

Access to dementia diagnosis and support in a diverse South Asian community: A qualitative study

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree
elsewhere.

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Abstract

Although members of the United Kingdom (UK) South Asian population appear to have an elevated risk of developing dementia, this population accesses dementia services less frequently, compared with the majority white population. The disparity between the prevalence of people with dementia and the reported incidence of dementia, especially among South Asian populations (the UK's largest ethnic minority), is of concern to public health service providers. This study aimed to identify the socio-cultural issues in accessing dementia services in the population living in Blackburn with Darwen [BwD], in the Northwest of England.

This qualitative study explores how members of the BwD South Asian Indian and Pakistani population perceive dementia, and how their family members engage with local dementia care services and with healthcare professionals providing dementia services. Data collection included: three focus groups with thirteen people involved in a community project; two interviews with people living with dementia and their family members; and eight interviews with nine dementia services healthcare professionals [HCPs]. The data was analysed using thematic analysis.

The findings suggest that members of the South Asian population are under-represented in dementia diagnostic services. Firstly, this appears to be due to a lack of knowledge in the Muslim South Asian Indian and Pakistani community about the nature of dementia. Various negative perceptions of dementia, influenced by cultural beliefs, were also identified which lead to people with dementia being stigmatised and hidden from public view by their families. This may explain why health professionals report that this population seeks help at a later stage of the illness, and thus there is an argument for public health services to develop culturally relevant outreach programmes.

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Chapter 1: Introduction

Dementia has become a global health challenge: an estimated 47 million people are living with dementia, with the number projected to increase to about 140 million by 2050 (World Health Organisation [WHO] 2015) and the associated costs to the state and families are expected to rise significantly. Addressing the impacts of dementia on people and society is thus an enormous international health priority. Evidence of the growing burden of dementia has resulted in the development of many strategies and initiatives. National dementia strategies have been initiated to ensure that the needs of people with dementia are appropriately addressed in years to come (Ablitt et al., 2009). The strategies include compelling improvements in health and care, creating dementia-friendly communities and improving dementia research.

Chapter 1 offers the reader some background knowledge of dementia, the primary focus of this thesis. The aim of the study was to identify the socio-cultural issues underpinning access to dementia diagnosis and support services in the BwD South Asian population. An outline of the signs and symptoms of dementia in people from ethnic communities is followed by a discussion of the rationale and scope of the thesis. The chapter concludes with an overview of the whole thesis.

1.1 Dementia in ethnic communities

‘Dementia’ is an umbrella-term for progressive conditions leading to memory loss, mood changes, and problems with reasoning and communication (WHO, 2015). Over time it alters the individual’s brain structure and chemicals, resulting in loss of capacity to understand, remember and reason. It is closely linked to a decline in mental capacity and is severe enough to affect a person’s everyday routine. The Alzheimer’s Association (2016) points out that

while dementia does not influence a person's consciousness, it affects the individual's memory, thinking, learning capacity, and language. The impairment of an individual's cognitive functions is due to organic brain changes which impact on emotional, motivational, social engagement and behaviour. Dementia signs and symptoms are broadly similar in a larger proportion of people who develop the condition. Primarily, dementia affects older adults who are vulnerable to high blood pressure, heart disease, stroke, and diabetes – all of which are risk factors for dementia, particularly vascular dementia (Burns et al., 2006). These risk factors pose health problems, preventing the implementation of the various measures intended to reduce the likelihood of individuals developing dementia, which is discussed later in the section. As dementia progresses, the linked functional and behavioural deterioration necessitate daily support and care of the individual – and here the role of family as caregivers can be substantial (James, 2011).

There are over one hundred types of dementia but the most known types include Alzheimer's disease, Lewy body dementia, frontotemporal and vascular dementia. Alzheimer's disease is the most common type of dementia and is caused by the build-up of beta-amyloid proteins in the brain which form structures called tangles and amyloid plaques. This results in the loss of connections between nerve cells which then die, leading to a loss of brain tissue. It is a progressive disease in which the symptoms slowly worsen over time as the brain becomes more damaged. Thus, the symptoms gradually become severe enough to disrupt everyday activities. Alzheimer's disease accounts for between 60 and 80 percent cases of dementia. Lewy body dementia is caused by abnormal proteins which appear in the brain's nerve cells, thus impairing its functioning (Alzheimer's Association, 2016). Lewy body dementia can present with many symptoms including problems with memory, moving, sleeping and thinking. Vascular dementia is another common type of dementia that arises when the brain is damaged as a result of strokes or cumulative damage from a number of transient ischaemic

attack (TIAs) or sub-clinical ‘mini strokes’. Vascular dementia typically has a stepwise progression, rather than a gradual decline. Frontotemporal lobe dementia (FTD) is believed to be caused by damage to or shrinkage of primarily the frontal lobes of the brain. It has its own set of symptoms; however, there are cases when symptoms of most dementia overlap. Each type of dementia is concerned with specific brain cell damage which affects a particular area of the brain.

Memory loss is one of the earliest symptoms associated with dementia (James, 2011). The brain has several distinct areas, each responsible for performing different functions including judgment, movement and memory. Thus, when damage occurs to specific cells in a given region, its efficiency is reduced, and it functions increasingly poorly. When an individual experiences regular memory challenges, it is important that people do not in delay seeking medical attention (Douglas, 2016). Medical interventions can be helpful if dementia is diagnosed early enabling treatment to begin, this has been shown to in some people to slow the disease process (Douglas, 2016). This enables individuals to make decisions about legal, financial and long-term care, and to make their wishes known to their family members (Prince et al., 2011). Furthermore, seeking help early means appropriate information can be given to the person and they can then decide to whether they want an early diagnosis or to wait for a timely diagnosis (i.e., when it is right for the person with dementia and their family members). Some may prefer a timely diagnosis as they may be frightened and do not feel ready to deal with the stigma. However, seeking help early enables healthcare professionals to address any concerns people with dementia and their family members may have about the disease, and support they could access (Prince et al., 2011).

The first strategy for determining the appropriate treatment is to diagnose the condition’s primary cause. Lievesley (2010) emphasised that no single test is used to diagnose dementia in individuals. The individual’s disease is identified by considering the medical aspects of a

person's history, physical examination, and the common characteristic changes in association with cognitive processes and the mannerisms typical of each kind of dementia (Fogel & Greenberg, 2014). It can be difficult for the clinician to identify the exact type of dementia an individual may have because symptoms sometimes overlap and scan findings are not always conclusive (Downs & Bowers, 2014). Nevertheless, dementia treatment is based on various causes and aspects of the individual's presentation. For instance, in cases of dementia such as Alzheimer's disease, no cure can halt its progression, although cholinesterase inhibitors can slow the progression of Alzheimer's disease (Hogan et al, 2008). A number of antipsychotic drugs - Bupropion, Trazodone and Haloperidol – may be prescribed at later stage for behavioural issues (Douglas, 2016). There are currently no specific drugs available to treat or cure FTD (Bartlett, 2010).

Several researchers have pointed out that diet, physical fitness, and cardiovascular-related factors are among the prevention measures which patients also need to consider (Desai, 2010; Isaacson, 2011; Lievesley, 2010). Isaacson (2011) asserts that diet has an effect on brain health, because of the effect of diet on the heart. Heart-related healthy eating patterns - such as the Mediterranean diet - can improve brain function (Desai, 2010). Maintaining physical fitness can be effective in lowering the various risks factors associated with the different types of dementia. Research reveals that regular exercise directly benefits the brain cells by increasing the blood and oxygen flow to the brain (Lievesley, 2010). Other preventative measures are those commonly used to prevent heart diseases: avoiding smoking, taking steps to maintain optimum blood pressure limits, and maintaining a healthy weight (Isaacson, 2011).

Living with dementia will probably affect an individual socially, psychologically and economically (Ablitt et al., 2009). Greater medical attention should be given to how an individual with dementia experiences daily and emotional life. Numerous dementia-related

conditions play a role in modelling a person's experiences: relationships, their environment and the designated support they receive. Caregivers and friends and family can assist an individual living with dementia to continue experiencing value and a sense of belonging. These are attained primarily through the provision of physical, emotional and mental support, which are crucial to promoting wellbeing and enabling the person to meet their healthcare needs (Lievesley, 2010). While providing care to a person who has dementia, it can be vital for carers to explain the condition to the individual, and be aware of how the person might reason and experience feelings, which will affect how they act. It has been clinically proven that the changes associated with dementia impact on how an individual behaves (National Collaborating Centre for Mental Health, 2007). Explaining the illness to the person, however simply, will be beneficial if the caregiver is supportive, while trying to gather as much information as possible about the person's behavioural changes.

Since each person has a unique personality, life history, likes and dislikes, it is important to focus on what the individual can still do, rather than on what he or she may have lost (Lievesley, 2010). It is also essential to focus on what the person experiences rather than what they remember. Dementia has many impacts, as a result of which the majority of individuals will experience memory challenges and other associated health issues. Despite these challenges, an individual can still retain some of his or her capabilities, and still experience an emotional link with other people and their surroundings.

A dementia strategy is currently being introduced at global and national levels which are intended to improve the lives of people living with dementia (see Chapter 2). Weiner (2009) maintains that it is important to ensure that the various strategies put forward to address the challenge of dementia are carefully and appropriately adopted. The strategies should take into account that appropriate information and support should meet the needs of individuals living with dementia and their community (see Chapter 2). This research focuses on a specific

community's dementia needs, exploring the sociocultural issues underpinning how dementia diagnosis and related support services are accessed in the South Asian population in Blackburn with Darwen (see chapter 3).

1.2 Scope of this research

With the introduction of person-centred approaches (Kitwood 1995), placing the person with dementia at the core of research and service development, there has been a shift toward understanding dementia in terms of the psychological and social factors which impact directly on an individual's experience of the illness and the healthcare attention they receive. Kitwood (1995) highlights the importance of constructing dementia and dementia services to reflect the lived experience of a person with dementia, and the impacts on them of negative and positive interactions. The current evidence emphasises the importance of identifying people who are regarded as being at greatest risk, either from advanced risk factors or current warning signs (Mackenzie, 2006). There is a need for a biopsychosocial model (as Tom Kitwood promotes) that looks at the person as a whole and individual. Kitwood (1995) person-centred approaches have been used in more than two decades and it is still relevant (Victor et al., 2012). That said, the scope of this research is located within a social understanding of dementia. The biomedical model of dementia focuses on physiological deficits for the person; in contrast, the social model focuses on the lives of people with dementia, how they are supported, and their social environment. Consequently, this research is focused on people with dementia, caregivers and HCPs, to obtain clear information about their understanding of this disease. There is little background information and knowledge about the needs of people with dementia in the South Asian community (Jutlla, 2015), and a widespread lack of awareness amongst community members about the difference between dementia and normal ageing.

Even though Mackenzie (2006) has explored the experience of stigma for people with dementia, there is limited information about its impact on the experience of dementia. The existing research identifies the need for further exploration of the South Asian community experience of dementia, the impact of negative cultural attitudes, including stigma, and the economically and politically driven medical world underpinning access to dementia diagnosis and related support services for the South Asian population (Mittal et al., 2014). Further research is needed because stigma has been extensively linked to the process of addressing countless social forces about dementia. This thesis explores stigma and how individuals with dementia and their families face stigma in the South Asian community.

The research draws on the Habermas' theory of communicative action and Goffman's Theory of Stigma. The two theories were applied for their relevance to the research. Habermas's theory of communicative action is used to underpin this research. Many people struggle to find a balance between their personal life experiences and social structure; problems arise when their personal life world is adversely affected by the social structure (the system world) (Habermas, 1984). In the space or sphere where community members interact, exchanging ideas and opinions about their social problems, it is proposed people can formulate their opinion on political action. The experience of education and learning allows individuals to realise the rights and power of the government over individuals through actions and policies (political legitimisation) and take action free from political control. Given the issue of stigma reportedly attached to mental illness, I draw on Goffman's Theory of Stigma in describing the stigma attached to mental illness in the community studied in this research. The stigma theory provided detailed insight into how individuals living with dementia in a family setting collectively experience stigma in their community (Arboleda-Flórez and Sartorius, 2008).

The research inquiry was addressed using a qualitative approach. The key reason for employing such an approach was that it facilitated an in-depth subjective understanding of

individual experiences (Ormston et al., 2014). The method is beneficial in cases where the research aims to understand people's reasons, beliefs and opinions regarding a given topic.

1.3 My personal perspective

This research was an Economic and Social Research Council funded CASE studentship in partnership between Blackburn with Darwen Council and Lancaster University. The studentship was developed at Lancaster University in response to a research request by Blackburn with Darwen Council (BwD) Public Health Department, with the aim of better understanding the perceived incidence of young onset of dementia within the South Asian population and the need for and access to dementia services. In particular BwD were keen to determine the actual levels of dementia in this population, in order to plan for the future commissioning of dementia services. In 2013, I was awarded the studentship, and commissioned to develop my doctoral research. Specifically, I was asked to explore the apparent disparity in numbers of people from the South Asian community accessing the dementia diagnostic service (memory clinic), versus the number of older people from this community that anecdotally were reported with memory problems, when accessing other drop-in or support services such as local community groups, Age UK and the 50+ Partnership (see section 2.7 for further discussion).

The research objectives were to ask people with dementia and their family carers or other members of the community about their experiences of the disease. I was most interested to undertake this PhD because it matched particularly well with my previous interest and personal experience of caring for someone with a mental health condition, although this experience was also the most challenging aspect of my decision to study the psychology of healthcare and its relationship to this particular subject.

I am the youngest child of three, born and raised in a small clustered South Asian community in Northwest, England. In 2007, when a family member was diagnosed with a mental health condition, my desire to understand more about her condition led me to undertake a first degree in psychology with counselling, and later a Masters in Psychology. During this time, I became her primary carer, chiefly because I had first-hand personal experience of how mental health is viewed in the South Asian community and its impact on a person living with the condition.

Through my personal experience, I realised in my professional role that a large percentage of individuals from the South Asian community had difficulty accessing adequate mental healthcare services. I have subsequently dedicated my career to improving access to mental health services for this community. Given the increasing incidence of dementia, many people - including members of the South Asian community - may now be either caring for someone with dementia. Most have absorbed a cultural understanding of dementia and their journey is likely to be affected by the South Asian community's construction of dementia. With my roots in the South Asian community, I passionately believe my research has the potential to contribute to improving access to dementia services. To achieve that, it is essential to understand the needs of the South Asian community to improve their understanding of dementia.

With predicted global lifestyle changes, the kind of healthcare individuals receive as they grow older has changed radically. A clear understanding of those changes and consequences requires a more detailed discussion about the provision of adequate healthcare to people with dementia. This research integrates additional information from the literature review, which was initially undertaken for the purpose of identifying certain diagnoses and demographic details pertaining to the South Asian community in Blackburn with Darwen.

1.4 Overview of the thesis

The thesis is sub-divided into eight chapters, summarised below.

Chapter 2 is concerned with the background to dementia in relation to ageing globally, nationally, and locally in Blackburn, where the study is based. Dementia is a globally recognised condition caused by brain disease or injury which results in progressive dysfunction of the cortical and subcortical functions and a loss of cognitive ability caused by physical changes in the brain (Prince et al., 2013). ‘Ageing’ is a term used to describe the process of getting older. The immune system becomes weaker, making it more difficult to fight diseases compared to a younger person, because of cell death caused when cells lose their ability to multiply. An individual may develop brain diseases such as dementia which result in memory problems and affect how the individual understands and communicates with others. A declining immune system and cognitive function can profoundly affect a person’s quality of life. As older people are now living longer, there is an urgent need to take action, which the chapter goes on to discuss. The chapter present figures on the presence of people with dementia in BwD.

Chapter 3 is the literature review; an integrated literature review was conducted to evaluate literature on the experiences of South Asian individuals and families with the dementia diagnosis process and their engagement with health services. This section of the thesis aims to comprehend the understanding of dementia among South Asian Indians and Pakistanis. The chapter addresses how various social factors - qualifications, family structure, control, and reputation, social character, ethnic personality, and ethnic qualities - may influence the experience of a person with dementia. This wide-ranging section seeks to explore how social institutions and practices, wellbeing strategies, and ethnic-social qualities affect the diagnosis and treatment of dementia in an ethnically diverse group originally from South Asia. The two

groups were combined to give the study a broader understanding of dementia in that population. The global literature includes evidence on the experiences of diverse populations with dementia, but little research has been done with Pakistani and Indian communities. This study therefore aims to bridge the gap in knowledge by collating the sparse existing literature.

Chapter 4 discusses the theoretical framework adopted for the study. In this section, Habermas's theory of communicative action and Goffman's Theory of Stigma add to understanding the socio-cultural issues which affect how the diagnosis of dementia is made and how relevant healthcare services are accessed by the South-Asian Indian and Pakistani people living in Blackburn with Darwen. Goffman's stigmatisation hypothesis can be applied across different disciplines, here including brain research, wellbeing and pharmacology (Arboleda-Flórez and Sartorius, 2008). Habermas's (1984) notion of reason engendering an emancipated open act can also be applied to the population under study here.

Chapter 5 discusses the methodological approach used to carry out this research. There is a consideration of the distinctive underlying ontological, epistemological, and methodological assumptions. These are addressed within the context of the social constructivism paradigm, which was chosen as a research philosophy as it helps to reflect issues relating to the South Asian community's access to dementia healthcare services. This choice of paradigm informs the adoption of a qualitative methodological approach, which facilitates an in-depth understanding of the underlying reasoning, beliefs and thoughts people have in relation to the issue of dementia (Ormston et al., 2014).

Chapters 6,7 and 8 explore the themes identified in the analysis of the findings. Chapter 6 explores how the South Asian community's understanding of dementia influences the experience of living with dementia: the importance of community ties, and the differences between the host Western culture's construct of dementia as a treatable condition and Eastern

culture's perception of dementia as an unfamiliar invisible illness with spiritual causes. People from the South Asian community have distinctive connections to their community's social values and convictions, which are to some extent influenced by their level of knowledge on the given topic.

Chapter 7 discusses the consequences of stigmatisation: many families hide the condition from the wider community by managing it at home. Participants' perceptions of the consequences of the South Asian community's beliefs and views about dementia are discussed, in terms of how stigmatisation leads to hiding the person with dementia. HCPs suggested that removing shame about dementia in the South Asian community would enable individuals to have a better introduction to dementia policies. The stigma attached to dementia leads relatives to attempt to maintain a strategic distance from divulging that the family is living with dementia by concealing or hiding the person with dementia.

Chapter 8 focuses on the provision of health and social services, drawing chiefly on the findings from Chapters 6 and 7. Here 'access' is discussed, drawing on evidence from the participants' discussions about their perceptions of the South Asian community's choice whether or not to use dementia services. Consideration is given to how people in the South Asian community are both integrated in and yet segregated from dementia services, and to the participants' perceived unmet needs in the community, addressing how current health promotion strategies fail to take into account the needs of the South Asian community. The chapter concludes by summarising the key findings from the themes discovered in the discussions about access to dementia services.

Chapter 9 interprets and discusses the findings of the study more comprehensively and takes account of the wider literature including material introduced in Chapters 2, 3 and 4. The qualitative approach enabled the understanding of the sociocultural issues underpinning the

process of accessing dementia diagnosis and support services in the BwD South Asian population. This is examined by drawing on Goffman's stigma theory and Habermas's theory of communicative action which help understanding of socio-cultural issues, supporting how the dementia diagnosis is made and how related support services are accessed by the South-Asian Indian and Pakistani populations. Lastly, the strengths and limitations of undertaking the research are discussed, augmented by reflections on the researcher's experience of undertaking the study.

Chapter 10 summarises the study's findings, and considers the research's contribution to knowledge and policy, offering recommendations for future research. The study findings explored and interpreted the understanding of dementia in the broader context of community, health, and illness. The study participants indicated that most people from the South Asian Indian and Pakistani community struggle to understand dementia, and the study discovered a range of understandings of dementia in the South Asian community. This research, therefore, takes into account various intertwined factors associated with the patient's needs and the wider public's emotional responses to their own needs. The study emphasises the importance of avoiding discrimination against people and families experiencing dementia in the South Asian community, to eliminate fear and the concealment of dementia.

Chapter 2: The Background

Chapter 1 introduces the research topic. A considerable number of people over the age of 65 have dementia, which in fact represents the majority of people with this disease; nevertheless, a proportion of younger people under the age of 65 are also affected by dementia (Prince et al., 2014b). Dementia can adversely affect life quality. This chapter addresses global, national United Kingdom (UK), and local contexts regarding dementia prevalence and incidence, where known.

2.1 The global dementia picture

Dementia is one of the world's largest public health challenges (Prince et al., 2014). The numbers of people living with dementia globally must be examined if we are to assess its impact. A reported 47 million people are living with dementia, representing 0.6% of the world's population (World Health Organisation [WHO] 2015), which indicates an estimated 7.7 million new cases annually: every four seconds a new case of dementia is diagnosed (WHO, 2012; Alzheimer's Disease International, 2013). However, relying on this data has certain implications; the figures are estimated based on the number of people diagnosed with dementia. The data do not accurately reflect the actual number of people with dementia as they do not take into account the number of people living with dementia globally who have not received a diagnosis or are misdiagnosed.

Bernard and Scharf (2007) and Alzheimer's Disease International (2013) suggest that dementia diagnosis is poor in countries like China and India and other South Asian and Western Pacific low- and middle-income countries: in India, an estimated 10% of people with dementia are diagnosed (Alzheimer's Disease International, 2013). However, even in

high-income countries such as the United States and the UK, only 20–50% of dementia cases are recognised and documented (Alzheimer’s Disease International, 2013). Using these figures – which are based on the assumption that the occurrence of dementia is similar in each country - Alzheimer’s Disease International (2013) estimated there are 28 million people with undiagnosed dementia globally.

Each country, however, has its own diverse culture, with different education levels and economic strengths, both of which are factors known to affect the diagnosis of dementia. O’Connor et al. (1991) suggested that lower education levels and socioeconomic status are risk factors for scoring poorly on the Mini-Mental State Examination and cognitive screening tests. They argued that epidemiological surveys of dementia need detailed assessment procedures.

2.1.1 Worldwide economic costs of dementia

Dementia poses both a health challenge and an economic challenge (WHO, 2015). Annually billions of dollars are spent globally to provide care for people with dementia - in 2010, an estimated US\$604 billion (Prince et al., 2014; WHO, 2015). The cost of dementia is distributed similarly in different countries, but in low-income countries dementia costs are lower compared to high-income countries (Table 2.1)(WHO 2015b; Alzheimer’s Disease International, 2013). This may be the result of lower diagnosis rates of dementia in lower-income countries, which means less money is spent on informal, social, and medical care for people with dementia, which accounts for the majority of the global economic costs of dementia (Alzheimer’s Disease International, 2013). Some spending also occurs globally to improve dementia diagnosis to increase the diagnosis rate and improve the underutilisation of existing interventions (WHO, 2015b).

Table 2.1: Care costs per person with dementia (cited in WHO 2015b)

Countries	Money spend on dementia in US\$
Low income	868
Lower-middle income	3,109
Upper-middle income	6,827
High income countries	32,865

The estimated worldwide spending on dementia is expected to rise by 85% by 2030 (WHO 2015b), based on the estimated increase in the number of people worldwide currently with dementia. Based on the projected increase in the number of people with dementia, estimated worldwide spending on dementia is expected to rise to 85% by 2030 (WHO 2015b). This predicted estimate takes account of the ageing global population, as ageing is the major cause of dementia (WHO, 2015b). Thus, as the ageing population increases in all regions of the world, so too will the prevalence of dementia (WHO, 2015). However, several research studies (Akushevich, et al., 2013; Qiu, et al., 2013; Rocca, et al., 2011) undertaken in technically developed countries have indicated that the prevalence (the proportion of people with dementia) and incidence (the proportion of people developing dementia in a given time) of dementia has begun to decline (Matthews, et al., 2016). This is attributable to the fact that, in high income and upper-middle income countries, the diagnostic methods and criteria used to identify people with dementia have improved, as have measures to improve health such as education and mid-life health promotion programmes targeted at smoking reduction, diet and exercise. These may therefore be reducing the risk of dementia in some countries, an issue that will be considered in more detail in section 2.2. However, a lack of progress regarding access to education, childhood malnutrition and persistent inequalities within and across

lower and lower-middle income countries means that dementia will continue to have a major global impact. Thus, the burden of dementia will continue to have a significant societal impact given the growing proportion of older people (see section 2.2). Searching for new ways of preventing and treating the disease therefore continues to be of paramount importance.

2.2. Global population ageing and dementia

Population ageing will be the major cause of the projected increase in the number of people with dementia (WHO, 2015b). In order to understand the impact of increased longevity on dementia, it is important to analyse the demographic data on international ageing. Of the 6.5 billion global populations, an estimated 627 million people are aged 60+, and in high-income countries, 20% of the population is aged 60+ (Bernard and Scharf, 2007). It is estimated that by 2025 the number of older people (aged 60+) will increase by 200% in low- and middle-income countries and by 68% in the technologically developed world (Alzheimer's Disease International, 2009).

Currently, an estimated 3% of people aged 70–75 and 25% of people aged 85 years or older are living with dementia, which is expected to increase with the global increase in the number of older people (Ferri et al., 2005). Over the last century, people have begun to live longer lives compared to their ancestors as a result of decreased mortality rates and increased life expectancy (Alzheimer's Disease International, 2009; Yi et al. 2006). Alzheimer's Disease International (2009) has argued that over the past twenty years, the health and social welfare of older people has improved, now they are included in global public health policy, which has resulted in a growing recognition of their importance in all parts of the world. It is uncertain if this change is because of the improvement in public health policies or the result of

increased population ageing, which has transformed global demographics and thus impacted on global and national policies. This has resulted in policy-makers placing emphasis on older people and including them in the health agenda. Older people were formerly neglected by policy-makers, researchers, and practitioners (Bernard and Scharf, 2007).

The continued increase in the elderly population is largely due to effective health policies which have resulted in improved healthcare for older people and a shift in the causes of disease and death (WHO, 2011). With effective health promotion, people now make better health choices - exercise and better diet - which improve their quality of life. If this is the case, it calls into question why global health promotion for older people continues to be neglected. Current international health promotion for older people does not clearly distinguish between health or social interventions - such as rehabilitation and interventions to reduce isolation - and central health promotion actions, such as improving access to services and helping people make better health choices (McMichael, and Butler, 2007). Furthermore, the current international health promotion agenda for older people does not take into account the heterogeneity of this group in terms of gender, race, and ethnicity (McMichael, and Butler, 2007).

