like that, so we are noticing things that years ago they would have said maybe, oh well he's doting, or he's just getting old, or doesn't know what he's doing, whereas now we're looking for an answer why this is happening, or is there any way we can help it?"*

Some older participants expressed concern that they would encounter an ageist attitude from their GP if they were to approach the GP with concerns about dementia:

*SEFI: "They call it age related." (66-80yrs)*
*SEFER: "The grey matter has dried up!" (66-80yrs)*

Despite the evidence of ageism there was also evidence that many participants were keen that people with dementia had the opportunity to be involved in decisions about their care. This was qualified by the 'stage' of dementia, with people suggesting that where people could be involved then they should be. The support for involvement was not influenced by the age of the person with dementia.

In summary, the data provide considerable evidence of ageism with assumptions made about the abilities and desires of older people, and particular characteristics attached to those who are older. It is interesting that some of the participants were as old and older than some of the vignette characters they were discussing, but did not appear to empathise any more or less than other participants with the character. This may be related to the character being described as having dementia, so that participants created psychological distance, a theme to be discussed later in this chapter. Prior to considering the use of psychological distance the next section will examine evidence of the desire for social distance among participants.

**Social Distancing**

Social distance refers to "the perceived feelings of separation or distance between social groups" (Abercrombie, Hill & Turner, 2006: 355). The literature has identified the desire for social distance as a significant indicator of stigma in terms of people living with dementia (Deitrich et al., 2004; Werner & Davidson, 2004). I began the investigation of a desire for social distance with a question in the survey. Participants were asked to respond on a Likert scale to the statement *"It is better*

*for people with dementia and their families if they are cared for in a residential or nursing home".*

Over a third of those surveyed agreed or strongly agreed with this. If we interpret this response as confirmation of a desire for social distance, more participants in the older age group (65+) agreed with this statement (50%) compared with 35% of the 18-24yrs age group. This supports the findings of previous research (Jorm & Griffiths, 2008; Jorm & Oh, 2009). The lowest levels of agreement to this were in the 35-44yrs group (23%) and the 45-54yrs group (25%). A third of those surveyed selected *"neither agree nor disagree".* This could suggest awareness among participants of the progressive nature of dementia and of a degree of variance in people's circumstances (Mc Parland et al., 2012). Age was again significant with 45% of 18-24yr olds selecting *"neither agree nor disagree"* compared with 21% of those over 65yrs. However, it is not possible to conclusively associate these responses with a desire for social distance. Factors such as the desire for good care and the consideration of risk may also have influenced participants' responses. To explore this further, I used two questions at the beginning of the focus groups, asking participants where they thought most people with dementia lived and then where they thought people with dementia should live. As already discussed, participants felt that most people with dementia lived at home and that this is where they should live if possible. Participants suggested that this depended on the individual and the extent to which dementia had impacted on their life. It was also acknowledged that this depended on the level of family support available. This is an interesting finding as most of the stories told by participants had links with care environments and the belief that people with dementia should live at home may suggest an ideal or aspiration,

rather than an expression of reality. Participants described people living in their own homes until those supporting them can no longer cope:

*BFF: "Then if you can't cope, maybe at a later stage you would have to put them into a nursing home."*

In the next example one participant talks about how some families are not supportive and "want rid of the problem". In the last sentence he refers to the placing of people in homes because *"of this whole – they're ga-ga":*

*SEFD: "I think we also have to accept that not everyone's family is supportive of people who have it and what we are talking about it, what we believe, and we are all supportive families, we should be looking after them, but in reality what work do a lot of families want? They want rid of the problem, therefore a lot of people end up in homes not because they cannot, or couldn't be supported by some sort of care package, but because of this whole - they're ga-ga."*

I wanted to explore how the desire for social distance might impact on participants' responses when it was suggested that a number of people with dementia might be living close to them. Vignette 8 asked participants to consider how they would feel if plans were made to develop a dementia specific unit in their street to house forty people with dementia. In this first excerpt participants are describing their response and it's interesting to note that they spoke in the third person, distancing themselves from the opinion, suggesting that other people generally would think this way:

*NFJ: "May not be a risk but a lot of people have the impression these things are all right but not in my back yard."*

*NFA: "A bit like prisons and all of that."*

*NFJ: "Yes but don't put them close to me I don't want them beside me."*

*NFA: "Oh yes that would be the general opinion."*

*NFJ: "People have got that stigma I don't want them beside me. So you could get opposition that way."*

The following quote from another focus group triggered a quite intense response. As with the response in the Northern focus group, BFP had originally suggested it was a case of *"Not In My Back Yard" (NIMBY)* and then went on to consider how he would feel if he had children. He uses words like *"escape"* implying the need to keep people with dementia secure, away from others. He then refers to media hype about paedophiles. While attributing this reference to the media he has clearly made an association between people with dementia and paedophiles in terms of risk to others:

*BFP: "I think it depends on, like I don't have any children, so I wouldn't be thinking oh my children are at risk whatever, at this stage in my life I wouldn't have any objections, but if I'm being honest, if I had young children I'd be thinking about them and their exposure to those risks and what would happen if someone escaped or*

*whatever. There's a lot of that out there. I think the media don't help the way they sort of tell us there's a paedophile in every park and it's ignorance I suppose."*

This is picked up on by other members of the group who attempt to clarify what is being said:

*BFJ:* **"***It makes it sound like they're all dangerous though, you know, I know it's awful to say. It makes then sound like they're all dangerous to children, dangerous to everybody really."*

*BFC: "Is this dementia patients you're talking about?"*

*BFJ: "Yes, yes."*

*BFC: "Oh right."*

*Patricia: "Are you thinking the media makes it sound like that BFJ?"*

*BFJ: "No, no, just the way BFP said it there ...I mean chances are 99% of the time they'll* (people with dementia) *be inside, and it could be anybody living in there and you wouldn't know, I would say. I know exactly what you mean cause I would be the same, but most of the time they'd be inside. I mean they're not going to be wandering about the streets really. It's not like you're putting in convicts."*

While ensuring that there is clarification on the issue of paedophilia, BFJ suggests that *"they'd be inside"*, not *"wandering about the streets".* She points out that she

knows exactly what BFP means and that she would feel exactly the same way.  Her way of reassuring the members of the group that there is no danger is to emphasise that 'they' will be secure, not with the rest of us.  This is also evidenced in another group:

SEFER: *"If they were in a home and they weren't actually out, well, wouldn't annoy me."*

This confirms the notion of people with dementia being kept away from the rest of society, enclosed, safe and potentially out of sight.  Out of sight of course offers an opportunity for out of mind.  In effect it facilitates removing the idea of dementia from awareness, thus going some way to removing personal fears.

Concerns pertaining to children were also raised in several other focus groups:

NFP: *"Yes I suppose it depends on how it affects you personally, you know, if you don't have little children I suppose, it's quite different, everybody looks at it from a different point of view."*

When this issue of fear in terms of children was once again raised in the Western group in very vague terms, I asked the participant if she could name the fear:

WFG: *"No, I think there would be an element of fear with me, if there were children about and stuff like that.  I would just have that fear."*

Patricia: *"Can you name that fear, WFG, or what do you think you'd be fearful of?"*

*WFG: "I'd just be fearful of maybe something happening, or maybe somebody would wander off, or.....you know."*

*Patricia: "Yeah, okay."*

*WFG: "Especially if there's residents and..".*

*Patricia: "Oh, it is a residential area."*

*WFG: "I mean children, people like children playing and stuff like that there, I would have that fear."*

The participant is either unwilling or unable to be specific about her fear, rather there is the vague sense of threat, or perhaps more accurately, the unknown. The discussion continues below:

*WFR: "I think I would ask the question well, what would happen? Because again, I'm not really clear about dementia. You hear about you lose your memory, you get confused, you might be a bit ratty, so I suppose I would be asking the questions as to well, what is the risk, what may happen if somebody got out, what is the risk?"*

*WFB: "Could they be violent or something?"*

*WFR: "Could they be violent? Could they be, so I would want to know those answers and then make up...but I doubt it wouldn't... But then my children are off now, though,*

*as well. But I suppose, yeah, you can imagine people wanting to ask the questions, what is the risk there? And then base your answer on that."*

*WFH: "Well, I would like just to ask that question too, whether it would be a risk to anybody. Other than that, if it wasn't, I would have no problem at all, absolutely none."*

Participants were seeking assurance that there was no risk and that people with dementia were not dangerous. This suggests that participants are unclear about what behaviour could be expected from someone with dementia and that in the absence of this knowledge they are erring on the side of caution. This sense of risk and unpredictability are, as already detailed (Crisp et al., 2000), factors influencing the desire for social distance. A number of younger participants in this focus group voiced that they would have no problem with a unit like this being built in their street, supporting the theory that younger people may have less desire for social distance.

In another focus group the participants agreed that they wouldn't have a problem with a dementia specific unit being built, but they would have concerns about the safety of residents. They made reference to stories of other less secure environments where people with dementia had left the building and been found some distance away. The notion of a paternalistic approach can be seen here with the reference to some people needing a secure environment for their own good. The next participant's response in this excerpt suggests a desire for responsibility for the security of the people in the unit being someone else's, distancing herself from the situation:

*SFJ: "Well I think that will be somebody else's, this sounds awful, problem, but as regards the facility being built or that beside you I don't think that it should matter."*

Other participants are quite clear that there is a stigma attached to dementia and dementia homes:

*NFJ: "And people's ignorance of dementia. I mean I'm like you, I don't really know an awful lot about it, but people say they are all mad, I couldn't live beside them, you know, is there, so that without meaning to, without understanding that, I think these people could be criminals as far as they are concerned coming to live beside them."*

This quote is another example of the participant distancing herself from her comments by transferring them onto other people *"but people say they are all mad"*. She also makes the association with criminality *"these people could be criminals as far as they are concerned"*, moving people with dementia into a group associated with risk for others. The next participant is also quite clear about the stigma he associates with a dementia unit:

*SEFE: "It's got this taint then that there's something bad about it, nursing homes OK but dementia unit."*

But later in the same discussion he suggests that stigma is not as strong as it used to be:

*SEFI: "Eh I would be inclined to accept it."*

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*Patricia: "OK, accept not welcome?"*

*SEFI: " Subtle difference, yes I would accept it, I would accept it."*

*SEFE: "Yeah I think I would accept it yeah.  I don't think stigma is strong as it used to be, I think people are moving away from that, it's just eh another nursing home but…"*

The participant finishes with a *"but"*, leaving something unsaid.  The group process would appear to have softened his initial response.  In this group I then asked everyone if the decision was theirs alone to make, what would they do, and most participants adopted the word raised earlier by SEFI saying they would "accept" it.  This idea of acceptance versus welcome was echoed in other groups, where there was some debate about how actively people might object to such a development, with most participants agreeing they might not actively object, but would not welcome such a unit.

Another survey question asked participants to respond on a Likert scale to the statement  *"People with dementia should be involved in activities in the community".*  There was strong support for this statement with 87% agreeing or strongly agreeing.  However, many care environments now include activities as part of the caring environment and this response did not clearly indicate in what context people thought someone with dementia should be involved in community life.  To explore this further, vignette 9 (Appendix 6) suggested that a man who had recently been diagnosed with dementia was going to be placed with a local business as a volunteer.  Participants were asked to consider if they thought this was OK and what the businessman might need to consider, if anything.  A lot of the

discussion centred on the idea that the person with dementia might be able to do *"menial tasks",* but that their ability would be limited. In one group the discussion developed to consider whether the person could work *"front of house":*

*BFJO: "Depends on the nature of the job, if it's front of house with customers as opposed to back of house sorting out the store room or whatever."*

*Patricia: "So you think there might be an issue front of house?"*

*BFJO: "I think it could be an issue front of house."*

*Patricia: "Like?"*

*BFJO: "Just is he gonna say the right thing to the customer?"*

*BFC: "I think he could put the customers off very quickly."*

*BFJ: "Will he give the right change?"* (Laughs).

*BFJO: "Well I think there would be a tendency to hide them away towards the back."*

This excerpt from the narrative suggests a homogeneous view of a person with dementia. No account has been taken of individual ability, but assumptions are made based on the label of dementia. Thus the person is viewed as the 'demented other'. As in other examples, the last part of the excerpt is referred to in the third person distancing the participant from ownership of what is being said.

In the next excerpt from another group, participants' responses are again indicative of a desire for social distance and a concern about the risks associated with working alongside, or employing someone with dementia. The first participant raises the issue of the additional responsibility this might place on other employees and the next participant supports this in their response. In all focus groups there was general agreement that this might be a good idea for the person with dementia, but inevitably this developed into a discussion about the practicalities involved and there was little sense of the person with dementia contributing something meaningful and valuable. Rather it was seen as something that might help them if others could manage it properly:

NFP: "I think it depends on how menial a task because it is bound to be good for someone to have a focus on life. Unfortunately I have no understanding of dementia or any of that, so I don't realise how quickly it sets in, you know, how debilitating it actually is, I can't really answer that. Certainly, I would have thought the gentleman can carry out the task in hand, if it's lifting boxes from A to B and B to C, how difficult can that be, but it is a whole risk assessment and then also to take into consideration the other employees involved, because they are employed to do a job and they can't be expected to be looking after him."

NFS: "Yes minding somebody else."

In another focus group, the emphasis on the problematic nature of such a placement is evidenced. Once again assumptions are being made. In the first part of the excerpt SEFI expresses concern that the person with dementia might not be suitable, might not fit in, or might cause problems. SEFED supports this when he

says that other employees may not want to work with this person. These are clear indications of the desire for social distance and in the final part of the quote there is evidence of a nihilistic understanding of dementia where SEFE reminds participants that it can only get worse:

SEFI: "I think James yes should take him on with a proviso that he'll, let say, give him 3 months trial just in case then he's not suitable, he doesn't fit in, or he causes problems, then at least he has a way out, eh, which will not cause any difficult relationships."

Patricia: "Alright."

SEFE: "I agree with that, 3 months, 3 months trial. There's not only James he has to consider himself, it's the other employees as well. And do you bring them all in and say look this guy's coming in, he's got Alzheimer's and they say we don't want to work with him, what's this here? You know? It's very difficult one."

Patricia: "OK."

SEFE: "But you'd like to help the guy to get back into work if he was capable of doing that."

Patricia: " Yeah."

SEFER: "Although there again it would be limited, limited time, cause it can only get worse."

In the Western focus group, participants were concerned about the risk to the person with dementia and there is further evidence of stereotyping when WFV suggests that the businessman is "*not going to give some highfalutin computer thing to somebody*":

*WFR: "Obviously you would have to consider things."*

*Patricia: "Things like?"*

*WFD: "Just the risks, you know."*

*WFR: "If he was to walk out, or if his business was on a roadside or..."*

*WFD: "It just depends on what business it is too, really."*

*WFV: "And whether this person with their business must have weighed the situation before going for it, so he is not going to be somebody who doesn't know the worker's condition, so he will have the right job for the right person; he is not going to give some highfalutin computer thing to somebody, instead of putting...in he puts the lead; you know, like I would do so. It's very vague; you would need to know what the person's business is."*

The theme of social distance was developed further during the interviews. I asked participants how they would respond to a friend who had decided to marry someone with a diagnosis of dementia. Responses ranged from participants saying they couldn't get a picture of that in their mind to one participant who felt that the

couple could look after one another. Most participants wanted to know why they would get married. In general, participants said they would try to support the friend's choice, but that it wouldn't be a good idea based on the eventual outcome of dementia. Responses were often placed within an ageing framework as described earlier:

*SEIE: "I don't know. I'd want to know why, maybe they'd been friends, and maybe, they intended to make a commitment, or get married. It depends on the age, again, too. This would only happen to people who are older, wouldn't it be?"*

The data indicate that participants found it hard to understand why you would choose to marry someone with a diagnosis of dementia, with many feeling they would need to warn the person about what they were committing to:

*WIR: "I would be saying are you sure, are you up to this, do you know what's ahead of you? I would just talk with them about, I would say I'll be here to support you, I would be able to support my friend better than her partner and to be there for them, but ehm, I would just say gosh is that, do you really want to go down that road? Do you know the responsibility that you're going to have and I don't mean that I would be trying to put them off, but I would certainly feel that I would need to make them aware of what they would be taking on."*

Taking into account the concerns participants had for the caring role the person might eventually find himself or herself in, this still indicates the person with dementia being viewed in terms of the label of dementia. No one asked how this person with dementia was living. The concern was with the ultimate destination

of the person, into the worst-case scenario described often in this analysis. It also suggests that participants had little sense of the person with dementia bringing anything of value to the relationship.

While research suggests that increasing contact reduces the desire for social distance (Werner, 2005), a review of the literature by Jorm and Oh (2009) found that some of the research indicates the quality of the contact is important. Reduced desire for social distance only occurs where the relationship is strengthened by the contact, not when the relationship remains the same or worsens (Martin, Pescosolido, Olafsdottir and McLeod, 2007). The findings, detailed here, confirm that participants desire social distance from people with dementia and this desire is not diminished among those who know someone with dementia; rather the data indicate a greater desire for distance. This desire for social distance is closely related to the creation of psychological distance and the next section explores evidence of whether participants create psychological distance from people with dementia.

**Psychological Distance and the Person With Dementia as 'Other'**

As described above, people often desire social distance from those who are perceived to be mentally ill. The literature suggests that people will also find ways to distance themselves psychologically from that, which triggers fear (Greenberg et al., 2002). In this way they can convince themselves that this is something that happens to other people. In the case of dementia, a manifestation of this fear is to believe that people with dementia are not like them; they are different. Greenburg et al.s' (2002) exploration of terror management theory within ageism can equally

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be applied to dementia. The idea is that younger people are presented in the old and dying with an image of their future and the prospect is so terrifying that they must remove themselves physically and psychologically in order to deny it. In the earlier section on ageing and dementia, the data have confirmed that the public continues to associate dementia with the most vulnerable and frail old, with decline and ultimately death.

The participant below indicates a desire to distance himself from, in his words, his own "potential future weaknesses":

*SEFD: "I suppose it's part of this thing again that as an individual you don't want to be reminded of your own potential future weaknesses, there's an element of that. You don't want any interruption to life as it is and any further complications and issues."*
*Patricia: "To normality?"*

*SEFD: "To perceived normality in case you're taking me down that road. Em, is it something to do with the stigma? I don't know, I'd have to run that through the streets and avenues of the brain a bit more."*

In the survey, participants were asked to respond to the statements, *"There comes a time when all you can do for someone with dementia is keep them clean healthy and safe"* and *"once they have dementia the person you knew eventually disappears."* These have been explored in the section on hopelessness (page 173), but are also relevant here. The statements convey the idea of the person as a physical being, but no longer an intellectual, social, or emotional being. If all the care that is required is to attend to the physical needs of the person then there is the potential

to view the person as not fully human (Twigg, 2004). A high percentage of participants agreed with these statements (see page 173), with the highest level of agreement among those over 65yrs (94% and 85% respectively).    One might expect that there would be less support for these statements among those who knew someone with dementia, but this is not in fact the case (Table 17), with the more emphatic agreement (strongly agree) being higher among those who knew someone with dementia.