2.2.1 Representations of older people and dementia

I argue that if improved healthcare is the cause of the recent increase in the ageing population, this raises the question of why older people and ageing remain largely negatively represented in the health literature. The language used by health and social policy-makers, commissioners, and service designers includes terms such as 'disaster', 'burden', 'rising tide', and 'impending crisis' (Bond et al., 1993, pg 1; Victor, 2006). This negative representation of

older people persists, as noted in a recent quote from Health and Social Care Information Centre Lead Clinician Martin Severs:

"Today's report gives fresh insight, with original analysis, into the typical profile of an older person in England today. By looking at change over time our report provides a broad understanding of an ageing population and the implications this group may have for health and care services" (Health and Social Care information centre, 2014).
<http://www.hscic.gov.uk/article/4804/National-report-sheds-new-light-on-the-health-and-care-of-older-people>

The use of words such as 'implication' may suggest that older people are still perceived as problematic and a burden to society. This negative representation of older people can be dated back to at least the early twentieth century (North and Fiske 2013), when older people were already perceived as a 'social problem' (Bond et al., 1993; Victor, 2006). The negative representation of older people in the literature and health agenda results in a negative perspective on the ageing population by society, which shapes not only the experience of older people but also how they perceive themselves (Victor, 2006). A similarly negative representation of dementia as an illness and people with dementia appears in the clinical media, literature, reports and articles. Kastenbaum (1988), for example, used the term 'death in life' to describe clinical dementia, suggesting that people with dementia are socially dead (cited in Sweeting and Gilhooly, 1997). Although this is an older text and there are implications of relying on such literature, this representation of older people and dementia unfortunately still dominates our modern society in which media plays a major role. More recent work by Collin and Hughes (2011), and Williamson et al. (2011) argues that it is important to understand the representation of dementia, especially in the media, which shape public understanding of the illness and perceptions of people living with the condition.

Negative representation of an illness can result in negative public perceptions of people living with the condition. Media discourse plays a major role in shaping the negative representation and perceptions of dementia and people living with dementia (Collin and Hughes 2011, Lyons 2000, Seale 2002, Williamson et al. 2011). The media often represent dementia as a damaging, threatening disease with headlines such as “Brain disease on rise: Alzheimer's epidemic” (Hamilton 2010) and “Dementia: A bomb ready to explode –Warning” (Mirror 2011) (cited in Peel, 2014, pg. 2-3). The media also compare dementia with other problematic diseases like cancer with headlines such as “Cancer and Alzheimer's most feared of diseases” (Morning Star 2011) (cited in Peel, 2014, pg. 2-3).

Dementia is perceived as a demographic time-bomb when describing the importance of dementia as a public health issue. In the media, dementia has long been considered a problem, as evidenced by the negative terminology used to represent dementia: ‘tsunami’, ‘tidal wave’ and ‘worse than death’ (Peel, 2014, pg. 1). Clearly, negative representations of ageing and of people with dementia may add to the difficulties they face. A sustained global effort is underway to advocate for action on dementia and address the difficulties faced by people with the condition (WHO, 2015). The next section discusses global action against dementia, giving consideration to the global strategies which have been developed and implemented.

2.3 Global action on dementia

Dementia is globally recognised as the third leading cause of disability (Horton, 2012). The scale of dementia discussed earlier has resulted in dementia becoming an international public health priority. Alzheimer's Disease International (2012) argued that the international public health priority of dementia can only be achieved by each nation collaborating to develop

overarching priorities. These can only achieve success if each nation uses them as a guideline to produce its own national dementia strategy which reflects the context of each country, each with its own diverse culture and demographic profile, different education levels and economic strengths, which are factors known to affect diagnosis of dementia and cannot be addressed through international initiatives (Batsch and Mittelman, 2012; WHO, 2015)

In December 2013, the world's first G8 dementia summit of research experts, pharmaceutical companies, ministers, and charitable organisations developed and agreed a list of central international priorities (as in DOH, 2014):

- A cure for dementia
- Increased funding for dementia
- Increased involvement of people with dementia in research and clinical trials, who have capacity
- A new global representative for dementia action
- Sharing information and data from dementia research studies across all G8 countries in order to receive a return on investment made and allow open access to publicly-funded dementia research data and results.

Other underlying concepts and approaches considered integral to global efforts were agreed at a Ministerial Conference on Global Action Against Dementia held on 17th March, 2015 hosted by WHO (2015). There were:

- To reform the care of people with dementia by inspiring researchers to collaborate with stakeholders.

- To incorporate dementia in policies on ageing, disability, and non-communicable diseases to establish dementia care, and rehabilitation.
- To use existing expertise to maximise impact when developing collaboration arrangements.
- to continuously develop and improve the care, needs, and support of people living with dementia and their caregivers, whilst efforts are made to develop a cure for dementia.
- To ensure open access to data and research to facilitate faster information dissemination, teaching and action.
- To ensure that policies, plans, services, interventions, and actions meet the needs and expectations of people living with dementia.
- To facilitate equal access to health and social care services for all those living with dementia and their caregivers.

2.3.1 Reflection on global action on dementia

This list of international priorities may seem overly optimistic and does not take into account the rigorous and extensive research procedures, such as ethical approval, required when working with people with dementia (Whitehouse, 2000). This can pose problems for researchers applying for ethics approval as Research Ethics Committees are always cautious about approving research involving participants with reduced or fluctuating mental capacity, particularly if they are deemed vulnerable because they are unable or have reduced ability to give informed consent except by proxy (Farrimond, 2013). The G8 priorities do not take into account the difficulties researchers encounter to include the perspectives of people with dementia at any stage. Most dementia research aims to understand its impact and/or experience from the perspective of family members or caregivers, as it is easier to obtain

research ethics approval this way (Wilkinson, 2002). This is perceived as an adequate way to understand the experiences of a person living with dementia.

In this thesis I argue that all people with dementia should be treated equally, and be valued and respected in dementia research. People with dementia could be involved at later stages by considering the methods which correspond to those capacities (Alzheimer's Europe, 2012). Care is required when designing a study to use a data collection method which does not exclude people with dementia from certain groups (see Chapter 5 for a detailed discussion about how this research was designed to include people at all stages of dementia). Qualitative research on dementia mainly includes people with early-stage dementia. This matter has been of concern for over a decade (Wilkinson, 2002; Cacchione, 2011; Schrems, 2014). People with late-stage dementia are usually involved only in quantitative studies. Why, then, are the experiences and needs of people with late-stage dementia not considered important? Do they not deserve dignity and respect? At the 2013 G8 summit, both Jeremy Hunt, UK Secretary of State for Health, and Margaret Chan, Director General of WHO, remarked that the major reason for responding to dementia is not the financial burden or cost but to give people living with dementia the help, support, dignity and respect they deserve (Department of Health, 2014).

Research involving people with late-stage dementia is often regarded as inaccurate, as the subjects are perceived to have lost their mental capacity to make a decision (Warner et al. 2007). The Mental Capacity Act suggest, the loss of capacity could be partial or temporary and it is possible for a person to lack capacity to make one specific decision but not about another (British Medical Association, 2007). An assessment that a person lacks capacity to make decisions should never be based simply on the person's age, appearance, assumptions about their condition (includes physical disabilities, learning difficulties and temporary

conditions (eg, drunkenness or unconsciousness), or any aspect of their behaviour. Mental capacity guidelines state that capacity can be assessed by ensuring that a person understands the information and retains it long enough to make decisions and then communicate these to the researcher (British Medical Association, 2007). If the person is deemed to have lost capacity, they are perceived as having lost their ability to express their wishes and thus cannot consent to participating in research. Their proxy is asked to decide what they think the person with dementia would have done if they were able to consent, making them objects (Kitwood, 1995; Wilkinson, 2002). Dewing (2007) argued that the process of informed consent for people with dementia is unnecessary and prevents them from being considered persons through their exclusion from the consent process and thus from research.

Global Action Against Dementia (WHO, 2015c) has acknowledged the need to overcome dementia-related stigma and discrimination, believing it is necessary to involve people with dementia who have capacity and are active in research, together with their family members and caregivers. There is a question of whether it is discriminatory to disregard the needs and experiences of individuals because they lack capacity to consent. People who lack capacity may nevertheless provide important insights on dementia or a different perspective (Wilkinson, 2002), so it is important to determine how to overcome stigma and discrimination when policies and practices result in the perception of people with dementia as vulnerable, thus adding to the discrimination.

During the 2013 G8 summit (DOH, 2014), politicians discussed how they planned to develop a global effort to empower people with dementia, giving them a voice by designing dementia services from their perspective. Committee members discussed empowering and giving a voice to all people with dementia, but suggested excluding people with insufficient cognitive capacity - mostly those in the late stages of dementia. If researchers, policy-makers, and

health professionals fail to include people who lack capacity, they are discriminating against them, disempowering them from having their voice heard in developing and designing dementia services. It is important to ensure that when designing the service, the approach adopted does not exclude particular groups with dementia (Alzheimer's Europe, 2012).

Researchers are now pushing boundaries, attempting to involve people with dementia in both planning and designing services and data-collection aspects of their research (Cacchione, 2011; Schrems, 2014). A dementia campaign group suggested at the international conference that they can express their wish to be valued and their interest to be involved in research, which can result in positive, lasting changes to their lives and those of people affected with the condition in the future (Scottish Dementia Working Group, 2014).

Current overarching policies and strategies do not adopt a holistic approach, failing to take into account the social and cultural elements which are important for greater patient satisfaction and adherence and to improve patients' healthcare outcomes (Martin et al., 2005). Prince et al. (2014) argued that international public health agencies and governments must develop adequate strategies which adopt a holistic approach to tackle both risk reduction for future generations, appropriate care and ongoing support for people living with dementia (Prince et al., 2014). Although the global approach emphasises equal access to health and social care services by all, this will be difficult to achieve if the social and cultural elements are not considered when designing and implementing dementia-related services.

The WHO has vowed to lead and support efforts on dementia, pledging to monitor the occurrence of dementia and dementia care and follow up on the development of national dementia plans and policies by developing a 'Global Dementia Observatory Team' (WHO, 2015). Currently, there is data on the global prevalence of dementia in different ethnic

groups and social classes; it will be interesting to see if diversity is acknowledged in future reporting on the prevalence of dementia. Rizzi et al, (2014) stated that the global distribution of dementia varies in proportion to national socioeconomic and cultural differences.

The WHO (2015) will provide guidance on evaluating and sharing best practice between different countries, to bring global benefit. The next section focuses on how the UK is tackling the impact of dementia.

2.4 Dementia in the United Kingdom

Dementia is one of the UK's greatest public health challenges, following the earlier challenges of HIV, cancer, and heart disease (Department of Health, 2013). An estimated 815,827 people currently have dementia in the UK (Prince et al., 2014b), a number predicted to rise to over a million by 2025 (WHO, 2012). 42,325 are affected with early-onset dementia and 773,502 with late-onset dementia (Prince et al., 2014b). The figures does not accurately reflect the actual number of people with the condition, as they are based on the number of diagnosed cases and do not take into account undiagnosed cases. The figure is far from accurate as only 44% of people with dementia in the UK are estimated to have actually received a formal diagnosis (Kane, 2013).

2.4.1 UK Dementia diagnostic scheme

Given its severity, there has been a call by Alzheimer's Disease International (2012) to urgently review the system used to diagnose dementia, to ensure that people with dementia and their caregivers receive appropriate care, support, and treatment. For example, there are some indications that, in the UK, there are a large number of people with undiagnosed dementia. Indeed, the current health Secretary, Jeremy Hunt, has argued that it is a source of

national shame that only half the people with conditions such as Alzheimer's disease are properly diagnosed (Department of Health, 2014). As part of a pledge by ministers to improve rates of dementia diagnosis, the UK government introduced a dementia identification scheme, under which the National Health Service of England paid general practices £55 for each new patient diagnosed with dementia by March 2015. The government hoped that this would increase rates of diagnosis (British Medical Association [BMA], 2014). Somewhat controversially, this scheme was also the first national initiative to offer doctors financial rewards for diagnosing patients with a condition.

Following its introduction, Quality Outcome Framework Data shows that the number of people diagnosed with dementia in England increased from 280,000 to 344,408 cases. However, when the payments stopped the diagnostic rate decreased dramatically (cited in Alzheimer's Research UK, 2017). This suggests that diagnostic targets should not be achieved through financial incentives as these may cloud the judgments of those making the diagnoses and damage the doctor-patient relationship. Financial incentives may also lead to an over-diagnosis of dementia and encompass those who do not actually have the condition (BMA, 2014). The money earmarked for financial incentives could perhaps be better spent on improving the system used to test for an early diagnosis. Early diagnosis means early intervention, closing the treatment gap which, in turn means the government would need to spend less money on research (Prince et al., 2011). Moreover, interventions are most efficacious when administered at an early stage as they can improve symptoms by making existing brain cells work harder. For example, prescribing Donepezil, Rivastigmine and Galantamine can all be used to treat Alzheimer's disease in this way (WHO, 2012). People could then choose to continue working, contributing to the economy rather than relying on government support. It would also improve the quality of life for people with dementia

because early diagnosis will enable them, and their families, to receive practical advice, information, and support in a timely manner. Diagnosis is also the key to gaining access to drug and non-drug therapies that may improve cognition and enhance their quality of life (Department of Health, 2009; WHO, 2012; Prince et al., 2014).

Equally importantly, an early diagnosis can also empower people with dementia, enabling them to plan their future care while they still have the capacity to make important decisions. They will then have a say in their future care rather than relying on a proxy to make decisions on their behalf (Department of Health, 2009; WHO, 2012). They can also choose whether to participate in research for the benefit of future generations, helping researchers to gain a better understanding of the experiences of people living with dementia, how their families are affected, and how healthcare, social services, and government services can raise awareness, prioritise, and focus their efforts on improving the lives of sufferers and their caregivers (Alzheimer's Disease International, 2012). Kitwood, for instance, argued that only when people with dementia become truly empowered by their wishes being heard, will they be able to function as people rather than objects who are forced to rely on consent from proxies (cited in Dewing, 2007 and Britten, 2008). This would also meet the global priority of ensuring that dementia services, policies, and treatments are developed with input from people with dementia. In so doing, it will enable governments, healthcare providers, and social services systems to prepare more effectively for the future and reduce the societal and financial costs of dementia (Wimo et al., 2013; WHO, 2012).

Government savings, for instance, could be invested in improving social services that provide daily care to people with dementia and their caregivers (Department of Health, 2013) yet have recently been affected by 'austerity' cuts in social services budgets. In 2013, the then UK Prime Minister, David Cameron, expressed his commitment to an overarching global principle of developing specific strategies, including dementia-friendly communities, that can

improve the quality of life for people with dementia. In practice, this may have had little impact because many local authorities have had to cut back social services due to a reduction in available funding (Alzheimer's Society, 2013b; Local Government Association, (2014). This reportedly has profoundly affected vulnerable people with conditions such as dementia, negatively affecting their own and their families' quality of life (Alzheimer's Society, 2013b).

2.4.2 Profit versus Individuals

In 2009, the then UK Prime Minister Gordon Brown, proposed an increase in dementia research funding from £28 million in 2009 to £52 million in 2013 (Department of Health [DH], 2013) to facilitate investigation into early diagnosis, effective treatment, and the possible development of medications to treat dementia (Alzheimer's Society, 2013b). Consequently, there was an increased focus on both funding and developing dementia medication and cures, rather than improving the lives of people suffering from dementia through the provision of early diagnosis and better care and support. The UK has committed itself to supporting global efforts to improve the care, needs, and support of people with dementia and their caregivers, and to finding a cure for dementia (WHO, 2015). According to WHO (2015), plans and policies should prioritise raising awareness of dementia and its causes to ensure timely diagnoses, improve the quality of care and services, support caregivers, train the workforce, and conduct research (WHO, 2015). The impact of current policies suggests it is important to consider all these factors and not over-emphasise one whilst neglecting the others.

While it is essential to look to the future and search for a cure for dementia (Alzheimer's Disease International, 2009), there is also a need to act in the present. Currently, treatments are available which provide temporary respite and relief to people in the early stages of

dementia (Alzheimer's Disease International, 2012). Governments, however, continue to search for a drug to cure dementia, although it can take up to twenty years to develop medications (Alzheimer's Society, 2014). This is due in part to the revenue pharmaceutical companies contribute to the world economy, which may result in the individuals' needs being overlooked in pursuit of profit (Britten, 2008). Although medication can save lives by managing and preventing disease, healthcare in UK may be entering a period where the quality of life of people who rely on medication is no longer the primary focus (Britten, 2008). Arguably, medication has in effect become the leading cause of death in the population (Britten, 2008). A balance must therefore be struck between the need to save life vs. the quality of life, and the needs of healthcare vs. commercial interests.

Bond et al. (1993) argue that, rather than improving treatment for the condition once it has been established, we should focus on addressing the physical, social and cultural environments which give rise to the condition. Strategies that have been adopted to improve early diagnosis and the quality of life for people with dementia have paid little attention to factors influencing decision-making in diagnosis, treatment and care (Cooper, 2002). Cooper argues that such strategies fail to consider how decisions about seeking help and accessing services and treatments can be influenced by socio-cultural factors. Such factors include people's understanding of dementia, their lack of knowledge, cultural perceptions of dementia, dementia stigmatisation, the barriers individuals encounter when accessing dementia services, and a lack of culturally appropriate and accessible local health and social services (Purandare et al., 2006). Cooper calls for a better understanding of how socio-cultural factors relate to existing health inequalities which are attributable to socio-economic status and vary between different ethnic populations (Cooper, 2002). The next section

therefore discusses the minority that exists within a minority: the occurrence of dementia among ethnic minority groups in the UK.

2.5 Dementia in UK ethnic minority groups

Of the UK's estimated cases of dementia, 11,392 are in black and minority ethnic groups (BMEs) (1.3% of the white population and 0.2% of the population in black and minority ethnic groups) (Knapp et al., 2007). Dementia UK (Knapp et al., 2007) stated that the current prevalence of early onset dementia in the UK for BMEs is 6.1%, compared to 2.2% for the UK population as whole. These estimates are based on the assumption that the prevalence of dementia in ethnic minority groups will be similar to the UK population as a whole. In reality, there are no specific estimates on the prevalence of dementia in UK ethnic minority groups (Knapp et al., 2007) as data for these groups is missing.

It can be argued that there appears to be a parallel between the ignored requirements of marginalised older people and ethnic minority groups within the UK. Consequently, minority populations continue to be under-represented in both dementia service use and research (Purandare et al., 2007) because of their exclusion from the healthcare agenda (Mackenzie et al., 2005). The limited research into older people with dementia in ethnic minority groups emphasises the power disparity between oppressed and privileged groups (Bernard and Scharf, 2007). Johnson (2001) argued that in a system of oppression in twenty-first century Britain, power is awarded to white, upper-class/wealthy, male, heterosexual, young to middle-aged, able-bodied, Christian adults. This hierarchy is reproduced in social institutions - government, education, the media, religion and family - normalising the dominant culture so it appears natural or normal in the hierarchical order based on gender, race, and other social aspects to ensure that power remains in the hands its members (Johnson, 2001). The

Dementia UK report (2007), for example, places lower emphasis on ethnicity despite clearly noting lower diagnosis rates and less access to care in ethnically diverse communities and the absence of data on people from disadvantaged socio-economic backgrounds (Moriarty et al., 2011). Mackenzie et al. (2005) and Marshall and Tibbs (2006) argued that discriminated groups are entitled to the same quality of life as groups with power, as they are citizens with rights equal to those of other members of society, including the right to be socially included (Marshall and Tibbs, 2006).

Moreover, current estimates on the number of people with dementia from an ethnic group do not take into account the heterogeneity of this group, as many different ethnic groups are clustered under the ethnic minority group label. Ethnicity data and figures are usually aggregated collectively, without specific statistics about the prevalence of dementia in individual ethnic groups (Knapp et al., 2007). Where data on different ethnic groups is aggregated collectively, how can dementia services be improved to increase access to services by all, one of priorities for global action? Lawrence et al. (2008) found that South Asians are less likely to access specialist services and dementia diagnoses, and access to services in this community are limited despite it being the largest ethnic minority group in the UK. In conclusion, aggregating data from different ethnic groups is questionable, as the needs of the different groups cannot be acknowledged because of current data collection methods.

2.6 Dementia in the South Asian population

Four per cent of people in the UK identify themselves as South Asian - the term used to refer to people of South Asian descent (India, Pakistan, Bangladesh, Sri Lanka, and Nepal) (Adamson, 2001), making this the largest ethnic minority group in the country (Lawrence et

al., 2008; La Fontaine et al., 2007). Of this group, 11.3% are 50-64 years old, and 5.7% are over 65, a number which is likely to increase over the next decade (Office for National Statistics, 2018). As the South Asian migrant population born in the 1960s ages, there will be a large number of older people from this population. As dementia is an age-related illness, it is important to understand the needs and experiences of this group in order to ensure that suitable services are established to meet their health needs.

Little emphasis has been placed on the prevalence of dementia in the South Asian population and there is currently no specific data on this. It is becoming increasingly clear that the incidence of dementia in South Asians is proportionally higher than in the white UK population although the prevalence of dementia in South Asian population is lower, as explained below (Turner et al., 2012). Bhattacharyya et al. (2012) argued that this is because the South Asian population is at greater risk of developing dementia compared with other populations as they are more likely to experience high blood pressure, which increases the risk of vascular dementia. South Asians may have a greater risk of developing dementia (incidence) but poorer access to dementia-related services (Bhattacharyya et al., 2012; Turner et al., 2012). Despite this, the South Asian population's needs have not been taken into account and are absent from the healthcare agenda (Mackenzie et al, 2005).

La Fontaine et al. (2007) suggested an estimated 5,000 people with dementia in the UK South Asian population, drawing on Patel's (1998) study. Relying on such old literature may be misleading, as the dementia diagnosis pathway has been amended and improved since the study was published. The research suggested that many older South Asian people do not access mainstream mental health services, supported by more recent research which suggests that when dementia services are accessed on behalf of a person with dementia, it is typically at a very late stage of the disease. The community may restrict access of the person living

with dementia to appropriate services for socio-cultural reasons (Bowes and Wilkinson, 2003).

Although numerous socio-cultural factors (see Chapter 3) may influence the South Asian population's access to dementia services, this chapter discusses the key factors which may influence personal decisions to seek help for dementia. Firstly, knowledge and understanding of dementia is lacking in the South Asian population (Mackenzie et al., 2005; Uppal and Bones, 2014). Dementia is usually perceived in this group as a normal part of ageing; as the dementia progresses and becomes severe, the person with dementia is perceived as becoming insane (Mackenzie et al., 2005; Uppal and Bones, 2014). Secondly, Urdu, Gujarati, Bangladeshi, Hindi and Punjabi all have no word for dementia (Botsford and Denning, 2014). The negative connotations of the term often used to refer to dementia - losing memory, possession by an evil spirit, unable to remember things - shape negative perceptions of dementia (Jolley et al., 2009; La Fontaine et al. 2007). Jolley et al. (2009) argued that this has resulted in the South Asian population's associating fear and shame with dementia, which prevents family members from seeking help or admitting publicly that someone in their family has dementia, in order to maintain community ties. Thirdly, the South Asian population has lower levels of 'acculturation' - the process of modifying a group's culture to adapt to another culture, usually that of the host country where they have been raised and engaged in since childhood or for prolonged periods of time (Sam and Berry, 2010). Acculturation shapes individual experiences of diagnosis, treatment, and care for dementia (Farver et al., 2002; Uba, 2007). The difference in the level of acculturation between South Asian minority groups compared with other ethnic minority groups may result in delays in access to dementia services by the South Asian population, which shapes the experiences of those living with dementia (Kahan et al., 2006).

When those barriers are overcome and South Asian families decide to seek help for dementia by accessing appropriate dementia services for their family member, it appears that the services often do not meet their needs (Adamson, 2001). Adamson (2001) argued that current dementia services exclude people from the South Asian population as they do not take into account their cultural needs. The lack of linguistic or culturally appropriate services can result in further delays or underuse of dementia services.

McCrae and Banerjee (2011) argue that the Mini-Mental State Assessment is too Eurocentric to provide culturally appropriate assessment, resulting in many South Asian families becoming reluctant to access dementia services and instead deciding to carry on caring for family members with dementia without support. These socio-cultural factors shape the South Asian community's experience of dementia and are likely to influence their personal decisions to seek dementia diagnoses and access dementia support services (Knight and Sayegh, 2013). NICE (2007) also argue that healthcare professionals should not simply rely on the MMSE score in cases where the individual has a limited education, speaks little English, or there are substantial cultural differences. NICE proposes that different ethnic groups should be given equal access to treatment and should not be discriminated against simply because they are unable to complete the MMSE (NICE, 2007). In such cases alternative measures should be used, although NICE do not mention any specific measures. This may be because there are currently no validated and standardised tools available that are appropriate for non-English speakers, equivalent to the MMSE and have proven utility in decision making with respect to treatment.

Cerejeira and Mukaetova-Ladinska (2007) reported that healthcare professionals currently working with individuals from ethnic groups are continuing to use MMSE to support their professional clinical judgement when making decisions. Although Sallam and Amr (2013)

argue that the MMSE is not suitable for making a diagnosis they do point out that it can be used to indicate the presence of a cognitive impairment, such as a person with suspected dementia or a head injury. The MMSE is much more sensitive at detecting cognitive impairments than cruder methods such as informal questioning or the overall impression given by a patient's orientation. However, there is a greater risk of the BME groups being wrongly labelled as having cognitive impairment, if clinicians seeking a dementia diagnosis rely only on the MMSE (Khan et al., 2014). There are alternative informant measures such as the Clinical Dementia Rating scale (CDR) and the Alzheimer's Disease 8 questionnaire (AD8), both of which have been reported to be successful in measuring cognitive impairment in older adults from East/Southeast Asia with less access to formal education (Lim et al., 2014 and Galvin et al, 2005). One of the challenges of these informant measures is the knowledge and reliability of the informant's, which could be assessed using linguistically adapted MMSE (Lim et al., 2014). A combination of the informant measure with a cognitive testing tool has been recommended in screening less educated older adults (Tam et al, 2007).

Delivering adequate services requires an understanding of the mechanisms which generate patterns of health and illness in particular groups and places at particular times and how people interpret and respond to these patterns and to their experiences of poor health (Popay et al., 2003). There is thus a need to explore why there is a difference in dementia diagnoses and access to services in the South Asian population and to gain an understanding of expectations of and experiences with the services (Bowes and Wilkinson, 2003), to determine how culturally sensitive and individually responsive services can be developed.

The need to ascertain whether there is a difference in access to services in non-South Asian populations is particularly important given problematic factors such as socio-economic disadvantages and a lack of knowledge, are also found in the white British population, but

may disproportionately impact the South Asian (Bowes and Wilkinson, 2003). Mackenzie (2006) has claimed that in the UK people of South Asian origin often experience socio-economic deprivation, because migration after the Second World War subjected citizens to housing and employment controls. The power in these sectors was controlled and exercised by the dominant groups in society (Johnson, 2001; Mason, 2000), laying the foundation for the social and economic experiences of many older pioneer migrants today. Subsequently, when second- or third-generation migrants became unemployed because of their traditional family caring responsibilities, this had an unavoidable impact on their socio-economic status and their identity as UK citizens. Mason argued that cultural, socio-economic and education level are risk factors which contribute to the disadvantages and difficulties faced by service users from different ethnic backgrounds in British society. However, Fischer et al. (2009) concluded that in inner cities age is more strongly associated with a diagnosis of dementia than socio-economic factors such as low education and low annual income.

In conclusion, despite research into these more subtle and subjective factors, it remains unclear whether there is inequality in the diagnosis of dementia in the South Asian population. The data and figures from this group are usually collectively aggregated and there are no specific statistics about the prevalence of dementia in the UK South Asian population (Knapp et al., 2007). Recent research suggests a lack of reporting of dementia in the South Asian population. In the past, little emphasis was placed on the prevalence of dementia in this group (e.g., in the Dementia UK report, 2007) (Moriarty et al., 2014), and the current literature does not explore or take into account the factors which may cause low prevalence (Moriarty et al., 2014). Research is needed into the needs of people with dementia from this ethnic group when they access dementia support services.