**Table 17: Dementia measures 4a and 4c by knowing someone with dementia.**

| STATEMENT | Responses | Know someone with dementia | |
|---|---|---|---|
| | | Yes | No |
| Dementia Q4a: There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe | Strongly agree | 28% | 21% |
| | Agree | 55% | 62% |
| | Neither agree nor disagree | 5% | 5% |
| | Disagree | 9% | 8% |
| | Strongly disagree | 4% | 3% |
| | Don't know | 1% | 1% |
| Dementia Q4c: Once they have dementia the person you knew eventually disappears | Strongly agree | 22% | 13% |
| | Agree | 56% | 59% |
| | Neither agree nor disagree | 9% | 13% |
| | Disagree | 10% | 12% |
| | Strongly disagree | 2% | 1% |
| | Don't know | 1% | 2% |

The notion of the disappearing self (Sabat, 2008) ran like an undercurrent to most of the narrative.   An interview participant who had a relative living with dementia commented:

*SEFT: "It was difficult to see somebody like that go to what she is now and the process of getting there, which was basically a degeneration of her human state."*

Some participants ascribed characteristics of the non-human or the living dead to people with dementia. In the quote below the participant is discussing the vignette about building a dementia specific unit.  She describes imagining *"people in zombie like state".*  Even while defusing the statement with *"in reality that is probably going to be very far removed"* the participant uses the word *"probably"*:

*NFP: "Yes I suppose initially you might imagine, it sound sounds awful people in zombie like state wandering round the street, but in reality that probably is going to be very far removed."*

When this participant began to think about a dementia unit in her street, the images triggered in her mind were of zombie like people wandering the streets. Behuniak outlines seven characteristics associated with zombies in popular culture and suggests these "form a powerful metaphor that is utterly recognisable and so familiar that only a few need to be invoked to imply the others" (2010:78). The image of zombies was used in another group when describing people in nursing homes:

*SEFJ: "It's the loneliest place, and it's either they are just sitting now like zombies, they are comfortable enough but there's no real conversation between them you know?"*

This quote came as part of a discussion responding to the vignette (5, Appendix 6) about a friend with dementia now living in a nursing home.  SEJ assigns a level of

comfort to the residents, but refers to them *"like zombies"* with *"no real conversation"*. Here, the image of the person as sitting unable to converse, or interact with those around them has been sufficient to invoke the zombie image. The participant has suggested that people with dementia may be comfortable enough in a physical sense, but they aren't real in a fully human sense. They are other than us. Responding to the question about what comes to mind when she hears the word dementia, NIP says:

*NIP: "I think you expect the people nearly to have two heads whereas that's not really the case."*

This ascribes a 'monster like' quality to people with dementia. In another interview, a participant made reference to people with dementia in the same context as animals:

*SEIE*: *"I certainly wouldn't want to be hanging about, and not able to do, not able to see, just an entity, like an animal in a cage, sort of thing".*

In the Belfast focus group the following are a series of excerpts that also took place in response to vignette (5, Appendix 6):

*BFT: "I think it would be very sad, people like that, it's just existing. They don't have a life."*

*Patricia: " Just existing."*

*BFT: "They're breathing, that's about it."*

*BFC: "I would think about euthanasia."*

*BFP: "I could see that."*

*BFT: "That's what I'm saying, why, why? They're just there, all they're doing is breathing, they can't think, can't talk, can't do anything."*

*BFC: "It's an awful thing to think, but it is something you would have to think."*

These comments resonate with Gilleard and Higgs' description of the fourth age, "a location stripped of the social and cultural capital that is most valued and which allows for the articulation of choice, autonomy, self-expressions and pleasure later in life" (Gilleard & Higgs, 2010:123).   Participants are clearly repelled and frightened by such a life.   Outside of the vignettes, references are made to similar situations in real life experience:

*SEFT: "Well I know I sit there with her and I look around the room, and at the other people as well and I can remember what she used to be like, and you say this is no life at all.  I know the argument about she's not in any pain and all that, but it's not a life, that's not a life."*

This also resonates with Behuniak's thoughts on the shared status of zombies and people with Alzheimer's disease as being "not quite; they are neither fully dead nor do they appear to be fully alive" (2010:80).

In another focus group the idea of people with dementia as being 'other' is referred to in the context of ageing. This quote also highlights a perceived lack of usefulness or value associated with older people with dementia. The person with dementia is cared for and fed, but no longer considered an active participant in the world. They are re-categorised:

NFA: *"I think when you're growing up you do remember old people in people's houses sitting in the corner and nobody bothering very much with them, because they are fed and looked after and cared for, but they don't talk any more. I do remember people like that in their homes. Uh huh, you know, they would have sat in the corner, well they might have shelled peas or something, you know, tried to give them something to do, but they didn't walk about or do very much."*

Later the same participant says:

NFA: *"There's nothing easy with them anymore, you know, you're not easy with them, you are going to see them differently, you are going to react differently, you are going to talk to them differently. Well I don't know why that is, but that's how I have found it. We don't really know how to cope with it, you're getting nothing back, you see. You're giving, but you're getting nothing back, so there is nothing to carry you on into a conversation, or interest of any kind really."*

This reflects a dilemma often voiced by carers. When a person with dementia's ability to communicate is compromised, the people around them struggle to adapt. It also emphasises the discourse of deficit and disability. The next quote is

evidence of the need for some people to believe that the person with dementia is happy in their world and this is also something I have often heard carers refer to:

*SFJ: "I think I would try and content myself that they are content, that it is awful for them but are they happy in their own mind or do they realise?"*

The implication is that while the situation is *"awful",* the person with dementia, now considered to exist in another reality is not aware of how awful it is. This idea is voiced in another form by BFT when he talks of people with dementia living in another world, confirming the idea that they are not part of the 'real' world, our world:

*BFT: "I think that for a lot of people with dementia, they stop worrying don't they, cause they're not living in the real world, don't they?"*

As described above, one of the vignettes (4, Appendix 6) explored the possibility of a friend or colleague developing dementia and how this might affect the participant's friendship with their friend. Vignette 5 (Appendix 6) set the scene of the friend 10 years later, living in a nursing home and needing help with daily living. As discussed earlier, the latter vignette triggered a lot of discussion about how participants felt about the life their friend might be living. There was a significant expression of this not being a life in any real sense and during the interviews I took the opportunity to explore this further with participants.

Many interview participants had reflected on this since taking part in the focus group and some referred to having discussed it with family or friends. The tone in

the interviews was less strident than in the focus groups, but the view of the life of a person who now needed support for all daily living activities and was living in care remained fundamentally the same:

SIM: *"I would have agreed with that, but I think in my focus group something came round where we really don't know what that person is thinking, or are they thinking and possibly, possibly even if they were or they could, if they have emotions, maybe that's even worse, maybe that really isn't living, but maybe they're happy enough just to sit and I don't know, I find that very difficult. Looking in at it, I would say I don't really think that's living, you know in the very later stages, but until I suppose you knew more about whether, about what they're thinking, you know what I mean, it's hard to...."*

SIM is expressing her consideration of this topic since the group discussion but now she suggests that it might be worse to think that the person remains emotionally intact. She goes on:

SIM: *"Yes, I never thought of it that way. I just assumed that once you reached the later stages you were just there, you know your body was just living, but your mind and that wasn't, that you would have no emotion, your heart, your soul was gone but nobody knows, you know and if it is still there, if those things are still there, does that make it worse for that person or easier for them, I don't know."*

SIM describes her previous understanding of a body with no emotion, heart, or soul. She is unsure if her reflection now, that these things might still be intact, imply it is worse or better for the person with dementia. This is an example of a

participant trying to manage her fear by believing that the concerns of her world are no longer real or present for the person with dementia; that although it is painful and frightening for her, the person concerned is experiencing none of those emotions. This resonates with the earlier reference from SFJ who voiced that it was easier to think people living in the later stages of dementia were happy in their own world.

Another participant recalls her caring role, again suggesting that the person no longer understanding what was happening or recognising people, was sometimes a good thing:

SEFJ: *"Although when my father in those days, he's dead 30 years now, but when we were helping to look after him he didn't know who we were. I could work with him, I could give him a bed bath; he didn't have a clue who you were, you weren't embarrassed. I just put a towel over him and washed him and that, and then my mother she died of cancer and when I was helping to wash her she would say, I'll wash myself."*

During another interview, BIC refers to someone she knows when talking about whether it is possible to sustain relationships with someone who has dementia:

BIC: *"The daughter couldn't look after her and so that's where she ended up and I don't really know if the person that you were friendly with was no longer within that physical body, that you would really keep a friendship going."*

She confirms the notion of the person no longer residing in the physical body. The next quote from WIH's interview also refers to the person no longer residing in their body. WIH suggests that someone is in their body but not the person she knew:

WIH: *"I myself because of this friend of mine, I have become very interested in it now, Alzheimer's, because…I only saw this lady periodically although she lived on my street and that, but she seemed to overnight seemed to just, one minute she was just slightly eccentric you thought and the next day she had disappeared. There was somebody there, but it wasn't the woman I would have known at all."*

Another participant who had a relative with dementia says:

SEIT: *"Oh, well it hasn't changed my relationship. I still think the same thing that I always thought. It's just it's not the same person sitting there. It is physically, yes of course it is, but the essence of what she used to be isn't there or at least it doesn't seem to be."*

There is contradiction in this quote where the participant asserts that their relationship has not changed, but then suggests that the other person in the relationship is no longer there in any real sense. This idea of the person no longer existing in the body is a dangerous concept in the sense that it allows for a dehumanisation of the person. If the emotional, intellectual person no longer exists and is simply a physical mass responding to physical stimuli, there is no need to attend to the emotional or intellectual in interaction or care. The

maintenance of self is increasingly difficult without the support of others in interaction (Goffman, 1963; Sabat & Harré, 1992; Sabat, 2001).

The last two sections evidence participants' desire for both social and psychological distance. They consistently conceptualise the person with dementia as different from them and as belonging to another world. Previous sections have also highlighted the hopelessness associated with dementia in the minds of the public; when participants psychologically situate people with dementia in a different, less real world than their own, this is also seen as a world from which there is no return. Dementia is regarded as a tragedy by participants and the next section will examine what participants reveal about euthanasia in this context.

**Euthanasia**

Until relatively recently euthanasia was not considered an option for people living with dementia based on notions of the capacity to make an informed decision. This is changing and pro euthanasia activists are now promoting it not just as a bona fide medical option at end of life, but also as a desirable and even responsible choice when living with dementia (Johnstone, 2013). Participants in this study expressed the desire to have a way out if they were to have dementia:

*NFJ: "Personally I wouldn't want to live a life where I only existed."*

*WFR: "I'm even thinking from my own point of view, because if it was me and you knew you were going downhill, I think personally if I had Alzheimer's, I would just carry on the process, in fact speed it up, rather than prolong. That would be me, personally. I'm talking from a personal point of view."*

The participant above suggests that rather than hope for recovery she would prefer to speed her journey towards death, voicing the idea of death as a release from dementia. In another group BFJ asks:

BFJ: *"Can you, could you live another 10 or 15yrs with Alzheimer's."*
(lots of yes, oh yeah) *I thought it was the sort of thing that would be a quick merciful release, like you'd go quite quickly."*

Patricia: *"That feels terrible BFJ does it?"* (This reflection was based on BFJ's expression).

BFJ: (Laughs) *"Yes, if you knew the sort of thing, it was only gonna last a year or two, it would be easier to deal with, than thinking he could live for another 20 years and look at him, do you know what I mean. If somebody is so (indistinct), he's not really living at all and you think gosh he could live like that for ages. If you know there's an end in sight, well at least you've only got a year or two, well struggle on. You can see why people would put someone in somewhere."*

BFJ describes the idea of dementia being tolerable if it was only for a short time but that living for another 20 years, as she describes it *"not living at all"* is something quite terrible. She also makes the link again to nursing home entry *"you can see why people would put someone in somewhere,"* implying this is the final stage, the putting away of the person.

Participants also moved beyond the discussion of a life with dementia as not really living to quite specific discussion of euthanasia. There was reference made to Terry Prathchett's expressed wish for euthanasia on a TV documentary:

*BFJ: "He just wanted it to be over, I thought I'd heard that (pauses). That's not very encouraging really, sure it's not, if you're given a diagnosis, that somebody famous is gonna do that. No you wouldn't think sure it's all gonna be ok, I'm gonna top myself when the time comes."*

Most commonly, references were made in terms of the personal choice participants would make if they found themselves living with dementia:

*SEIT: "Oh I would do it, for me I would do it, if I thought I was gonna be that way. I've already said to xxxx I'd go to the doctor and say I can't sleep and get sleeping pills and don't take them and just keep them. The problem with it is, you get to a stage like that, have you got the wherewithal to know that you should do it?"*

*BFC: "I would think about euthanasia"*

While participants most often referred to euthanasia in the context of personal choice they also made references to other people with dementia, sometimes suggesting that the life of a person with dementia was not a life you would wish to try to preserve. There was a sense of allowing someone with dementia to die peacefully without intervention. Participants seem to see this as a kindness or act of mercy for those who were living, what participants viewed, as a *"terrible life":*

*NFA: "It's a terrible life, I mean you wouldn't wish it on your worst enemy".*

*SFMA: "I don't know what way you would put this, but if they got a sickness when they were like that and they are fighting for their life, you know, putting up drips I just would not, well it wouldn't be my decision I suppose, but you wouldn't want that for them, their life to be extended, I would just like to see them just pass away peacefully, I think. That's maybe stupid."*

*SFJ: "No I would agree with that I would."*

On other occasions participants were quite explicit that people with dementia should have a way out of their situation:

*SEIE: "....and people with Alzheimer's do realise that, that they're not going to get better, therefore there must be some way for them to get out, you know, without doing drastic things, you know? There must be some law, or some help within the medical profession, that allows these people, once they get to a certain stage, to get out, I think, you know?"*

SEIE talks about people being able *"to get out"* emphasising the sense of a person being trapped by dementia. He also makes an indirect reference to euthanasia saying, "*there must be some law, some help within the medical profession, that allows these people, once they get to a certain stage, to get out*". In the next quote the participant talks about having considered ideas around quality of life and the difficulties in making judgments, but concludes by stating that she would choose euthanasia; making the comparison to the way we deal with suffering animals:

BIC: *"Well now we were just discussing this the other day in our family and we were saying about that, eh somebody was saying like who are you to say who's life's what? You know, like you mightn't like it and maybe if you were living it and it was actually somebody who was in a vegetative state, you know that one, and they were saying and people were saying there's a case on at the moment where they're wanting to turn off the life support, and somebody else wrote an article that said well I was like that and I recovered. You know what I mean, you can't, but I'm inclined to be a wee bit sort of, if somebody is suffering, if they're, well we do it for animals and I'm sorry I am inclined to be, I would go for euthanasia, but it's a very, very, very tricky situation cause you don't know how happy, or how sad, or how anything anybody is, you know, eh, it's very tricky."*

BIC has clearly given this some thought between the focus group and the interview and her initial thoughts are about the possibility for recovery. She then goes on to suggest that if somebody were suffering then she would support euthanasia. This excerpt took place after I had drawn BIC's attention to the suggestion made during the focus group that a life with 'late-stage' dementia was not really a life at all, so while she does not make a direct reference here, it can be assumed she is referring to people with dementia.

This section has evidenced the lack of value and the hopelessness participants attach to a life with dementia. In many respects, as evidenced earlier in this thesis, people with dementia are no longer regarded as part of our world; they are socially dead. This social death sets the scene for consideration of euthanasia and participants indicate that euthanasia would be a desired option for many of them.

**A Complex Picture**

To date, the findings have documented what the general public knows and believes about dementia followed by their self-reported responses to dementia. This has been a thematic analysis and the emerging themes have been explored discretely. However, what has emerged is that the themes do not stand in isolation but rather are intricately woven to form the very complex understanding and response of the general public to dementia. This concluding section will provide examples of how this appears in the data. The reader will recognise some of the quotes as small sections may have been used in earlier parts of these chapters.