2.7 Study context and location

This study is located in the Blackburn with Darwen local authority area. Blackburn with Darwen has one of the UK's most ethnically diverse populations and high levels of socio-economic deprivation (Blackburn with Darwen Borough Council, 2011). Anecdotal evidence suggests low reporting of dementia in the BwD South Asian population, and the local authority has become aware of a disparity in the (low) published prevalence estimates of dementia in BwD, and the *prima facie* evidence of higher levels of cognitive impairment and potential early-stage dementia amongst local ethnic minorities, particularly in the South Asian community. This observation echoes similar discrepancies across the UK (Alzheimer's Society, 2013).

Blackburn with Darwen has an ethnically diverse population. The area has almost four times the national average of people from non-white ethnic backgrounds, primarily South Asians (see Table 2.2 below) (Blackburn with Darwen Borough Council, 2011). The local authority has been concerned about the projected rise in the number of older people with dementia and in particular how the existing local socio-economic and ethnic inequalities may affect the estimated future health and health service needs of these populations and they called for research into the issue, as discussed in section 1.3.

Table 2.2: Composition of Blackburn with Darwen and England populations by ethnic group (%)

Ethnicity	Blackburn with Darwen %	England %
Indian	13.4%	1.5%
Pakistani	12.1%	2.7%
Bangladeshi	1%	0.7%
Chinese	0.5%	0.7%
Black African	0.4%	0.8%
Black Caribbean	0.1%	0.3%

Data from Blackburn with Darwen Borough Council, 2011

(<http://www.blackburn.gov.uk/Lists/DownloadableDocuments/EthnicityAndReligionProfile2011.pdf>)

Little background information on dementia prevalence existed for the study. To get a firm foundation for statements on the levels of dementia in the BwD council area I used records on dementia diagnoses held by the local memory assessment clinic. The methods used to access and abstract data on diagnosed cases of dementia in our study are given in Appendix 1. What follows here, by way of background information, is a brief description of the cases of dementia documented by the Lancashire Care Foundation Trust between September 2007 and July 2015.

These memory assessment clinics are where suspected cases of dementia are assessed, and where appropriate, diagnosed. With this in mind, East Lancashire Memory Assessment Clinic made available records of 2,225 individuals diagnosed with some type of mental, behavioural and/or neurodevelopment disorder (see Table 1.3, appendix 1). Of these 462 had a diagnosis of dementia and met other inclusion criteria. Details of the data abstraction process, the assessment of its content and the development of the dataset to fit the purpose of this study are reported in appendix 1.

Table 2.3: Cases of dementia diagnosis according to ethnicity, gender, and age in BwD from 2007 to 2015.

Variable		Number of cases of dementia diagnosed	%
Ethnicity	South Asian	25	5
	White British	415	90
	Not known	22	5
	Total	462	100
Gender	Women	287	62
	Men	175	38
	Total	462	100
Age at diagnosis	Early onset (prior to age 65)	17	4
	Late onset (aged 65 and over)	445	96
	Total	462	100

Table 2.3 shows that of the 462 cases of diagnosed dementia in the dataset, 5% were from the South Asian population, 90% were White British, and 5% of cases were ‘not known’ (the study findings of this data is discussed in more detail in section 8.1). Among the diagnosed cases of those living with dementia in Blackburn with Darwen, 62% were female and 38% male. The percentage of cases of early onset dementia was 4%, while 96% were late onset dementia. The average age of all cases was 64 years, with the youngest being 52 and the oldest 98 years of age.

Among South Asians, 88% of dementia cases occurred in people age 65 and over, with 12% occurring before the age of 65. Among the white British population in BwD these figures are: 97 % of people age 65 and over, with 3% occurring in people before the age of 65.

When we looked at our 462 cases of dementia stratified by gender and ethnic group it became clear that a higher percentage of men in the South Asian population were diagnosed with dementia when compared to the local white British population (see Table 2.4). In the South Asian population 48% of women and 52% of men were diagnosed with dementia compared to 63 and 37% in the white British population.

Table 2.4: Dementia cases by ethnicity and gender between September 2007 and July 2015

<u>Gender</u>	<u>Ethnic group</u>							
	South Asian		White British		Other		Total	
	Cases (n)	%	Cases (n)	%	Cases (n)	%	Cases (n)	%
Women	12	48	261	63	14	64	287	62
Men	13	52	154	37	8	36	175	38
<u>Total</u>	25	100	415	100	22	100	462	100

I was also able to look into background information on the types of diagnosis of dementia among members of the South Asian community (see Table 2.5). Of the twenty-five cases of dementia, the most common type of diagnosis was Alzheimer’s disease follow by vascular dementia. There were a few cases of ‘unspecified dementia’ and the least common diagnosis was ‘Dementia in other diseases’.

Table 2.5: Cases of dementia in BwD 2007-2015 by type of diagnosis in the South Asian group

<u>Type of Diagnosis</u>	<u>South Asian</u>	
	Cases (n)	%
Alzheimer’s disease	12	48
Vascular dementia	6	24
Dementia in other diseases	3	12
Unspecified dementia	4	16
<u>Total</u>	25	100

This is interesting because nationally Alzheimer's disease accounts for around 62% of all dementias, with vascular dementias accounting for around 17% (Alzheimer's Society, 2018). It is difficult to draw conclusions from this without an ethnic-group specific comparison, and the figures in this study are based on small number, but it is interesting that the rates differ so markedly.

2.8 Conclusion

This chapter outlines the global, national, and local picture of dementia, to help understand why it is important to understand the South Asian community's needs and experiences with dementia. It is important to determine the South Asian population's expectations of local services and to understand how current diagnostic services can be improved whilst promoting early diagnosis and access to services for all ages and ethnic groups. Previous efforts have failed to find data about the risk of dementia in South Asian communities. It is also unclear why there is a relatively small amount of research on the difference in access to dementia diagnosis and services by the South Asian population, including the lack of culturally appropriate services, and insufficient understanding and awareness of dementia in the population. Another notable gap in the research, touched on in this study, is the role of acculturation in shaping individual experiences of dementia diagnosis, treatment, and care, which may influence inequalities in diagnosis. This could have important consequences for planning, strategies and policy developments in access to and dementia diagnosis and services.

Despite the emergence of research into various factors influencing diagnosis of dementia, it remains unclear whether there is inequality in the diagnosis of dementia in the South Asian population. The data and figures from this group are usually aggregated collectively and there are no specific statistics about the prevalence of dementia in the UK's South Asian

population. The current literature does not explore or take into account the factors which may cause low prevalence. Research is therefore needed into the needs of people with dementia from this ethnic group when accessing dementia support services, which will be discussed in more detail in Chapter 3.

Chapter 3: Literature Review

The literature explored in this chapter on the South Asian community's experience of dementia was reviewed using an integrative literature review. The review identifies, critically evaluates and integrates the results of qualitative and quantitative studies, providing a comprehensive understanding of the review question, followed by an account of the systematic integrated literature review. The chapter concludes with a critical synthesis of the literature review findings which informs the research aims and objectives.

Given the gap in current research on South Asians, this research focused on British Indians and British Pakistanis. Narrowing the focus to these two communities, more accurate and reflexive definitions of ethnicity and culture could be employed, to emphasise the relevant contexts informing the experience of people with dementia (Parveen et al., 2011). This section, focusing on the South Asian Indian and Pakistani understanding of dementia, addresses how certain social variables - power, notoriety, family structure, demeanour, cultural qualities, indigenous personality, social character, and differences in various dementia symptoms - may affect the experiences of people with dementia. It seeks to reveal how institutional practices and communities, ethnic-social factors and welfare strategies affect the analysis and reinforce dementia treatment in an ethnically diverse South Asian group (see Appendix 4 for papers selected and included in the systematic literature review). This review aims to fill the gap left in a previous review conducted by Uppal et al. (2014) which, although it usefully highlighted a lack of understanding of dementia among members of the South Asian community, implied this was the only factor likely to be implicated in the low uptake of services. They did not consider other factors that may impact on low uptake.

This was subsequently addressed by Mukhdam et al (2011), who explored barriers to seeking specialist help for dementia among people from minority ethnic groups. They identified several cultural and service level barriers that included; not conceptualising dementia as an illness; dementia seen as a normal part of ageing; a belief that dementia has spiritual, psychological, physical health, or social causes; a belief that caring for the person with dementia was a personal or family responsibility; experiences of shame and stigma within the community; believing there was nothing that could be done to help; and negative experiences of healthcare services. The limitation of this review is that it combines south Asian groups with other ethnic groups, and therefore does not consider how the cultural values, beliefs and traditions of the South Asian community impact on the experiences of individual South Asians and their families undergoing the process of dementia diagnosis and engaging with health services. Understanding the complex and dynamic experiences of people with dementia and their caregivers offers insight into potential gaps in current health services. Improving current services or adopting new care models to address these gaps may improve the outcomes for people with dementia in the South Asian community.

This research regarded the South Asian community as a diverse heterogenic community. Although it focused on the Indian and Pakistani community, the literature encompasses the global South Asian community, as the amount of UK-focused literature is limited (Lawrence et al., 2008).

3.1 Review question

The review question is: “What are the experiences of South Asian individuals and families with the process of dementia diagnosis and their engagement with health services?” The analysis and literature framework sought to identify what is known about the South Asian population’s experience of dementia, with specific reference to access to dementia services.

Appropriate literature on the South Asian experience of dementia was sought with a systematic literature review in 2014; repeated in 2017; and discussed here in detail.

3.2 Systematic literature review

An integrative review method was used (Whittemore and Knafl (2005), to provide a systematic review of quantitative and qualitative papers relevant to the review question. This type of literature review allows various types of research to be incorporated, and to combine different research methods, all of which were included in the literature review. Aveyard and Sharp (2011) argue that a literature review should not be restricted to the type of study - i.e. quantitative or qualitative - but rather, should be appropriate to the discussion question. Whittemore and Knafl (2005) suggest that an integrative approach to analysing literature allows for an innovative combination and interpretation of the review which is both thorough and unbiased, by enabling the research to define concepts, analysis of theories and methods.

In a systematic literature review, the search term must adequately incorporate the differences between quantitative, qualitative and mixed-methods research (Shaw, 2003), so that the researcher can be confident of identifying all relevant quantitative, qualitative and mixed-methods research papers, thus providing a better understanding of the research problem (Cooke et al., 2012).

The review explores the literature reporting on research conducted to better understand the South Asian experience with dementia. The search strategy adopts an SPIO framework (Study design, Population, Interventions, Outcomes), based on Kerr et al.'s (2013) practical use of this framework in their systematic literature. They conclude that this framework allows the researcher to articulate quantitative, qualitative and mixed-methods research search terms (see Table 3.1) to answer the review question and achieve an efficient literature search.

Table 3.1: SPIO categories and targets

SPIO categories	Targets
Study design	All quantitative, qualitative and mixed methods
Population	Family caregivers, People with Dementia of any type, from South Asian cultural background i.e. India, Pakistan, Bangladesh, Sri Lanka, and Nepal
Interventions	Experience of living with dementia, perception of dementia diagnosis, cultural awareness, community understanding of dementia
Outcomes	Representation in dementia services, diagnosis of dementia, access to health service, engagement with health service, involvement in decision-making.

3.2.1 Identifying of the search terms

An initial search of Lancaster University Library’s web-based databases produced recommendations for health research (subject) databases, from which appropriate databases were chosen for their relevance to the review question: Academic Search Complete, CINAHL, EMBASE, Medline, PubMed, PsycINFO, PsycArticles, Scopus and Web of science. The databases were used to retrieve relevant journal papers on dementia (see Appendix 2 for search terms used in each database). The search was initiated with an analytic exploratory search in the library database using subject headings (e.g. Mesh terms), Truncation (*) and a different Boolean search (AND, OR), to enable a more efficient search, producing more relevant results. Limiting the search by the use of “AND” and “OR” restricted it to specific documents containing the two keywords. Associated words were identified from previous readings, to ensure that the relevant literature was identified for screening. The search terms were checked in each database (see Table 3.2 for search terms used in Academic Search Complete, CINAHL, Medline, PsycArticles and PsycINFO) and

attention was given to truncating the words to ensure the inclusion of plurals and associated terms (Kable et al., 2012).

The search span was limited to publications from 2000 onwards (the pre-2000 searches found few publications, none relevant to the review question). This yielded relevant literature (Adamson, 2001; Bowes and Wilkinson, 2003; and Mukadam, et al., 2015), identified after applying the inclusion and exclusion criteria (see Table 3.3).

Table 3.2: Database and search terms

Database	Search terms
Electronic database searched <i>Academic Search Complete</i> (for multi-disciplinary literature), <i>CINAHL</i> , <i>Medline</i> , <i>PsycArticles</i> and <i>PsycINFO</i>	Dementia OR "Frontotemporal dementia" OR "Frontotemporal lobar degeneration" OR "Alzheimer disease" OR "Dementia, Vascular" OR "Lewy body disease" OR Cognitive OR Memory OR Forget* AND Asian* OR South* Asia* OR India* OR Gujrat* OR Hind* OR Nepal* OR Pakistan* OR Punjab* OR Urdu OR Muslim OR Bangladesh* OR Bengal* OR Sri Lanka* AND Spiritual* OR Cultur* OR Ethnic* OR Religio* OR Community OR Understand* OR Coping OR Impact OR Living OR Experience* OR Perspective* OR Belief* OR Attitud* OR Perception* OR Awareness OR Recognition AND Diagnosis OR "Health care utili*" OR "Health service utili*" OR "Health care use" OR "Health service use" OR Service* OR Pathway* OR Engag* OR Consult* OR Involv* OR "Illness representation*" OR "Decision making" OR Participation AND Limit to English, between 2000- 2017

3.2.2 Hand searches

Hand searches were completed using contents pages and reference citations in journals focusing on dementia and related healthcare cases. Systematic reviews were included of papers reporting the experiences of patients and families of dementia-affected members of South Asian communities and their strategic methods for diagnosis. Some of the data sources included CINAHL, Medline, PubMed, PsycArticles and Academic Search Complete.

After removing duplicates, the articles eligible for screening resulted in a broad selection of items for consideration, from which the relevant literature for the literature review is selected. A range of research was thus synthesised, thematically explored and appraised in the review.

3.2.3 Inclusion and exclusion criteria

The studies retrieved using the search terms above were manually evaluated using the inclusion and exclusion criteria (see Table 3.3), to decide on the inclusion of appropriate research articles on dementia focusing on the South Asian experience. Applying the inclusion and exclusion criteria to the title and abstracts produced 69 papers with potential relevance to the review question (see Figure 3.1). This was further appraised using a full text review.

Table 3.3: Inclusion/exclusion criteria for the experience of South Asian people on dementia diagnosis and other health services

Inclusion	Exclusion
<ul style="list-style-type: none"> • Related to South-Asian; Indian, Pakistani, Bangladeshi, Sri-Lanka and others classified as South Asian 	<ul style="list-style-type: none"> • Non South-Asian studies e.g. China
<ul style="list-style-type: none"> • All empirical research designs and methodologies (quantitative, qualitative and mixed methods) will be included 	<ul style="list-style-type: none"> • All non-empirical papers • Meta-analysis • Systematic review • Laboratory research. • Reports • Grey literature • Position papers • Clinical/ pharmacological case studies • Theoretical papers
<ul style="list-style-type: none"> • Published in English 	
<ul style="list-style-type: none"> • Primary and secondary studies 	
<ul style="list-style-type: none"> • Adults over 18 living with dementia, family caregivers, and relatives members • All types of dementia • All stages of dementia 	<ul style="list-style-type: none"> • Subjects under 18 years of age
<ul style="list-style-type: none"> • Explore the experience of dementia from the perspective of people with dementia • Family caregivers' or members experience • Healthcare professional experience of dementia diagnosis. • Needs of affected individuals and family caregivers 	<ul style="list-style-type: none"> • Medical interventions • Quality of life of people with dementia i.e. standard of health, comfort, and happiness experienced by an individual or group.
<ul style="list-style-type: none"> • Experience of using dementia services • Engagement with dementia services 	<ul style="list-style-type: none"> • Other lifestyle behaviours such as weight management, diet, and physical activity

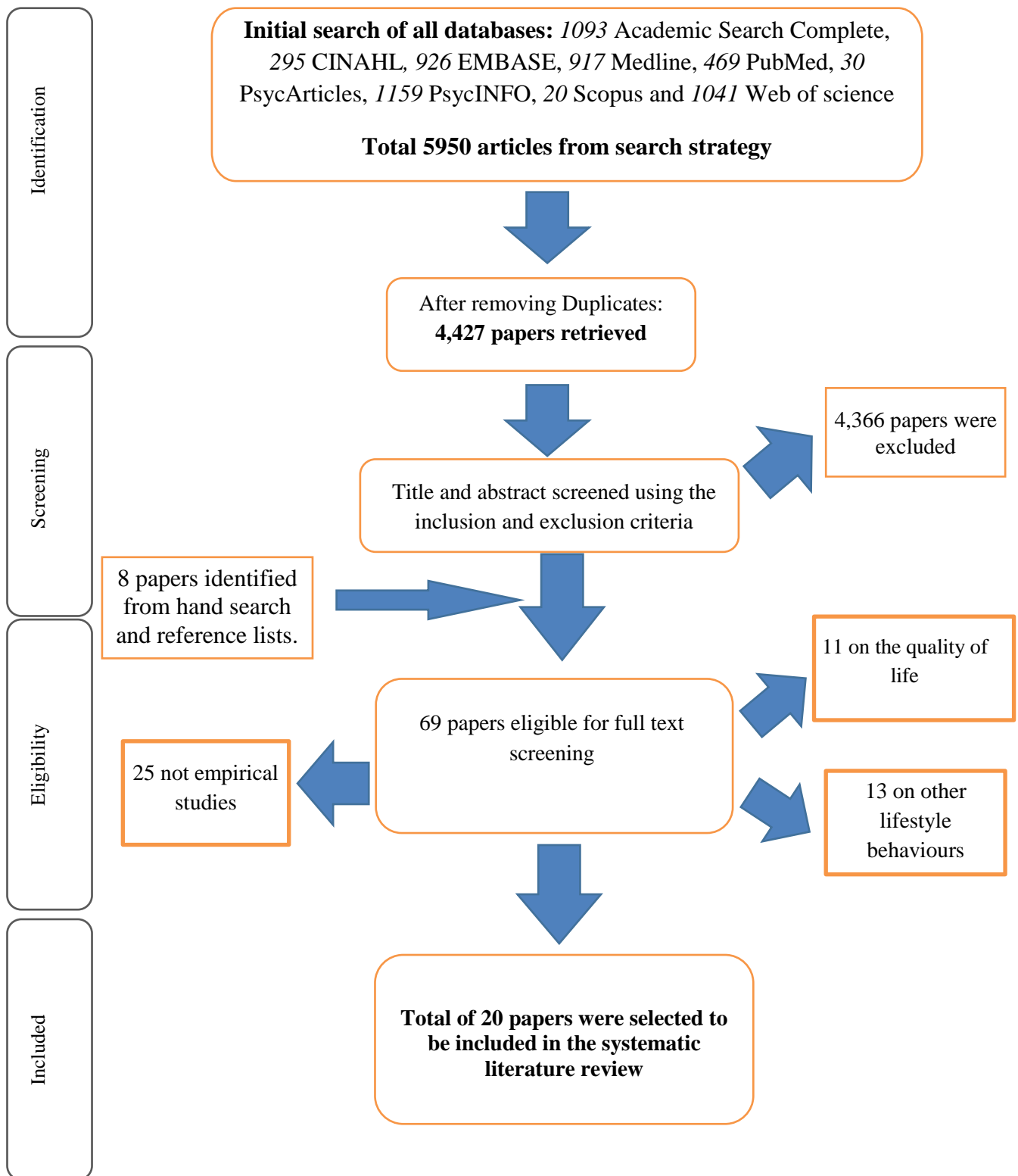


Figure 3.1: Flow chart of the review process

3.2.4 Appraising the papers

The next step was to appraise the quality of the studies identified by the systematic review process, which had identified journal articles with different research designs and methodological approaches. The use of different appraisal tools for quantitative, qualitative and mixed-methods studies can be complex, and render the review process less rigorous (Crowe et al., 2011). Each included study should be appraised for internal validity using a standardised approach to rate the quality of individual studies. According to Crowe et al. (2011), the search strategy should employ a comprehensive, methodical approach to capture all possible evidence relevant to the question of interest.

To adopt a consistent approach to appraising the quantitative, qualitative and mixed-methods studies, the Crowe Critical Appraisal Tool (CCAT) was used to assess the quality of the studies. This appraisal tool comprises a CCAT Form (see Appendix 3) and user guide, which must be used together to ensure the legitimacy and reliability of the scores obtained (Crowe et al., 2011). According to Crowe et al., (2011), when appraising quality, it is important to recognise that the process is highly subjective, because the questions asked in the article may be more or less useful depending on the type of research. Any alterations made to the classes, things, or descriptors, regardless of how small, may lead to deviations in the acquired results. The appraisal tool is quite demanding as the papers being appraised must clearly outline the research plans, sampling designs, data collection techniques, and statistical and non-statistical investigation methods. Crowe et al., (2011) suggested using the CCAT user guide together with the CCAT form when evaluating the papers.

Crowe et al.'s (2012) review of this tool concluded that it is effective for providing legitimacy and reliability when appraising research papers with different research methodologies and designs. Crowe argues that the tool does not rely on researcher levels and

types of knowledge about research methodologies and designs, thus allowing different researchers to reach similar conclusions about a journal article.

Studies identified through the systematic review process were assessed for quality based on the scores obtained against the following eight categories (see Table 3.4), which can be found on the CCAT form (see Appendix 3).

Table 3.4: Eight categories on the CCAT form and their items and total score.

Category	Items	Score between 0 (poor) and 5 (good)
1. Preliminaries	3 Items	Preamble score out of 5
2. Introduction	2 Items	Introduction score out of 5
3. Design	4 Items	Design score out of 5
4. Sampling	3 Items	Sampling score out of 5
5. Data collection	2 Items	Data collection score out of 5
6. Ethical matters	2 Items	Ethical matters score out of 5
7. Results	3 Items	Results score out of 5
8. Discussion	3 Items	Discussion score out of 5
Total score	Add all scores for categories 1-8	Total score out of 40

The CCAT form comprises eight categories and twenty-two items (see Table 3.4 above). Each category receives its rating according to a 6-point scale from 0-5. The minimum rating a category can receive is 0, the maximum is 5. Classifications must be scored in whole numbers, i.e. 0, 1, 2, 3, 4, or 5; half-checks are not permitted. The total score given to a paper can be expressed as a percentage or it can be recorded as total number, by adding the marks from each of the eight categories to give a total score out of 40 (see Appendix 4 for the scores given to papers critically appraised in this study).

The CCAT scores enabled the quality of each research paper identified in the systematic literature search to be assessed (see Table 3.5 for a summary of overall CCAT scores). All 20 research papers were included in the literature review as they were relevant to the review question, and all were acknowledged to be of good quality except for one paper by Mograbi et al. (2012). However, this paper was not excluded as it scored low on the following two CCAT categories: i) preliminaries- the authors did not provide sufficient detail for others to reproduce through clear/concise writing, tables, diagrams and figures; and ii) the description of data collection methods was poor as the authors did not explain the reason behind the chosen data collection methods and the suitability of collection methods to the phenomena being studied. It was thought that these two unmet criteria in this study would not alter or impact the conclusions drawn from the research but rather added to the researcher's understanding of the topic, which will be discussed in detail in section 3.2.5.

Table 3.5: Summary of CCAT scores given to each paper included in the literature review.

Author and Year	Total Score
1. Adamson and Donovan, (2005)	32
2. Lawrence et al., (2008)	35
3. Adamson, (2001)	24
4. Victor et al., (2012)	28
5. Giebel et al., (2015)	32
6. Purandare et al., (2007)	32
7. Shaji et al., (2002)	29
8. Katbamna et al.,(2001)	28
9. Turner et al., (2005)	34
10. Mackenzie. (2006)	34
11. Hailstone et al., (2016)	27
12. Karim, et al., (2010)	36
13. Lawrence et al., (2011)	28
14. Mograbi, et al., (2012)	20
15. La Fontaine, et al., (2007)	26
16. Mukadam et al., (2011)	32
17. Mukadam et al., (2015)	29
18. Bowes, and Wilkinson. (2003)	35
19. Jutlla. (2015)	31
20. Bamford and Bruce (2000)	28

3.2.5 Method of extracting the data from the literature

This section briefly describes the step-by-step method outlined by Whitemore and Knafl (2005) to synthesise the literature findings to answer the review question. Integrative review (as described by Whitemore and Knafl, 2005) determines current understanding about a precise subject, as it is conducted to identify, analyse and synthesise results of studies on the same subject. I used integrative review to discover gaps in what is already known, infer

generalisation of a phenomenon, specify central themes and make correlations between areas of specialisation. Firstly, it was important to define the guiding question to determine which studies would be included, the method for identification, and information to be collected in each selected study. The second step was to search the literature in various broad databases, including electronic databases and a manual search of journals, to identify the key sources relevant to the literature review. After identifying the literature, the next important step was to evaluate the data in those sources to ensure they were relevant, minimise the risk of errors in transcription, and guarantee precision. The fourth step demanded an organised approach to weigh the features and consistency of each study.

Some papers included in the review included more than one population e.g. South Asian and Latin, Caribbean and Chinese. At this stage, the primary focus was the South Asian community as per the review question. Pursuant to the identification of relevant studies each paper was reviewed closely in terms of the review question. This aided the identification of predominant or recurring themes and formed the basis for the synthesis and presentation of the findings (Aveyard, 2007). These will now be discussed below.

3.3. Synthesis of the literature findings

The analysis of papers discussed above gave rise to the following three themes: South Asian people's experience of living with dementia (addressed in 10 papers); dementia diagnosis and engagement with health services (discussed in 11 papers); and a common understanding of the experience of Indian and Pakistani populations accessing dementia services (addressed in 12 papers). The research findings in relation to each of these themes will now be presented, alongside a critical appraisal of the evidence.

The heterogenic South Asian community shares several cultural beliefs and norms, particularly in the management and diagnosis of dementia. Although the existing literature

yields substantial evidence regarding the needs and experiences of different population groups with dementia, few studies have been conducted specifically on the Indian and Pakistani population. This research bridges this gap in current knowledge by including evidence from this limited pool of literature. This research regards the South Asian community as a diverse heterogenic community. Although this study narrows the focus to the Indian and Pakistani community, the literature is focused on the worldwide South Asian community, rather than only the UK, because of the limited UK-focused literature (Lawrence et al., 2008).

3.3.1 South Asian people's experience of living with dementia

The experiences of people with dementia and their caregivers have received considerable attention in recent research and in the development of healthcare services. Victor et al. (2012) explored the South Asian community's understanding and experience of care and support within the context of their family lives and social networks. They found that the family remain central to the provision of care and support within this group, noting that power can shift as people with dementia attempt to understand their condition. Thus, emphasising the need to involve people with dementia in research, policy-making and design practices will establish a better understanding of the needs and experience of this population, while also helping people with dementia to manage their condition more effectively and understand their symptoms. Notably, Victor et al. (2012) have not made the logical assumption that the individual accepting care is in poor health and the individual giving care therefore holds all the power. Instead they focused on the need to empower individuals with dementia from the south Asian community through research, policy and practice. This supports Adamson's (2001) research, which examined the awareness, recognition and understanding of dementia symptoms among families of South Asian and African/Caribbean descent in the UK. She found that most participants from the South Asian community were aware of dementia but

used different terms to describe the disorder. She argued that the way in which people conceptualise dementia and its symptoms is subjective and thus there is a need to understand how people with dementia from the South Asian community understand dementia and its impact on their quality of life.

With the emergence of global policies and healthcare strategies on dementia, further research may include South Asian experiences of dementia from the early to the late stages of the condition (Adamson, 2001). Few studies - other than Lawrence et al.,(2008) and Victor et al. (2012) - have scrutinised the experience of South Asian individuals with the condition, notwithstanding the increasing recognition of the importance of people's voices. According to Lawrence et al., (2008) the focus is only on the early-stage experiences, and later-stage data is usually confined to quantitative studies. Limited qualitative research has focused on the experiences of South Asian people with more advanced stages of dementia, providing few opportunities to observe how individuals' dementia experiences progress. Those limitations are key to this study as they emphasise the importance of documenting a complex understanding of dementia which includes the experience of people living with early to late stage dementia.

The knowledge gap remains about how dementia is experienced, understood, and managed among South Asian groups in the UK and other countries. Previous research published by Victor et al. (2012) found that people from the South Asian community are under-represented in dementia services, less likely to receive a diagnosis or are diagnosed at a more advanced stage of the illness than are people from other cultures (Giebel et al., 2015). These challenges potentially affect wellbeing, causing excessive strain for South Asian families, and lead to the need for rigorous, high-cost care approaches.

The number of people with dementia in the UK South Asian population is expected to increase significantly as the population ages. According to the 2011 Census Report, British South Asian inhabitants - which include individuals of Bangladeshi, Pakistani, and Indian origin living in the UK - increased from 3.9% of the total population in 2001 to 5.3% in 2011 and will continue to grow (Mukadam et al., 2011). It is currently estimated that about 25,000 people from South Asian in the UK have dementia, a number which is expected to rise to almost 50,000 by 2026, and over 170,000 by 2051; consequently, as the South Asian population increases, so will the occurrence of dementia in this group (Jutlla, 2015). The high number of people with dementia also indicates that their caregivers in this marginal population will be affected (Mukadam et al., 2015). This study seeks to understand the experience of living with dementia in the South Asian population from the perspective of people with dementia and their caregivers.

Turner et al. (2005) argued the experience of dementia greatly depends on the individual's knowledge of and attitude towards the illness, addressing that South Asian languages have no term for dementia and often referring to the condition as 'being forgetful', 'losing memory' or being 'unable to remember' things. This is supported by Mukadam et al., (2015) findings, that South Asian culture lacking an equivalent word for 'dementia', use instead a translation of dementia symptoms. Bowes and Wilkinson (2003) also found evidence of lower levels of awareness among South Asian community of the causes of dementia and its impact on lives of people living with dementia. Researchers have also noted that the level of understanding and awareness of dementia, even among caregivers, was important in South Asian community.

Jutlla's study (2015, p.145) found most respondents associated dementia with "getting old" or a mental disorder. Caregivers interviewed in the research remembered seeing older adults acting abnormally, which they associated with old age (Jutlla, 2015). As symptoms became more severe, it was assumed the individual was "going insane" (Mackenzie, 2006 pg. 107).

Sometimes, dementia symptoms are thought to be linked to another illness or to be a side-effect of medication, rather than caused by a specific mental health condition (Mackenzie, 2006). Turner et al. (2005) assert that people from South Asia associate dementia symptoms with a normal process of ageing and decay, and similarly attribute their isolation and the decline in social provision. Most of Turner et al.'s South Asian participants attributed this to a lack of family attention and social support. Raising awareness is a significant first step to ensuring that people with dementia and their caregivers receive the support they need (Mackenzie, 2006). Turner et al. (2005) argue that lack of understanding, knowledge, appreciation, and awareness of dementia can result in difficulties in managing the condition, and has an impact on the lives of individuals' with dementia and their relatives. Mukadam et al. (2015) found poor knowledge of dementia among member from South Asian community, as people with dementia try to understand their health problems based solely on what they know, which later affects the decision to seek professional help which will be discussed in the next section.

3.3.2 Dementia diagnosis and engagement with health services

This section examines the South Asian community's experience of accessing dementia diagnosis and engagement with health services, in terms of the socio-cultural factors influencing their access to dementia services. Hailstone et al. (2016) found that barriers to health systems -prejudice and the lack of linguistic or culturally appropriate services - can result in delays or underuse of dementia services (Mackenzie, 2006). Lawrence et al. (2008) reported that when a South Asian population in their sample consulted healthcare services about their concerns and dementia-related symptoms, health professionals dismissed their concerns and focused on other chronic conditions. These results confirm Adamson and Donovan's (2005) findings that Pakistani participants did not receive a dementia diagnosis

earlier, as the GP in the study reported that they had come across other examples of signs of dementia being hidden by families.

3.3.2.1 Socio-Cultural factors influencing access to Dementia Services

Although limited data is currently available on the prevalence of dementia in various ethnic groups, dementia will probably become more common among older adults from ethnic minorities, compared with the white population. Lawrence et al. (2011) assert that older adults are vulnerable to high blood pressure, heart disease, stroke, and diabetes - all dementia risk factors and more common in South Asian community. Only a few studies (including Shaji et al., 2002), have provided evidence of ethnic differences between the South Asian and white populations in dementia-related behavioural and psychological symptoms. Shaji et al. (2002) reported that at the time of dementia diagnosis, South Asian individuals, especially older adults, had higher levels of illness-related difficulties such as depression, physical aggression, and problems with everyday activities.

Adamson and Donovan (2005), however, reported no difference between the South Asian populations and white or European-origin populations in access to dementia diagnosis services, arguing that this is due to a high level of acculturation - changes in culture caused by the incorporation of different cultures - amongst the sample of participants. The researchers stated that the level of acculturation may be associated with a delayed dementia diagnosis. Acculturation affects the different relationships people share with different elements of their culture. Adamson and Donovan (2005) also reported that amongst their sample of caregivers, a lower score on the acculturation survey is linked with a less positive attitude towards dementia treatment, and argued that a lower level of acculturation might affect South Asian groups' perception and awareness about dementia. They found a significant correlation between the perception of barriers involved in the diagnostic assessment of dementia and the time waited before attaining an evaluation.

This thesis reflects on the role of diverse cultures as an important aspect in determining dementia awareness and care-seeking behaviour. Hailstone et al. (2016) argue that the lower level of acculturation shapes the perception and knowledge of dementia, because of the culturally-related beliefs and values ethnic minorities assign to dementia. This may influence the level and type of help members of the South Asian community will seek to address the problem. Victor et al. (2012) state that, even after controlling for education levels, dementia caregivers from Asian, African, and Hispanic families still conceptualised dementia differently from the biomedical model. It is therefore important for healthcare professionals to understand the cultural meanings, beliefs, and values associated with dementia, as poor understanding can delay diagnosis and impacting the quality of life for people with dementia (Karim et al., 2010).

Mograb et al. (2012) reported that the myths and misconceptions attached to dementia act as a barrier to accessing services for people from South Asian community with dementia and their caregivers. Hailstone et al. (2016) finding supports Mograb et al. (2012) research, suggesting there are many myths and misconceptions attached to dementia in some South Asian communities. Delayed diagnosis arises because of cultural beliefs which characterise dementia as insanity rather than as a neurodegenerative disorder, as discussed above in section 3.3.1.

Research has suggested low levels of service use among South Asian populations, although there is limited evidence on which to base the development and delivery of the appropriate level of ethnically sensitive care (Victor et al., 2012). Health policy has also been blamed for the lower number of individuals in dementia services from South Asian groups (Lawrence et al., 2011). Purandare et al. (2007) argue that this inequality in access to dementia services by the South Asian community remains a concern for policy-makers, because of the implications for poorer outcomes in dementia treatment amongst minority ethnic groups. The expected

increase in the number of people with dementia from South Asian groups demands urgent action to improve healthcare services delivery and address the low rates of seeking diagnosis. There is a global and national appeal to enhance similar dementia services for minority groups, including the South Asian population, to guarantee access to services and offer the same potential health benefits for everyone. The UK government has recommended a particular memory service for ethnic groups to ensure that services are ethnically targeted and appropriate (Giebel et al., 2015).

3.3.3 Common understanding of the experience of Indian and Pakistani populations accessing dementia services

This section examines the mutual understanding of the experience of Indian and Pakistani groups accessing dementia services, in terms of their common knowledge about dementia, dementia-related stigma and cultural stereotyping and myths. While some families are well-prepared and choose to cope without external services, a lack of support can lead to tremendous pressure on caregivers (La Fontaine et al., 2007), which can have a damaging impact on the individual with dementia if caregivers are struggling to cope. Relatively little is known in the UK about how dementia is understood and experienced by people of Indian and Pakistani groups. Blackburn with Darwen was chosen here as the area of study because of the large South Asian population, particularly the Indian and Pakistani communities, who represent more than a quarter of the district's population at all ages.

3.3.3.1 Lack of knowledge of dementia

In Hailstone et al.'s (2016) study, thirty of the thirty-seven Indian and Pakistan interviewees showed a minimal understanding of dementia, which affected their willingness to seek healthcare services. Mukadam et al.'s (2015) survey found that UK Pakistanis and Indians had little awareness of dementia and other chronic degenerative brain conditions. The eighteen interviewees said that the characteristics of dementia are regarded as part of ageing,

or a non-pathological deviation from common ageing. Giebel et al. (2015) reported that thirty out of thirty-three Indian older adult interviewees regarded memory problems as “given by God”, saw acceptance of fate as an alternative to treatment, and did not identify medical support as appropriate. This group regards forgetfulness in the older people as a normal aspect of ageing, and most recognise it only at a much later stage as dementia.

Adamson and Donovan (2005) confirmed that South Asian languages have no words for dementia or to directly describe the illness. The Asian population commonly regards dementia and cognitive decline as a common disorder which occurs in old age, as a result of changes in memory rather than dementia symptoms. The authors concluded that the Pakistani community’s perception of dementia confirms their relative absence from diagnostic clinics (Adamson and Donovan, 2005). Poor understanding of dementia indicates that it is neglected, in comparison with other ailments, despite an accessible healthcare system, so it is a barrier to accessing supportive services in the Indian and Pakistani community (Katbamna et al., 2001). These findings may be important to the present research, as it is potentially occurring in BwD and may result in the South Asian population’s limited use of dementia services. The research will explain why the disparity is evident in the population.

Mackenzie (2006) contends that poor knowledge and understanding prevent most people with dementia and their family caregivers from seeking diagnosis, as it shapes an alternative explanation, meaning and interpretation of the disease. Nevertheless, unlike culturally-related beliefs – stigma and shame – variation in dementia knowledge across ethnic groups is also linked to educational and language proficiency differences, which could have a bearing on the current research, as dementia affects older South Asian adults, many of them migrants for whom English may not be their primary language. Participants were, accordingly, asked about the effect of education on accessing dementia services. Adamson and Donovan (2005) assert that a common language enhances communication between the people with dementia

and healthcare professionals, which is pivotal for understanding the nature of the disease and maintaining a healthy, sociable, favourable environment for the person affected. The South Asian community's lack of interest in understanding dementia affects their decisions about seeking or accessing dementia services. The research examines this issue further, as it could be an ongoing problem in BwD.

3.3.3.2 Cultural stereotyping and myths

Some healthcare professionals in the Indian and Pakistani community have commented that South Asians tend not to seek healthcare services (Mackenzie, 2006). The reasons people and families may not seek support include a desire to care for their relative and community pressure to do so even when the condition is severe. However, it is unclear whether kinship ties and social support have a positive impact on the wellbeing of some people with dementia. Hailstone et al. (2016) argue that it is therefore hard to know the importance of the support caregivers give their family members with dementia. The UK South Asian community's kinship ties and family beliefs could be given new consideration - those beliefs are likely to be contested in a modern world undergoing social changes, and family kinship ties may be broken by migration from one area to another.

A lack of culturally-sensitive dementia services, and health professionals' prejudices against the South Asian community, may make it hard to obtain referrals to secondary services or a recommendation to another specialist (Katbamna et al., 2001). People often feel the available healthcare services are inappropriate, failing to meet their cultural and faith needs, so families are reluctant to use the available services and try to manage without support. British Muslims of Pakistani origin may be particularly reluctant to attend support groups to share experiences, because their beliefs about dementia make them unwilling to admit openly that someone in their family has the condition (Katbamna et al., 2001). These findings may

contribute to exploring why the South Asian community is poorly represented at dementia services.

3.3.3.3 Stigma related to dementia

Jutlla (2015) noted the high level of stigma in the Indian and Pakistani community towards people with dementia, commenting that people from this community regard dementia as an illness with certain causes rather than as a biological brain dysfunction. Of 8,000 caregivers from the UK South Asian community, 4,800 said they feel isolated because they regard dementia as possession by evil spirits (Jutlla, 2015). Mackenzie (2006) reported that people with dementia in the Pakistani community were worried about breaking with traditional beliefs and concerned about what others may think about their condition. Turner et al. (2005) report that dementia, like any other mental illness, may be regarded as shameful, because of a sense of stigma among the South Asians. The authors report that the stigma about caring for a person with dementia is rooted in a widespread belief in the South Asian community that the condition is caused by tension between good and evil. South Asian healthcare practitioners suggested that South Asian people have strong beliefs about the causes of dementia (Lawrence et al., 2008), believing that if someone does evil things, something bad will occur to them or to their grandchildren. Critical health complications are assumed to be a result of past wicked deeds (Karim et al, 2010), which negatively affected the caregivers' emotional wellbeing and thus the welfare of those they looked after (Mackenzie, 2006).

Jutlla (2015) reported that dementia prompts social isolation for the Pakistani families affected, resulting in delayed diagnosis. Patients hide and avoid seeking medical attention because of the stigma associated with dementia. Jutlla's (2015) research among caregivers from the Pakistani and Indian community suggests that they often feel very isolated. Mackenzie (2006) found that South Asian people with dementia in this community have no

external assistance, often relying on the sole family caregiver, and lack a wider network of people for regular support..

The tendency in the South Asian community to hide people with dementia as the disease progresses keeps the affected person away from public view (Mackenzie, 2006). Hiding people with dementia is also linked to caregivers' concerns about being embarrassed by their relatives. Concern for family honour and respect results in delayed diagnosis and impacting the quality of life for people with dementia. Adamson and Donovan's (2005) qualitative study confirmed that fear and shame may result in hiding people with dementia, and not seeking medical help. Concealment may also occur in Blackburn with Darwen, resulting in limited access to dementia services by the South Asian population. The study hopes to identify the differences and shared understanding of dementia between the various BwD South Asian populations.

Victor et al. (2012) reported that stigma and misconceptions attached to dementia can lead to people affected becoming isolated, noting that this currently affects Pakistani people, where intense community pressures are typical. An individual with dementia symptoms, such as memory loss, may become stigmatised by a negative labelling process, which may affect the person's social activities and interaction, leading to declining social status (Mackenzie, 2006). Family members may also face stigmatisation because they, like the person with dementia, are negatively labelled. Only very close family associates will be aware of the situation, the condition kept secret from everyone else in the community. Mukadam et al. (2011) reported that their respondents gradually lost their social network, as people recognised their condition. Furthermore, presumptions that South Asian caregivers always "look after their own" can trigger social isolation (Victor, et al., 2012). Isolation prevents caregivers from having the emotional and practical support needed for people with dementia.

Research conducted among caregivers from diverse ethnic communities shows that they often feel excluded (Karim et al., 2010).

Lawrence et al. (2011) emphasised that stigma and shame may be a barrier in the South Asian context of common family-centred cultural values when trying to understand delayed dementia diagnosis. Poor understanding of dementia and stigmatisation make it more problematic for people to access the support they need. Family members usually decide to keep dementia-related problems and symptoms private, because of the embarrassment and shame they will bring (La Fontaine et al., 2007).

Recent research by Hailstone et al. (2016) on South Asian caregivers about dementia-related stigma found that it could induce fear in the family, leading to the individual living with dementia being hidden to protect both the family's reputation and that of the individual. Cultural and mystical explanations influenced how caregivers managed and learned about dementia. Adamson and Donovan (2005) suggest that it is unsurprising that, when exploring participants diagnosed with dementia, the community in question is less inclined to name this psychological illness Alzheimer's disease (AD) than are African-Caribbean groups. Lawrence et al. (2008) state, the understanding and attitudes about dementia among South Asian individuals influenced their experience of dementia. The current research also determines whether shame, stigma, and fear can influence how UK Indians and Pakistanis access and use dementia services.

3.4 Conclusion

This chapter has reviewed a range of literature reporting research which has examined the perceptions and experiences of South Asian individuals and families' access to dementia diagnosis and engagement with health services. There is little published research on the experience of dementia in the UK South Asian population, and similarly little in the global

literature, with few identified studies which have explored South Asian people's experience of living with dementia, or examined the relevant issues for ethnic minorities with dementia, which would have helped identify the gap in the research knowledge on dementia as it relates to the UK South Asian population.

The literature review suggests that most people in the South Asian community do not understand what causes dementia or how it can be treated, which prevents them from identifying the symptoms (La Fontaine et al., 2007; Purandare et al., 2007). The South Asian community's poor knowledge of the causes of dementia is linked with a belief that dementia is caused by evil spirits. Many believe behavioural dementia symptoms are caused by possession by evil spirits, as a result of a person's sins (Mackenzie, 2006). Poor knowledge and negative attitudes about the causes of dementia can result in delay in engaging with health services, so families manage the condition without help or advice, which impacts the lives of those with dementia and their family members (Turner et al. 2005; Mackenzie, 2006). Insight is needed about the BwD South Asian Indian and Pakistani community's knowledge of and attitudes towards dementia, through the perspectives of other South Asians who do not have a dementia diagnosis, including caregivers and healthcare professionals involved in the dementia diagnosis process.

Bamford and Bruce (2000) have argued that the perspectives of the family caregivers of people with dementia should be used to evaluate the relevant outcome criteria for dementia care interventions and services. There is clearly a need to understand the experience of dementia from the perspectives of those living with it, including their family caregivers and healthcare professionals who play a crucial role in providing diagnoses and support to the South Asian population in this region, as they have the relevant expertise. Their thoughts and opinions can contribute to formulating recommendations on developing and designing more

appropriate dementia-related services for the BwD South Asian Indian and Pakistani community.

The following aims and objectives have been defined on the basis of the policy and demographic context as presented in Chapter 2, and the results of this literature review:

Aim

The research aim is to identify the socio-cultural issues underpinning access to dementia diagnosis and support services in the BwD South Asian population.

Research objectives

- To explore the experiences of South Asian people with dementia and their family caregivers about obtaining a dementia diagnosis, and ongoing care and support.
- To explore healthcare professionals' experiences of working with and providing care and support to people with dementia from the BwD South Asian Indian and Pakistani population.
- To understand the knowledge and attitudes of dementia among members of the South Asian Indian and Pakistani population.
- To provide recommendations for commissioners and healthcare policy-makers to plan and develop services which encourage greater equality of access to and outcomes of care across all ethnic groups.

Chapter 4: Theoretical Framework

This chapter discusses two key theories which contribute to understanding the sociocultural issues underpinning how a dementia diagnosis and related support services are accessed in Blackburn with Darwen (BwD) South-Asian Indian and Pakistani communities.

It draws on the German philosopher and social theorist Jürgen Habermas's account of a theory of communicative action (Habermas, 1984). The key elements of his theory are introduced: the concept of the system world (the dominant Western economic/political system) and the 'lifeworld' (all the direct experiences, activities, and contacts which make up the world of an individual life); a discussion follows of the tensions between the lifeworld and the system.

Whilst Habermas' theory of the system world's colonisation of the lifeworld is the central theory underpinning this thesis; this chapter integrates it with another theoretical perspective, Goffman's (1963) theory of stigma (see Chapter 3). Stigma is present for people with a mental illness (and, consequently, dementia) in the South Asian community (Turner et al., 2005), so Goffman's theory of stigma provides a way to understand how people living with dementia and their family members experience stigma in a South Asian community.

The two social theories differ in their assumptions when attempting to understand individuals' subjective experiences. Habermas adopts a more structural approach to understanding the consequence of the bureaucratic system and its influence on the social interaction of individuals working within the system. In contrast, Goffman's work is embedded in an empirical and ethnographical approach as a means of understanding subjective experiences. As discussed in section 4.2, Goffman is more concerned with the consequences of social interaction on individual subjective experience through his theory of

stigma and presentation of self. Similar to Goffman, Habermas does discuss individual and their subjective experiences through the discussion of his concept of life world, (this is the lifeworld experience of stigma and this is how they manage it). Habermas addresses the concept of self and presentation of self through his discussion of communicative action (section 4.1.4), where he talks about the communication taking place and identifying this as the place where potentially social interaction can bridge the gap between the system and lifeworld. Thus, Habermas addresses Goffman's concept of social interaction through this concept of communicative action. In another word Habermas perceive social interaction occurring between individuals in his concept of communicative action, see section 4.1.4 for detail discussion. This section intends to demonstrate how the adoption of the theories of Habermas and Goffman in this thesis can help understanding of the socio-cultural issues that underpin the process of accessing dementia diagnosis and support services within the South Asian population in Blackburn with Darwen.

4.1 Introduction to Habermas

Jürgen Habermas developed a theoretical perspective exploring the liberation, rational-critical communication and the likelihood of reason in contemporary institutions and in the human ability to pursue rational interests. Modern society's impact on the lives of individuals is central to his 1984 theory of communicative action.

Figure 4.1 illustrates the two key features of modern society Habermas (1984) identified: the lifeworld (which exists within a large social equilibrium – the “system” world) and the system itself, each with a set of principles and values, institutions, and behaviours. Habermas (1984) argue that daily lives are played out in two different spheres: the private sphere - the shared space between individuals with similar backgrounds - and the public sphere, where individuals can come together and exchange ideas and opinions on the societal problems

which concern them. Habermas called the private sphere the lifeworld and the public sphere the system, the larger structure in which humans live.

This section first describes Habermas's system world concept, followed by a discussion of Habermas's life world, clarifying his concept of the colonisation of the lifeworld by the system. The section concludes with a discussion of Habermas's view of the importance of communication and action in overcoming the tensions between the lifeworld and the system, and how it applies to this thesis.

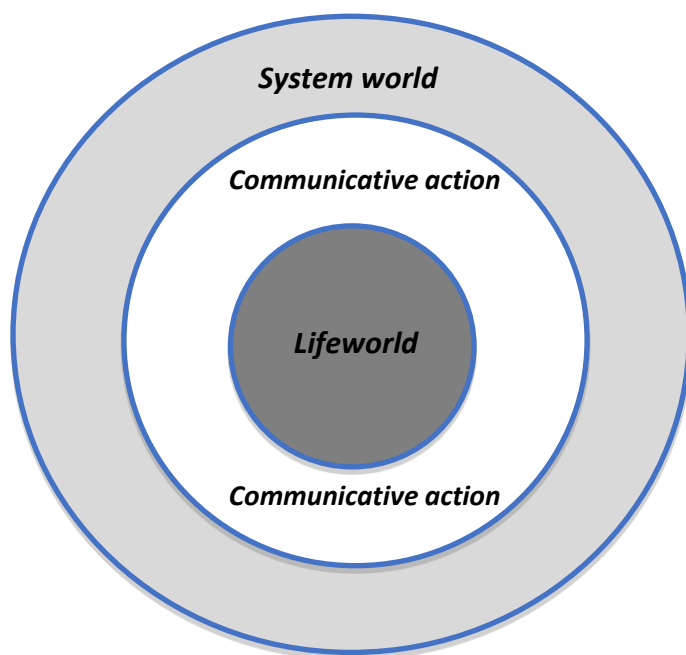


Figure 4.1: Habermas's theory of communicative action

4.1.1 The system world

The system is described as having its own self-contained subcomponents: power and money, the common patterns of strategic action which serve the interests of organisations and institutions. In Habermas's theory, the system is shaped by power (the political state) and money (the economy), both of which manipulate people's everyday social life – how to behave and what to believe – through social actors practising the system's ideology. These do

not coincide with people's objectives, so strategic actions are aimed at accomplishing specific ends: money and power control how people live in society. The dominating system ideology is infused into people's social reasoning through manipulative action. Habermas refers to manipulative action as an 'instrumental' action (Habermas, 1987, p.127). Finlayson (2006) argued that regardless of an individual's position and job role (whether an executive director or a lower-level employee in an organisation), everyone's behaviour and job roles are guided by actions which result in a financial benefit. Individuals are thus treated as numbers or categories, objects whose values shape the system.

The devaluation of lifeworld properties is based on the instrumental rationality of the system practical reasoning. Instrumental rationality involves focusing on the most efficient means to accomplish a specific end; however, not in itself reflecting on the value of that end. At the very least, the system relies on people who can communicate effectively and are neither demoralised nor manipulated to the extent of being unable to co-operate. This issue raises a question about the viability of Habermas's perspective on the system world as a balance (see Figure 4.1), within which resides the lifeworld of individuals; everyone in the system is a component of the system. Habermas suggests that actions are guided by a specific aim of the system (an end goal) through collective action, which is where members work toward an orientated outcome to benefit the system (Habermas and Outhwaite, 1996). Habermas's theory of the system world suggests it is not necessary for its members to achieve consensus in their understanding. Habermas and Outhwaite (1996) both state that the system reduces the degree of control an individual may have over his or her decisions. Habermas's concept has been criticised for proposing that people within the system have no control over themselves and are therefore passive agents of the system (Calhoun, 1992).

Habermas (1987) suggests that the system's effects are infused, and the resulting correlating action occurs through system integration. System integration is described as an interrelated

relationship between different aspects of the social system, so the role of system integration is to interlink the components of society and its institutions to form a macro-society, which will allow the system to continue reinforcing and reproducing its aims and effects through instrumental action. In contrast to the lifeworld, which allows individuals to reflect critically on their actions through communication and discourse and where individuals possess a choice, the system is driven by instrumental action (power and money) (Habermas, 1987). The next section considers Habermas's (1984) key points about the lifeworld.

4.1.2 The lifeworld

Habermas adopted Husserl's (1936) term 'lifeworld': the term Husserl used to describe the everyday universal experiences of people who share the world. Husserl (1936, cited in Hitzler, and Eberle, 2004) suggested that the lifeworld is at the heart of all knowledge inquiries. Habermas (1984) defines the lifeworld as the social context of individuals, which can then be divided into a public and a private sphere (space). Habermas attempted to answer fundamental questions about the lifeworld: What is the public sphere, and what types of power does it have in a typical democracy? How does the public sphere differ from the private sphere? How is the system of political power preserved in a democracy? How does public opinion form political policy and power? Habermas (1987) describes the private sphere as an individual's 'habitus' – the shared space between individuals with similar backgrounds (for example, social status, ethnicity, job, religious beliefs, or education level). The public sphere is typified as an open, shared public space where individuals meet to exchange ideas and opinions on the societal problems which concern them, and thereby inform political action.

Koselleck (1988) challenges Habermas, disputing the ability of the public sphere to inform new political action, policy, and legitimation. Koselleck (1988) maintained that a public

sphere is a place for open discourse where political authoritarianism is a challenge. In contrast to Habermas (1996), Koselleck (1988) states that the public sphere gives rise to democratic regimes, which may not necessarily shape political action but weaken political regimes. Both Habermas (1996) and Koselleck (1988) argue that the public sphere can affect justice and actions from political organisations, because the public sphere balances politics and social order.