The quote below appeared in the section discussing the use of stories by participants to communicate their knowledge. This quote provides evidence of the link with old age *"now she was 82"* to the rapid deterioration after diagnosis *"she went downhill very quick"*. It also evidences empathy with carers *"he was in an awful predicament"* and an association between entry to a care home and decline and death *"she basically had to go into care and she was only in about a month and died"*. The images associated with dementia are seen to be frightening *"not able to dress, screaming in the street, not knowing where she was":*

*SIM: "Just myself, my brother-in-law's mother was diagnosed just there at Christmas and she just seemed to have gone downhill.* **N**ow she was 82*, but* **she went downhill very quick** *and she was a sprightly woman, very fresh and she just went from being diagnosed and out on the street, couldn't be left alone.* **He was in an awful predicament***, he was over here and he only had one sister over there, and* **she basically had to go into care and she was only in about a month and died***. Just really drastically from seeing her at Christmas chatting away and then the lady is*

*dead."*  It was **such a shock to realise that someone could go downhill from being, having a normal conversation with you, to not be able to dress, screaming in the street, didn't even know where she was** *and her neighbours had to go out, it must have been* **very frightening for that person**, *awful."*

In the next quote taken from an interview, NIP associates people living with dementia with 'monsters' *"you expect the people nearly to have two heads".*  She also refers to a time gone by when someone who was *"going demented"* *"sat in the corner and twiddled their thumbs cause they totally had lost the plot"* making the association with madness.  She describes not really having experience of dementia, but immediately makes a connection with a nursing home.  She then asks how can you tell the difference between being really old and having dementia while acknowledging there must be a difference:

*NIP: "I think* **you expect the people nearly to have two heads** *whereas that's not really the case.  I just, I didn't really know, I mean when you think about years ago and you thought* **someone was going demented, you thought they sat in the corner and twiddled their thumbs because they totally had lost the plot,** *and ehm, I don't know because I have never really experienced it, I'm not really sure, I mean I think I've only ever been in a nursing home once in my life, you know to have a look around and I was with a friend visiting a friend, and I couldn't have pinpointed in there the people who had dementia and the people that didn't so I couldn't have, because* **the people all just looked old to me, and what is the difference from being really old to having dementia or Alzheimer's or whatever?** *There obviously is a big, big difference, but you know I just don't know, I think it must be something very difficult to have to deal with."*

In the next excerpt, the first participant is speaking about a close family member. The situation is located in a nursing home, so there is an immediate association with a care environment. The participant then evidences his understanding of her life with dementia as *"not a life"* and refers to his own fear *"does that mean I'm going to get it, does that mean I'm going to end up in this situation"*? Another participant responds by asking if it is hereditary and SEIT goes on to hint that he would consider euthanasia:

SEFT: *"**My sister's in a home right** and she recognises us from when we go and see her, but when I sit there with her and I look around me and I say to myself, **this is not a life because it isn't,** especially with the people that are there and the condition that they are in as well. I mean there is one woman there and with, from the moment that you arrive to the moment you leave, she constantly sings and she can't sing. It's a very high-pitched voice. Now it would drive me round the bend never mind she's in. Eh some of them react to it and then there's a reaction from her, but it's just the fact that you are sitting there and I'm saying my sister has it; **does that mean I'm going to get it, does that mean I'm going to end up in this situation?"***

SEFJ: *"Yeah is it hereditary, **is it hereditary**?"*

SEFT: *"Yes well that's what I don't know, that eh, and if I do, or if I think I'm going to, **having watched certain programmes on television where people go to Switzerland and drink the drug and die in five minutes you know, is that the way to go?** Because you just don't know if you're going to end up like that, you've no idea. Even though you might think you're getting dementia."*

In the next excerpt from an interview WIR talks about the horrible sound of the word *"demented"* and describes what she associates with it, from confusion to loss of self and independence. She does refer back to a conversation at the end of the focus group about the Scottish Dementia Working Group, referring to it as something *"that was lovely"* and later in the interview she describes this as giving her hope. The picture she describes of her understanding of dementia is located in a care environment with no real quality of life. She makes the link between dementia and ageing, and suggests that with dementia she would not be taken seriously and would not be heard. She says she would not like to live her life this way. The same participant later goes on to say she would seek euthanasia:

WIR: *"When you say **demented and connect it with dementia** its, well its sounds **horrible** doesn't it, obviously **demented, not of right mind**, I suppose is how you would think of linking those two words together. It's not really how I would link them, but I would think **confusion, and then loss of faculties and not being able to look after self, or be independent** and live an independent full life, and I suppose what I link that with, cause we talked a wee bit before with you the last time, was about people in the community and I thought that was **actually lovely, that there were some people you know still in the community** and walking about and neighbours maybe take them you know and although there may be a small risk ehm, I just thought that that was quite nice. Because **my idea of somebody that has dementia** or Alzheimer's is that **you end up in a home** sitting by a window, **not cared for** and I don't mean not cared for, the basics, but the quality of life. I would think that **the quality of life wasn't there** because for me – somebody **might not be taking me seriously, or my needs seriously,** or **just see me as being the word you used demented, or that I didn't matter enough**. It's probably."*

*Patricia: "So fairly negative images."*

*WIR: "Negative, yeah.  **I wouldn't want to live my life that way** unless it was, you mentioned briefly the last time about **somehow some women are still lobbying,** and that has given me **a glimmer of hope** almost, well an interest.  I would love to know more about that I suppose because I do feel we are very ignorant on the fact. You just feel **somebody gets dementia, they get old,** slowly or quickly, but **the mind goes**, no longer able to look after themselves.  **Family can't or don't look after them**.  If they do, there's **pressure on them,** but I just feel,  I probably feel that if **you go into care**, although it's a place of care, that quality of life, your independence, **you lose your independence** and I think that would be worse with not having your mind because **how can you speak up or who's going to listen** to me if I do speak up."*

**Summary**

This chapter has documented the self-reported responses of participants to people with dementia, taking account of the reported understandings of dementia detailed in chapter 4.  The data suggests that participants respond to issues of risk and safety from a position of beneficence and paternalism, prioritising physical safety over emotional well-being.  Ageism is a significant factor in public responses to dementia and contributes to the desire for social and psychological distance evidenced throughout the data.  Participants regard people with dementia as 'other', residing in an almost parallel reality.  This social death is a factor in the view of physical death as a release from a very personal tragedy.  The final section of the chapter has aimed to situate the more detailed analysis of each theme within

the context of the overall narrative.

# Chapter 6: What Comes to Mind?

This was a mixed methods study exploring how the general public understands and responds to dementia. As already stated, there was a limited, if now expanding body of research examining what the public think about dementia. Existing research has generally focused on awareness, knowledge and symptoms of dementia (Alzheimer Scotland, 2002; Bond et al., 2005; Anderson et al., 2009; Low & Anstey, 2009). A smaller and exclusively quantitative body of research has examined the attitudes of the general public to dementia (Crisp et al., 2000; Sahin et al., 2006; Tsolaki et al., 2009) and an equally small body of research has examined the emotional responses of the public to dementia (Werner & Davidson, 2004). This is the first national study to try to establish what the general public understands (knows and believes) about dementia and how members of the public respond to dementia, examining their responses in the context of what they report to know and believe about dementia.

The previous chapters explored literature and research related to this study. They outlined both the theoretical and methodological framework for this thesis and documented my findings. In this chapter, I will discuss my findings in the context of literature already documented, and in some instances more recent literature emerging post my initial review. I will document what this study has contributed to the field in terms of new knowledge and discuss the implications of this knowledge for policy, campaigning, practice, and academia. I will comment on the strengths and limitations of the study and consider areas for future research.

The chapters documenting study findings were presented thematically, with Chapter 4 examining findings most closely related to questions 1 and 2, that is, what the general public understands dementia to be and what factors contribute to that understanding.    In Chapter 5 the findings were more closely related to questions 3 and 4 examining how the general public responds to dementia and what impacts on these responses.  I will present the discussion chapter in a similar format, but the nature of discussion and the complexity of the issues under discussion means there is an inevitable overlap.   The chapter will begin by discussing how the public understands dementia and what has contributed to that understanding (Questions 1 and 2).

## A Paradoxical Understanding

A key finding of this study is that the general public's understanding of dementia is the result of a complex interplay between the experiences participants have had, the experiences of others communicated through stories, and information they have gleaned from the media and other sources. This understanding is often paradoxical in nature.   Assumptions, anecdote and individual experience contribute to an everyday knowledge, but this everyday knowledge is often elevated to the status of empirical knowledge, co-constructed in interaction as the facts of dementia and the data suggest this understanding continues to be framed within a bio medical model of dementia.

Scientific and medical knowledge, as described in Chapter 1, is knowledge that is socially constructed.  Experts and professionals in the field are subject to the influence and experience of existing constructions even while in the process of new enquiry (Bury, 1986; Harding & Palfry, 1997; Knorr-Cetina, 2005).   In tracing

the history of Alzheimer's disease, I documented how for many years dementia was viewed as an aspect of old age; senility. It was the merging of Alzheimer's disease and dementia in the 1970s that changed this landscape. Dementia as a disease offered the opportunity to find a cure and to access increased funding and resources (Fox, 1989; Harding & Palfry, 1997; Cheston & Bender, 1999). In the years since this reframing, dementia has become an increasing priority for scientists, academics and more recently governments, with a resulting highly publicised model of dementia and particularly of Alzheimer's disease (Robertson, 1990). This highly publicised model continues to place emphasis on defect, loss and the elusive search for a cure. Dementia is marketed as a devastating disease (Johnstone, 2013) where there is no cure and no hope of a life well lived with the condition. The media use individual stories of tragedy and devastation to raise the profile of this condition, including films such as 'Iris', or documentaries such as that made by Terry Pratchett. Even campaigning organisations perpetuate notions of loss and the disappearing self; a recent advertising campaign to promote early diagnosis shows a person with dementia fading away until they are diagnosed (Alzheimer's Society, 2012).

It is within this landscape that the general public understands and experiences dementia. The data confirm that the frame of decline, loss and hopelessness is well established in the minds of the general public with an associated language of terror evidenced (Whitehouse, 2008). Innes (2009) suggests that the bio-medical model restricts the research questions asked about dementia. This study confirms it also restricts the way the general public thinks about dementia and thus the questions people are likely to ask (see pages 143, 146 & 147).

Survey findings suggest that the general public has a reasonably good knowledge of the symptoms and progress of dementia as defined within a bio medical model. The majority of survey participants were aware that there is no cure for dementia, that dementia is a disease of the brain, that it is not part of the normal process of ageing, that there are many kinds of dementia, and drug treatments that can help. However, the focus group and interview data indicate a more complex, nuanced picture. The data suggest the general public has a theoretical awareness of bio medical aspects of dementia, for example, that there are lots of sub types of dementia, but they demonstrate no knowledge of what these are, or of there being any difference in terms of the experience of dementia. While participants recognise dementia as a disease of the brain, they also regard it as a mental illness and refer to people with dementia as being mad. While acknowledging that dementia can occur in younger people, they consistently refer to it in the context of older people and the images they access are of the most vulnerable old. Indeed I will argue notions of old age and madness are implicit in images of dementia and more specifically Alzheimer's disease.

The data support Downs et al. (2006) who suggest that individuals and society may hold one or more model of dementia at any one time, or may fluctuate between them, with the findings suggesting that the model or models create a framework for the public to try to make sense of their experience, and that the interplay of theoretical and empirical knowledge is both complex and often contradictory.

The differences in findings across datasets may in part be down to the form and setting of data collection. I argue, it is also ongoing evidence of the paradoxical

nature of the general public's understanding of dementia. It was the mixed methods used and a holistic approach to analysis that allowed this understanding to be unpicked. Thus what might have initially seemed to be opposing opinions are ultimately revealed as complex and sometimes contradictory aspects of a set of beliefs and knowledge that constitute the general public's understanding of dementia.

**Storytelling**

The general public communicate their understanding of dementia in the form of stories. The stories told are of personal experience or an experience told second or third hand. This also includes stories told by the media. The stories are overwhelmingly negative, associated with tragedy and loss. The literature suggests that a bio medical model fails to adequately explain the process and experience of dementia (Lyman, 1989; Chung, 2000; Graham et al., 1997), and Chung (2006) suggests that inadequate explanations of dementia, provided by healthcare professionals, prompts carers to develop a story to help explain their experience. This study finds that stories are also the primary mechanism used by members of the general public to help explain dementia. Often these stories relate to a care environment and almost without exception they refer to people living with the most severe cognitive decline.

The absence of positive or hopeful stories, and the retelling of dramatic and often terrifying experiences evidence the bolstering of a nihilistic construction of dementia. There is clear evidence of individual experience being generalised so that the experience becomes 'something that happens to people with dementia'.

Johnstone (2013) describes "the fallacy of hasty generalization" (Johnstone, 2013:96) used by the media and this generalisation as part of public storytelling contributes to an inaccurate and somewhat mythical understanding of dementia, as suggested by Rimmer et al. (2005). An example from the media can be found on page 135 where a participant refers to Peter Suchet's wife, Bonnie, and there are many other examples in participant stories; BFP described telling his colleagues at work that he was attending a focus group on dementia, prompting them to tell him two stories of people with dementia (see page 138). Both stories described bizarre behaviour and were told in a humorous style. These stories, originally told among their respective families, have been told to BFP and his work colleagues and then told again to participants in the focus group. From here they are added to the catalogue of stories held by participants to be retold when dementia becomes a topic of discussion, or to contextualise a participant's future potential encounter with someone who has dementia. There was often agreement or murmured assent from other participants when stories were being told evidencing a validation of the story, a shared understanding.

It could be argued that what the stories reported here convey is the reality of living with dementia. The stories are reflections of the participants' experiences or the experiences of others told to them, so perhaps we should accept this as the truth of dementia. However, stories told were generally told from the perspective of a carer, or a person other than the person with dementia. There was evidence of a greater tendency to empathise with those around the person living with dementia than the person living with the condition. The evidence suggests this is linked to fear and the need to create psychological distance from the condition and this will be discussed later in this chapter. However, a consequence of this is that despite

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moves in research and policy to ensure the voice of the person with dementia is heard, the story of the person living with dementia continues to be excluded from public discourse, so that perceptions of a life with dementia as portrayed among the public are told exclusively from the perspective of 'spectators'.

I have suggested that the general public's understanding of dementia continues to be framed within a bio medical model even while there is evidence of beliefs that contradict this model.  This is not that surprising.  A person living with dementia and those who support them will almost certainly enter the world of medics and health professionals at some point.  The literature confirms the power of science and medicine in terms of knowledge (Bury, 1986; Harding & Palfry 1997; Knorr-Cetina, 2005), so that there is weight attached to any information received from the 'experts'.  This powerful world offers the illusion of some order in a situation perceived as frightening, chaotic and confusing. Despite the influence of other models such as the social psychological and citizenship models, in academia, policy, and to some degree among professional carers, there is no evidence that these have significantly influenced public understanding.

I suggest that stories do indeed fill the gaps in scientific and medical explanations of dementia as already suggested in the literature (Chung, 2000), but I also suggest they may offer the general public a way to create distance between themselves and the reality of dementia.  The word 'story' implies something that may not be quite real and as a medium allows people to create distance from the event they are recalling. Hasselkus (1997) discusses how people tell stories to recall experience in a way that justifies the approach they are taking.  Dementia raises many difficult ethical and moral issues, and the narrative in focus groups and interviews

evidenced the complexity of these issues and the justifications voiced by participants, for example when describing how things should be done *"for their own good"* or in stating that 'they' don't understand.

## A Language of Terror and Fear

In chapter 2, the literature explores images as a symbolic medium with Featherstone and Hepworth (1993) suggesting that verbal and non-verbal images are only available within a certain socially constructed range of symbolic language. The data indicate that even where there may be more positive social constructions of dementia, these are subjugated by a dominant bio medical model. The general public are evidencing no access to positive verbal or non-verbal images within the current social construction of dementia. Throughout the narrative of focus groups and interviews, participants talked of dementia using language that was both negative and divisive. Sabat et al. (2011) comment on the power of language to label and create distance, specifically in the case of dementia, creating the 'demented other'. Jolly & Benbow suggest Alzheimer's disease "commands fear before sympathy because it has been marketed largely through its most debilitating, demeaning and despairing features" (2000: 117), and Holstein (2000) suggests that the terror associated with a diagnosis of dementia is sourced in this current construction of dementia. Whitehouse (2008) goes so far as to assert that even the word Alzheimer's now has the power to strike terror. The data in this study confirm that dementia does indeed strike terror and fear among the general public, and the language used by participants is also effecting division between 'them' (people living with dementia) and 'us'.

Having discussed the paradoxical nature of the general public's understanding of dementia, the next sections of this chapter will discuss the complex and intertwining influences on that understanding.

**People with Dementia – The Unsuccessful Old**

Chapter 2 documented the changing political and social landscape of ageing. Previously viewed as a social and medical problem, more recent 'new gerontology' has embraced the idea of successful ageing. Holstein and Minkler (2003) describe the emphasis this new gerontology places on a healthy and engaged old age while McHugh (2003) highlights the ageist script embedded in such an approach; for where do we situate those who arguably fail to age successfully? Previous studies have documented that the general public continues to associate dementia with old age (Alzheimer Scotland, 2002; Bond et al., 2005; Sahin et al., 2006; Arai et al., 2008; Tsolkai et al., 2009). Policy also continues to emphasise dementia in terms of the growing numbers of older people and the associated prevalence of dementia (DHSSPS, 2011). This study has confirmed the ongoing association with old age among the general public, particularly among older participants. These results are not surprising for, as already detailed (Table 1, page 38), the prevalence of dementia increases quite dramatically with age, so that most of the general public who meet someone with dementia will be meeting someone older. However, I argue that the association is not quite so straightforward. Most of the encounters with someone who has dementia or the stories the public have heard about someone with dementia are, as already detailed, stories of people who are often older, but who also have quite severe cognitive decline. Many of these stories take place in care homes and as already evidenced there were very few positive

descriptions of these environments, so that the associations the general public makes are between advanced dementia, old age, and a poor care environment.

**An Age and Stage**

The association with old age is often made explicit in the narrative but is also consistently implied. Page 158 provides a number of examples of this where it is clear from the age of the participant speaking, that when they talk of a father, grandmother or brother's wife, they are speaking about an older person. There were a few references to younger people with dementia, but these were the exception. In these conversations it is clear that the public are making little distinction between the very old and people with dementia; *"it will come to us all'" "I just thought it was an age and stage in life", "it's part of growing older", "what's the difference between being really old and having dementia"* (see pages 156, 157, 160 for full quotes). This points to an expectation among the general public that the losses they associate with dementia will come with *"an age and stage in life".* The data suggest that the public have a theoretical awareness of dementia as a disease, while their experience suggests it is associated with age. The subtle but significant clarification that risk of dementia increases with age, but it is not a normal part of ageing is either lost or not perceived as significant.

Given the ongoing debate in science and academia about the exact relationship between normal ageing and abnormal ageing (Holsein, 2000), it is not surprising that the public is also unsure ,but in this situation of doubt participants clearly are more influenced by notions of dementia in keeping with earlier ideas of senility as an aspect of old age. As De Beauvoir suggested (1977) this status is being imposed

on an older person by society.  Unable to match up to notions of successful ageing: productive, healthy, active, youthful and independent, more vulnerable, potentially more dependent older people are categorised here as the old and 'demented'; the diseased old (Harding & Palfry, 1997).

Werner (2005) highlighted a gap in existing research on attitudes, in terms of the age of participants and the age of the person with dementia.  This thesis suggests that participants assume people with dementia are older, but participant age has also emerged as significant with the data indicating it is older people who hold the more negative attitudes.  Middle aged and older participants were particularly fearful of dementia, with participants talking of it always being at the back of their mind and of forgetting something and wondering "*Oh god is this gonna start?*" (see page 133).  This fear is evidenced in the data as linked to a loss of dignity, control, autonomy and independence.  This corresponds with Ford et al.'s (2000) view of dependency as an indicator of unsuccessful ageing.  Again, much of this was made explicit by participants in response to the question about how they thought they might respond to finding out they had dementia, but also occurred throughout the narrative, as people talked about the various vignettes and told stories of their experience.  Decline and death are potentially less real and therefore less emotive for the young, whereas for those in mid life and beyond, decline and death are much more threatening and imminent.

**The Fourth Age**

Participants' expressed fear fits closely with Gilleard & Higgs' description of the fourth age "A location stripped of the social and cultural capital that is most valued and which allows for the articulation of choice, autonomy, self-expressions and pleasure later in life" (Gilleard & Higgs, 2010:123). Branelly (2011) highlights how younger, healthier people distance themselves from older, incapacitated people suggesting that one explanation is the creation of a protective distance; the younger healthier person cannot envisage themselves in the position of the older incapacitated person and cannot empathise with them. The result is the incapacitated older person is positioned as less than human and Kitwood (1997) suggested people with dementia are positioned as though another species. Participants positioned people with dementia as less than human explicitly with references to 'animals', 'monsters' and 'zombies', and implicitly by frequently positioning them as 'other' than 'us'. This will be discussed later in this chapter.