Social integration occurs in Habermas's lifeworld, reaching a mutual understanding of shared norms, values, and practices (Finlayson, 2006), established and maintained through face-to-face interaction occurring over time within numerous social groups. This results in groups of people with shared norms, values, and practices forming families or creating communities (Habermas and Outhwaite, 1996). Bohman (1997) points out that this view of adhering to behaviour norms and values is problematic, because it requires recognition of collective reasoning over individual reasoning, which is difficult to achieve in a world influenced by individuals' needs and interests. In Habermas's vision, individuals who are a part of a collective group are made up of multi-faceted experiences and interpretations (Outhwaite, 1994). Habermas proposes that a key component of the lifeworld is that individuals may relate to each other based on a shared mutual understanding of a particular situation, and may also be part of a collective group and share cultural knowledge.

Habermas (1987) theorised that the public sphere can be most effectively maintained and constituted through discussion, debate, acts of speech, and dialogue. Through the public sphere people share mutual understanding and collective knowledge with their communities, families and friends. Habermas (1987) suggests that individuals' cultural identities or communities are established through shared interactions between two or more conscious thoughts, and that shared interactions are developed and maintained through collective action. Realising a shared understanding and commitment to values is crucial to Habermas's

definition of the lifeworld; if the lifeworlds of two individuals are closely associated, they will probably reach a shared collective understanding through less discussion. However, Pronin et al. (2002) argue that biased views of individuals toward politics can arise while maintaining the public sphere.

Bohman (1997) challenges Habermas's concept that in a modern society, with access to scientific development and technology, it may be difficult to suspend individual reasoning and action shaped by individuals' needs. Finlayson (2006) acknowledged that in a changing society (the technical, moral, and scientific development of society) the lifeworld will be subject to adaptation and changes of content. Finlayson (2006) describes the lifeworld's function as providing a platform of common contexts, which allows a group or community to critically reflect on issues arising within that changing society. The group will reach a collective consensus, agreeing or disagreeing with the changes in society, through communication and open discourse.

Habermas's lifeworld is a medium through which society's collective knowledge is established, reproduced, and inherited. The colonisation of the lifeworld by the system will now be discussed in detail.

4.1.3 Colonisation of the lifeworld by the system world

Historically, the system world concept emerged from the dominant social conditions of the late twentieth and early twenty-first century (Habermas, 2006), when advanced capitalist societies or systems had emerged, and the core integrative function of communication had been largely disabled - which Habermas referred to as 'colonised'. The system is thus implanted in the lifeworld. Scambler and Britten (2001) asserted that the system develops at the cost of the lifeworld: the relationship between the system and the lifeworld underpins the theory of colonisation. At a personal level, many human beings struggle to find the balance

between personal life and work, and in most scenarios colonisation means losing the struggle because of the intrusion or invasion of the system. In Habermas's (1987) system theory (in comparison with the self-maintained independent medium of the lifeworld), the system world operates on the same basis as the lifeworld.

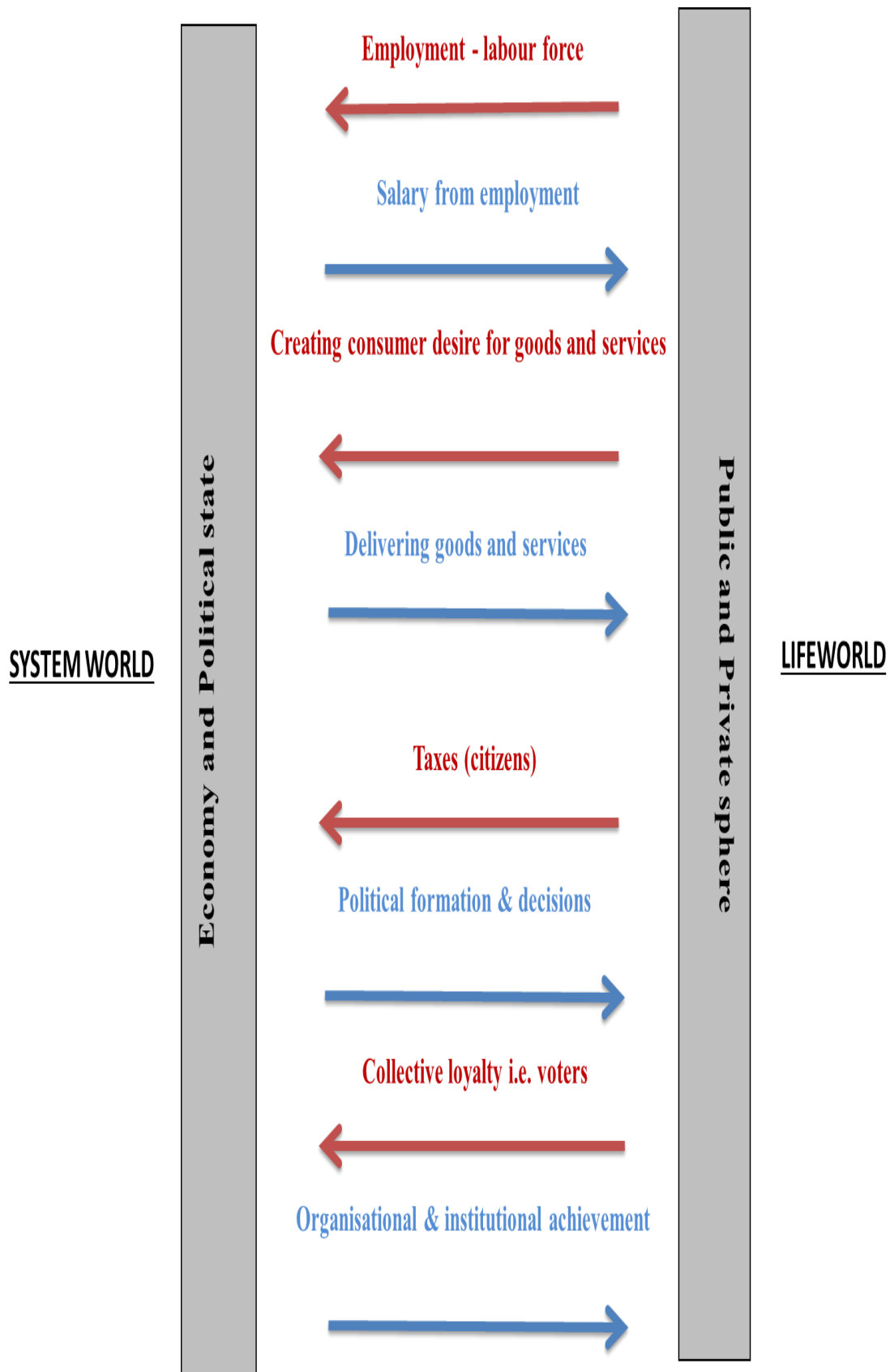


Figure 4.2: Colonisation of the lifeworld by the system

Habermas's theory suggests that individuals or communities become invisible and are reduced to the status of clients of the civil service (providing voters for the political system), consumers, and the economy's workforce (Kemmis, 1998). The idea of an inherited inequality between citizen and state is also supported by Scambler and Britten (2001), who share Habermas's perspective. Both share the same ideology on inequality.

To understand how the system is related to the lifeworld, one must understand the roles power and money play in the colonisation process: through power and money most people are manipulated and demoralised. Those who possess power and money can influence stakeholders' choices while avoiding the rational dialogue (or consensus-oriented communication) which is typical of the lifeworld. The lifeworld is thus diminished, becoming decreasingly significant in people's everyday lives. The colonisation of the lifeworld leads to numerous dysfunctions, all noticeable in the contemporary world. Colonisation can be manifested in the community through a general logic of hostility from the community and poor communication among its residents. Comprehensive social development encompasses both the internal change of lifeworld components and the developing separation between symbolic-communicative patterns and the productive activities controlled by standards. Habermas describes this process as an 'uncoupling' of systems and the lifeworld (Habermas, 1987, p.169).

The system operates by material production and financial benefit; it intrudes into the lifeworld through the political state and the economy, invading the individual's lifeworld through planned action (Figure 4.2). When systems are no longer merely integrated with communicative patterns but start to conquer lifeworld communication patterns, Habermas referred to this as the uncoupling of the system, where the lifeworld is completely colonised or taken over by the system world. The uncoupling means the system control dominates the communicative design of the lifeworld. The individual becomes the means by which the

system can serve both the interest of the establishment and the political and economic institutions. As a result, the lifeworld begins to be absorbed and obscured in effect causing people to become a means to economic and political ends, that are not in their control or according to their interest (see 4.1.2). Over time, strategic decisions are left in the hands of experts infused by the dominant system's ideology, which reduces the communicative patterns and practices of a particular lifeworld group (whether cultural, for enjoyment, or for interpersonal communication).

The lifeworld of a group or community is subjugated to alien standards, experiencing a loss of meaning and crisis in its laws and judicial systems. An environment of collective agreement is appropriate in the lifeworld, while systematic necessities prevail in the system. Habermas's theory of communicative action places emphasis on the colonisation of the media and government by the marketplace. Although Habermas uses this theory to comment on society, modernisation does not simply coincide with the variation of communicative components, as material production cannot be reduced.

In a society characterised by progressive difference and the moderate independence of economic and political-legal systems, Habermas points out that individuals and groups increasingly define themselves and their aspirations in relation to systems. Correspondingly, Mishler (1984) states that the lifeworld of a patient using health services is colonised by the demands made by the economically-driven health system. This limits the lifeworld communication action which occurs between patient and practitioners (to establish a shared understanding of the best resources available for the individual), creating a situation where medical interventions dominate, increasing the lack of legitimacy experienced by the individual as a patient. It is a colonisation in the sense that the system requirements negate the internal communication action, which supports the creation and reproduction of lifeworld, offering in its place an external context of values, language, norms, and understandings based

on systems. In such scenarios, symbolic lifeworld processes are restricted by a discourse of features, roles, and functionality, reshaping personal and collective relationships, self-understandings, and practices (Scambler and Britten, 2001).

When introducing Habermas's theory of colonisation, Finlayson (2006) outlines the impact of the colonisation of the lifeworld on society, noting that colonisation limits opportunities to develop a shared consensus of understanding, resulting in a loss of social ties. Colonisation also increases the sense of isolation, alienating people, and reducing the individual's ability to take responsibility for or to control his or her actions. Finally, Findlayson says it decreases the number of opportunities individuals have to enforce their ideas. Barry et al. (2001) assert that in practice for example patients can limit the influence of the healthcare system on the colonisation of their lifeworld through communicative action, by expressing their disagreement to the healthcare professional. Habermas's communicative action theory as a way to resist the influence of the system is discussed in the next section.

4.1.4 Communicative action

Through communicative action Habermas (1984) proposes it is possible to minimise the influence of the system's instrumental action on the lifeworld. As he explains it, the lifeworld is where actions (social goals) can be discussed reflectively and critically; he suggests that the tool of language can liberate modern societies from the effects of the instrumental action. He proposes that language is fundamentally universal to all humans and that the ability to communicate rationally (in a sensible or logical manner) is a perfect human ability. He attempts to outline freedom in society through his concept of communicative rationality, which evolved over time through his expression of the critical theory of communicative action (Habermas, 1984).

Habermas (1987) suggests that the human impulse to communicate is a fundamental universal reasoning underpinning all human interaction. He notes that communicative rationality may not instantly discard prejudice or achieve rational consensus but that negative communicative aspects can be weakened over time through reasoning. However, Susen (2011) criticises this concept of reasoning, querying whether a rational consensus can, in fact, be achieved by any society. The key reason for communicative rationality is to enhance equality.

Habermas and Outhwaite (1996) argue that human linguistic reason can form a bridge between societal integration and cultural and individual identity formation. Habermas, however, does not propose rehabilitating system thoughts, as they serve an important social function and provide a foundation for knowledge (see Figure 4.3, which represents and describes the intersubjective relationship between the lifeworld and the system world). They are connected by culture, social life, beliefs and values, opinions, planning, and performance. Habermas emphasises the importance of developing a universal intersubjective relationship between the objective system and personal lifeworld thoughts, and the legitimisation of authority in modern society.

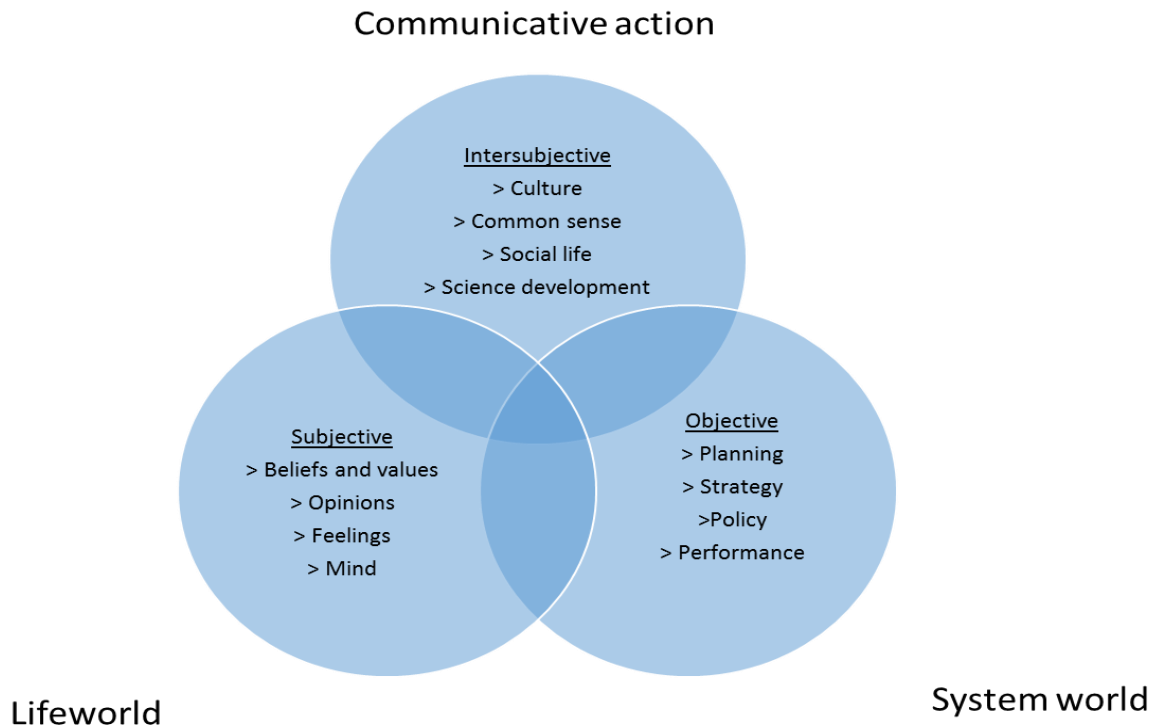


Figure 4.3: The intersubjective relationship between the lifeworld and the system world

Habermas (1984, 1987) emphasises the power of communicative action in policy formation, maintaining that communication, open discourse, and debate in the public sphere will empower people or groups to confront state authority for the purpose of political action. This may happen when individuals' or groups' moral, cultural values, and practices (lifeworld aspects) have experienced prejudice from or have not been incorporated into the dominant world's political state and economy (the system world). This results in an equal presentation of needs and experience by the community, which have been incorporated into the system - as, for example, in health policy formation.

The principal point of Habermas's (1984, 1987) theory of communicative action is to develop a shared understanding between the communicators: the person who is listening (the hearer) and the speaker. "Shared" here is not about sharing the same view or being similarly influenced by instrumentalism - both listener and speaker, rather, share the presupposition of equality. Instrumentalism is a practical philosophical approach which involves an activity

(e.g. science, law, or education) primarily as an instrument or tool for some practical purpose. Habermas (1979) proposed a validity claim model to assess levels of equality between communicators; this model tests the communication's sincerity, trustworthiness, and suitability to the circumstances, and whether one communicator can understand what has been expressed by the other i.e. whether it is intelligible.

Cohen (1995) and Flyvberg (1998) regard Habermas's theory of communicative action as insufficient, their argument focusing on what would happen if the validity claim between communicators is faulty – especially in a society dominated by politics and economic growth, which increase the opportunity for opposing discourse. Cohen (1995) emphasises the subconscious influence of power, proposing that during the discourse a communicator may feel less powerful and hence less vocal in comparison with the other communicator. Conversely, he states that the communicator with power, who is more vocal, will direct and steer the direction of the discourse. Extending the argument, Fraser (1992) states that the various manners of speech and methods of influence create an action which promotes the marginalisation of particular groups through factors such as race, gender, and ethnicity. Fraser uses Tannen's (1992) research to illustrate the marginalisation of women by men in group conversation: men may dominate the discourse by talking extensively and to a greater degree. Critics of Habermas's theory ask whether it is possible to realise an environment which is free from domination.

In response, Habermas (1996) asserted the need to institutionalise discourse ethics, proposing that the criteria for discourse should require a shared public space where information can be shared inclusive of all, everyone having the same opportunity to take part, and that a conscious effort should be made to ensure that no-one is excluded. Central to the institutional discourse criteria is that there should be no external influence, as everyone is bound only to the principle of what is rational, and that all must have a fair chance to introduce their issues,

be heard, and make suggestions. This will then free the discourse from internal coercion (Habermas, 1987) and allow unity among participants when reaching a decision or mutual understanding of needs. Thus, the interests of the community at large will be served, free from the bureaucracy of power and money.

Fleming (2002) supports Habermas's idea that discourse promotes freedom, equal opportunity, and care, to establish a democratic society. However, Fleming also states that the process of arriving at an agreement requires that participants disclose their ideology, any internal or external influence (coercive), and any non-democratic constructs which may affect the process of developing democracy. Collins (1991) argues that this suggests that discourse is rational, free of restraint, and power, stating that freedom from all of these is required to reach an agreement.

The principle behind Habermas's concept of civil society and democracy is that both are dedicated to establishing a learning community to enable disparate groups live together. In this community, efforts would be made to establish an agreement about societal problems or difficult issues through open, honest discourse, liberated from the dominant influence of the system world (Fleming, 2002). Habermas (1984) acknowledges that higher education (in this context, "higher education" denotes "research") as a public sphere allows discourse to occur through the learning community, enabling a critical reflection of the lifeworld while continuing to support the functions of money and power.

This section introduced Habermas's theory of communicative action, his lifeworld/system world concept, and how colonisation of the lifeworld by the system world occurs. It examined Habermas's resulting theory of communicative action as a saviour of modernity. Modernity involves both a historical period and the combination of specific socio-cultural practices, norms, and attitudes which emerged in post-medieval Europe, to advance in many

forms and in various periods around the world (Bos et al., 2013), and involves a wide range of interrelated historical processes and cultural phenomena. To understand how communicative action can inform and maintain stigmatising characteristics and attributes, the next section considers Erving Goffman's theory of stigma as an attribute of communicative action.

4.2 Introduction to Goffman's theory of stigma

The influence of Goffman's theory of stigma is not limited to its discipline, extending to include the disciplines of psychology, health and medicine, and criminology (Bos et al., 2013). As the literature on stigma has expanded, so have the definition and concept of stigma. This section first defines the term 'stigma' as it is used in this thesis, followed by a detailed discussion of Goffman's concept, with a particular focus on social shame. Finally, I examine how stigma affects people with dementia and their family members.

4.2.1 Goffman's concept of "stigma"

Stigma is defined as something which prevents an individual from being accepted into an ideal society (Link et al., 2004). However, Goffman (1963) describes stigma as the response to characteristics which are perceived as dishonourable or disgraceful; individuals with these attributes are perceived as stigmatised (a "tainted individual", p.3), reduced to something less than a whole person. Stigma is normally prompted by fear of things perceived as uncharacteristic. Goffman (1963) identified three types of stigma: physical, group association, and character. Physical stigma is associated with an individual's physical looks e.g. an unusual appearance or deformity. Character stigma, associated with some aspect of an individual's personality, is usually verbalised by the common system of ethical values by which society evaluates personality. Group association stigma, imposed on an individual

because of their association in a particular group, may be based on religion, an ethnic community, or even a political party. Goffman emphasises that group association is typically connected to entire families and inherited by future generations.

Stigma is variously challenged; some people attempt to eliminate stigma by changing either their physical appearance or character; others may try to eliminate it by associating with other people with a stigma attached to them. In some cases, people try to disregard stigma by presenting an appearance of themselves which shifts attention from what is observed as an abnormality. Although various definitions of stigma have been developed from Goffman's original concept, Major and O'Brien (2005) suggest there is consistency in how stigma is defined. Stigma, depending on social constructs and context, devalues the characteristics an individual possesses which mark him or her out as different.

The stigma concept has been criticised for addressing few of the myriad societal forces which promote certain people's exclusion from social life (Parker and Aggleton, 2003). In response to criticism of the stigma framework, this thesis expands the concept of stigma by linking it to the interrelated multi-faceted aspects of the social world (stereotyping or rejection) observed in the sociocultural environment of the stigmatised person (Link and Phelan, 2001).

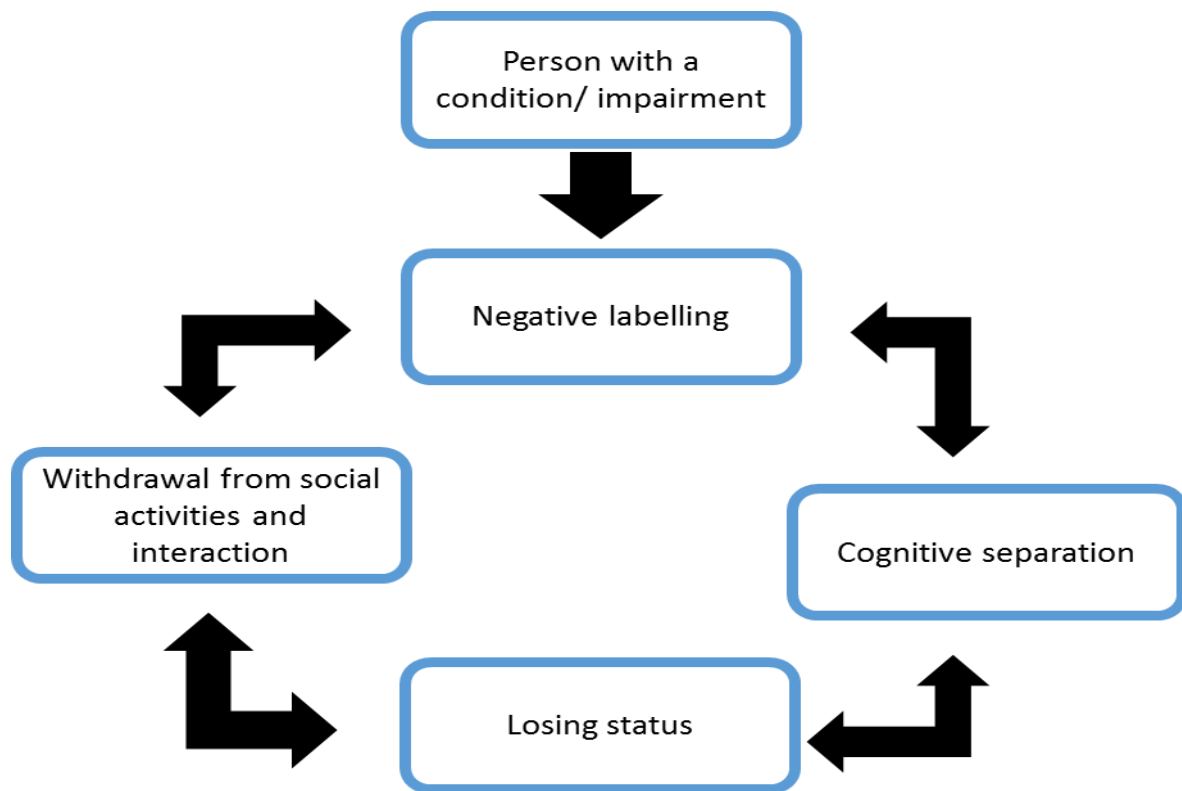


Figure 4.4: The process of labelling a person with a condition/impairment

Link et al. (2004) describe the multi-faceted aspects of stigma: the person with a condition is labelled and negative stereotypical views are attributed to that person. Perceived separation – isolation from the aspects of modern life – then occurs (‘normal’/healthy people cognitively detach from people with a condition, viewing them as different: “them and us” (Link et al., 2004, p.149)) – which informs the emotional reaction toward people with that condition. Individuals with a particular condition are thus negatively labelled, experience a loss of community status, and are likely to experience an unequal outcome as a result of community-level stigma and institutional-level stigma.

Institutional-level stigma (Link and Phelan, 2001) suggests that power plays a role in the creation of stigma. Link et al. (2004) argue that, rather than viewing stigma as a discrete event, it is a process created by societal, economic, and political power (Goffman refers to

this as structural power). Goffman, in an attempt to bridge the divide between the structure and agency (i.e. individual choice to act independently) addresses how institutional discrimination limits a group's decision-making abilities through policies which underline the adverse effects of a stigma attached to mental illness (Corrigan et al., 2004). People with mental health issues, for example, may lose their right to vote, or it may be implied that a special dementia service for ethnic minority groups would restrict money spent on other healthcare services. The role played by power is further supported by Das et al. (2001) and Corrigan et al. (2004), who suggest that power rests in the authority of the state, which has the power to stigmatise particular communities or groups.

Rothman (1971) asserts that structural power can influence the stigmatisation of individuals with mental illness. He suggests that, historically, treatment facilities for mental illness tended to be in an isolated setting, away from other people, which would then result in the development of a stereotypically stigmatising view toward people with mental illness, implying that they pose a risk. Many people perceive them as insignificant individuals who cannot benefit society. Link and Phelan (2001) state that individuals are likely to receive fewer rewards and more censure as a result of developing a stigmatised illness. Stigma thus exposes the individual to a host of untoward circumstances. In response to this assertion, Luengo-Fernandez et al. (2012) suggest that less funding is dedicated to research on dementia than to other illnesses and that less money is allocated to the adequate care and management of those with dementia. As a consequence, people with dementia benefit less from scientific discoveries than they would if the illness they happened to develop were not stigmatised.

Goffman's view is that what is classified as stigmatising by a particular group or community is developed and maintained through the process of a social construct i.e. a shared understanding of the world among those members of a community who share a mutual assumption of reality. In his view, a particular group or community establishes how to live

and what is classified as normal behaviour through a social construct, referring to this as a “virtual social identity”. Stigmatisation arises when there is a discrepancy between the virtual social identity and the actual attributes individuals possess (Goffman, 1963).

Kusow (2004) argues that Goffman’s (1963) concept of how to develop a collective normative understanding of criteria for stigma has been contested because it naively assumes that everyone in a community will share a single mutual understanding of what is classified as stigma and what is not. Here I argue that Goffman’s concept of stigma does not, in fact, suggest that society is simply divided into normative and stigmatised individuals. His theory of stigma points out that certain characteristics are regarded as honoured or dishonoured, depending on the nature of the illness or the situation’s historical and social context, particularly when it involves understanding stigma within a racial or cultural group. Jones et al. (1984) expand on Goffman’s definition of stigma as dishonoured characteristics, factoring in the impact of certain conditions which are perceived by society as deviant behaviour, which then has an impact on an individual’s social identity.

Goffman (1963) places emphasis on the importance of the social context when defining what is classed as a deviant condition. Structural power has a role to play when classifying individuals with mental illness as deviant. With the emphasis on the social context, Hebl and Dovidio (2005) suggest that belonging to a particular social group may result in perceiving certain characteristics as stigmatising, thus devaluing an individual’s social identity or social status within the group.

Although Kusow (2004) argues that Goffman’s theory of stigma is outdated as society has changed, Link and Phelan (2001) argue that Goffman’s concept is still relevant today. Link and Phelan (2001) state that the influence of structural power is currently substantially less than and different from its influence in 1963, arguing that the Immigration Act 2002 and the

Equality Act 2000 (introduced to prevent discrimination against a person on grounds of race or disability) have reduced the impact of the power to stigmatise individuals and their social identity.

Kusow's (2004) research on the impact of stigmatisation on Somali immigrants in Canada, reports that participants confirmed that the cultural context in which stigmatising attitudes are formed toward the Somali group is based on their social identity. The participants reported that, after migration to the West, they learned for the first time about social exclusion and stigmatising attitudes based on social identity. Some of Kusow's participants shared their lived experiences of the stigmatising attitudes and behaviour projected on them because of their skin colour.

Kusow (2004) concluded that the stigmatisation of a particular culture or group resulted in people from the Somalian culture reinstating their separate system through the formation of a community, to protect and reproduce the cultural identity they brought with them from their native country. Kusow thus challenges Goffman's concept of the impact of stigma on an individual's social identity. The research has particular relevance to this thesis and is explored further in the findings and discussion chapter, to examine stigmatising attitudes toward individuals and their cultures, especially those in the South-Asian Indian and Pakistani community living in Blackburn with Darwen.

To summarise, this section has examined the evolving definition of stigma as proposed by Goffman (1963), including the role played by social domains when constructing and articulating how stigma works. Further examination of comparative literature on Goffman's (1963) theory of stigma supports the negative effects of the social process of stigma on affected individuals and their family members, which is discussed in the next section.

4.2.2 The social process of Goffman's theory of stigma

According to Goffman, a stigma is a reputation, behaviour, or attribute which is socially discredited i.e. a person is subjected to others' pejorative excluding labels rather than experiencing acceptance. Goffman (1963) identifies individuals' experience of stigma as being in a social context in which the individual's characteristics are categorised as undesirable. Jones et al. (1984) observe that this results in devaluing the stigmatised person, thus further shaping the individual's social identity. Werner and Davidson (2004) applied Goffman's (1963) theory of stigma to people with dementia, suggesting that people with mental health issues are perceived as 'dangerous'; people with dementia thus experience rejection, social distance, marginalisation, and discrimination.

Crocker et al. (1998) proposed a theory of how individuals maintain their sense of self and social identity, which can be better understood when integrated with Major and O'Brien's (2005) model of identity threat. Major and O'Brien's (2005) model is developed from Goffman's concept of the social actor in his 1959 book on the presentation of the self in everyday life. Goffman used the imagery of theatre to show the distinctions and importance of direct social interaction, asserting that social interaction may be compared to a theatre and people in daily life likened to actors on stage, each playing multiple roles. Goffman suggested that people, as they socialise with each other in social settings, are continually involved in a process of warding off humiliation of themselves or others.

People can develop either a self in relation to the group, which comprises distinctive characteristic information about themselves, or a collective self, which comprises information about the group they belong to. People can both perceive themselves as committed to their specific group and consider their group as more substantial and moral than others. A group provides a sense of belonging to the social world, and to improve their self-identity, people

boost the status of the group to which they belong. Major and O'Brien suggest that individuals can identify perceived risk and situational cues, and that individuals develop a collective knowledge of negative stereotyping and cultural views about mental health, identifying those which could dishonour their characters; individuals thus strive to maintain their social identity.

4.2.2.1 Processes of stigmatisation and mental health

Corrigan and Watson (2002) and Link and Phelan (2001) state that, before becoming mentally ill, people are aware of the negative cultural beliefs and values associated with mental health issues by other members of their community. An individual who is developing a mental illness will have knowledge of how other members of the community might stigmatise them and their families. Ottati et al. (2005) and Sabat (2001) concur with this view.

Goffman (1963) asserts that when people with a mental illness (a non-visible stigma) understand the social viewpoint (cultural understanding) of what it might be like to live with mental illness within a community, they and their family members will be afraid to disclose their illness or diagnosis to the community. This fear is rooted in the fear of losing status (going from "normal" to "discredited"; Goffman, 1963, p.32); Goffman describes how 'discretisation' ('othering') by the individual's society or community results in the individual forming a new identity (i.e. as a person with mental illness). Developing Goffman's (1963) theory of stigma, Scheff's (1966) labelling theory suggests that a person with mental illness learns society's negative stereotypical standpoint on mental health through socialisation, reinforced by regular interaction. Elaborating on this concept, Link et al. (1989) state that the impact of stigma (i.e. devaluing through social labelling and a rejection of individuals with a mental health condition) makes the individual more vulnerable to mental relapse. Central to

Scheff's (1966) and Link et al.'s (1989) concepts of stigma is the role the social sphere plays, where a shared cultural understanding of what is perceived as stigmatising behaviour is established and reinforced through social interaction.

4.2.2.2 Goffman's theory of stigma

Goffman's (1959) dramaturgy concept generates insight into how individuals with stigmatisable attributes try to avoid situations where they might be demeaned. Goffman suggests that the social world is a stage, comprising a front and a back stage. Here social actors (i.e. people with a particular condition) play different roles in their everyday lives. Social actors will behave differently depending on the familiarity of the setting, where they are, who they are with, and what role they play. The front stage is where humans behave and interact when they know they are being watched and attracting attention. For a person with an illness, the front-stage interaction and behaviour will be informed by how it is reflected by the setting and how they may be expected to behave (i.e. the social script learned from cultural norms). This informs the intention behind and purpose of the performance an individual gives on the front stage, because front-stage behaviour is driven by an individual's acknowledgment of how they are perceived by others and what is expected of them; both factors will shape how they choose to behave.

'Backstage' is how someone behaves when they are not being watched. Raffel (2013) asserts that backstage is different from the front stage, as it is where individuals can be themselves and express that they are in pain or feeling low. Backstage, the actors may conduct themselves differently from when in front of the audience on the front stage. The actors can rehearse certain interactions or behaviours to prepare themselves for their next front-stage performances. Only backstage are people really themselves, shedding the roles they play in front of other people. Even when actors are backstage, they are aware of expectations and

norms, which influence what they think and do. The place for backstage interaction and behaviour is an individual's home, with their family members, and with different groups in communities and workplaces. 'Backstage' behaviour is informed by a different set of expectations, norms, and values compared to that of 'front stage' behaviour. Such awareness shapes the behaviour and encourages people to do things in private they would never do in public.

For the most part, how people or actors behave 'front stage' and 'backstage' varies considerably. When a performance reserved for one area makes its way into another, misunderstanding, embarrassment, and even disagreement can arise. It is important, therefore, to work, consciously and subconsciously, to ensure that front stage and backstage remain distinct. Central to Goffman's ideas about the social interaction which takes place front stage and backstage is the lived experience of the stigmatised person and group. Goffman thus acknowledges the influence of historical, social, and cultural contexts on the stigmatised person's experience. Dovidio et al. (2001) and Riessman (2000) argue that Goffman's concept ignores the role played by social class, which then affects how stigmatised individuals may respond to the situation (by resisting, rejecting, or accepting the stigma attached to the condition). In response, Yang et al. (2007) argue that Goffman acknowledges the impact of social class on stigma through his recognition of the "moral component" (a term referring to the degree to which status, money, jobs, relationships and health, and practical engagements matter to an individual). Yang et al. suggest that the moral component of stigma can be perceived as the greatest contribution made by Goffman's (1963) theory of stigma.

The key idea in the moral of stigma is that the act of stigmatising someone is rooted deeper than solely in the cultural understanding of the issue, which suggests that both stigmatised and stigmatisers are engaging in the process of maintaining that which matters the most to

individuals (Kleinman, 2006). The stigmatised individual may try to guard what matters most to them, which may otherwise be lost or threatened by the stigmatisation. Both stigmatised and non-stigmatised individuals may marginalise and discriminate against a person who appears to possess stigmatising characteristics, either as a defence mechanism or through a desire to preserve their moral and cultural experience, which they may believe to be threatened by the stigmatised person (Yang et al., 2007).

The moral experience of stigma can be understood through Erikson's (1963) explanation that stigma may threaten people's ability to attain a balance between self-reliance on one's ability yet maintain a sense of normality, which threatens personal growth and development. Through stigma people understand the behaviours of both the stigmatised and stigmatiser, for it allows an examination of both as living with what really matters and what is threatened. Stigma exerts its primary effects by threatening the loss or decrease of what is most at stake or by, in reality, lessening or destroying that lived value.

This section has discussed Goffman's theory of stigma, examining how it informs the presentation of the self in a stigmatised person's everyday life. This thesis suggests that to apply Habermas's theory of communicative action – now nearly forty years old - to current social situations, Goffman's concept of the social world must be acknowledged. Goffman's concept will then provide new knowledge about and insight into the empirical social world (Chriss, 1995). The following section attempts to integrate Habermas's theory of communicative action (the central theory underpinning this research) with Goffman's theory of stigma.

4.3 An application of Habermas's and Goffman's theories

Habermas's theory of communicative action and Goffman's concept of stigma both address the importance of the three 'worlds': the subjective, intersubjective, and objective.

Habermas's theory self-reflexive and supports any type of argument by reflecting on premises and aspects of cultural background knowledge. The theory is an important component of this thesis because it ensures a comprehensive exploration and understanding of the sociocultural issues underpinning how a dementia diagnosis and related support services are accessed in the South Asian Indian and Pakistani communities living in Blackburn. Chriss (1995) states that some might criticise the use of both Habermas's and Goffman's theories in a single thesis, as Habermas's theory of communicative action was influenced and developed through a critique of Goffman's theory of communication action.

These two theorists have different perspectives on how communication and communicative action is understood. Habermas's (1987) understanding of communicative action implies that people from a particular community (e.g. the South Asian community in this thesis) could engage in an open shared space where individuals meet together to discuss their opinions and societal problems freely (i.e. free from power and money), and to initiate political action (transformation). However, from a Goffman perspective the social actors engaging in social interaction are sincere in their presentation of self. In Goffman's theory, in daily communication social actors present a particular version of the self, and are guided how to conduct themselves by cultural norms to present a consistent and rational self with whom others can identify and connect. Habermas's concept lacks the need for presentation of a rational self. Goffman (1981) argues that use of the pronoun "I" in a conversation highlights the constant reflection of self and how to present the self-prior to speaking.

Goffman's is perhaps the most recognised communication theory in the contemporary world. He uses theatrical representation to describe how competent social actors perform their variously situated roles in order to present the optimal appearance of themselves. Habermas's communicative action, although confined to daily life and collective understanding, is reasonably focused on the shared values of social life. Habermas emphasises the theoretical

role of communication which is free from oppression and restraint, in constructing the democratic informal environment of the public sphere. Adopting both perspectives allows the thesis to establish new knowledge about collective cultural understandings in South Asian, Indian and Pakistani communities living in Blackburn.

Habermas (1984) and Goffman (1963, cited in Chriss, 1995) may differ in how they construct the world in which communication takes place. There is a shared understanding between how Goffman sees society in his theory of stigma and Habermas's position on an anti-essentialist community (the theory of communicative action - see Table 4.1). Both Habermas's (1984) and Goffman's (1959) theories regard individuals in the social context as social actors functioning in the system, thereby informing the social order. Habermas's theory of communicative action and Goffman's stigma theory will now be applied to a health setting to demonstrate how individual lifeworld are colonised by the health system.

Table 4.1 Comparison of Habermas’s theory of communicative action and Goffman’s communication theory

Habermas’s theory of communicative action	Goffman’s communication theory
The theory involves a critical theoretical perspective and reconstructs a concept of reason in an emancipatory communicative act.	The theory involves a sociological perspective which focuses on the management of everyday interaction.
Habermas’s goal was to develop a framework for universal pragmatics which identify and reconstruct the universal conditions of possible understanding between actors.	Goffman’s goal was to specify the criteria or conditions for universal practical discourse aimed at understanding rather than at realisation.
Human reasoning is first established through interaction before being reproduced and inherited.	The underlying components of human reasoning are learned first through socialising, then by imitating, and lastly through the experience of identifying cultural cues.
Social actors engaging in social interaction are sincere in their presentation of self. They engage in an open shared space where individuals come together to discuss their opinions and societal problems freely.	Social actors are guided in how to conduct themselves by cultural norms to present a consistent rational self with whom others can identify and connect.

Goffman’s (1959) theory suggests that the underlying components of human reasoning are learned first through socialising, then by imitating, and lastly through the experience of identifying cultural cues about what is classified as reasonable behaviour or action in a given social situation. Habermas proposes a similar concept in his definition of the lifeworld, where collective group knowledge is first established through interaction then reproduced and inherited. However, Habermas further draws on the notion that the system uses dominant

instruments (i.e. the political state and money) to maintain its influence through strategic action. In a health setting, strategic action is embodied by health policies, which distort interaction between the patient and healthcare professionals, allowing the system to control the patient to achieve the endpoint (which is driven by power and money). In contrast, Goffman's theory stands alone as a presentation of the lifeworld processes of social relationships and direct behaviour. When connecting Goffman's concept with Habermas's theoretical perspective on the processes of communication, Habermas's theory of communication action may serve well because it has integrated key aspects of Goffman's representation.

Habermas's objective was to outline a research model for a universal pragmatics to identify and reconstruct the broad conditions of probable understanding between actors. Habermas's attention was then drawn toward the area of practical discourse; to stipulate the standards for conceivable non-coerced action, this rational discourse must be directed toward consideration instead of success. Habermas's theory can thus provide an overly strategic positioning which typically overrides the objective of understanding in communication. Conversely, Goffman's concept demonstrates that Habermas's difference between achievement and understanding is an analytical process in communication. Goffman uses the phrase 'structural power' (societal, economic, and political) to describe Habermas's concept of the dominant instrument. Goffman's ideas are similar to this concept (see 4.2.1.), as he explains how societal, economic, and political power will first create a stigmatising view directed toward people displaying characteristics of a mental illness. The power portrays them as dangerous and someone to be fearful of; policies and practices then limit the choices of individuals with mental health issues.

Applying Goffman's ideas and Habermas's concept of a dominant instrument or structural power in the context of this research would suggest that the South Asian community may be

unwilling to develop a shared collective understanding, to determine how these criteria are influenced by dementia and mental health's historical and social contexts. In historical and contemporary social contexts, the system stigmatises the everyday life of an individual with dementia through policies and practices such as institutionalising people with mental illness.

According to Goffman's theory (1963), the South Asian communities experience group association stigma, unable to seek assistance because of shame and cultural differences associated with mental illness and mental healthcare. Ethnicity and culture are thus the key aspects to consider when constructing effective approaches and treatment strategies (Habermas, 1984), especially in the earlier stages before the illness progresses. People with dementia and their family members can, by socialising in the community, identify cultural cues about what it means to live with or have a family member with dementia in that community. Goffman's theory suggests that people with dementia will try to conceal their subjective identity (dementia) in front of the group (see section 4.2.2). During the later stages, most people with dementia become increasingly weak because of the strains of the illness. When people with dementia lose the ability to conceal their subjective identity or their condition prevents them from playing a different role, the everyday life of an individual with dementia will be stigmatised through the process of labelling. Although the later stages of dementia can be distressing, the sole option regarding the welfare of individuals is left to the family, which the patient depends on.

Applying Habermas's (1984) theory would suggest that, in contrast, the system (using power) will take the view that the condition can only be managed through medical dependence. Giving power to healthcare professionals (a component of the system-operated health setting) colonises the lifeworld of people using dementia services, through economically-driven health policies (e.g. five-minute GP appointments). This limits opportunities for communicative action to occur between healthcare professionals and people with dementia,

or for the best resources to be made available to the individual. This distorted pattern of communication in a person's lifeworld allows healthcare professionals to maintain their power by dominating communication and imposing medical interventions. This in turn creates medical dependence in the everyday lives of people with dementia (see Chapter 2) and generates profits for pharmaceutical companies. Mishler (1984) draws on Habermas's theory of communicative action to suggest that despite healthcare professionals' good intentions and a willingness to help, they do not realise they are a part of the system. The system imposes expectations which they indirectly comply with, to meet the system's needs (e.g. the "five minutes per patient" rule (Mishler, 1984, pg. 274)).

4.4. Conclusion

The theoretical framework adopted by this study has been comprehensively discussed here. Habermas' theory of communicative action and Goffman's theory of stigma provide a way to better understand the focus of this research.

This research is concerned with the participants' subjective lifeworld experience of dementia. Influenced by the Habermas analytical approach, the study adopts the use of in-depth interviews to explore participants' subjective lifeworld experience and understanding of dementia, using prompts and follow-up questions to probe participants' subjective views. The approach encompasses the direct experiences, activities, and contacts which make up the participants' world, to establish the reality of what the participant was saying.

Chapter 5: Methodology

The purpose of this chapter is to describe the research methodology and methods used in this research study. Firstly, I outline and discuss the theoretical philosophical assumptions and research paradigm underlying this research. As a paradigm includes a distinct worldview and makes assumptions about types of knowledge, it informs the methods of investigation which guided the research. An explanation of the philosophical assumptions underlying this research explains the rationale for adopting a social constructivist's paradigm.

I describe the qualitative methodological framework adopted in this research. Building on the discussion in Chapter 1, I explain how a qualitative methodological framework can be applied to a research project such as this, describing the rationale for adopting a qualitative approach. Lastly, I explain how the qualitative data was collected, followed by an examination of the data analysis, rigour and quality, and the ethical issues addressed in this research.

5.1. Theoretical assumptions and research paradigm

Various ontological, epistemological and methodological assumptions underpinned the research objectives, and these can be understood through the concept of a paradigm. Bryman (2004) defines a paradigm as a set of beliefs or a worldview that informs a researcher from a distinct discipline about which phenomena to study, how the research should be conducted and how to explain the research findings. Denzin and Lincoln (2005) and Guba (1990) have suggested that paradigms differ in terms of their worldview and are based on different assumptions about the nature of reality (ontology) and the type of knowledge (epistemology) that can be obtained. The type of paradigm a researcher chooses to understand a research

topic demonstrates his/her assumptions about the nature of reality and knowledge and guides the direction of the research.

The choice of paradigm was thus informed by the qualitative research design. This means that neither positivism nor a post-positivism paradigm could be adopted because these would have been based on an objective worldview. As Table 5.1 indicates (below), different paradigms view the world from different perspectives: ontologically, epistemologically and methodologically. The social constructivism paradigm is based on the relativist assumption that there is no shared social reality but instead there are many different constructions of reality which can be captured by understanding an individual's subjective worldview (Ormston et al., 2014).

I chose the social constructivism paradigm for my study because I wished to explore subjective experiences and knowledge of dementia in the South Asian community. A social constructivism paradigm - defined as a single paradigm, which enables subjective philosophical assumptions and methodology to be adopted (Ormston et al., 2014)- was ideal for this study. The social constructivism paradigm is described in the literature as a sensible and realistic approach to research that aims to understand human experience, rather than formulate a hypothesis- the ontological position of naïve realism. Naïve realism implies that reality can be observed directly and accurately (Madill et al, 2000). A variation of naïve realism is critical realism, which assumes that the interface between the natural and social worlds can only be known approximately (Fletcher, 2016).

Table 5.1: The ontology, epistemology and methods of the four paradigms of inquiry (adapted from Tashakkori and Teddlie, 1998, p.23)

	Ontology	Epistemology	Methods
Positivism	Naïve realism	Objective worldview – hypothesis testing	Quantitative
Post-positivism	Critical realism	Objective worldview – use of natural settings	Essentially quantitative
Social Constructivism	Relativism	Subjective worldview	Qualitative

The social constructivism paradigm was adopted because it enabled me to understand what was happening in individual’s lives and how knowledge could be developed through an understanding of their experiences. This paradigm focuses on understanding how human beings interpret the social world rather than relying on direct observations as suggested by positivists and post- positivists (Murphy et al., 1998).

It therefore rejects the assumptions underlying the objective positivist and post-positivism paradigms; emphasising instead the importance of understanding human experiences. Constructivists argue that individuals construct their own reality (Ormston et al., 2014). Therefore, reality can never be accurately captured. (Guba and Lincoln, 1994). This paradigm thus gives primacy to the lived experiences of individuals. Constructivism adopts an inductive approach (qualitative) to research that contrasts with hypothesis testing and deductive reasoning (quantitative). Constructivism also argues that theories may influence the ideas and assumptions of the researchers. This research therefore adopts the inductive approach of grounded theory, in that the research does not try to fit the data into a pre-

determined theory but instead adopt a theory that fits best with the data (this will be discussed in more detail in section 5.3.6). The constructivist approach also implies that researchers become engaged with the research and cannot simply observe without influencing the phenomena under investigation.

I believe there are objective data recorded in situations and, in such cases, quantitative research methods are the correct approach to use, for example when examining diagnostic rates. This is essentially a positivist/post-positivist approach. However, for this thesis and its research objectives, I adopted the constructivist position. Nevertheless, I acknowledge the value of alternative approaches.

The ontological position adopted, which guided me in this thesis is that there is no external reality. Instead, reality is an interaction between the inner world of the individual's and their beliefs and understandings and the outer social world they inhabit. These are socially constructed and thus I can only understand the world by tapping into the experiences of others. In this sense there is no collective or shared understanding, and thus I adopted a relativist approach. The epistemological position I took for this thesis was an approach which fits within constructivism, in that I adopted a subjective approach to gain an in-depth comprehensive understanding of the factors influencing those seeking help for dementia and accessing memory services. This influenced my choice of methodology for the current research. This is discussed in more detail in the next section, which focuses more directly on the qualitative methodological approach.

5.2 Qualitative methodological approach

The qualitative methodological approach entails the adoption of an exploratory approach, enabling the researcher to gain an understanding of the underlying reasoning, beliefs and motivations of individuals (Denzin and Lincoln, 2011). This positions the qualitative methodological approach within a social constructivism paradigm, which seeks to explore thoughts and beliefs relating to the research topic (Ormston et al., 2014).

The nature of qualitative research has been debated at length for many years and no unified position has been agreed upon (Ormston et al., 2014). Ormston and colleagues argue that this is because researchers often take different approaches to qualitative research based on different beliefs about the social world and the purposes and aims of qualitative research. Some adopt a naturalistic and interpretative approach, exploring phenomena from an individual's point of view (Flick, 2009). Qualitative methodology also employs many different methods of data collection including interviews, field notes, photographs and recordings (Denzin and Lincoln, 2011, Ormston et al., 2014).

However, as Denzin noted, there are no universally agreed upon procedures or methods for eliciting data (Denzin, 2009). Qualitative research questions usually address the 'how and why' while quantitative research usually considers 'how many' (Murphy et al., 1998). Qualitative research is also often described as providing rich data from which theories can be derived and generated rather than using a hypothesis to dictate the research and the data analysis (Silverman, 2011).

A qualitative methodological framework therefore enabled me to design and integrate qualitative approaches, practices and methods to help me understand the experiences and

attitudes of people with dementia in the South Asian community (Ormston et al., 2014). In so doing, I addressed questions about the what, how or why of this phenomenon rather than how many or how much. (Murphy et al., 1998).

To collect the data, I used semi-structured interviews and focus groups (this is discussed in more detail in section 5.3). This provided rich, in-depth, and detailed subjective descriptions and an understanding of individuals' experience of dementia. Thus, to understand participants' experiences fully, direct quotes were analysed rather than numerical measures (Silverman, 2011).

The focus of the research was therefore to provide an in-depth, exploratory understanding of a South Asian community's access to dementia services. The steps taken to collect the data are described in more detail in the next section.

5.3 The South Asian community's experience and attitudes to dementia

This qualitative thesis has been designed to gaining an in-depth comprehensive understanding of the factors influencing those in the targeted South Asian community who have sought help for dementia and accessed memory services. This was achieved for this phase using semi-structured interviews and focus groups methods. This section firstly discusses the rationale for adopting the data collection methods. Secondly, a detailed description is given of the steps taken when using these two approaches (see Figure 5.1), in order to achieve the overarching qualitative aim already described.

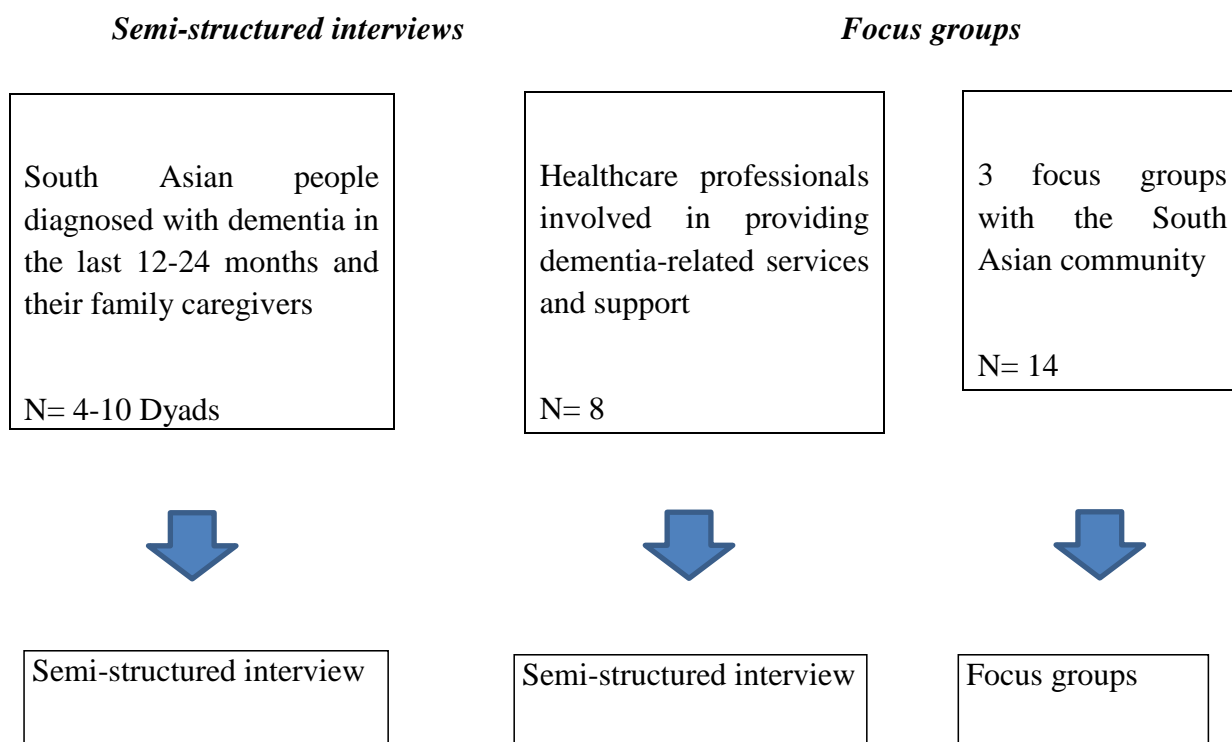


Figure 5.1: Data collection methods

5.3.1 Semi-structured interviews

The first data-collection step for this phase was semi-structured interviews to gain an in-depth understanding of the South Asian community’s experience of accessing dementia services from the perspective of people with dementia, their family members, and the healthcare professionals who provide dementia diagnostic services in Blackburn with Darwen. Hannabuss (1996) has suggested that this popular data-collection method improves researchers’ understanding of the topic, allowing them to use questions which prompt further exploration of new information from the participants. A semi-structured interview method was chosen as being more appropriate than other methods because it allowed me to understand individuals’ experiences while exploring the reasons underlying the choices made by people with dementia and their family members. This helped identify possible barriers the South Asian population may experience when accessing dementia diagnostic services. Other

methods, such as case study or participants' observations, would demonstrate the South Asian community's lived experience of dementia, but would not help in understanding the reasons behind the choices which shape their experience of dementia.