There is much in the data to support Greenberg et al. (2002) when they describe how old age represents to the young the threat of losing their youth and beauty. They argue that this terror is managed by regarding older people as intrinsically different from them. Jonson (2013) refers to the temporal construction of old age where people believe that old age will be different for them, another way of creating distance from the experience of the old of today. Again, there is much in the data to support the literature. Participants appear reluctant or unable to empathise with the older person living with dementia. There is evidence of stereotyping of older people and people with dementia, and this will be discussed

in the section on ageism. The experience of old age with dementia is constructed as something that happens to 'them'. This is further evidence of a contradictory understanding where there is an acknowledged fear of old age and dementia, while at the same time regarding people with dementia as fundamentally different from 'us'. The data suggest dementia represents the fourth age to the public. This is the most terrifying prospect of old age (Fox, 2000) representing, as many participants described, a life *"not worth living"* (see pages 168-169, 175-176).

**A Metaphor For Unsuccessful Ageing**

Lakoff & Jonson (2003) explore metaphor as a way of understanding one kind of experience in terms of another. They are referring to what might be described as larger concepts such as love or health, arguing that metaphorical definition is needed when the way a concept is delineated is not adequate in terms of our day-to-day functioning with it. I argue that in the absence of a complete understanding of dementia and the ongoing association with the old and infirm, people living with dementia personify the notion of unsuccessful ageing to such an extent, that dementia has become a cultural metaphor for unsuccessful ageing. Existing literature suggests the onset of infirmity (Twigg, 2004), and entry to nursing home care (Gilleard & Higgs, 2010) mark entry to the fourth age and I argue that the findings in this study suggest that having dementia also marks entry to the fourth age in the minds of the general public.

The views of the general public reflect a stereotypical picture of dementia framed within old age and the most advanced cognitive and physical decline. This view is

generalised and outdated, bearing a closer relationship to views held in the early 20th century where senility and decline were synonymous (Holstein 2000). I argue this is linked to the ongoing professional nihilism associated with a bio medical model (Cahill et al., 2008), and the continued marketing of dementia in the media as a condition marked by tragedy, loss and terror (Jolly & Benbow, 2000; Johnstone, 2013). Dementia continues to be constructed as an aspect of old age even where the public explicitly acknowledges it as a brain disease.

**Dementia as a Disease of the Brain**

While there is overwhelming evidence that the public continue to associate dementia with old age, the data also evidenced an understanding of dementia or specifically Alzheimer's disease as a disease of the brain. Downs et al. (2006) assert that progressive brain diseases are associated with loss of self, with a resulting disenfranchisement for the person with dementia while Davis suggests "dementia as disease epitome does indeed offer a more palatably reassuring image of ageing" (2004:371). There is evidence in this study of a link to the social construction of people with dementia as zombies (Behuniak, 2010), suggesting a link to the concept of the diseased or dying brain. Brain disease offers its own set of fears as does loss of function as a part of old age and here the two are evidenced as linked in the minds of the public. Ballenger (2006) argues that the efforts to inform and educate the public that dementia is a disease and thus not the responsibility of the person, fail to understand the true nature of stigma, which is "the amount of anxiety surrounding the boundary between the normal and the pathological" (Ballenger, 2006:114). The contradictory nature of public understandings and responses would support Ballenger's stance, that to some

extent, it appears irrelevant to the public whether it is brain disease or old age. It represents the polar opposite to a well-lived healthy life and triggers not just anxiety but terror.

**Public Perceptions of Care and Caring**

Dementia is frequently talked about in the context of nursing or care homes. Northern Ireland has traditionally had a built-in bias towards nursing homes as a care choice (DHSS, 1991; DHSSPS, 2007) and this may have influenced participants' responses in the sense that there may be a greater likelihood that they will encounter someone in care.

As discussed earlier, a person living with dementia will likely find themselves in the world of medics and/or other health care professionals at some point. At this point the person becomes situated as patient, but the person with dementia does not easily fit this role, as this is a condition for which there remains no viable treatment and no cure. The literature suggests that dementia is viewed as deviance (Bond et al., 2004) and the person with dementia as a sufferer, a passive victim of disease (Downs et al., 2006). Labelling dementia within the realm of psychiatric illness facilitates the handing over of control to medical experts. The data confirm the view of the person with dementia as a patient and most specifically a desire to hand over control to the experts. The general public views the medical world and the world of professional care as experts in dementia and they clearly indicate that there comes a time when someone with dementia will need to be handed over to the 'experts'. The decision to hand over care to others is often a response to a very chaotic situation and, as described in the data, is also

often related to the behaviour of the person with dementia. Viewing the person as a 'patient' or 'sufferer' may ease the emotional consequences of such a decision; people are ready to make decisions in the person's interest (as they see it) by ensuring the person is cared for by the professionals. This fits with Hughes et al. (2006) suggestion that a view of dementia as a psychiatric condition creates a sense of moral responsibility to intervene. A further factor emerging in the data, is that the situation is often viewed as more difficult for those around the person with dementia than for the person with dementia, as they are seen to no longer understand what is happening. Thus the needs of those affected by the situation, or by the person living with the condition appear prioritised by the public.

The stories told of placing people in care are often described in the context of there being 'no other choice' and of this being 'the last resort'. This perception suggests that policies (DHSSPS, 2011) outlining support for people with dementia to continue to live well in their community, and to have real choices available in terms of their care, are not yet a reality in the experience of participants.

For the general public, nursing or care homes represent places for the 'elderly' and 'infirm,' who are no longer able to participate in 'normal' life. Images of care homes were overwhelmingly negative and they are clearly environments that trigger fear and dread of a particular type of life, a life the public associate with the 'demented old'. Perhaps as suggested earlier, nursing homes have become as dreaded as the workhouse once was (Gilleard & Higgs, 2010). Participants described locked environments, the unnecessary use of drugs, residents being ignored for hours, a total lack of stimulation, and a lack of respectful care (see pages 166-169, 175-176, 193-194). There is an implicit association in the minds

of the public between this type of environment and dementia. Despite this negative association, there is also a sense that this environment is the only choice for people at a certain 'stage' with dementia. The reasons participants give are often associated with perceptions of carer burden and aggressive behaviour. Entry to a care home acts as the marker for transition to another world. Participants described how people with dementia are no longer living in the 'real world' and the move to a care environment is perceived as the final separation. At this point there is truly a sense of 'them' and 'us' so that a care home is not perceived as a place to live well with support. It is instead a place created where the 'others' may live in a world defined as 'other' than ours.

**Shame and Embarrassment**

The association with age and the complex perception of care environments are two aspects of how the general public understand dementia. A further factor is the ongoing sense of shame and embarrassment associated with this condition (Link et al., 1999). While many participants were explicit in associating a stigma with dementia, others stated that they believed there was no stigma attached to dementia. However, the evidence in their talk often contradicted this. There is much in the data to confirm that dementia, while viewed sympathetically from a distance, triggers feelings of shame and embarrassment, particularly when participants are asked to conceive of the possibility for themselves (see pages 130 & 172). Most participants felt they would not tell others about their condition if they had dementia. A consequence of the sense of shame associated with this condition is the potential to ignore 'symptoms' and delay a diagnosis, as has been documented in existing literature (Crisp et al., 2000). A further consequence of

decisions to keep dementia secret, is that dementia only becomes known to those beyond immediate family when people are experiencing more severe cognitive decline and this has been documented throughout this thesis. There is significantly less chance that the general public will be interacting with someone who is living well with dementia, or if they are, that they will know the person has dementia, resulting in the perpetuation of a limited and stereotypical picture of the experience of dementia (Rimmer et al., 2005; Hughes et al., 2006; Sabat, 2008; Scholl & Sabat, 2008).

The general public clearly feels pity for those affected by dementia but the stories told reflect an understanding of the condition as an embarrassing one and something that reflects on them at a very personal level *"wouldn't want to be remembered like that",* with references made to the embarrassment 'they' cause for their families and the distress, for example, of watching someone *"screaming in the street"* (see pages 140, 172 & 238). The descriptions and stories of helplessness, loss of control, and behaviour that might be described as bizarre, trigger embarrassment among the public. The notion of loss of self (Sabat & Harré, 1992; Sabat, 2001), no longer being in position to take control of one's own life and of behaving in ways perceived to be both out of character and even as 'mad' are understood as shameful. Cognitive function is so closely aligned to the participants' understanding of who they are, that the deterioration or loss of cognitive function is perceived as a personal reflection on this concept of 'self'. The fact that diminished physical capacity and loss of control over bodily function is often closely aligned to any loss of cognitive function, serves to emphasise the embarrassing nature of this condition for the public. While the general public recognises at an intellectual level that a person is not responsible for their

condition (dementia), that it is not a shameful thing, their response is not an intellectual one. It is an emotional response linked to experience and fear.

**An Absence of Hope**

This study confirms that the public views dementia as a condition entirely without hope; hope of a cure or of a life well lived. The data confirm that Alzheimer's disease is now part of our everyday language but associated with tragedy, loss, defect, fear and ultimately death (Whitehouse, 2008, Johnstone, 2013). The ongoing professional nihilism (Cahill et al., 2008) associated with a bio medical model is also evidenced in public understanding, supporting Iliffe et al. (2006) when they suggest "therapeutic nihilism is associated with images of dementia as a severe disability and with the stigma of mental illness (a literal loss of mind) held more broadly in the population"(2006:356). The data in this study indicate that the nihilism evidenced among the general public is indeed associated with images of dementia as a severe disability and a mental illness, but is also complicated by the association with the most vulnerable and frail old, already discussed. It is this association that accentuates the link with decline and death. The general public does not regard a life with dementia as a 'real life'. They see it instead as an existence and view people with dementia as existing in a world that is not 'real' or the same world that they continue to reside in (see pages 234-240). Vangorp and Vercurysse suggest "The person with dementia, but also those around them become embued with the idea that life comes to an end as soon as the diagnosis is pronounced" (2012:1274), so that the sense of hopelessness begins early in the journey with dementia. The final relegation to another world is often associated with the move into care discussed on page 259. Entry to the care home truly

marks the end of hope; it is in many ways regarded as a sentence. The person has moved into the fourth age and *"God's waiting room"* as described on page 175. Speaking about people with dementia ,Aquilina and Hughes suggest "These are not the 'living dead'. They are the dying who live and who deserve our care and concern because of their continuing place as persons in the world" (2006: 158). I argue that it is not helpful to regard people with dementia as the dying who live; they simply live.

**How The General Public Responds to Dementia**

The first sections in this chapter discussed the nature of the public understanding (knowledge and beliefs) about dementia, focusing on how stories are the building blocks with which the public co-construct a paradoxical understanding of this condition. There is an enduring association in the minds of the public between dementia and old age, and I have argued that dementia has come to be a cultural metaphor for unsuccessful ageing marking entry to the fourth age. Almost exclusively negative perceptions of care are also evidenced to influence this understanding, with the labelling of the person with dementia contributing to a reliance on 'experts' to take over at a certain 'stage' in a person's life with dementia. Dementia remains something that participants feel to be shameful even while they deny there is a stigma attached to the condition with most participants suggesting they would not want other people to know if they had dementia. This condition is viewed by the public as hopeless, with the inevitable conclusion of death; viewed in the first instance as a 'living death' to be followed by physical death.

An almost exclusively negative and hopeless understanding such as this has an inevitable impact on how the public responds to dementia. This study finds that response to be a stigmatising one and I will argue that the stigma attached to dementia is unique. This section will discuss the psychological and social tactics employed by members of the public to manage their feelings and responses to dementia. There will be some inevitable overlap between what has already been discussed for the nature of the responses under discussion is both complex and interwoven.

**Dementiaism**

In chapter 2, the literature relating to stigma generally and stigma in terms of old age and mental illness was explored. The World Health Organisation (2001) define stigma as "as a mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society" (2001:16). Goffman described stigma in terms of a person being "reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963:12). I argue that the very complex and contradictory understanding evidenced here results in an equally complex response and that response is a stigmatising one. The term 'dementia-ism' was used by Brooker (2003) to highlight the double jeopardy of age and cognitive decline experienced by people with dementia. I will develop this concept, arguing that the stigma associated with dementia is in fact more complicated than double jeopardy or indeed multiple jeopardy (Bowes & Wilkinson, 2003). These terms have been used to describe discrimination on the basis of, for example, age, ethnicity, race and cognitive decline. Hulko (2009a) has used the term

intersectionality to describe the labelling of people with dementia, based on the amount of privilege or oppression they possess in terms of the labels of race, ethnicity, class, gender, disability, age and others. She suggests that the applications of these constructs by others can either add or detract from an individual's experience. I argue that the stigma attached to dementia is an incredibly complex interplay of many of these 'jeopardies' or labels but also associated with existing perceptions of care, feelings of hopelessness or futility, and a profound fear of developing a condition that appears utterly arbitrary in selection, and totally beyond the control of the individual or the world of science and medicine. Dementiaism is driven not only by the social location or labelled identity of the person with dementia, but also by the emotional responses of another to this social location and labelling, and most specifically the response of fear. Participants visualise a potential future that symbolises loss of control, loss of self, living in poor care, and being viewed as mad among many others. Part of the unique nature of dementiaism is that it has a growing public profile and continues to be marketed as, perhaps, the defining and problematic condition of an ageing society. Despite this rising profile, policy attention and increased funding, the public have been offered no reason why one person develops dementia and another does not, offered no hope of cure, or of any viable treatment. Thus they are increasingly aware of dementia as a real possibility, but one over which they would seem to have absolutely no control. Dementia triggers a unique fear, viewed as something extraordinary and bizarre while also recognised as a possible future. Struggling to come to terms with this anomaly, participants simultaneously experience feelings of sympathy and terror. Perhaps dementiaism is more closely aligned with Hughes' description of people living with a disability, viewed "as symbols of tragedy, as reminders of the frailty of existence" (Hughes, 2002:581).

Participants' struggle with this is evidenced in compassionate but paternalistic decision-making, that often results in the creation of distance desired by participants. People with dementia are relegated to the category of 'other' and viewed as no longer part of the 'real world'. Residents of an 'other 'world, different rules are applied and decisions made that would not ordinarily be taken in relation to people still regarded as part of 'our' world. I argue that all of these factors result in a unique stigma; dementiaism. The next sections of this discussion will focus on aspects of the public response to dementia that I argue constitute a stigmatising, dementiaist response. This will begin with a discussion of the desire for social and psychological distance including a discussion of the person with dementia as 'other', and will then discuss ageism and paternalism. Euthanasia as perhaps the ultimate nihilistic response to dementia will be discussed and the chapter will conclude with a summary of dementiaism.

**Social and Psychological Distance**

The findings provide consistent evidence of a desire for social and psychological distance among the general public from the responses to a potential dementia unit being built (Vignette 8, Appendix 6), to the responses to a person with Alzheimer's disease working as a volunteer (Vignette 9, Appendix 6) and numerous participant stories. The public has a desire to see itself as separate (Abercrombie, Hill & Turner, 2006) from people with dementia. People with dementia were described as 'mad' and 'ga-ga'. Themes of risk to themselves and others were highlighted, the inevitability of people reaching a 'stage' where they couldn't continue to live in the community and a lack of any sense that a person living with dementia could

contribute in any meaningful way. People with dementia are viewed with sadness and pity, but equally as separate. The literature suggests that social and psychological distance may be the most significant factors in stigmatising responses to people living with dementia (Deitrich et al., 2004; Werner & Davidson, 2004)

### *'Other'*

While there are occasional incidences in the data that suggest participants are aware of the progressive nature of dementia, they continue to most frequently reference it in terms of the most advanced dementia. This continued accessing of the most frightening images of dementia facilitates a stereotypical notion of the person with dementia as 'other' and allows people to legitimately create both social and psychological distance from them. They are seen to be separate, different and deviant. Innes suggests that the categorisation of 'demented' offers a way to place order on a confusing and chaotic situation and there is much to support this in the data, as has been discussed earlier, in the section on care and caring. However, the category of 'demented' also offers a way to separate this group of the 'diseased old' from 'us'. If, as Jonson (2013) suggests, the public have a temporal construction of old age, the perception of people with dementia as 'other' offers reassurance that our old age will be different.

Werner and Davidson (2004) identified 'rejection' as the primary factor in stigma associated with dementia. This included feelings of disgust, rejection, ridicule and impatience, and Behuniak (2010) suggests a life with dementia is viewed with fear and an element of revulsion (Behuniak, 2010). The data supports this, with the

survey confirming that the general public believes the person with dementia eventually disappears and the focus groups providing numerous references related to people with dementia *"no longer being there"* (see pages 175-176, 226-227 & 231-232), confirming the notion of a living shell (Woods, 1989). Even where participants are clearly sympathetic, the views expressed continue to support the idea of people with dementia being separate and other than us with allusions to madness, creatureliness, and zombies. People with dementia are not regarded as whole or complete, but rather are viewed in terms of loss. They are positioned socially (Sabat, 2001) in terms of a public understanding of dementia that culminates in a total loss of self, so that the person is no longer considered to reside in the physical body. They are indeed perceived as not quite human (Kitwood, 1997), or as though "they are neither fully dead nor do they appear to be fully alive" (Behuniak, 2010:80). Peppered throughout the data are less obvious references to people with dementia as 'other', from descriptions of them not living in the real world to stories of people with dementia sitting in corners being fed, but not talking or walking. Participants talked of "*getting nothing back"* and described people with dementia as not really being alive, but *"existing rather than living"* (see pages 176 & 226-230). This study suggests that while sympathetic to individual situations, the general public cannot identify with the person who has dementia, for they must continue to see this person as 'other' if they are to manage the terror triggered by the current cultural construction of dementia.


**Ageism**

In many ways the response of the general public to dementia is perfectly defined by Butler's description of ageism "a deep seated uneasiness on the part of the

young and middle aged- a personal revulsion to and distaste for growing old, disease, disability; and fear of powerlessness, "uselessness" and death" (Butler, 1969:243). Ageism is one aspect of the public's response to dementia and another way to create distance from people living with dementia. As discussed earlier, there is a symbiotic relationship in the minds of the general public between dementia and old age. People are not only associating dementia, almost exclusively, with old age but they are also ascribing characteristics they associate with dementia to the very old. The quotes referenced on pages 154-156, 158-161 & 199-202 evidence this. This two-way relationship creates the potential for ageist responses and discriminatory behaviour in two directions. People with dementia are regarded as old, frail and incapacitated regardless of their age and level of capacity, and older frail people are often assumed to have dementia, or at least problems with their memory and ability to process information. As Angus and Reeve (2006) suggest, the data indicate widespread and unquestioned ageism.

While the findings confirm that ageism is an intrinsic aspect of the general public's responses to dementia, they also suggest that participants are aware that older people and people with dementia may be victims of ageism. Older participants would expect to encounter an ageist response if they were to attend the doctor with concerns about their memory, and research acknowledges that ageism influences GP responses to older people reporting difficulties with their memory (Kane 2002).