Semi-structured interviews are a good compromise between unstructured interviews and questionnaires. Unstructured interviews would have been too loose, as they do not provide topic guidance to ensure that the researcher asks the same questions in a similar order in order to compare participant responses. Questionnaires would have been too rigid, as they do not allow the researcher to further explore what participants are saying or emerging themes which could provide new useful information on the research topic. In contrast to open interviews, the semi-structured format provides some direction to interviews by allowing the researcher to ask prompt questions to guide the enquiry, to ensure that all the topics to be addressed are discussed during the interviews (Mertens, 2010).

The strength of the semi-structured interviews approach here was that it enabled people with dementia, their family caregivers and healthcare professionals to add their own experience of dementia, generating information in a conversational manner to formulate the research data. The conversational and situational nature of semi-structured interviews, however, runs the risk of failing to note salient information about participants' experiences of dementia. To counteract this, I had to be proactive by practising active listening and asking for clarification, exploring relevant topics in detail where needed (see section 5.3.3: a detailed account of data-collection using semi-structured interviews).

5.3.2 Focus groups

The second step of data-collection for this phase was to adopt a method which would allow me to understand the South Asian community's knowledge of and attitudes towards dementia. I chose a focus-group approach over other qualitative methods because it would allow me to explore the opinions, beliefs, perceptions, knowledge and attitudes of a large group of people towards the research topic (Greenbaum, 2000).

A focus group allowed me to ask questions in an interactive setting where the participants would be free to discuss and share their thoughts within the group, resulting in an in-depth discourse on the South Asian community's knowledge of, and attitudes towards, dementia (Greenbaum, 2000). The strength of this approach over other methods, such as survey data, was that it allowed participants to exchange their knowledge and views of dementia in an open-group setting, and exchange ideas (and perhaps learn from) each other. The focus-group experience should be enlightening for both the participants and the researcher (Harding, 2013).

Although similar to group interviews, focus groups depend on interactions between individuals in the group to answer the questions posed by the researcher (Morgan, 1997). In contrast, group interviews depend on the interaction between the researcher and each participant, with each individual answering the same question posed by the researcher, much like one-to-one interviews (Morgan, 1997). The focus-group approach has been chosen because it allows the participants in a group setting to come together and answer the questions. It can both provide a great insight into community knowledge of, and attitudes towards, dementia, and help the researcher understand participants' concerns and any

improvements they would like to see to local dementia services (see section 5.3.5: a detailed discussion about focus-group procedure and how focus groups are conducted).

In the next section I describe the sample, recruitment, data collection and data analysis process for **semi-structured interviews** with:

- people with dementia and their family caregivers, followed by
- Healthcare professionals.

This process is then described for **focus groups**, including the sampling, recruitment, data collection and data analysis.

5.3.3 Interviewing people with dementia and their family caregiver

As already stated, this research is based on the area of Blackburn with Darwen Borough, which has a higher than average number of people from the South Asian Indian and Pakistani community. The target population for this research is people from the South Asian Indian and Pakistani community living in Blackburn with Darwen Borough, from which a sample of four to ten families with experience of living with dementia was selected. This sample size was considered sufficient to allow a wide range of perspectives, which would produce representative data, since larger sample sizes may stifle the emergence of themes and issues (Bowling, 2009).

5.3.3.1 Sampling

The study sampling was informed by the research topic, which meant that I could not understand an individual's experience of having a dementia diagnosis if I included someone

with no prior experience of using or receiving a dementia diagnosis. I needed to find people with knowledge and experience of living with dementia, and chose a purposive sampling method to select people with dementia and their family caregivers, which allowed me to select participants, based on their knowledge and experience of the research topic (Sale, et al., 2002). This research aims to explore participants' experiences of receiving a dementia diagnosis. How were they diagnosed and why did they seek help at specific stages? What barriers did they experience? It was important to include people with experience of using dementia services, whilst also acknowledging that participants are not representative of everyone in the United Kingdom. Although random sampling provides a representative group and thus a generalisable result, considering the aim of this research, purposive sampling also allows for rich data to emerge, as it emphasises the inclusion of individuals with expertise based on experience (see Table 5.2).

Table 5.2: The inclusion and exclusion criteria for a person with dementia and their family caregiver

Inclusion	Exclusion
Over 18 years of age	Under 18 years of age
South Asian heritage: Indian or Pakistani	Not from the South Asian (Indian or Pakistani) community
Living in Blackburn with Darwen Borough	Not living in Blackburn with Darwen Borough
Dementia diagnosis within the previous 12-24 months or family caregiver who is directly involved in the day-to-day activities of the person with a dementia diagnosis given within the previous 12-24 months	Dementia diagnosis over 24 months ago or family caregiver of a person given a dementia diagnosis over 24 months ago
Capacity for providing consent to be included in the study	Lack of capacity for providing consent
Diagnosed with any type of dementia or the family caregiver of a person with any type of dementia	No dementia diagnosis
Ability to communicate in English and a range of South Asian Indian and Pakistani Languages: Urdu, Punjabi, Pashto, Sindhi, Gujarati, Hindi, Tamil, Telugu, Kannada, and Malayalam.	Ability to communicate in languages other than English and a range of South Asian languages: Urdu, Punjabi, Pashto, Sindhi, Gujarati, Hindi, Tamil, Telugu, Kannada, and Malayalam.
Male or female	

People with dementia or their family caregivers were not excluded because of their inability to speak English, or where English was not their first language. If a participant belongs to a South Asian community, it cannot be assumed that English will be his/her first language. Dementia is an illness mostly affecting people over the age of 65, so first-generation South Asian people may be living with dementia, for whom English may not be their native

language. They may have learnt English as a second language and since dementia is an illness which may affect an individual's language ability, it was not considered appropriate to exclude people based on their inability to communicate in English. In order to ensure that language was not a barrier, every participant was provided with the option of having a professional interpreter present, thereby giving people with dementia a voice and the opportunity to have their opinions heard. The healthcare professional ensured that people with dementia had capacity to consent under the Mental Health Act 2005 (cited in British Medical Association. (2007), as discussed in section 2.3.1 and 5.5.1.

The participants were initially to be recruited through the Memory Assessment Clinic in Burnley and Roman Road Health Centre under the Lancashire Care NHS Foundation Trust (LCFT). The recruitment sites were pragmatically selected, where staff were willing to take part in the research, as the service manager knew about the research and was familiar with the aim and recruitment process. Both sites had a reputation for delivering quality care and support to the South Asian community in the region.

5.3.3.2 Recruitment Procedure

Since this research involves people with dementia, it was assumed that not all participants with dementia would have the capacity to consent. The staff at the recruitment sites were asked to ensure that, before being approached for the study, potential participants who met the criteria set out by the research were also able to provide consent and were aware of their diagnosis. The potential participants who met the inclusion criteria would be provided with an information pack containing the advertisement flyer, the expression of interest form, a simplified participant's information sheet for people with dementia, a consent form for

people with dementia, a participant's information sheet and a consent form for the family caregiver, and a prepaid envelope to post the expression of interest form to the researcher.

Once potential participants had expressed an interest in the research and agreed to be approached by the researcher to further discuss the research, I arranged to contact the person nominated as the first point of contact on the expression of interest form completed by the person with dementia. At this stage, participants would be made aware that the person with dementia and his/her family caregiver could participate in a joint interview. If the person with dementia or his/her family caregiver expressed a wish to be interviewed separately, or where either the person with dementia or his/her family caregiver wanted to take part in the research and the other did not, this would then be made possible.

Participants were given the choice of when and where they wanted introductory meetings and interviews to take place, either at their home, at One Voice offices, at hired meeting-rooms in Blackburn or at Blackburn with Darwen Public Health Department's meeting room. During the introductory meeting, potential participants were briefed about the research project and provided with additional details about the study, its aims and what it intended to investigate, with information about how this might be helpful to the commissioning of services, and how their participation/experience as a person with dementia or as a caregiver would be useful to the research. I outlined details of the participant's information sheet and consent form, and ensured that participants understood the relevant information to make the decision about their participation. If potential interviewees had the capacity to provide consent and agreed to participate in the study, a non-recorded preparatory meeting was arranged to sign the consent form (see section 5.5.1 on Informed Consent).

Once consent was obtained from participants, they were requested to complete demographic forms, to provide insights into their demographic characteristics. At this stage, the researcher discussed with the person with dementia and his/her family caregiver whether he/she would prefer the interview to be conducted in English or in another language. If people wanted interviews to take place in a language other than English, I speak Urdu and Gujarati fluently. Where another South Asian language was spoken, they had the option to have a professional interpreter present, who would be expected to sign an interpreter confidentiality agreement.

5.3.3.3 Data Collection

Clearly, it may be difficult to achieve the aim without asking some sensitive questions. I chose a semi-structured interview method, as this method places emphasis, firstly, on developing a rapport with participants by asking more general questions, then, as rapport develops during interviews, I could ask more sensitive questions (see section 5.3.1: a detailed discussion of semi-structured interviewing methods).

Semi-structured interview procedure

As discussed earlier in Chapter 3, Bamford and Bruce (2000) suggested that the perspectives of family caregivers of people with dementia were used in evaluating outcome criteria for dementia care interventions and services, although the perspectives of people with dementia and those who speak on their behalf did not always necessarily correspond. In this research, a dyad of the person with dementia and their family caregivers was conducted using semi-structured interviews as a means of including alternative perspectives of the person with dementia and their family or carer. The dyads were chosen to enable the research to include two people with similar characteristics in a two-way dialogue. Applying this approach, I would ask a question and the people with dementia would be given the opportunity to share

their thoughts first, followed by their family caregivers sharing their opinions. This approach allowed me to observe whether there were similarities between the perceptions of the experience of dementia of those living with dementia and those of their family caregivers.

Interviews began with general questions; as rapport developed between the interviewer and interviewees, I was able to address more sensitive questions (see Appendix 5 for interview questions with PwD and their family caregivers). The presentation of the questions and the time and attention given to each question depended on participants' own concerns and interests (Robson, 2002). During interviews, participants with dementia and their family caregivers were viewed as experts, so I drew little inference from what I already know about the South Asian population's experience of dementia. I endeavoured to understand the participants' experiences by using open-ended and non-directive interview questions and actively followed the experiences shared by participants, probing areas of interest to the research when they arose (Willig, 2001).

The semi-structured interview method places emphasis on perceiving participants as experts, thus participants' thoughts, concerns and interests about the research topic guided the interview forward (Robson, 2002). The challenge for the researcher using this method is to ensure that interviews remain focused on the relevant research topic. During interviews, I ensured that interviewees remained focused on the relevant topic. The interviews focused on the participants' experiences of dementia, their individual journeys in finding out that they had dementia, how they had coped with the diagnosis, their experiences of dementia services, barriers they had faced which may have prevented them from seeking help or accessing appropriate services (even after receiving their diagnosis), their understanding of dementia, their cultural attitudes towards dementia and their expectations of services. The interviews lasted forty to sixty minutes, depending on the length and depth of the stories participants

wished to share. If meetings lasted longer than the projected period of time, participants were offered the opportunity to have a break.

Following interviews, participants were given the opportunity to ask me any questions or discuss issues raised in the interview. At this stage, participants were also asked whether on completion of the study they wanted to be sent a summary.

5.3.4 Healthcare Professionals Involved in Providing Dementia Services and Care Provision

During the setting up of the research project a consultation exercise was conducted with healthcare professionals working in Blackburn with Darwen (BwD) who were involved in dementia diagnosis pathways – found by using opportunity sampling methods - about their views on South Asian individuals’ and families’ experience of dementia and access to dementia services. Responses were sought from staff at the Alzheimer’s Society, the memory assessment clinic, GPs and support workers from Age UK.

Healthcare professionals who responded to the initial call for participation were invited to an informal discussion to scope the extent, range and nature of the review question. The six healthcare professionals who took part in the consultation exercise were two dementia advisors, two consultant psychiatrists, a GP and a support worker. The key concept which emerged from the consultation exercise arose from the healthcare professionals’ observation was that visibility/access to dementia diagnostic services is limited across all South Asian sub-groups. This indicated the importance of including the perspectives of persons with dementia about the barriers which may have prevented them from seeking help or accessing appropriate services, the subsequent burden of care on family caregivers, the South Asian population’s lack of understanding of dementia, and their expectations of the available

services. These findings were further explored in semi-structured interviews and focus groups.

This part of the qualitative research aimed to understand healthcare professionals' experiences of supporting people with dementia from the South Asian community living in Blackburn with Darwen Borough. The target population would evidently be healthcare professionals involved in providing dementia services to residents living in Blackburn with Darwen Borough. A sample was selected of six to eight healthcare professionals experienced in providing dementia services to members of the South Asian Indian and Pakistani community living in Blackburn with Darwen Borough. The sample size was sufficient as this research included the perspectives of healthcare professionals from a wide variety of settings, providing comprehensive and representative data, allowing a range of themes to emerge.

5.3.4.1 Sampling

The sampling method for this part of the research was informed by the research topic. It was therefore evident that I could not include healthcare professionals who had no experience of providing dementia services to the Blackburn with Darwen Borough population, such as cardiologists or Consultant Psychiatrists from Manchester. It was crucial to recruit healthcare professionals who had a connection with the Blackburn with Darwen Borough population and who could give insights into the experience of the Borough's South Asian community living with dementia. A purposive sampling method was chosen to select individual healthcare professionals with knowledge and expertise of the research topic (Sale et al., 2002). It was necessary to have inclusion criteria to recruit healthcare professionals with characteristics relevant to the research topic (see Table 5.3).

Table 5.3: The inclusion and exclusion criteria for healthcare professionals involved in dementia diagnosis

Inclusion	Exclusion
Involved in providing dementia services	Not involved in providing dementia services
Experience of working with people from the South Asian Indian and Pakistani community with dementia	No experience of working with people from the South Asian Indian and Pakistani community with dementia
Work with Blackburn with Darwen Borough population	Do not provide services to Blackburn with Darwen Borough population
Male or female	

Individual healthcare professionals were selected from a variety of healthcare roles: GPs, psychologists, psychiatrists, nurses, carers, social and support workers, neurologists and clinicians involved in dementia-related services. Undoubtedly, including healthcare professionals' perspectives from a wide variety of settings would enable me to put forward beliefs and attitudes of healthcare professionals from different disciplines of dementia services, enhancing the exchange of discourse between interviewer and interviewees, resulting in more comprehensive data.

Healthcare professionals were recruited from the National Health Service, social care services and other charitable organisations in Blackburn with Darwen Borough. Healthcare professionals from these sites willing to take part were pragmatically recruited, and services managers were aware of the research aim and mindful of their reputation in providing dementia-related care and support to the South Asian community in the region.

5.3.4.2 Recruitment Procedure

Since this research topic involves including the perspectives of healthcare professionals from various dementia settings in Blackburn with Darwen Borough, clearly healthcare

professionals from a wide range of healthcare roles need to be included in the study. With help from my supervision team at Lancaster University and at Blackburn with Darwen Borough Council Public Health Department and Age UK Blackburn, a list was compiled of eight potential participants from the recruitment sites who met the inclusion criteria.

All the healthcare professionals on the list were sent an introductory email containing a participant's information sheet and consent form. If healthcare professionals expressed interest in taking part in the research by replying to the email, they were asked for potential dates and times which best suited to them.

At the interviews, I briefly explained the research, its aims and what it intended to investigate, how this might be helpful to commissioning services, and how their participation would be useful to the research. Individuals still willing to take part were asked to sign a consent form confirming their agreement to take part in the research.

5.3.4.3 Data Collection

This research hopes to gain a comprehensive understanding of healthcare professionals' experiences of providing dementia services to the South Asian Indian and Pakistani community. I needed to choose a data collection method which would allow me to make a detailed account of healthcare professionals' experiences, informing the research objective. Clearly it would be inappropriate to adopt a method which did not allow me to explore participants' experiences by asking for clarification on issues or ideas introduced during individual interviews, and did not allow an element of flexibility for participants to tell stories or give examples (Mertens, 2010). I therefore chose a semi-structured interview method for data-collection, which allowed flexibility for participants to share their ideas about the South

Asian community's experience of dementia, giving examples by storytelling and suggesting ways to improve dementia services for the South Asian community living in Blackburn with Darwen Borough (see section 5.3.1 for a detailed discussion of semi-structured interview methods). In contrast to other approaches, this method gave me the opportunity and flexibility to reflect on what was said and ask participants to elaborate on any ideas or issues mentioned, whilst putting forward the ideas, beliefs and attitudes of healthcare professionals from other disciplines of dementia services (Mertens, 2010). This undoubtedly added to the richness of the narrative obtained from each individual interview, providing rich data.

The strength of this method compared with other methods, such as unstructured interviews, is that it allows the researcher to ensure that all topics intended to be covered are answered, while allowing healthcare professionals to express and add their own ideas. It is widely acknowledged that this conversational aspect of the data-collection is the strength of this approach, with the caveat that the researcher must be vigilant to pick up new or emerging ideas which may have been mentioned earlier by other healthcare professionals (see section 5.3.1: semi-structured interviews).

Semi-structured interview procedure

The interview procedure is informed by the data-collection method – the interview started with more general questions, such as eliciting how often people from the South Asian Indian and Pakistani community present with memory problems (see Appendix 6 for interview questions with HCP). I then explored the stages at which the South Asian Indian and Pakistani community present themselves. As the interview progressed I introduced more sensitive questions, such as determining how people's personal experiences shape professionals' approaches to working with people with dementia (Robson, 2002). As already discussed, the strength of semi-structured interviews is that they gave healthcare professional

participants the flexibility to share their thoughts and concerns about the South Asian community experience of dementia, so the time, attention and presentation of the questions varied depending on the healthcare professionals' own concerns and interests (Robson, 2002).

The semi-structured interview method places emphasis on perceiving participants as experts, so healthcare professionals' thoughts, concerns and interests about the research topic guided the interview forward (Robson, 2002). The challenge for a researcher using this method is to ensure that interviews remain focused on the relevant research topic, so an effort was made to ensure that interviews focused on the healthcare professionals' understanding of how and when the South Asian Indian and Pakistani community present to dementia services, the barriers and challenges they believed that community may experience (pre- and post-diagnostic barriers), community knowledge and understanding of dementia, difficulties and barriers experienced by them when working with this community, how their personal experiences shaped their professional approaches to working with people with dementia from this community and ways to improve dementia services for them. Few references were made to the interview schedule, but before concluding an interview, I ensured that all the topics in the interview schedule had been discussed.

Throughout the interviews, I actively followed experiences shared by healthcare professionals, while using open-ended and non-directive interview questions to explore any relevant issues mentioned, and probing any emerging ideas which may have also been mentioned previously by another healthcare professional (Willig, 2001). Although it may be useful to understand healthcare professionals' thoughts and opinions on a relevant topic previously raised by another healthcare professional, clearly each participant is an individual with different experiences and perceptions of supporting people with dementia from the

South Asian community (Robson, 2002). I did not draw conclusions from what was said in a previous interview by another healthcare professional, but rather tried to understand each individual healthcare professionals' experiences of supporting people with dementia from the South Asian community through the stories they told me.

Interviews with each healthcare professional lasted forty-five to sixty minutes, depending on the length and depth of the stories the healthcare professional wished to share.

5.3.5 The South Asian Indian and Pakistani community's awareness of dementia

This part of the research aimed to understand the knowledge of, and attitudes towards, dementia in a clearly identified community: the people from South Asian Indian and Pakistani community living in Blackburn with Darwen Borough. A total sample of thirteen people from the community was selected for focus groups, with a subset of four to five participants in each group. The sample size was large enough to provide a good compromise between a smaller and a larger group. Too small a group would not allow the research to include a wider perspective, so the findings could not be applied to the general target population; too large a group would not allow the research to explore emerging themes and issues (Bowling, 2009).

5.3.5.1 Sampling

The sampling method here was informed by the research objective: to understand the knowledge of and attitude towards dementia among members of the South Asian Indian and Pakistani population, with no prior diagnosis of dementia. I could not include people who already had first-hand experience of the research topic – such as a person living with

dementia. If I were to include people with dementia or their caregivers (family or professional), their knowledge of dementia would be based on their own personal experience, and may not accurately reflect South Asian Indian and Pakistani knowledge of, and attitudes towards, dementia – knowledge and attitudes which could act as a barrier to identifying dementia and accessing dementia services. Accordingly, a purposive sampling method was used to select a subset from the target population who had no prior diagnosis or experience of dementia. I therefore needed inclusion and exclusion criteria to ensure that participants from the South Asian Indian and Pakistani community had the required characteristics to achieve the research objective (see Table 5.4).

Table 5.4: Inclusion and exclusion criteria for South Asian Indian and Pakistani community

Inclusion	Exclusion
Over 18 years of age	Under 18 years of age
South Asian heritage: Indian or Pakistani	Not from the South Asian (Indian or Pakistani) community
Living in Blackburn with Darwen Borough	Not living in Blackburn with Darwen Borough
Ability to communicate in English	Only able to communicate in a language other than English
Capacity to consent	Lack of capacity to provide consent
No prior diagnosis or experience of dementia as an individual or as a family member.	Diagnosis or experience of dementia.
Male or female	

In each group, the research required participants from the Indian and Pakistani community who are heterogeneous in their characteristics i.e. different genders, ages, job roles, to allow

diverse perceptions and experiences to be included and produce comprehensive data (Morgan 1988).

Individuals from the Indian and Pakistani community were recruited through 'One Voice', a charitable organisation based in Blackburn with Darwen, selected because of its willingness to be involved in the research project and their good reputation for working closely with the South Asian community of Blackburn with Darwen.

5.3.5.2 Recruitment

Participants needed to meet certain criteria in order to be included in this part of the research. The staff from One Voice assessed whether potential participants met the inclusion criteria. Those who met the criteria were given an information pack containing an advertisement flyer, an expression-of-interest form, a participant information sheet for the focus group, a consent form and a prepaid envelope to return the expression-of-interest form.

Potential participants interested in taking part in the focus group could opt to complete the expression-of-interest form included in the information pack and return it to the researcher at the address provided, or could contact the researcher by phone or email, expressing their interest in participating in the research. Once a participant had expressed interest in taking part in a focus group, the researcher phoned the potential participant, keeping a log of all calls made. I discussed the project with each potential participant in detail, giving them an opportunity to discuss the project and ask any questions they might have. If they still wished to be involved in the focus group, they were sent a letter confirming the focus group date, time and place. Participants were asked either to post the signed consent form to the researcher or to bring it to the focus group.

5.3.5.3 Data collection

Since this research aims to gain an understanding of South Asian Indian and Pakistani community knowledge of, and attitudes towards, dementia, I needed to adopt a data-collection method which would allow me to understand multiple perspectives on the research topic. The focus-group method was chosen because it allows insight into shared understanding of dementia in the South Asian Indian and Pakistani community of Blackburn with Darwen.

Focus-group procedure

Before starting a focus-group discussion, it is advisable to do an icebreaker activity, because, unlike semi-structured interviews, focus groups rely on group interaction. It is important for the group to feel free and comfortable to share their thoughts in a group setting. I started the icebreaker activity by giving my name and position and a brief description of my hobbies; then, starting from the right, asked each participant to do likewise.

I then initiated the discussion with the question: *What is dementia?*- a non-restricted, open question intended to generate unstructured discussion and debate among the group (see Appendix 7 for focus group questions). My role was to listen actively, and pick up on points relevant to the research topic, which were then explored using further prompts.

I was careful to ensure that all participants in the group contributed. A difficulty with focus groups is that some participants hold back their thoughts and give consensus to group thinking (Harding, 2013). To avoid this, I asked each participant to share their thoughts on each question, changing the order of who answers each question first to ensure that the same person is not the first one answering every time. I also asked each participant to explain the thoughts behind their answer – i.e. why and how they had reached this conclusion – asking

for as many examples as possible. Where participants seemed to contradict their previous answer in order to conform to the group, I asked why they had changed their mind (Harding, 2013).

I had to be careful not to give too much approval or favour to those points of view which happened to coincide with my point of view. Where possible, I facilitated and encouraged the discussion, asking for clarification and examples in order to understand the wide range of perspectives and meanings attached to the question under discussion (Kreuger 1988). Through forming a trusting relationship with the participants, they opened up and shared their thoughts with me and with each other. This was achieved by actively listening to what was said, showing respect for the group and placing importance on what each participant contributed. The challenge for me as the moderator was to keep the focus group from drifting away from the research topic, by introducing prompts to steer the conversation back to the research topic.

Each focus group lasted about an hour, depending on the length of discussion and the stories the participants had to share with the group. If the session lasted longer than an hour, the participants were offered an opportunity to have a break. After each focus group the participants were asked if they had any questions or would like to discuss any issues raised in the group. They were thanked for taking the time to participate in the focus group and told that their participation was much appreciated.

5.3.6 Qualitative Data Analysis

Adopting the data-collection approach of using qualitative semi-structured interviews and focus groups has resulted in large datasets. A major criticism of qualitative research is that it

produces large sets of inadequately analysed data (Murphy, et al., 1998). I needed to choose an analytical approach/framework which provided guidance on how to interpret large amounts of qualitative data, and ensure that the data was thoroughly analysed. A thematic analysis method was therefore chosen over other methods because, as Guest and MacQueen (2012) noted, it emphasises an understanding of participants' subjective experiences of dementia by obtaining a comprehensive description by allowing them to express their experiences freely and in their own words.

The thematic analysis approach acknowledges that the analysis process is fundamental to making sense of participants' experiences. In order to ensure that the data is appropriately analysed, I needed to directly enter participants' experiences (Braun and Clark, 2006), by putting aside my own subjective understanding and experience and try to conceptualise and interpret the data from participants' subjective points of view. While acknowledging that this can be difficult to achieve, since as an individual I have my own perceptions, ideas and values, as a researcher it is important to put aside these perspectives through self-reflection and critical thinking, whilst systematically analysing the data through coding (Braun and Clark, 2006).

Coding is the preliminary process for identifying explicit and implicit patterns (themes) within a raw dataset, which are subsequently compared to discover recurring patterns, which in turn help to establish relationships between a range of themes (Guest and MacQueen, 2012). Thematic analysis is regarded as an effective data-analysis approach, as it captures details pertaining to meanings within text, such that the data supports the interpretation of themes (Guest, 2012). The advantage of the analytical approach is that it allows researchers to focus their responsibilities on theoretical and epistemological aspects of data. Thematic

data-analysis was chosen for the research because of its flexible open-ended nature and its correspondence with pragmatic research philosophies.

A thematic analysis approach enables the identification of new themes, which is informed by the theoretical perspective being drawn on in the thesis: following an inductive approach. The current research adopted an inductive approach to data-analysis: the coding process does not aim to fit the dataset into a pre-determined model or theory, thus allowing strong relationships to develop between the themes and the dataset (Boyatzis, 1998). Rather than letting a theoretical agenda drive the data-analysis process, the dataset drives the analytical process.

This approach suggests that participants' experiences of dementia may not be readily available, but can nonetheless be understood by constantly engaging with (reading) the transcript, allowing the researcher to analyse the narrative, in which codes (descriptions) are generated to help identify themes (interpretation), which are in turn compared and contrasted to help build on a theory. In order to achieve this, systematic guidelines on the phases of thematic analysis must be followed.