Participants made it clear that factors in decision-making were sometimes more about age than about dementia. This occurred in response to the vignette about a kidney transplant and in discussion about whether someone should be told a

diagnosis of dementia.  Responding to the vignette about a kidney transplant, there was a clear difference made between what actions should be taken based on the age of the character.  Most participants felt the transplant should not be an option for someone older regardless of the impact of their dementia.  In terms of diagnosis, participants suggested that older people had already lived a full life and wondered at the value of telling them, expressing fear that they might give up and lose hope.  It was suggested that older people might have less capacity to understand what was happening; linked to notions of cognitive decline in the old as there were not the same assumptions made about diagnosis among younger people.  Other examples of assumptions include references to older people being easily confused, upset when they are anywhere other than home and forgetful (see page 204).

Much of the data linked to ageism is also linked to 'othering', discussed above.  Older people, viewed as fundamentally different, and associated with vulnerability and cognitive decline appear to trigger fear, even disgust and disdain for not living up to the notion of successful ageing (McHugh, 2003).  Persistent generalised assumptions about people based on their age evidence ageism throughout the data.

**Paternalism**

Earlier in this chapter the negative perceptions of care and caring for someone with dementia were discussed.  There was evidence that the care home often marks the final separation of 'them' (people with dementia) from 'us'.  In line with Hughes et al. (2006) the data indicate the public feels it needs to take

responsibility for the care of this vulnerable group of people, but this is complicated by the desire to distance themselves from the most terrifying prospect of a potential future with dementia. The decision to hand over the care of someone to the professionals is one aspect of the paternalistic decision-making evidenced in the data. Beauchamp & Childress (2001) define 'weak' or 'justified' paternalism as intervening on grounds of beneficence or nonmalificence where a person's ability is compromised. The stories told in this study provide numerous examples, where one could argue, that paternalistic decision-making is justified. However, this study also finds that the general public is willing to make decisions that prioritise safety and reduction of risk for people with dementia, even where they acknowledge it may not support the overall well being of the person in question. The general public is unsure of how people with dementia might behave and err on the side of caution and in the interests of others who might be affected by the person with dementia. If we accept the principle of beneficence "People who are incompetent to exercise autonomy have a right to beneficence from those entrusted to decide on their behalf" (Dresser, 1995), then it is clear that decisions should be made for people with dementia who are potentially no longer able to make these decisions. However, the findings in this study raise significant questions in terms of beneficent and paternalistic decision-making. In the first instance any decisions being made for 'others' are made within a bio medical framework. While it could be argued that that there is an increasing move towards patient autonomy, this model is intrinsically paternalistic. Members of the public are undoubtedly sympathetic to people with dementia but perhaps more sympathetic to those who are supporting or caring for them, and the stance they took reflected this. Examples include the description of a woman with dementia moved to a secure unit in case she tried to get out (see page 194) and in response

to vignette 6 (Appendix 6) where participants prioritised physical safety over emotional well-being, and prioritised the needs of others around the person living with dementia. In response to vignette 9 (Appendix 6), participants consistently prioritised the safety and well being of customers and other employees. Priority was given to managing risk and safety and taking account of how the person with dementia's behaviour might affect others. On the occasions where I developed a scenario by asking participants to consider what they would like to happen if they were the person with dementia, they did not give the same responses, indicating that instinctively participants were more inclined to identify with those caring and making decisions for people with dementia, rather than with the person who had dementia. Paternalistic decision-making is facilitated by the view of the person with dementia as 'other', discussed earlier. No longer viewed as part of the 'real' world, with a 'real' understanding of what is happening, participants evidence a sense of duty and right to make 'appropriate' decisions. Thus paternalistic decision-making may evidence beneficence that is to some extent at risk, when influenced by emotional responses that include fear, disgust and even terror.

**Euthanasia**

Currently the data evidence such hopelessness associated with dementia that the general public view death as a release, an escape from such a life. In a critical examination of Dworkin's position on euthanasia and dementia, Dresser (1995) points out that research indicates many advance treatment directives are made in the absence of complete information. I would suggest that the data in this thesis indicate decisions are not only made in the absence of adequate information, but

also framed within, and therefore limited by, the current nihilistic construction of dementia. Johnstone suggests that the current portrayal of Alzheimer's disease in the media has triggered "a cultural language of distress and fear" (2013:10) where it is linked to a metaphorical loss of control and of self, and that euthanasia is being marketed as the ultimate solution; a way of regaining control and removing terror. The data in this study confirm that euthanasia is seen as a desirable personal option for some participants although many could not conceive of being involved in the euthanasia of another; instead they expressed a hope for a quick death for the person, a release from this *"terrible life".* Consideration of euthanasia as a viable option is perhaps the final result of the psychological distance desired by the general public when it comes to people with dementia. The data indicate that the public regards people with dementia as the 'non-dead' rather than the living so that they are already psychologically removed from 'our world'.

**Summary**

The data in this study has highlighted the incredibly complex nature of the public understanding of dementia. This understanding is constructed and reconstructed in interaction and evidences the influence of many different and sometimes contradictory factors. In the previous sections the most significant of these factors evidenced in the data have been discussed and, as suggested earlier, it is this complex understanding that results in a stigma unique to dementia that I am describing as 'dementiaism', a development of Brooker's original concept (2003). The general public has an awareness of dementia as a brain disease and this, as discussed, triggers its own fear; for a brain disease can happen to anyone. They also speak of dementia in terms of madness, further facilitating the view of the

person with dementia as different, deviant and a patient; prompting the desire for distance. At the same time they continue to associate dementia with ageing and consistently speak of it in terms of old age, so that it represents the most terrifying prospect of growing old. This prompts a fear response where the public distance themselves from the old and at the same time convince themselves that their experience of ageing will be different. These reactions are also linked to negative experiences and perceptions of care environments, with the public providing almost no evidence of positive experiences of care. Rather, care environments are seen as the waiting rooms for death (Tuckett, 2007) and places devoid of warmth and stimulation. This sense of hopelessness is associated with all aspects of dementia, with the general public viewing it as a condition of inevitable decline and death. Their frame of reference is evidenced as the most advanced images of dementia promoting a stereotypical, nihilistic understanding. People with dementia are not seen as belonging to the 'real' world and are perceived to be no longer living in their own body. Rather the 'person who was' is seen to disappear leaving behind a 'shell'. The creation of the person with dementia as 'other' is linked to the perception of the world of someone with dementia being almost a parallel reality. This parallel reality does not have the same value as 'ours', nor is it associated with the same rights.

This presents a very negative picture of public attitudes, but it would be a mistake to believe that the general public does not feel a great deal of sympathy for those affected by dementia. There was evidence of sympathy in the data but little evidence of empathy. "It is suggested that sympathy refers to the heightened awareness of another's plight as something to be alleviated, whereas empathy refers to the attempt of one self-aware self to understand the subjective

experiences of another" (Wispe, 1986:314).   The difference is significant in terms of this study, as I suggest that this lack of empathy means that although sympathetic to the situation people with dementia might be in, this sympathy is potentially overridden by the need to create distance and mitigate terror.   If members of the public were evidenced as feeling empathy, being able to identify with the person at an emotional level, they would be less inclined to make judgments and decisions about the 'other'.   Goldstein and Micheals suggest "The sympathizer, in contrast [to the empathizer] is more preoccupied with his/her own feelings in response to the other and thus less able to respond to, for or with the other in a manner sensitive to the other person's actual ongoing emotional world and context" (1985:8).   An empathetic response would reduce the likelihood that the person with dementia is regarded as different from 'us', as 'other'. Managing quite a primal terror of what is regarded as the ultimate loss of self, is a complicated process.   It is difficult to separate benevolent decision-making in the best interests of 'others' from the need to sustain individual confidence that "I am not the same as them".   The more that people with dementia are understood as a homogeneous group of people, perceived in a stereotypical fashion as the 'old', 'mad' and 'diseased' then the greater danger that the decisions made in the best interests of 'others' are in fact made in the best interest of the rest of society.


**Limitations**

It could be argued that my personal relationship to this topic created the potential for bias. As I detailed in the introduction, my mother lived with Alzheimer's disease for almost 20 years and she died while I was writing up my thesis. However, my personal experience has ensured that I remained focused on the

lived reality for people with dementia and those who care for them. It has provided me with an insight that allowed me to explore the issues in a way that someone less informed might not have been able to do. It has also forced me to be always mindful of the potential for bias ensuring I took a rigorous approach to analysis.

A further potential limitation is that this study was carried out in Northern Ireland and it could be argued that the results are specific to this location. However, Northern Ireland as a region in the UK, bordering the rest of Ireland and a member of the European Union could be argued to reflect what one might find in other parts of the UK and Ireland and potentially reflect some of the views in other parts of Europe.

In terms of data analysis, a thematic analysis was carried out for all data sources. Analysis of survey data was limited to bivariate analysis across demographics and there is no doubt that more will be revealed using multivariate analysis. This was a pragmatic decision based on the large and complex amount of data from all sources and also on the fact that the level of analysis carried out was sufficient to answer the questions in this study.

**Strengths**

This study is the first national study exploring the understandings and responses of the public to dementia. The module on dementia within the Northern Ireland Life and Times social attitudes survey provided a unique dataset on knowledge of, and attitudes to, dementia. A key strength is that the survey has national level

coverage and provides statistically representative data. It also offers the opportunity to revisit the module in a few years to measure any changes in levels of knowledge or attitudes to dementia.

The mixed methods approach to data collection has allowed this study to go beyond surface data, exploring for the first time the factors contributing to how the public understands and responds to dementia. This is covered in more detail under methodological contributions, but the use of a survey, focus groups and interviews has allowed for a more in-depth and robust analysis of public understanding and responses to dementia than has perhaps ever been carried out before. A further strength is that the participants for focus groups and interviews were recruited from the participants in the survey (excluding one location already detailed), providing continuity.

At the time of the initial conception of this study, little attention had been given to the general public in terms of dementia, either within policy or research. Much has changed in the last few years, particularly as a result of government attention and increased funding. The Prime Minister's Challenge to create Dementia Friendly Communities (DH, 2012) has seen increased attention given to community and societal responses to people with dementia. Dementia strategies across the UK, including Northern Ireland (DHSSPS, 2011) talk of prioritising public awareness and reducing stigma. The result is that this study has in fact become more relevant, providing new comprehensive data on public understandings of dementia, the impact of these understandings on the ways the public respond to dementia and specifically exploring the nature of the stigma evident in these responses.

**Contribution to The Body of Knowledge**

Limited previous research has explored what dementia means to the general public and any existing research has focused primarily on knowledge and awareness of symptoms. Much of the attitudinal work has been with regards to help seeking behaviour (Chung, 2000, Alzheimer Scotland, 2002; Bond et al., 2004; Werner, 2005; Sahin et al., 2006, Arai et al., 2008, Blay et al., 2008, Anderson et al., 2009, Low & Anstey, 2009; Tsolkai et al., 2009) and an even smaller body of work has examined public responses to dementia (Werner & Davidson 2004). This study has examined how the general public understands dementia; what they know and believe. It has also examined their self-reported responses to dementia and people with dementia, analysing these in the context of their reported understanding. Below I will discuss the specific contribution of this study in terms of theory and methodology.

**Theoretical**

There is a considerable body of research exploring stigma in 'mental illness' from Goffman's seminal work in the 1960s to the work of Link et al. in the 1980s and 90s. A much smaller body of work examines stigma specifically related to dementia (Kitwood, 1997; Sabat et al., 2004; Jolley & Benbow, 2000; Benbow & Reynolds, 2000) and a very limited body of work relates to stigma among the general public (Bond et al., 2004; Deitrich et al., 2004; Crisp et al., 2005; Werner & Davidson, 2005). The literature has previously considered older people with dementia as being at risk of 'double jeopardy' resulting from the stigma attached to being old and the stigma of cognitive decline, and Brooker (2003) argued this should be called dementia-ism. The concept of double jeopardy was extended to

triple and multiple jeopardy (Bowes & Wilkinson, 2003) identifying jeopardies such as race, gender, age and living with a disability, while Hulko (2009a) explored the social location of people with dementia in terms of oppression and privilege; intersectionality. I have expanded on Brooker's (2003) 'dementia-ism', arguing that the stigma associated with dementia is further complicated by a myriad of influences: the ongoing framing of dementia within a bio medical model where the person with dementia is viewed as patient and deviant, the enduring association with the old and frail, negative perceptions of care, risk averse and paternalistic attitudes, and a view of the person with dementia as 'other'. This is compounded by the nihilism associated with dementia; this hopeless condition over which there is no apparent control, triggers a primal fear for the individual prompting a desire for social and psychological distance. Thus the stigma response of the public is not exclusively linked to the social location of the person with dementia, but rather is complicated by their emotional responses. Dementia is generalised based on images of dementia, viewed homogeneously in terms of the condition, but individually in terms of the tragedy. This study's development of the concept of 'dementiaism' has revealed the complex nature of this stigma in a way that has not previously been considered. That is not to suggest that all factors potentially contributing to this stigma have been documented here, but these are the factors that have emerged as significant within this study. I am also mindful that this conceptualisation of dementia and stigma is at a very early stage and will require further work to enhance, clarify and confirm.

While not always directly related to dementia, much has been written within the field of gerontology on themes of successful ageing, and the impact of infirmity and dependency among the very old. Werner (2005) suggested that considerably more

attention needed to be given to the implications of age in dementia research; the age of participants and the age of people living with dementia. This study has provided new data on both. I have argued, that in the minds of the public there is an enduring association between dementia and the old and infirm, and dementia is, as Fox (1989) suggested, the most dreaded aspect of ageing. The recent emphasis on ageing well or successfully has had the effect of relegating those who are old, ill and dependant to the ranks of those who are not ageing successfully. In the minds of the public I argue that this view of unsuccessful ageing is so linked to the public's perception of what it means to live and die with dementia, that dementia has come to be a cultural metaphor for the unsuccessful old and to mark entry to the fourth age.

**Methodological**

The methodological approach taken to this study has been informed by social constructionism. An acceptance of public understanding as one that has been co-constructed in interaction has been fundamental in the decisions taken in research design. Previous research into public knowledge has been almost exclusively quantitative and has taken the form of surveys. Where vignettes and interviews were used they were most frequently used in the form of telephone interviews. The exception is Werner who used face-to-face interviewing to explore emotional reactions of laypersons to someone with Alzheimer's disease. This was a structured interview addressing quite specific criteria. My study is the first to take a mixed methods approach and the first to use focus groups and semi-structured interviews to examine this topic. This mixed methods approach and the latent thematic analysis employed, has created the opportunity to explore public

understanding and responses in a more comprehensive way than has been done in existing research. The holistic approach to analysis has produced a detailed and complex picture of the multi layered understanding and responses of the general public to dementia.

**Implications for Government and Campaigning Bodies**

As already stated there is no doubt that much has changed since the conception of this thesis, as dementia has increasingly become a government priority. The new drive to improve awareness and tackle stigma has received much attention, particularly in relation to creating 'Dementia Friendly Communities' (DH, 2012). Most of these initiatives target improving awareness and address issues such as shop signage, helping organisations to recognise when they are meeting someone with dementia and using strategies that facilitate better communication. While these are all valuable, I argue that these steps will not change ageist or 'dementiaist' beliefs, or the behaviour of those working within organisations. If the government wants to create truly Dementia Friendly Communities and, more significantly, to influence cultural understandings of dementia, there must be a better understanding of what factors are impacting on public understandings. This study goes some way to doing this. The findings of this study are both relevant and timely, offering new knowledge that could inform government policy and strategy with a view to addressing the underlying values and beliefs evidenced in this study that contribute to 'dementiaism'.

**Public Health**

Within Northern Ireland, the Department of Health, Social Services and Public Safety has responsibility for public health. This study provides new and timely data that could usefully inform their stated aim "to promote and protect the health and well-being of the population" (DHSSPS, 2014: page number if available). This study's findings deliver information on the current understanding of dementia within the general public of Northern Ireland, including analysis of variables impacting on knowledge and responses, such as participant age, gender and whether they know someone with dementia. This study also clearly suggests that education alone will not reduce stigma, a specific aim of the current Dementia Strategy (DHSSPS, 2011).

New evidence on how the general public responds to dementia offers fresh opportunities to target public health education, with the potential to address gaps in knowledge and perceptions while simultaneously challenging myths and stereotypes. The risk with a more straightforward dementia education programme, framed around improving awareness and knowledge of 'symptoms', is an increased level of anxiety and fear that may increase levels of stigma. Research indicates (Graham et al., 1997; Proctor et al., 2002) that increased bio medical knowledge resulted in increased anxiety among carers and this study confirms that the current emphasis on the ever growing numbers of people affected by dementia; often described as an epidemic and tidal wave, are contributing to a culture of fear and dread. Rather, an educational programme needs to take account of factors, such as the way that members of the public process additional information, and the potential affects on their behaviour. More research is required to investigate the relationship between public understanding or

knowledge, and behaviour: specifically risk modifying and help seeking behaviour, and behavioural responses to people with dementia.  The findings from this study, supported by the recommended research, would then provide a solid basis for developing a public health programme in dementia that might include:

- ❖ Individual risk and health promotion
- ❖ Psycho-social impact of dementia at an individual and societal level
- ❖ Influence of media on knowledge and responses to dementia
- ❖ Dispelling myths and stereotypes

Possible ways to implement such a programme might include:

- ❖ Media Campaigns
- ❖ Education programmes from primary level up; including more experiential learning such as debating competitions and getting involved in design of community campaigns.
- ❖ Poster campaigns in Health Centres and Pharmacies with an "ask me about this" emphasis, to be reinforced with additional information from health professionals
- ❖ Social media campaigns

**Campaigning Bodies**

This information is equally applicable in terms of campaigning bodies and specifically campaigns aimed at reducing stigma.  Campaigns that continue to use images of a disappearing self in promoting early diagnosis are perpetuating

stereotypes and must be addressed. Images and stories of people who are living well with dementia need to be prioritised but this must be done in a way that does not ignore those who are living with the most advanced dementia in very difficult circumstances.

**Implications for Practice**

Much of what has been explored in this thesis is linked to the enduring association between dementia and old age, and it is likely that ageism exists in the provision of care for people with dementia. Research has already established the existence of ageism among GPs (Kane, 2002). The evidence from participant stories would suggest that the understanding and responses evidenced here, may also be found in formal care environments. Despite formal education and training on dementia, issues pertaining to a stigmatising response may remain among professionals and informal staff working in the field. It is important to establish if the type of understanding and response evidenced in this study also exists in these more formal care environments. If this is found to be the case, then there are implications in terms of the type of training provided to staff and more fundamental issues relating to cultures of care and support.

**Implications for Academia**

A great deal has changed in terms of dementia within academia over the last 20 years. Dementia is now regarded as a field in its own right. In social science, models of understanding have moved from the social gerontological to the social psychological and most recently to incorporate ideas of social citizenship, with an

ever increasing emphasis on the experience and voice of the person with dementia. There is a great deal in this study to suggest that little of this work is filtering through to the general public. More must be done to consider how to apply new ideas and information in a way that makes it meaningful for the rest of society. The theoretical contribution of this study has implications for academia. I would suggest that the thematic analysis presented here has addressed a gap in terms of both ageing and stigma and has implications for future consideration of both themes.

**Recommendations for Future Research**

At an immediate level the survey dataset forms part of a large social attitudes survey that runs annually. There is the potential to further scrutinise the data and analyse them in the context of other datasets within the survey, such as attitudes to social care and attitudes to formal carers. There is also scope to use these data as a baseline against which to measure for change following awareness and/or stigma reducing campaigns.

The analysis carried out in this study, while informed by a constructionist approach, was essentially thematic. However, many of the cultural dimensions of dementia have been highlighted with an emphasis on the impact of the current construction of dementia. Further constructionist analysis would provide the opportunity to explore these dimensions in more depth and would fit well within the theoretical approach taken. It would also allow for a deeper analysis of the process of interaction in the production of talk within interviews and focus groups. This study has also highlighted the continued existence of a language of terror

used in the discourse on dementia and discourse analysis of qualitative data would perhaps provide another perspective and dimension.

The findings in this study have suggested that the public response to dementia is influenced by multiple factors. In a broader sense, there are a number of areas that emerge as worthy of future development. In terms of public policy, there has been a stated aim to reduce stigma among the general public. Much of the policy implies that improved knowledge and awareness will be effective in doing this. This study challenges that view and using further research to explore the implications of 'dementiaism' in reducing stigma could make a worthwhile contribution to policy and campaigning. An examination of potential ways to shift cultural understandings would also be beneficial. The study indicates that where policy has made efforts to provide a more positive framework of dementia, it is not filtering down to influence public understandings. A closer examination of policy in terms of 'dementiaism' might provide some insight as to why this is the case.

The study suggests that the concepts highlighted here are entrenched and internalised. The data also suggest that public understanding is framed within a bio medical model that continues to dominate the current construction of dementia. Thus an exploration of evidence of dementiaism in this bio medical world is perhaps crucial. Evidence of dementia in other areas of society such as business, campaigning and retail environments would all provide additional data and perhaps offer further clues as to why such understandings and responses persist. Documentary analysis of the literature and the media could also provide useful evidence of factors contributing to this stigma.

Globally it is worth considering whether this concept is related to our individualistic society. It is worth researching whether there is evidence of 'dementiaism' in other cultures and if so, to what extent. There may be lessons we could learn from these cultures.

I would also like to comment on the tension between different discourses on dementia that has emerged. The ideology of a person living within their community, valued for who they are and regarded as active citizens is one discourse often found in academia. Medical discourse continues to emphasise deficit and decline, and policy discourse is currently trying to reframe dementia in line with an academic discourse, as something one can live well with. However, living well with dementia implies caring well for someone living with dementia and the carer discourse is much more negative; being sourced in underfunded and under resourced formal support systems. More recently, the voice of people with dementia has contributed to discourse and Johnstone (2013) points out that this voice is generally less negative than other 'spectator' voices. The discourse among the general public seems to primarily reflect the medical and carer discourse, as most stories told originated in stories of care. These are competing discourses, again reflecting the complexity of dementia understandings and it is essential that this tension be taken into account when attempting to address or shift cultural conceptions of dementia.

**Concluding Comments**

This thesis is the result of a mixed methods study that took place in Northern Ireland and data were collected over a 12 month period. The study has established three key findings:

1. The understanding the public has of dementia is a paradoxical one, co-constructed in interaction and framed within a dominant bio medical model. Stories are the primary medium used by the public to gather and communicate this understanding.

2. There is an enduring association in the minds of the public between dementia and old age, and I argue that dementia has come to be a cultural metaphor for unsuccessful ageing, marking entry to the fourth age.

3. This complex and contradictory understanding of dementia results in an equally complex, and I argue, unique response. I suggest this response is conceptualised as 'dementiaism' expanding on previous concepts of dementia-ism, jeopardy and intersectionality. I am suggesting this response is primarily driven by emotion, most specifically fear.

The thesis has directly addressed a gap in the literature on public knowledge and responses to dementia. The first finding is a result of a much more comprehensive analysis of public understandings than has previously been documented in the literature.

This study has confirmed the work of previous research that evidenced the continuing association made between old age and dementia, but I have developed existing ideas around these links taking account of cultural understandings of both age and dementia. This has resulted in the argument that dementia is a cultural metaphor for unsuccessful ageing and, for the public, marks entry to the fourth age.

My development of Brooker's (2003) concept of 'dementia-ism' offers a new way of examining the stigma associated with dementia. It takes account of multiple interwoven factors that are not only linked to the positioning of the person with dementia but to the member of the public's emotional responses to their own potential future.

The approaches taken to this study from both a methodological and then research design perspective have facilitated the production of new data. Taking a social constructionist approach to public understanding has revealed a more comprehensive and complex production of knowledge and beliefs than has emerged in previous studies on the public and dementia. The resulting mixed methods design and holistic analysis facilitated the unpicking of this understanding, so that for the first time the contradictions could be held up for examination.

There is no evidence in the data that the public believe dementia could be anything other than the hopeless situation they have portrayed and this begs the question, could it? Existing literature and this study suggest that the way we understand

dementia shapes our experience of it. Potentially this experience could be different if people understand and respond differently. An example of this relates to the Scottish Dementia Working Group (SDWG, 2014). Members of this group, while not living without challenge continue to be actively involved as citizens in society. Is their experience of dementia different because of this involvement, because they continue to be valued as contributing members of society, or do they simply have a better clinical prognosis? The existence of this group came up at the end of one of the focus groups and participants expressed astonishment that people with dementia could be participating in such way. This did not fit in any way with how they understood people with dementia to live.

Clearly, if the experience of living with dementia and supporting those who live with this condition is to improve, the public must be made aware that there are possibilities to live well with dementia. The current reliance on stories of tragedy and loss as a way of raising the profile of dementia has no doubt served a purpose. These stories have attracted funding and contributed to government action, but perhaps it is time to change the message. Allowing members of the public to see that dementia need not always be the hopeless and tragic life they have documented here is crucial. However, their experiences suggest that the lives described here are still the reality for many people living with this condition. The balance is in changing the discourse to effect change, without losing sight of those living difficult lives with dementia. It is difficult to see how current understandings will change until we establish the level of dementiaism in our society. Dementiaism must then be tackled with the same strength of purpose as any other 'ism' such as racism, sexism or ageism.

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# APPENDICES

## Appendix 1: Risk Assessment

**Risk Assessment**  Department of Applied Social Science, University of Stirling

*All those doing the work must be involved in the completion of this form. Complete all sections, marking clearly those that are not applicable. The form must be signed by all involved, and copies made for each person. Hard copies of the completed form, with original signatures, must be sent by the principal investigator to the Departmental Administrator/Departmental Safety Advisor within 3 months of the start date of the project, or prior to the commencement of fieldwork, whichever is the sooner.*

| | |
|---|---|
| Head of Department | Dr. Douglas Robertson |
| Departmental Administrator | Mrs. Morag Crawford |
| University Safety Advisor | Mr. David Duckett |
| Completed by | Patricia Mc Parland |
| Date | 12th October 2010 |
| Contact in Emergency, name & telephone number | Martina Mc Garvey |

**Research Activity**

| | |
|---|---|
| Dates of activity: | April –September 2011 |
| Activity: Give title and briefly summarize | Focus Groups<br>A series of 6 focus groups – number of participants between 4 and 10. Discussion of their understanding of dementia |
| People involved: Give individual name(s) | Participants will be drawn from NILT Survey. Details will be released to the researcher by end of February |
| Location(s) of the activity: Give specific locations, e.g. name of hospital, or town | Focus groups will be held in community or public spaces such as hotels, convenient to the participants. To be confirmed after list of participants becomes available |

| Hazard(s) | Control Measures | Severity | Likelihood | | Overall | |
|---|---|---|---|---|---|---|
| **Working in a dangerous area:** e.g. high crime area, area of civil unrest. Give contact details and measures in case of emergency | *NOT APPLICABLE* | *NOT APPLICABLE* | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | |
| **Working in an isolated geographical area:** Give contact details and measures in case of emergency | *NOT APPLICABLE* | *NOT APPLICABLE* | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | |
| **Lone working:** Give contact details and measures in case of emergency | *The researcher will work alone in participants homes* | *Interview will take place in daylight hours. The researcher will carry a mobile phone at all times and inform a colleague of their location and expected time of return* | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | |
| **Working with Equipment:** Risks associated | *NOT APPLICABLE* | *NOT APPLICABLE* | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | |
| **Environmental hazards:** e.g. weather, terrain, animals, plants, earthquake, water quality | *NOT APPLICABLE* | *NOT APPLICABLE* | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | |
| **Chemical & Biological Hazards:** e.g. laboratory chemicals, crop spraying, diseases | *NOT APPLICABLE* | *NOT APPLICABLE* | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | |
| **Manual Handling:** e.g. loading and unloading equipment | *NOT APPLICABLE* | *NOT APPLICABLE* | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | High ☐<br>Med ☐<br>Low ☐ | |
| **Emotional Risks:** e.g. Sensitive research | *Potential for participants to find the discussion triggers strong or distressing emotions* | *Interviews will be handled with sensitivity & the researcher is a trained counsellor and a member of the British Association of Counsellors & Psychotherapists* | High ☐<br>Med ☐<br>Low ☒ | High ☐<br>Med ☐<br>Low ☒ | High ☐<br>Med ☐<br>Low ☒ | |

| | |
|---|---|
| **Legal compliance:** Are there any specific standards relevant to the research activities? | NO |
| **Training:** Has special training been given for fieldwork activities in relation to safety? | No although the researcher is a trained counsellor, has a qualification in risk assessment and health and safety. |
| **Supervision:** What level of supervision is required, and are there sufficient supervisors for research? | Two supervisors have been appointed by the University |
| **Medical conditions/allergies:** This information is to be kept confidential. | *I am not knowingly in a condition that could compromise my health and safety (or the safety of others) during the proposed research activities* |
| **First Aid:** Will a First Aid box be available? If research involves a group, name the First Aider(s) | No |
| **Disabled persons:** Detail any special arrangements required | None known |
| **Insurance:** Are all activities covered by University insurance? Provide confirmation that this has been checked and approved. Give details of any additional personal insurance. | I have professional indemnity insurance in my professional role as a counsellor and trainer. |

**Risk assessment:    Overall    LOW ☒    MEDIUM ☐    HIGH ☐**

**Safe system of work procedure (to be completed by research team on basis of above information. Continue on separate sheet if necessary)**

There are a number of low-level risks for the researcher. Individual interviews are likely to take place in the participant's home. I will ensure that I carry a mobile phone at all times, that I have informed a colleague of my location for the day and my expected time of return. Interviews will only take place during the hours of daylight. Emotional risks to the researcher are low, but in the event that I find any aspect of the interviews emotionally distressing, my counselling supervisor has agreed to provide support. Where any distress is related to the research itself I will seek the support of my university supervisors.

Date:............................................................................................

Agreed date for review:...................................................................

| Signed | Full Name | Role in Work |
|---|---|---|
| 1. ................................ | ........................................ | Principal Investigator |
| 2. ................................ | ........................................ | ................................ |
| 3. ................................ | ........................................ | ................................ |
| 4. ................................ | ........................................ | ................................ |
| 5. ................................ | ........................................ | ................................ |

**Appendix 2: Phone script**

Hello

My name is Patricia Mc Parland and I am a PhD student with the University of Stirling. A few months ago you took part in the Northern Ireland Life and Times Survey and you indicated that you might be willing to participate in further research about dementia. Would you still be willing to consider that.

I am holding a series of five focus groups, one in each trust area across Northern Ireland. The groups will be made up of between 6 and 10 people and will discuss what you think about dementia.

If you are still interested I will take your address details and post you out an information sheet. I will then call you again in about a week to confirm if you want to take part and we can take it from there.

**Information Sheet for Participants in Focus Groups (1)**

## Exploring How the General Public Understand and Respond to Dementia

This research project is part of a PhD study exploring how the general public in Northern Ireland understand and respond to dementia. The research team includes the PhD student, Patricia Mc Parland and two supervisors, Dr. Anthea Innes and Prof. Kirstein Rummery.

I would like to invite you to take part in this research project. Before you decide, I would like to explain why the research is being done and what it involves for you. I will go through this information sheet with you and answer any questions you may have. This will probably take about ten minutes.

**What is this research exercise for?**
The aim of this research is to find out what members of the general public know and think about dementia and how they feel they might respond to someone with dementia.

**What is my involvement in the research?**
To find out the views of the general public a series of focus groups will be held. The focus groups are groups of around 6 individuals and will be facilitated by Patricia Mc Parland. You are being asked if you would be willing to participate, as you indicated during the Northern Ireland Life and Times Survey that you would be interested in taking part in further research about dementia. Your participation is voluntary. If you decide to take part, you are still free to withdraw at any time.

Focus groups will take approximately 1 hour and will be held in a location close to where you live. You will only be asked to participate in one focus group.

**What will happen to the information I give?**
I would like to tape-record our conversations, but will ask your consent to do this. If you would prefer not to be recorded, I will respect this and will ask to take notes instead.

I will write a report on my findings and would like to quote you to illustrate the points I make. All quotes from participants will be recorded anonymously.

**Will the research benefit me?**

The numbers of people living with dementia in Northern Ireland continues to grow and the NI assembly has just released a Dementia Strategy. One of the issues raised is the need to improve public understanding and address stigma. While you may not benefit directly from this research, it is hoped the research will provide valuable information, which could be used to inform how public understanding can be improved and as a result improve the experience of dementia for people living with dementia, their carers and those in the wider community.

**Further information**

If at any time you wish to make a complaint, you may do so by contacting:
Professor Alison Bowes, Head of School
School of Applied Social Science, University of Stirling
Telephone: 01786 467740
Email: alison.bowes@stir.ac.uk
Should you wish to discuss the study further prior to making a decision the team can be contacted via e-mail or telephone:

Patricia Mc Parland: patricia.mcparland@stir.ac.uk
Telephone: 07912063448

Anthea Innes: anthea.innes@stir.ac.uk
Kirstein Rummery: Kirstein.rummery@stir.ac.uk
Telephone: 01786 467740

Thank you for taking the time to read this information sheet. If you are happy to take part in a focus group I will discuss the main points again when I meet with you and will ask you to sign a consent form then.

Patricia Mc Parland
PhD Student
School of Applied Social Science
University of Stirling

# Exploring How the General Public Understand and Respond to Dementia

This research project is part of a PhD study exploring how the general public in Northern Ireland understand and respond to dementia. The research team includes the PhD student, Patricia Mc Parland and two supervisors, Dr. Anthea Innes and Prof. Kirstein Rummery.

I would like to invite you to take part in this research project. Before you decide, I would like to explain why the research is being done and what it involves for you. I will go through this information sheet with you and answer any questions you may have. This will probably take about ten minutes.

## What is this research exercise for?

The aim of this research is to find out what members of the general public know and think about dementia and how they feel they might respond to someone with dementia.

## What is my involvement in the research?

To find out the views of the general public a series of focus groups will be held. The focus groups are groups of around 6 individuals and will be facilitated by Patricia Mc Parland. You are being asked if you would be willing to participate, as you have responded to a call for volunteers to take part in research about dementia. Your participation is voluntary. If you decide to take part, you are still free to withdraw at any time.

Focus groups will take approximately 1 hour and will be held in a location close to where you live. You will only be asked to participate in one focus group.

## What will happen to the information I give?

I would like to tape-record our conversations, but will ask your consent to do this. If you would prefer not to be recorded, I will respect this and will ask to take notes instead.

I will write a report on my findings and would like to quote you to illustrate the points I make. All quotes from participants will be recorded anonymously.

## Will the research benefit me?

The numbers of people living with dementia in Northern Ireland continues to grow and the NI assembly has just released a Dementia Strategy. One of the issues raised is the need to improve public understanding and address stigma. While you may not benefit directly from this research, it is hoped the research will provide valuable information, which could be used to inform how public understanding can be improved and as a result improve the experience of dementia for people living with dementia, their carers and those in the wider community.

**Further information**

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Kirstein Rummery: Kirstein.rummery@stir.ac.uk

Telephone: 01786 467740

Thank you for taking the time to read this information sheet. If you are happy to take part in a focus group I will discuss the main points again when I meet with you and will ask you to sign a consent form then.

Patricia Mc Parland

PhD Student

School of Applied Social Science

University of Stirling

**Information Sheet for Participants in Interviews**

# Exploring How the General Public Understand and Respond to Dementia

This research project is part of a PhD study exploring how the general public in Northern Ireland understand and respond to dementia. The research team includes the PhD student, Patricia Mc Parland and two supervisors, Dr. Anthea Innes and Prof. Kirstein Rummery.

I would like to invite you to take part in this research project. Before you decide, I would like to explain why the research is being done and what it involves for you. I will go through this information sheet with you and answer any questions you may have. This will probably take about ten minutes.

## What is this research exercise for?
The aim of this research is to find out what members of the general public know and think about dementia and how they feel they might respond to someone with dementia.

## What is my involvement in the research?
To find out the views of the general public a number of interviews will be held with people who have already participated in a focus group. The interviews are one to one and the interviewer is Patricia Mc Parland. You are being asked if you would be willing to participate, as you indicated during a focus group that you would consider taking part in further research about dementia. Your participation is voluntary. If you decide to take part, you are still free to withdraw at any time.

Interviews will take approximately 1 hour and will be held in your own home. If this is not convenient we can arrange to meet in a location convenient for you. You will only be asked to participate in one interview.

## What will happen to the information I give?
I would like to tape-record our conversations, but will ask your consent to do this. If you would prefer not to be recorded, I will respect this and will ask to take notes instead.
I will write a report on my findings and would like to quote you to illustrate the points I make. All quotes from participants will be recorded anonymously.

**Will the research benefit me?**

The numbers of people living with dementia in Northern Ireland continues to grow and the NI assembly has just released a Dementia Strategy. One of the issues raised is the need to improve public understanding and address stigma. While you may not benefit directly from this research, it is hoped the research will provide valuable information, which could be used to inform how public understanding can be improved and as a result improve the experience of dementia for people living with dementia, their carers and those in the wider community.

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Telephone: 01786 467740

Thank you for taking the time to read this information sheet. If you are happy to take part in a focus group I will discuss the main points again when I meet with you and will ask you to sign a consent form then.

Patricia Mc Parland

PhD Student

School of Applied Social Science

University of Stirling

**Appendix 3: Sample of Accompanying Letter**

Dear  xxxxxx

Thank you for taking my recent phone call.  Further to our conversation I am enclosing an information sheet on my research.  The focus group will be held on Monday 19th September at 7pm in Ballybot House, Newry.  Ballybot House is a few doors down from Blue Print Pizza.  There is limited parking behind the building but parking is also available in the street and in a large car park outside TK Maxx.  Tea and refreshments will be provided.  It should take about one and a half hours.

If it is convenient please let me know by email or text if you are able to attend.

If you are able to come along I look forward to meeting you.

Patricia Mc Parland

Email: patricia.mcparland@stir.ac.uk

Tel:xxxxxxxxxxxxxxxxxxx

**UNIVERSITY OF STIRLING**

University of Stirling
Stirling FK9 4LA Scotland

## Consent form for people participating in the Study of How the General Public Understand and Respond to Dementia

**This study is part of a PhD project. The research team consists of the PhD student, Patricia Mc Parland and two university supervisors – Dr. Anthea Innes and Professor Kirstein Rummery.**

**This consent form relates to your willingness to take part in a focus group. The groups will be facilitated by Patricia Mc Parland and are part of the above PhD study.**

### FOCUS GROUP

Please initial boxes

| | |
|---|---|
| 1. I confirm that I have read and understood the information sheet for the above research and have had the opportunity to ask questions. | |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. | |
| 3. I agree to take part in the above research. | |
| 4. I agree to take part in a focus group. | |

| | |
|---|---|
| 5. I understand that all information will be kept confidential. | |
| 6. I agree that the information can be used on condition that it is kept confidential and anonymised. | |
| 7. I understand that all information will be accessed only by the research team and that it will be deleted upon completion of the study. | |

**Please confirm if you wish to view the findings of this study on completion**

❑ **- Yes I would like to view the findings of this study**

❑ **- No I would not like to view the findings of this study**


Participant Name:                    Signature:                    Date:


Researcher Name:                    Signature:                    Date:

**Consent form for people participating in the Study of
How the General Public Understand and Respond to
Dementia**

**This study is part of a PhD project.  The research team consists of the PhD student, Patricia Mc Parland and two university supervisors – Dr. Anthea Innes and Professor Kirstein Rummery.**

**This consent form relates to your willingness to take part in an interview.  The interview is part of the above PhD study and the interviewer is Patricia Mc Parland.**

## Interviews

Please initial boxes

| | |
|---|---|
| 1. I confirm that I have read and understood the information sheet for the above research and have had the opportunity to ask questions. | |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. | |
| 3. I agree to take part in the above research. | |
| 4. I agree to take part in an interview. | |
| 5. I understand that all information will be kept confidential. | |

| | |
|---|---|
| 6. I agree that the information can be used on condition that it is kept confidential and anonymised. | |
| 7. I understand that all information will be accessed only by the research team and that it will be deleted upon completion of the study. | |

**Please confirm if you wish to view the findings of this study on completion**

❑ **- Yes I would like to view the findings of this study**

❑ **- No I would not like to view the findings of this study**

Participant Name:               Signature:               Date:

Researcher Name:            Signature:               Date:

**Appendix 5: Interview Volunteer Sheet**

| Volunteers for Interview | | |
|---|---|---|
| **Name** | **Preferred Method of Contact** | **Contact Details** |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |

**Appendix 6: Focus Group Questions and Vignettes**

**General Questions**

1. If you wanted to find out information about Alzheimer's or dementia where do you think you would look?

2. Imagine you have recently found yourself forgetting things and sometimes feeling quite confused. You are worried that something might be wrong. What do you think you might be feeling and what might you do?

3. Imagine you have been given a diagnosis of Alzheimer's disease.

4. What are the words that come to mind when you hear this? What are the feelings?

5. When you think about people with a diagnosis of dementia or Alzheimer's, where do you think most people with this diagnosis live?

   a. At home?

   b. In specialist units?

   c. Somewhere else?

6. Where do you think they should live?

7. When you think about the information or ideas you already have about dementia where do those ideas come from?

**Vignette 1**

Mary's husband is a plasterer and now 49 years old. As a result of the current economic climate he has only had a few weeks work in the last year. However, he has kept busy doing odd jobs for neighbours and friends. Recently he told Mary he was quite worried about his memory and she has noticed that he has become very short tempered and often repeats himself during a conversation.

Last week he called Mary in a very agitated state. He was in his car and had pulled off the road at a junction, as he couldn't work out which road would take him home. Mary drove out there but he had already gone. When Mary got home he was already there but refused to talk about what happened, asking Mary not to make a fuss. Mary is worried and unsure what to do.

How do you think you Mary could respond to this situation?


**Vignette 2**

Jane's neighbour, Liz has been living next door for the last 2 years. She is a retired teacher and they have become quite friendly. Recently Liz told Jane that she had been given a diagnosis of Alzheimer's disease.

Jane calls regularly with Liz to make sure that everything is OK. While she is sometimes more forgetful than before and occasionally a little confused, for the most part she seems to be doing fine.

Liz's niece is getting married in 2 months time and Liz keeps asking Jane to take her shopping for a dress. Despite Jane's reassurance that there is plenty of time, she continues to be insistent that they go shopping now.

What do you think is going on for Liz?

**Vignette 3**

Sean's mother is 74 and was admitted to hospital recently, having fallen and broken her wrist. Prior to this she was living at home with Sean's father who while in good health is rather frail. His mother has become increasingly confused while in hospital and the staff have suggested that she be assessed for dementia. Social services are suggesting that his mother is no longer able to live at home with his father and that she should be cared for in a residential environment.

What do you think Sean and his family should do?

**Vignette 4**

A work colleague who is 57 years old and has been your colleague for 10 years has just been given a diagnosis of early Alzheimer's disease. You have found him difficult to be around for a while now as he was irritable and liable to fly off the handle quite quickly. He has also fallen a number of times at work. He is leaving work as he finds it too difficult to continue and he has confided in you that he is very fearful for the future.

What do you think will become of your relationship with him?

**Vignette 5**

It is 10 years since your colleague was given his diagnosis and he now lives in a nursing home. You recently visited him. He no longer speaks and needs help with all of his daily activities.

How do you think you would feel about the life he leads there?

**Vignette 6**

Joe is 81yrs old and although he has a diagnosis of dementia he continues to live in the same community he was born into.  He regularly gets lost and neighbours bring him home or call one of his children to let them know.  He is rarely upset but sometimes refuses to come back with whichever neighbour has found him.  Someone has called social services and they are concerned that Joe is a risk to himself.

What do you think?

**Vignette 7**

James is 53 years old and 3 months ago his wife was told that her husband had vascular dementia.  James has not yet asked for his diagnosis but he has realised that there is something very wrong.  He has been off work on sick leave for approximately 6 months now.  His wife realises that James may be forced to leave work early and she is concerned that they will struggle financially.  She is also worried about how they will cope as a family.  James is forgetful and frustrated, sometimes becoming angry and fearful.

Should James be told his diagnosis?

Should James be involved in any decisions about the future?

**Vignette 8**

A proposal has been made to build a specialist dementia unit in your street.  The unit is intended to house approximately 40 people with dementia.

How do think you would you feel about this?

**Vignette 9**

James runs a small business in your area, which regularly takes in volunteers through a local volunteer bureau. It has been suggested that a man in his 50's who has a diagnosis of Alzheimer's disease will be his next volunteer. Is this reasonable and what do you think James needs to consider?

**Vignette 10**

Grace is 75 years old and has been forgetful for quite some time. She leaves herself notes around the home to make sure that she remembers important things like locking the door or switching off the cooker. She has been attending the memory clinic with the support of her son and daughter. They were recently told by the consultant that their mother has Alzheimer's disease.

Grace has asked her children what is wrong with her and they have put her off, unsure if they should tell her. They are also considering whether their mum will need to move into a home as they both work some distance from home.

Should they tell Grace?

Should Grace be involved in the decision about the home?

**Vignette 11**

A 75 year old woman has been admitted to hospital with renal failure. She has been living with dementia for 6 years and her family explains this to the hospital staff. During her stay her physical condition deteriorates and she becomes increasingly confused. The family are advised that this lady will need ongoing dialysis and ultimately she will require a kidney transplant. Questions are being asked by the hospital team relating to how appropriate it is to place this lady on the transplant list. It may be several years before a transplant is available and the

consultant has suggested that given the progressive nature of the lady's dementia she may not be a suitable candidate.

What do you think is the right course of action?

I might follow this by asking if the woman admitted had been 47yrs old would that change the way you feel about this situation?

**Vignette 12**

Jack is a 79 year old man has been living in a care home for the last 5 years. He has been diagnosed with vascular dementia. He appears to be happy in the care home although he is sometimes frustrated and confused. He recently fell and broke his hip. After surgery for a replacement hip he has become more confused than usual. He has been receiving physiotherapy and is now able to walk slowly with the assistance of two people. However, he has become increasingly aggressive during treatment and the physiotherapists have informed the family that they feel he is not able to make further progress and they are withdrawing the service.

What do you think about the choices being made by the physiotherapy team?

**Appendix 7: Semi structured Interview Questions**

1. I'd like to begin by asking if you know someone or have known someone with dementia or Alzheimer's?

2. Can you tell me about that?

3. What are the words or images that come into your mind when you hear words like:

   Dementia?

   Alzheimer's or?

   Demented?

4. How do you think you would feel about a close friend or relative getting married to someone with a diagnosis of Alzheimer's or dementia?

5. If you found out you had dementia or Alzheimer's do you think you would be comfortable letting other people know about your diagnosis?

6. Why do you think so many people keep it to themselves?

7. In the focus group, people talked about euthanasia as an option for people with dementia. How do you feel about this?

8. What do you think people with dementia need from the rest of us, from their friends, family and community?

9. How would you like to live your live or to be treated if you had dementia?

# BACKGROUND QUESTIONS

1. **NAME:** _____

2. **AGE**:

   18 - 30 ☐     31 – 50 ☐     51 – 65 ☐

   66 – 80 ☐                over 80 ☐

3. **Gender:**

   Male ☐                     Female ☐

4. **Level of Education:**

   Primary                    ☐

   Secondary/Grammer          ☐

   Third level                ☐

5. **Are you currently working?**

   Yes ☐                     No ☐

**6. If your answer to question 5 was no, are you**

Retired

Unemployed

Off work as a result of sickness

Other

**7. Please describe your type of work in your current or last employment**

---

**8. Would you describe yourself as a carer for anyone?**

Yes

No

**9. If you were to describe your current financial circumstances would you describe yourself as**

Doing OK

Struggling

Doing very well

In difficulty

**10.** **Do you know someone with dementia**

Yes ☐          No ☐

**If the answer is yes please tick one of the following boxes**

Family member ☐

Friend ☐

Acquaintance ☐

**11.** **How would you describe your own health?**

Very good ☐

Good ☐

Ok ☐

Not so good ☐

Not in good health ☐

**Appendix 9: Focus Group/Interview Participant Demographics**

**Focus Group and Interview Participants - Background Demographics**

| Participant | Age | Gender | Education | SES | Carer | Working status | Knowing someone with dementia | Health |
|---|---|---|---|---|---|---|---|---|
| 1 | 66-80 | M | Third Level | Doing OK | No | Retired | Family Member | Good |
| 2 | 66-80 | F | Primary | Doing OK | No | Retired | Yes | OK |
| 3 | 51-65 | M | Third Level | Doing OK | No | Semi-retired | No | Good |
| 4 | 66-80 | M | Third Level | Doing OK | Yes | Retired | No | Good |
| 5 | 66-80 | M | Secondary/Grammer | Struggling | No | Retired | No | Good |
| 6 | 66-80 | M | Third Level | Doing OK | No | Retired | Family Member | Very good |
| 7 | 66-80 | M | Third Level | Doing OK | No | Semi-retired | Friend | Good |
| 8 | 51-65 | F | Third Level | Doing OK | No | Retired | Family Member | Good |
| 9 | 31-50 | F | Third Level | Doing OK | No | Unemployed | No | Very good |
| 10 | 80+ | M | Secondary/Grammer | Struggling | | Retired | Friend | Good |

| Participant | Age | Gender | Education | SES | Carer | Working status | Knowing someone with dementia | Health |
|---|---|---|---|---|---|---|---|---|
| 11 | 66-80 | F | Secondary/Grammer | Doing OK | Yes | Retired | Friend | Not so good |
| 12 | 31-50 | F | Secondary/Grammer | Doing very well | No | Working | No | Very good |
| 13 | 31-50 | M | Third Level | Doing OK | No | Working | No | Very good |
| 14 | 66-80 | M | Third Level | Doing OK | No | Retired | Family Member | OK |
| 15 | 31-50 | F | Secondary/Grammer | Doing OK | No | Working | No | OK |
| 16 | 51-65 | F | Third Level | Doing OK | No | Working | Family Member | Not so good |
| 17 | 31-50 | M | Third Level | Doing OK | Yes | Working | No | Very good |
| 18 | 51-65 | M | Secondary/Grammer | Doing OK | Yes | Working | Friend | Very good |
| 19 | 31-50 | M | Secondary/Grammer | Doing OK | No | Working | No | Good |
| 20 | 51-65 | M | Third Level | Doing OK | Yes | Semi-retired | Family Member | Good |

| Participant | Age | Gender | Education | SES | Carer | Working status | Knowing someone with dementia | Health |
|---|---|---|---|---|---|---|---|---|
| 31 | 51-65 | F | Secondary/Grammer | Doing OK | No | Retired | No | Very good |
| 32 | 31-50 | F | Third Level | Struggling | Yes | Other | No | Good |
| 33 | 51-65 | F | Third Level | Doing OK | Yes | Working | Acquaintaince | OK |

## Appendix 10: Focus Group/Interview Participant Coding System

| Code | Trust | Location | Focus Group/ Interview | Person |
|------|-------|----------|------------------------|--------|
| BFC | Belfast | Belfast | Focus Group | Details removed |
| BFD | Belfast | Belfast | Focus Group | Details removed |
| BFF | Belfast | Belfast | Focus Group | Details removed |
| BFJA | Belfast | Belfast | Focus Group | Details removed |
| BFJ | Belfast | Belfast | Focus Group | Details removed |
| BFJO | Belfast | Belfast | Focus Group | Details removed |
| BFP | Belfast | Belfast | Focus Group | Details removed |
| BFS | Belfast | Belfast | Focus Group | Details removed |
| BFT | Belfast | Belfast | Focus Group | Details removed |
| SEFD | South Eastern | Lisburn | Focus Group | Details removed |
| SEFE | South Eastern | Lisburn | Focus Group | Details removed |
| SEFER | South Eastern | Lisburn | Focus Group | Details removed |
| SEFJ | South Eastern | Lisburn | Focus Group | Details removed |
| SEFI | South Eastern | Lisburn | Focus Group | Details removed |
| SEFP | South Eastern | Lisburn | Focus Group | Details removed |
| SEFT | South Eastern | Lisburn | Focus Group | Details removed |
| NFP | Northern | Antrim | Focus Group | Details removed |
| NFA | Northern | Antrim | Focus Group | Details removed |
| NFJA | Northern | Antrim | Focus Group | Details removed |
| NFS | Northern | Antrim | Focus Group | Details removed |
| NFJ | Northern | Antrim | Focus Group | Details removed |

| Code | Trust | Location | Focus Group/ Interview | Person |
|------|-------|----------|------------------------|--------|
| WFV | Western | Omagh | Focus Group | Details removed |
| WFR | Western | Omagh | Focus Group | Details removed |
| WFH | Western | Omagh | Focus Group | Details removed |
| WFG | Western | Omagh | Focus Group | Details removed |
| WFD | Western | Omagh | Focus Group | Details removed |
| WFB | Western | Omagh | Focus Group | Details removed |
| WFDE | Western | Omagh | Focus Group | Details removed |
| WFT | Western | Omagh | Focus Group | Details removed |
| SFJ | Southern | Newry | Focus Group | Details removed |
| SFM | Southern | Newry | Focus Group | Details removed |
| SFMA | Southern | Newry | Focus Group | Details removed |
| SFG | Southern | Newry | Focus Group | Details removed |
| BIC | Belfast | Belfast | Interview | Details removed |
| BIF | Belfast | Belfast | Interview | Details removed |
| SEIE | South Eastern | Lisburn | Interview | Details removed |
| SEIT | South Eastern | Lisburn | Interview | Details removed |
| NIP | Northern | Ballymena | Interview | Details removed |
| WIR | Western | Omagh | Interview | Details removed |
| WIH | Western | Omagh | Interview | Details removed |
| SIG | Southern | Newry | Interview | Details removed |
| SIM | Southern | Newry | Interview | Details removed |

Key: First letter refers to Trust name except in the case of the South Eastern Trust where it is the first 2 letters
Second letter refers to whether the setting is focus group or interview
Third letter refers to the initial of the participant's first name (where there is more than one person with the same first initial, the second letter is also included,
e.g. SFM- Southern Trust, Focus Group, Mark and SFMA - Southern Trust, Focus Group, Margaret

## Appendix 11: NVivo Codebook

| Phase 1 - Open Coding | | | |
|---|---|---|---|
| **Open Codes** | **Code Definitions (rules for inclusion)** | **Interviews & Focus Groups Coded** | **Citations (text segments) Coded** |
| **A living shell** | Ideas of people no longer "really being there". The idea that the body is a shell now. | 7 | 15 |
| **Age and Ageism** | Where views expressed are stated as being influenced by age or where they appear to me to be influenced by age. I refer here to the age of the person under discussion rather than the age of the participant. However, other comments related to age and ageism are included here. Also includes where the participants refer to their own age as a factor. | 8 | 74 |
| **Awareness and Education** | Where participants refer to levels of awareness or education. | 7 | 24 |
| **Care** | Where participants refer to care of people with dementia. This includes refs to carer burden and views of care environments. | 14 | 184 |
| **Community** | Ideas associated with community | 8 | 27 |
| **Costs** | Any reference to the financial costs associated with dementia and dementia care. | 8 | 15 |
| **Denial** | Examples of where people describe how they might respond with denial or where they have observed denial being used by people with dementia or others caring for them | 6 | 14 |
| **Dependence versus independence** | Ideas around whether or not it is possible to maintain independence when someone has dementia and how this works with providing the right level of care and support | 7 | 20 |
| **Diagnosis** | Views on diagnosis - whether or not people should be told their diagnosis. Also include references participants make about receiving a diagnosis themselves. | 14 | 148 |
| **Drugs or other treatments** | References made to different types of treatment or to the use of drugs. | 4 | 30 |
| **Electronic tagging** | References to the use of electronic tagging for people with dementia | 8 | 17 |
| **Euthanasia** | Any reference to euthanasia explicit or implicit | 13 | 42 |
| **Fear** | Personal fear about dementia or refs to the fear of others | 12 | 64 |

| | Phase 1 - Open Coding | | |
|---|---|---|---|
| **Open Codes** | **Code Definitions (rules for inclusion)** | **Interviews & Focus Groups Coded** | **Citations (text segments) Coded** |
| **Frustration** | Where participants have described how they might feel themselves on experiencing symptoms or how they might feel towards someone with dementia. Also includes references participants make to the frustration they imagine someone with dementia might feel. | 5 | 8 |
| **Humour** | Where participants use humour to talk about dementia or refer to humorous incidents. | 4 | 12 |
| **Infantilisation and role reversal** | References made to the process of infantilisation and to the idea of role reversal. Added during interview coding | 3 | 4 |
| **Knowing someone with dementia** | Contains references from participants who know or knew someone with dementia | 12 | 42 |
| **Labelling** | Views linked to the value or otherwise of the label of dementia or Alzheimer's. Also includes references where the language used by participants might contribute to the labelling of people with dementia. | 7 | 69 |
| **Personal understanding of dementia** | Meanings and understandings of dementia expressed by participants | 14 | 205 |
| **Quality of life** | Any references made to how the participants view the quality of life of a person with dementia or how they view their quality of life might be if they had dementia. | 13 | 104 |
| **Relationships** | Any references made to the maintenance or breakdown of relationships as a result of dementia. Code added during interview coding | 9 | 29 |
| **Responses to moving out of your home** | Where participants talk about how they might feel about moving out of their own home or how a person with dementia might feel. | 4 | 19 |
| **Responses to potential personal experiences** | What participants described they might feel if they received a diagnosis of dementia, or responses they made when any of the scenarios were changed to explore how it might feel if it was happening to them rather than to someone else. | 9 | 81 |
| **Responses to professionals** | Where participants have spoken of their experience with professionals such as doctors, social workers etc. or of how they think they might respond to professionals | 7 | 59 |
| **Responses to Vignette 01** | | 3 | 17 |
| **Responses to vignette 02** | | 1 | 8 |

| Phase 1 - Open Coding | | | |
|---|---|---|---|
| **Open Codes** | **Code Definitions (rules for inclusion)** | **Interviews & Focus Groups Coded** | **Citations (text segments) Coded** |
| **Responses to vignette 03** | | 5 | 46 |
| **Responses to vignette 04** | | 5 | 48 |
| **Responses to vignette 05** | | 5 | 69 |
| **Responses to vignette 06** | | 5 | 54 |
| **Responses to vignette 07** | | 5 | 34 |
| **Responses to vignette 08** | | 6 | 59 |
| **Responses to vignette 09** | | 5 | 44 |
| **Responses to vignette 10** | | 5 | 69 |
| **Responses to vignette 11** | | 6 | 63 |
| **Responses to vignette 12** | | 5 | 39 |
| **Risk** | Views expressed on management of risk for people with dementia | 10 | 91 |
| **Sadness and sympathy** | Expressions of sadness or sympathy related to the condition of dementia or people with dementia. Created during coding of interviews | 5 | 10 |
| **Secret** | Any reference where participants refer to people wanting to keep dementia a secret.  This could refer to a family member or to a personal reflection on how they might respond. | 10 | 29 |
| **Social distance** | Any views expressed linked to ideas of social distance where participants describe thoughts or ways of creating emotional or physical distance between them and someone with dementia | 12 | 105 |
| **Sources of information and knowledge** | Where participants have gathered information and knowledge from.  This includes e.g. literature, media, anecdotal and personal experience | 9 | 83 |

| Phase 1 - Open Coding | | | |
|---|---|---|---|
| **Open Codes** | **Code Definitions (rules for inclusion)** | **Interviews & Focus Groups Coded** | **Citations (text segments) Coded** |
| **Symptoms** | Things participants have described as being something they associate with dementia | 7 | 40 |
| **Value** | Anything where participants refer to the way people with dementia are valued or how they perceive others value those with dementia. This includes direct and indirect references. | 5 | 49 |
| **Views of late stage dementia** | Where people have expressed how they feel about the type of life they associate with late stage dementia. This is made explicit in vignette 5 but comes up in other contexts in both focus groups and interviews | 9 | 126 |
| **Views on where people with dementia should live** | Responses to the question on where people with dementia should live and where participants would like to live if they had dementia | 12 | 162 |

| Phase 2 - Selective Coding | | | |
|---|---|---|---|
| Open Codes | Code Definitions (rules for inclusion) | Interviews & Focus Groups Coded | Citations (text segments) Coded |
| A personal response | Categorical node - this is a master node. Codes associated with this will refer to spontaneous or elicited comment by participants on how they might feel if this was a personal situation rather than something happening to someone else. | 10 | 102 |
| Responses to moving out of your home | Where participants talk about how they might feel about moving out of their own home or how a person with dementia might feel. | 4 | 19 |
| Responses to potential personal experiences | What participants described they might feel if they received a diagnosis of dementia, or responses they made when any of the scenarios were changed to explore how it might feel if it was happening to them rather than to someone else. | 9 | 81 |
| Age and Ageism | Categorical node - A master node or theme. Where views expressed are stated as being influenced by age or where they appear to me to be influenced by age. I refer here to the age of the person under discussion rather than the age of the participant. However, other comments related to age and ageism are included here. Also includes where the participants refer to their own age as a factor. | 14 | 151 |
| Dementia associated with ageing | Where there is evidence of participants linking dementia to ageing or where there is confusion around this. | 15 | 112 |
| Dementia is not a normal part of ageing | Evidence that participants don't see dementia as part of the normal process of ageing | 8 | 24 |
| Care | Categorical node - This is a master node or theme and the description has been amended in line with this from the description in initial coding. Any nodes related to ideas of care will be associated with this node. This includes actual or perceived carer burden and views of care environments. | 14 | 184 |
| Community | References made to the idea of community, to care in the community and to what people with dementia might need from their community | 8 | 27 |
| Costs | Any reference to the financial costs associated with dementia and dementia care. May also include general references to care costs. | 8 | 15 |
| Dependence versus independence | Ideas around whether or not it is possible to maintain independence when someone has dementia and how this works with providing the right level of care and support | 7 | 20 |

| Phase 2 - Selective Coding | | | |
| --- | --- | --- | --- |
| Open Codes | Code Definitions (rules for inclusion) | Interviews & Focus Groups Coded | Citations (text segments) Coded |
| **Drugs or other treatments** | References made to different types of treatment or to the use of drugs in the treatment of dementia and Alzheimer's | 4 | 30 |
| **Electronic tagging** | References to the use of electronic tagging for people with dementia | 8 | 17 |
| **Responses to professionals** | Where participants have spoken of their experience with professionals such as doctors, social workers etc. or of how they think they might respond to professionals | 7 | 59 |
| **Risk** | Views expressed on management of risk for people with dementia | 10 | 91 |
| **Views on where people with dementia should live** | Responses to the question on where people with dementia should live and where they would like to live if they had dementia | 12 | 162 |
| **Deviance** | **Categorical Node - This is a master node or theme within the thesis.  Any codes linked to ideas of deviance will be associated with this code.** | **15** | **563** |
| **A living shell** | References to ideas of people no longer "really being there".  the idea that the body is a shell now, | 7 | 15 |
| **Embarrassment** | Expressions of embarrassment around people with dementia | 6 | 18 |
| **Infantilisation and role reversal** | References made to the process of infantilisation and to the idea of role reversal. | 5 | 6 |
| **Labelling** | Views linked to the value or otherwise of the label of dementia or Alzheimer's.  Also includes references where the language used by participants might contribute to the labelling of people with dementia. | 7 | 67 |
| **Sadness and sympathy** | Expressions of sadness or sympathy related to the condition of dementia or people with dementia. created during coding of interviews | 5 | 10 |
| **Social distance** | Any views expressed linked to ideas of social distance where participants describe thoughts or ways of creating emotional or physical distance between them and someone with dementia | 12 | 105 |
| **Stigma** | **Categorical node - master node or theme.  Codes associated with a stigmatised attitude to dementia or direct references to stigma in the transcripts.  This is a theme in it's own right but also a sub theme of deviance.** | **14** | **167** |
| **Aggression** | References to aggression or lack of aggression in dementia | 3 | 11 |
| **Dignity** | References to dignity or lack of dignity in dementia | 3 | 4 |
| **Other** | References that refer to people with dementia as "other", set apart, not necessarily using this language.  Also references that indirectly convey the message of people with dementia as other. | 10 | 57 |

| Phase 2 - Selective Coding | | | |
|---|---|---|---|
| Open Codes | Code Definitions (rules for inclusion) | Interviews & Focus Groups Coded | Citations (text segments) Coded |
| **Unpredictability** | References to people with dementia as being unpredictable | 5 | 16 |
| **Value** | Anything where participants refer to the way people with dementia are valued or how they perceive others value those with dementia. This includes direct and indirect references. | 5 | 49 |
| **Views of late stage dementia** | Where people have expressed how they feel about the type of life they associate with late stage dementia. | 9 | 126 |
| **Diagnosis** | **Categorical node - Master node or Theme. Codes associated with the process and of, and reaction to diagnosis. Original description referred to views on diagnosis - whether or not people should be told their diagnosis. Also include references participants make about receiving a diagnosis themselves.** | **14** | **148** |
| **Fear** | **Categorical node - Master node or theme. Codes associated with themes of fear, original description referred to where participants have expressed personal fear about dementia or described the fear of others** | **12** | **63** |
| **Denial** | Examples of where people describe how they might respond with denial or where they have observed denial being used by people with dementia or others caring for them | 6 | 14 |
| **Panic** | References to people with dementia experiencing panic or to the feeling of panic a person reports they would feel on knowing they or someone close to them had dementia | 3 | 4 |
| **Secret** | Any reference where participants refer to people wanting to keep dementia a secret. This could refer to a family member or to a personal reflection on how they might respond. | 10 | 29 |
| **Humour** | **Categorical node - Master node or theme. Nodes associated with the use of humour in the stories told about dementia. Original description referred to participants' use of humour to talk about dementia or reference to humorous incidents.** | **4** | **12** |
| **Knowledge and understanding** | **Categorical node - this is a master node or theme. Any nodes associated with knowledge, understanding and their sources will be linked to this node.** | **1** | **1** |
| **Awareness and Education** | Where participants refer to levels of awareness or education. This includes the need for increased awareness or education or reference to existing awareness or education | 9 | 31 |
| **Disease** | References to dementia as disease or to dementia as being different to other diseases | 7 | 20 |

| Phase 2 - Selective Coding | | | |
|---|---|---|---|
| **Open Codes** | **Code Definitions (rules for inclusion)** | **Interviews & Focus Groups Coded** | **Citations (text segments) Coded** |
| **Personal understanding of dementia** | Meanings and understandings of dementia expressed by participants | 14 | 245 |
| **Sources of information and knowledge** | Where participants have gathered information and knowledge. This includes e.g. literature, media, anecdotal and personal experience | 9 | 83 |
| **Campaigning Organisations** | References to using campaigning organisations such as the Alzheimer's society to access information on dementia. | 3 | 3 |
| **GP** | References to using the GP as a source of information on dementia or as somewhere you might seek support | 5 | 19 |
| **Internet** | Use of the internet as a source of information on dementia | 5 | 20 |
| **Media** | References to the media as a source of information or where participants have referenced items or articles in the media | 9 | 36 |
| **Negative** | References to the media which provide a negative picture of dementia | 4 | 11 |
| **Positive** | References to the media which reflect a positive picture of dementia | 4 | 5 |
| **Other sources of information** | Examples include phone books, leaflets | 3 | 10 |
| **Personal experience** | Where participants refer to personal experience with someone with dementia as contributing to how they understand dementia | 8 | 25 |
| **Stories** | Where participants refer to stories they have been told that have contributed to the way they understand dementia | 11 | 39 |
| **Stories Humorous** | Where humour is used to describe dementia in the form of a story. These stories are also likely to be coded to either negative or positive | 2 | 2 |
| **Stories Negative** | Where the stories told present a negative picture of dementia | 11 | 29 |
| **Stories neutral** | Where the stories told seem neutral, unlikely to stimulate a negative or positive picture of dementia | 4 | 5 |
| **Stories Positive** | Where the stories told present a positive picture of dementia | 0 | 0 |
| **Symptoms** | Things participants have described as being something they associate with dementia | 7 | 40 |

| Phase 2 - Selective Coding | | | |
|---|---|---|---|
| Open Codes | Code Definitions (rules for inclusion) | Interviews & Focus Groups Coded | Citations (text segments) Coded |
| **Nihilism** | **Categorical node - A master node or theme. Codes associated with concepts of lack of hope and nihilistic views of dementia** | **14** | **146** |
| **Euthanasia** | Any reference to euthanasia or other references which allude to this without actually stating it explicitly | 13 | 42 |
| **Quality of life** | Any references made to how the participants view the quality of life of a person with dementia or how they view their quality of life might be if they had dementia. | 13 | 104 |
| **Perceptions of the experience for the person with dementia** | **Where participants expressed perceptions of how the person with dementia might feel or where they express ideas of not being able to understand how the person might feel** | **3** | **4** |
| **Vignettes** | **Categorical code - this code includes all codes relating to the vignettes. Codes were associated with each vignette as a back up source of information** | **7** | **550** |
| **Responses to Vignette 01** | | 3 | 17 |
| **Responses to vignette 02** | | 1 | 8 |
| **Responses to vignette 03** | | 5 | 46 |
| **Responses to vignette 04** | | 5 | 48 |
| **Responses to vignette 05** | | 5 | 69 |
| **Responses to vignette 06** | | 5 | 54 |
| **Responses to vignette 07** | | 5 | 34 |
| **Responses to vignette 08** | | 6 | 59 |
| **Responses to vignette 09** | | 5 | 44 |
| **Responses to vignette 10** | | 5 | 69 |
| **Responses to vignette 11** | | 6 | 63 |
| **Responses to vignette 12** | | 5 | 39 |

| Phase 3 – Consolidated Coding/Themes | | | |
|---|---|---|---|
| **Open Codes** | **Code Definitions (rules for inclusion)** | **Interviews & Focus Groups Coded** | **Citations (text segments) Coded** |
| **Age and Ageism** | **Categorical node - A master node or theme. Where views expressed are stated as being influenced by age or where they appear to me to be influenced by age. I refer here to the age of the person under discussion rather than the age of the participant. However, other comments related to age and ageism are included here. Also includes where the participants refer to their own age as a factor.** | **10** | **153** |
| **Dementia as a normal part of ageing** | Where there is evidence of participants linking dementia to ageing or where there is confusion around this. also included references that indicate an assumption of old age in association with dementia | 10 | 65 |
| **Dementia is not a normal part of ageing** | Evidence that participants don't see dementia as part of the normal process of ageing | 3 | 8 |
| **Complexity** | **Any references that indicate an awareness of the complexity of living with dementia** | **11** | **60** |
| **Knowledge and understanding** | **Categorical node - this is a master node or theme. Any nodes associated with knowledge, understanding and their sources will be linked to this node.** | **14** | **412** |
| **Awareness and Education** | Where participants refer to levels of awareness or education. This includes the need for increased awareness or education or reference to existing awareness or education | 9 | 32 |
| **Disease** | Evidence of dementia being understood as a disease | 7 | 10 |
| **Personal understanding of dementia** | Meanings and understandings of dementia expressed by participants | 14 | 245 |
| **Sources of information and knowledge** | Where participants have gathered information and knowledge. This includes e.g. literature, media, anecdotal and personal experience | 9 | 83 |
| Campaigning Organisations | References to using campaigning organisations such as the Alzheimer's society to access information on dementia or as somewhere you might seek support | 3 | 3 |
| GP | References to using the GP as a source of information on dementia or as somewhere you might seek support | 5 | 19 |
| Internet | Use of the internet as a source of information on dementia | 5 | 20 |
| **Media** | References to the media as a source of information or where participants have referenced items or articles in the media | 9 | 52 |
| Negative | References to the media which provide a negative picture of dementia | 4 | 11 |

| Phase 3 – Consolidated Coding/Themes | | | |
|---|---|---|---|
| Open Codes | Code Definitions (rules for inclusion) | Interviews & Focus Groups Coded | Citations (text segments) Coded |
| Positive | References to the media which reflect a positive picture of dementia | 4 | 5 |
| Other sources of information | Examples include phone books, leaflets | 3 | 10 |
| Personal experience | Where participants refer to personal experience with someone with dementia as contributing to how they understand dementia | 8 | 26 |
| Stories | Where participants refer to stories they have been told that have contributed to the way they understand dementia | 11 | 75 |
| Stories Humorous | Where humour is used to describe dementia in the form of a story.  These stories are also likely to be coded to either negative or positive | 2 | 2 |
| Stories Negative | Where stories told present a negative picture of dementia | 11 | 29 |
| Stories neutral | Where stories told seem neutral, unlikely to stimulate a negative or positive picture of dementia | 4 | 5 |
| Stories Positive | Where stories told present a positive picture of dementia | 0 | 0 |
| Symptoms | Things participants have described as being something they associate with dementia | 7 | 40 |
| Nihilism | **Categorical node - A master node or theme.  Codes associated with concepts of lack of hope and nihilistic views of dementia** | **14** | **162** |
| Euthanasia | Any reference to euthanasia of other references which allude to this without actually stating it explicitly | 13 | 43 |
| Quality of life | Any references made to how the participants view the quality of life of a person with dementia or how they view their quality of life might be if they had dementia. | 13 | 110 |
| Stigma | **Categorical node - master node or theme.  Codes associated with a stigmatised attitude to dementia or direct references to stigma in the transcripts.** | **15** | **430** |
| Dementia- what type of life | References to the value participants attach to a life with dementia, to the type of life they perceive it to be. | 9 | 205 |
| Infantilisation and role reversal | References made to the process of infantilisation and to the idea of role reversal.   Added during interview coding | 5 | 6 |
| Labelling | Views linked to the value or otherwise of the label of dementia or Alzheimer's.  Also includes references where the language used by participants might contribute to the labelling of people with dementia. | 7 | 67 |

| | Phase 3 – Consolidated Coding/Themes | | |
|---|---|---|---|
| **Open Codes** | **Code Definitions (rules for inclusion)** | **Interviews & Focus Groups Coded** | **Citations (text segments) Coded** |
| **Other** | References that directly refer to people with dementia as 'other' set apart, not necessarily using this language. Also references that indirectly convey the message of people with dementia as other. Incorporates coding against living shell in selective codes | 14 | 88 |
| **Shame** | Expressions of embarrassment, loss of dignity, references implying shame around the condition | 8 | 24 |
| **Unpredictable** | Where people with dementia are referred to as being unpredictable. Includes previous coding for aggression. | 5 | 24 |
| **Support** | **References where people describe wanting to support people living with dementia** | **11** | **52** |