5.3.6.1 Process of Thematic Analysis

The transcript from semi-structured interviews will be analysed using the following guidelines in ATLAS.ti, as proposed by Braun and Clark (2006).

Phases of Analysis	Process	Self-reflection Journal
1. Making myself familiar with the data	I conducted each interview and once they had all been transcribed, they were read individually. At this stage, I made initial self-reflective and individual notes on each interview, noting my initial thoughts and comments in the right-hand margin. To work closely with the text, I repeatedly read the transcripts; information of interest was highlighted and notes were made in the left-hand margin. Attention was paid to any preliminary patterns (codes) generated by the transcripts	<ul style="list-style-type: none"> • What is each code? • What do codes mean? • The source, page and line number of each code
2. Initial codes were generated	Initial codes considered to be similar were reduced and merged to generate new codes. This exercise was repeated until it was deemed that the generated codes specifically and meaningfully reflected the interview data. Consistency and validity were obtained by sharing the anonymised data with my supervision team and an associated PhD student	<ul style="list-style-type: none"> • The reason for combining codes: why and how are they similar? • How are codes connected? • What question am I asking of the transcript data?

3. Identifying themes	The codes were categorised into themes and/or sub-themes, by writing them down on Post-it notes. These were organised and re-organised until key themes which accurately represented the data were identified through thematic mapping. Thus, to obtain inter-coder reliability, the thematic mapping was shared with my supervision team	<ul style="list-style-type: none"> • How were themes generated from the codes? • How were codes made sense of, to inform themes? • What do themes mean?
4. Themes were reviewed	Potential themes were reviewed and merged by re-reading specific information from transcripts from which codes and themes had been generated. To check if they correctly represented the meaning in the data, the extent to how they supported or fit with the research aims and theoretical framework was reviewed. If codes and themes did not support this, the thematic map was rearranged until an adequate map was created which recognised the themes reflecting an accurate account of the data	<ul style="list-style-type: none"> • How were themes formulated? • How do themes fit alongside codes? • What further analysis is suggested by data?
5. Naming and describing themes	The themes included in the final analysis were clarified and described at this stage, with an explanation about what each theme told us and how this related to the research topic, whilst using quotes from interview transcripts to support this. In thematic analysis, the researcher is expected to go beyond words in an attempt to explain underlying meanings of data and to correctly tell the story of what the data means, in order to truly make sense of the data and to accurately represent participants' stories (Glaser, 1965; Braun and Clark, 2006)	<ul style="list-style-type: none"> • Explaining each theme in a few sentences

<p>6. Writing the report</p>	<p>The themes which I felt provided a meaningful understanding of the data was identified and highlighted using direct quotes from the data (see Chapter 6). Due to limited space, not all quotes from the data could be included in the thesis.</p>	<ul style="list-style-type: none"> • Why were the chosen themes more effective in helping to understand what was happening and in making valuable contributions?
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This process of thematic analysis was followed in ATLAS.ti version 7 using the following steps.

Firstly, the interview and focus group transcripts were uploaded as primary documents on to Atlas.ti. I began the analytic process by auto-coding the transcript to who is speaking i.e. interviewer or family member. I then began to familiarise myself with the data by closely reading the transcripts and annotating any piece of text deemed interesting and relevant to the research by creating a free quotation. This process was conducted throughout the transcript data and repeated over the course of several days and weeks in case I observed something different at a later point in time. This was repeated until there was no discrepancy in the quotations which were created and I felt confident that I did not see any new ideas and insight emerging. Alongside creating quotations in ATLAS.ti, I kept journal memos of what I did, reminding myself what I needed to do next and, most importantly, of any emerging ideas for codes.

Once I started to note and comment on similar things several times, I collected the quotations and created initial open codes. Similar to creating quotations, data were coded repeatedly over time and codes analysed using a code co-occurrence explorer and query tool to categorise the codes further into themes (super codes) or sub-themes (compound codes); e.g. for South Asian cultural perspectives of dementia, the super code was stigmatising, under which *Bezati ho jayegi* [dishonour] and denial were compound open codes (see Appendix 6 for the codes). The themes were reviewed using analytic tools, and themes were renamed and merged; key themes which accurately represented the data were identified through thematic mapping and discussion with my supervision team. Each theme was given an operational definition and an explanation of when the code would be used.

Themes which provided a meaningful understanding of the research aims and objectives were identified and are reported in Chapters 6, 7 and 8.

5.4 Rigour and quality

This research adopts O’Cathain (2010) comprehensive framework which can be used to assess the quality of research by first describing varying conceptualisations of the research quality, exploring the gaps in the conceptualisations and contested areas, and testing the quality framework through its application to qualitative study. The author questions the methods through which the quality of the studies is assessed, and provides a comprehensive approach constituting eight domains as proposed by O’Cathain (2010): Planning Quality, Design Quality, Data Quality, Interpretive Rigour, Inference Transferability, Reporting Quality, Synthesisability, and Utility. Each of the eight domains is comprehensive. For instance, the well-researched interpretive rigour domain entails consistency of interpretation and theory, interpretive agreement, correspondence and distinctiveness, and integrative efficacy (Teddlie and Tashakkori 2009). In a previous study by O’Cathain et al., (2008) the authors argue that a good study should be clear in justifying the suitability of the approach, offer a transparent account of the design, give suitable sampling data-gathering and analysis of each component. The reporting quality domain entails transparency in reporting, and as O’Cathain et al., (2008) assert, a good study must describe the justification for using the approach to the research question, offer an explanation of design in relation to purpose, the methods sequence, give a description of each method in relation to sampling, collection of data and analysis, explain any form of integration in terms of its occurrence and participants, discuss the limitations of the method, and give insights achieved from the study.

This research used O’Cathain’s (2010) comprehensive quality framework for assessing the rigour and quality of research, which helps ensure that the study is responsible for rigour and quality in each of the eight domains (see Table 5.5: how the eight domains of quality framework are met through the study). The domains represent the various stages in the study’s design, dissemination and implementation. The quality from each of the above domains is assessed and all the issues are analysed from all the listed stages which are relevant to all the issues presented. In research, the literature review explains the domains; during the description of the domains, the issues in the various stages are covered, giving clarity to the research being conducted. O’Cathain et al. (2008) reveals that guidelines were developed after reviewing research into the health service. The research guidelines which were used ensured that most aspects of the research were described. Thus, in order to ensure that most of the parts of a study are covered, the universal guidelines must be considered. The aspects include:

- Describing each method
- Describing the design of the study including both methods and aims
- Describing the methods chosen as the design of the study
- Describing the limitations of methods used
- Describing the insights.

Using O’Cathain’s (2010) framework helped to ensure that the research took into consideration quality and rigour in the domains present in this study (see Table 5.5).

Table 5.5: How the 8 Domains of a Quality Framework were Met Through the Study

Domain			
Planning	Quality of planning	<ol style="list-style-type: none"> 1. The literature was comprehensively and critically reviewed 2. There was transparency of the rationale 3. Transparency in planning 4. Viability or practicability 	<ol style="list-style-type: none"> 1. A chapter of literature review was included in the thesis 2. The research design section offered an explanation 3. The paper provided paradigm, design, collection of data and a dissemination plan. 4. The study was feasible in relation to time, finances and personnel
Design	Quality of design	<ol style="list-style-type: none"> 1. Transparency of design 2. Suitability of design 3. Strength of design 4. Rigour of the design 	<ol style="list-style-type: none"> 1. A clear explanation of the research design 2. The research design section gave an explanation of its suitability 3. All the strengths and weaknesses of the methods was discussed in each methods section 4. The methods are inflexible as they strictly followed the study design. The qualitative data were collected and analysed separately prior to integration
Data	Quality of data	<ol style="list-style-type: none"> 1. Transparency in data collection 2. Suitability of the collection method 3. Strength of the collected data 4. Data rigour 	<ol style="list-style-type: none"> 1. All methods were explained in detail, including their significance and role, data collection, study sample and size 2. the suitability of the method and data collected were explained 3. All methods were implemented with thoroughness and fidelity. All forms of data cleaning were accounted for 3. Sampling and sample size explanations were outlined. 4. Data analysis was appropriate to guarantee answering every research question
Interpretation	Interpretive Rigour	<ol style="list-style-type: none"> 1. Transparency of interpretation 2. Consistency of interpretation 3. Consistency of theory 4. Agreement of interpretation 5. Distinctiveness of interpretation 6. Efficiency of interpretation 7. Bias reduction in interpretation 8. Correspondence of interpretation 	<ol style="list-style-type: none"> 1. Data was first analysed separately to guarantee clarity regarding which findings emerged from each method 2. Findings were reported in conjunction with inferences 3. Inferences were associated with present knowledge and principle 4. Agreement was ensured in all interpretations 5 and 6. Interpretations were efficiently made through evidence-based associations 7. Inconsistencies will be explained. 8. The research questions were identified and answered correctly
Inference	Transferability of inference	<ol style="list-style-type: none"> 1. Ecological transferability 	In areas concerning ecological, population, progressive and theoretical transferability,

		2. Population transferability 3. Progressive transferability 4. Theoretical transferability	the findings of the current research were transferable to other service providers to enable improvement of access to dementia services by people from South Asian population
Reporting	Quality of reporting	1. Availability of report 2. Transparency of reporting 3. Yield	1. The study was feasible in relation to time, finances and personnel 2. Data provided insights into the research problem which was included in the discussion section of the current study 3. Data identifies the whole being more, compared to the sum of the parts
Synthesisability	Real-world application	Quality criteria	At the end of the study, it would be easy to conduct the study within a systematic review of studies
Utility	Quality of Utility	Utility quality	The study results will be applied in clinical practice

5.5 Ethical Considerations

This research project received full ethical approval from the National Health Service (NHS) Research Ethics Committee [REC] (Appendix 8) The ethical conduct of research is a major consideration which goes beyond truthfulness and honesty (Burns and Grove, 2004). The ethical considerations underpinning a research project are intended to protect participants from harm by safeguarding their rights (Orb et al, 2000). As a qualitative study was planned, it was important to ensure that all participants' rights were protected and given equal consideration. Due to the nature of qualitative research, the qualitative phase presented more ethical issues. All ethical issues were reflected upon and addressed before the research began. In this section, I shall outline and discuss the ethical issues underpinning this research project with respect to the British Psychological Society (BPS) and NHS Ethical Guidelines.

5.5.1 Informed Consent

In the second phase of the research, I read the participant information sheet to all participants, ensured that they fully understood their participation, and provided the opportunity for them to ask questions. Written informed consent was subsequently sought from all participants. However, with respect to

people with dementia, the informed consent process was slightly different, because people with dementia are deemed to have fluctuating mental capacity, which means that under the Mental Capacity Act 2005 (see Section 5.4.3.2) they may lose the ability to make a decision, in this case about taking part in the study. Before informed consent was sought, a healthcare professional at the study sites assessed potential participants' capacity to consent under the Mental Capacity Act 2005, ensuring that people with dementia were not excluded based on their diagnosis or stage of dementia. The guidelines state how to ensure that potential participants retain information, use the information to decide whether to take part in the research, and clearly communicate their decision to the researcher (British Medical Association, 2007). I also checked the original consent by recording verbal consent on the day of the interview.

If a person with dementia had lost the capacity to give informed consent, then s/he was withdrawn from the study. I checked with family members or carers that there had been an enduring change in the person's capacity as opposed to just a 'bad day' (Dewing 2002). Informed consent was reconfirmed at the second meeting, prior to the interviews, in order to ensure that the person living with dementia fully understood his/her participation (Murphy and Dingwall, 2007).

After providing the participant with information at the introductory meeting, the researcher sought written or verbal consent; potential participants were asked if they were willing to give their consent to take part in a forty-five to sixty-minute semi-structured interview. Informed consent was sought only after participants had reread the participant information sheet, fully understood their participation, and had the opportunity to ask questions.

5.5.2 Consent as an on-going process

This approach is influenced by Dewing's (2002, 2008) person-centred approach to consent who argues that a *one-off* act of attaining consent is inadequate for people with dementia, rather there should be a

procedure to obtaining consent; Kayser-Jones & Koenig 1994, Dewing, 2002, Hubbard et al., 2003, and in McKeown et al., 2010 have concurred with this view. However, the NHS REC required me to use formal, standardised information sheets and consent processes which did not fit with the process consent method. A compromise was reached, by using the information sheets when first introducing the research to a person, but to give people with dementia the option of giving verbal rather than written consent, witnessed by a carer or member of staff. Consent was then revisited each time the researcher met with the person with dementia. While the information sheets were available to use as a tool in such interactions, the focus was on the participant's willingness to be involved.

5.5.3 Accepting verbal consent from people with dementia

Drawing on current research into dementia, and after attending a seminar on working with people with dementia, it was noted that being presented with a lengthy official-looking form requiring a signature is often the most stressful aspect of participating in research for people with dementia. For example, there were instances when a person would understand the information and clearly state their willingness to take part in the research, but found the form off-putting, with its multiple statements, tick-boxes and the need for two signatures. The researcher therefore accepted verbal consent from people with dementia in order to reduce the anxiety which can be associated with having to sign formal paperwork. When consent was obtained verbally, the researcher read out each statement on the consent form, ticking it if the person with dementia agreed, and a signature from the family member or carer was obtained to witness this.

5.5.4 Confidentiality

On completing each interview and focus group, the researcher or a professional transcriber transcribed the discussion. At the beginning of the data-collection process, the professional transcriber was asked to complete the project's transcriber confidentiality form. Any identifiable details in the transcripts

were anonymised to protect participant confidentiality. Participants' names were changed, as were the names of anyone referred to in interviews or focus groups.

Personal data was stored separately from the data collected from the interviews and focus groups, kept either in a locked filing cabinet or in a locked office. The data from both phases was stored in an encrypted password-protected Lancaster University server, held in a locked office in the researcher's university base. The researcher held the master copy of the code for encryption, and data transfer using USB hardware was therefore minimal and secure. Data from this research was stored in a locked filing cabinet at the researcher's university in accordance with the Data Protection Act 1998 (Department of Health, 2005; BPS, 2014). The data was stored in a locked filing cabinet, and all electronic data was stored on a password-protected computer to comply with the BPS Ethical Guidelines on data retention (BPS, 2014).

Owing to the sensitivity of the study, it was possible that during the interview a participant might disclose a plan to self-harm or disclose instances of abusive or unprofessional behaviour or actions. They were informed that in such circumstances confidentiality must be breached by the researcher, who would discuss her concerns with her senior academic supervisor. Participants were made aware by the researcher of events which can and do lead to breaches of confidentiality, and that in such events their clinician at the memory assessment clinic would also be informed.

5.5.5 Anonymity

I ensured that all data was anonymised and any potential identifying features, initials or culturally appropriate names were removed from the transcript. Participants were assured that any identifying documents such as their signed consent forms and personal contact details would be stored separately and securely from the qualitative data and destroyed once the thesis is submitted and assessed

(Smajdor et al., 2009). The researcher had access to the personal contact details, and the raw anonymised data could be shared with my supervisors.

When conducting focus groups, it is not always possible to maintain participants' anonymity and confidentiality, because participants reveal something of themselves by taking part in focus groups. All participants were made aware of this issue during the telephone conversations discussing the research project further. Every effort was made to maintain participants' anonymity and confidentiality, and at the beginning of each focus group participants were asked to keep the discussion and peoples' identities confidential within the group.

5.5.6 Support for participants

Owing to the sensitive subject matter, participants could become upset, which is a natural response to discussing issues relating to their experience of dementia. If participants became distressed, I could suspend the interview at any point and resume it when they recovered, if they so wished. Before the interviews began, participants received a list of people they could contact for support: their GP, Age UK or the Alzheimer's Society Blackburn were all listed on the participant information sheet. After the interview, the researcher drew participants' attention to the available support sources; the list was also given to them on a separate sheet of paper on the day of the interview.

After taking part in focus groups, participants could become aware of alarming or concerning issues either about their own memory problems or their loved ones'. Participants' concerns about such issues may be expressed to the researcher. The participant information sheet states that in such situations participants would be referred to appropriate organisations or professionals for further information and support.

5.5.7 Avoiding coercion

In the second phase of the research project, I ensured that all participation was voluntary and free from coercion (Smajdor et al., 2009; Gjerberg, et al., 2013). As part of the recruitment process for interviews and focus groups, participants were asked to complete a consent form clearly stating that their participation was voluntary and that they were free to withdraw from the study without giving any reason. As discussed in Section 5.7.2, people with dementia would only be recruited for semi-structured interviews once they had given written informed consent during the first meeting and verbal confirmation of informed consent during the second meeting.

5.6 Conclusion

In conclusion, this chapter has presented a philosophical approach that is primarily concerned with how human beings interact with the world. The ontological position it adopts is based on assumption that there is no shared social reality but instead there are many different constructions, and thus it views reality as understood through understanding individual's subjective world. Furthermore, an understanding of lived experience can be enhanced through the adoption of a participative and subjective epistemology. Therefore, to meet the overall aims of the study, a qualitative approach was used to provide insight into the research topic. The findings are presented in Chapters 6, 7 and 8. Chapter 6 presents the south Asian community's understanding of dementia; the consequences of such understanding on people living with dementia will be discussed in Chapter 7. Lastly, in Chapter 8 I will outline the provision of health and social services for people from the South Asian community.

Chapter 6: Seeking help and access to dementia services

After considering participants' demographic information, this chapter explores what it means to be a part of the South Asian community and how it affects some South Asian people's world views of diverse Western culture, mental health, and their understanding of dementia. Many of the South Asian community participants perceived dementia as an unfamiliar illness (section 6.2.3), with no physical cause (section 6.2.4), some attributing its cause to spiritual factors.

As noted in Chapter 3, the research findings are based on South Asian community participants' perceptions and attitudes, which may be informed by their culture: values, beliefs, practices and customs. However, as shown here the strength of the relationship an individual shares with their cultural ideology varies depending on the level of attachment they may have toward the host culture and how much they identify with the diverse elements of Western culture.

6.1 Demographic information

The data were collected in accordance with the data-collection methods discussed in sections 5.3 (for qualitative data). In this section, I describe the demographic information of participants who took part in one-to-one semi-structured interviews with people with dementia and their family caregivers, healthcare professionals and, and in the qualitative focus groups.

6.1.1 Semi-structured interviews with a person with dementia and their family caregiver

Three people with dementia, two male and one female, initially agreed to take part and were sent the information pack to complete the expression of interest form. However, when followed up by the One Voice team to enquire if they had registered their expression of interest with the researcher, two people with dementia declined to take part in the research. The reason given to the One Voice team by the

man with dementia was that he did not want to disclose his condition to non-family members. The family members of the woman with dementia felt it was not a good idea to take part in the research. At this stage the people with dementia and their family caregivers were reminded that if they wanted to take part in the research and their family member did not, this would be made possible.

Consequently, of the three people with dementia who expressed an interest, only one person with dementia completed the expression of interest form and returned it to the researcher. The characteristics of participants who took part in the semi-structured interviews are summarised in Table 6.1.

Table 6.1: Demographic information of the person with dementia and family caregivers interview participants

	Participant	Age	Gender	Ethnicity by region
Interview 1 (Dyad)	Person with dementia	81	Male	South Asian Indian
	Daughter	47	Female	South Asian Indian
Interview 2	Granddaughter of person with dementia	26	Female	South Asian Pakistani

Interview 1 was with a person with dementia and his family caregivers. Interview 2 was an individual interview with the family caregiver of a person with dementia. Both family caregivers were female; one was from the Indian community, the other from the Pakistani community.

6.1.2 Semi-structured interviews with Healthcare professionals

At the start of the study, nine healthcare professionals were invited for a one-to-one semi-structured interview, to share their experiences as a service provider working with the South Asian community. The job title and gender of the healthcare professionals participating in each semi-structured interview are in Table 6.2:

Table 6.2 Demographic information of the healthcare professional (HCPs) participants

	Job Title	Gender	Ethnicity
HCP 1	Consultant psychiatrist	Male	British Asian
HCP 2	Dementia advisor	Female	British Asian
HCP 3	GP	Male	British Asian
HCP 4	Nurse independent prescriber	Female	White British
HCP 5	Dementia advisor	Female	White British
HCP 6	GP	Male	White British
HCP 7	Community development worker	Male	British Asian
HCP 8	Support worker and care service development manager	Female Female	White British British Asian

An equal number of male and female healthcare professionals from a wide range of health settings took part in the individual interviews.

6.1.3 Focus groups with members of the South Asian community

Twenty-five potential participants expressed an interest in taking part in the focus group, of whom three returned the expression of interest form by post and twenty-two contacted the researcher by telephone. Of the twenty-five participants the researcher contacted to discuss the project and answer

any of their questions, twenty were interested in joining the research and taking part in one of the three focus groups.

As the researcher, I was interested in exploring the views and understanding of dementia of different age-groups among members of the South Asian community. After the first focus group I noticed that in a mixed-age group younger people were less able to talk about their experience. I set up a separate group to allow the voice of younger people to be included. The participant make-up in the focus group by age, gender and ethnicity is shown in Table 6.3 below.

Table 6.3 Demographic information of the participants in the group discussions

	Age range in years	Gender		Ethnicity		Total number of participants in each group
		Male	Female	Indian	Pakistani	
Group 1	19 – 52	4	1	2	3	5
Group 2	44 -56	1	3	0	4	4
Group 3	18	3	1	1	3	4
Total	18 – 56	8	5	3	10	13

Focus group participants were aged between 18–56 years old. The majority of the participants (8/13) were male from a Pakistani ethnic background and all were living in Blackburn with Darwen.

6.2 Understanding dementia

The data collection included interviews with people with dementia and their family caregivers, interviews with health care workers, and focus groups with members of the South Asian community. These were then collated for analysis. They were treated as one dataset; there was no ‘between groups’ comparison, as the aim of the thesis was to identify common themes across all three datasets. The participants’ discussions emphasised their sense of their own community, suggesting that the community’s cultural values and beliefs have provided a framework guiding them on how to live and what is regarded as appropriate behaviour, which in turn is influenced by their ancestry and country of origin. However, individuals from the South Asian community have differing relationships with the community’s cultural values and beliefs, often influenced by their own level of knowledge and expertise in a given area (discussed in detail in section 6.2.1). This suggests that members of the South Asian community conceptualise dementia according to their existing knowledge and their cultural understanding of memory loss and mental illness. This section explores how people in the South Asian community understand dementia.

In this section, five key findings are discussed: (i) the meaning of community for those of South Asian heritage, (ii) the South Asian worldview of Western culture, mental health, and dementia, (iii) dementia as an unfamiliar illness, (iv) dementia as a mental illness which cannot be seen - an invisible illness and (v) how signs and symptoms of dementia are regarded in the South Asian community as a case of possession by a spirit.

6.2.1 “We are stronger together than we are alone: community [is] a pillar of strength”

This section explores the meaning of the South Asian community to its members and the relationship between community and family-level cultural values which may influence an individual’s perspective on their lifestyle.

The participants explained what seemed to them the essence of community for people of South Asian heritage: community creates an honourable, purposeful, and safe basis on which to live. The participants explained the importance of being integrated in their community, perceiving integration as providing a sense of self, identity, “belonging”, unity, and interdependence, without which individuals may feel vulnerable and unprotected:

“Mental wellbeing and how positive you feel, do you know, within yourself, depends on what your family structure’s like and how included you are in the community – because those are all big, big prevailing factors...” (HCP7)

It was commonly perceived across all three group discussions that the community provides meaning for its members. This understanding was discussed in detail by the groups and by two healthcare professionals, who alluded to the concept that the community members are stronger together than they are alone, as the quote below illustrates:

“They are stronger together than alone, strong is good... strong is perceived as a pillar”.
(HCP7)

The participants explained the experience of being part of a close-knit community, where one person’s business becomes everyone’s business:

“The family is potentially - certainly in the way they live and conduct their day to day business - a tighter, closer-knit family than a lot of Caucasian families... And I think because of that, if you’re living basically very much within the same house, the same community, the same Mosque, it’s gonna be harder to keep a secret potentially... I think you could live with a diagnosis at a distance and have that greater degree of privacy.” (HCP6)

Participants across the study agreed that the close-knit South Asian community will only provide strength and support to those members of the community who adhere to the community cultural values on how to live and a certain accepted way of being. Throughout the study, some participants identified these community cultural values: the need to be perfect, to attain high academic standards, to achieve high status and to be married. Members from the South Asian community who appear not to meet these accepted values because of illness are perceived as being possessed; causing them to deviate from the cultural norms (this is discussed in more detail later in the chapter):

“They’ll always have a negative effect, be laughing at him like, ‘Oh, look at him, he walking wonky’ and stuff. And they’ll be saying it to his face. So obviously that, obviously pulling that person more down...” (FG1 M3)

“I think as a community, because we don’t talk about things, we don’t talk about how we’re feeling and express ourselves, I think it must be internalised... I think because we... we have to be so perfect, we can’t talk about things, so it’s gonna be somewhere stored and having an effect”. (FG1 F1)

“Or a status thing. So if someone has it, it might put shame to the family or they might look down on the family.” (FG3 M2)

As the quotes above illustrate, participants in Groups 1 and 3 discussed the perceived negative impact of these cultural values (or, according to some participants, ‘cultural biases’ (FG1 M2) on individuals with social, emotional, and mental health difficulties, who are perceived as being possessed by an evil spirit as they cannot follow cultural values, behavioural norms and expectations and so are excluded, which creates social divisions. This seems to suggest that for these participants the South Asian community’s values and beliefs carry an expectation to conform, otherwise you may be “looked down

upon” (FG1 M3) by the community, or find your family experiencing embarrassment and discrimination in the community. This affects their status within the community: the person with an illness and their family will be stigmatised (this is discussed in detail in section 7.1). They and their family therefore feel ashamed and fearful of talking openly about the illness or their diagnosis to other members of the community. Consequently, the family members will try to hide the illness and try to manage it or deal with the matter at home (this is discussed in more detail in 7.1).

In contrast, three healthcare professionals explained that they see the characteristics of the South Asian community changing, with more people pursuing higher education, working in professional job roles, and having easy access to the internet. However, most focus group participants suggested that higher education does not equate to medical knowledge of dementia. Given this, they believe a higher education qualification will not necessarily change their views on dementia unless they also acquire accurate medical information about this illness, relying instead on the cultural definition and understanding of the condition. One participant gave an example of a civil engineer, highly educated in his area of expertise but who may not have the necessary medical knowledge about health issues. In these circumstances, people may rely on ‘home knowledge’ defined by cultural understandings and beliefs about health, which in turn informs their perspectives of illness. The quote below illustrates the process by which an individual’s understanding is influenced by cultural knowledge. However, giving appropriate information to an educated person such as a civil engineer may lead them to listen to what is being said and they may not necessarily adhere to existing cultural beliefs and values regarding illness. This perspective is discussed in detail in Chapter 8: HCPs from the South Asian culture who work in dementia services use their individual knowledge to re-assess their cultural knowledge and make a choice about what they take from their cultural beliefs and values.

“I think the assumption that some people have made – and this is my opinion – that if you’re educated you’re in a better position to deal with things. I would disagree because being

educated – I might be an educated civil engineer... so that might not help. I might be educated as a health [professional] or you're a teacher or whatever, so it's not necessarily... and somebody's who's not educated... doesn't that mean he or she's going to be able to be less able to deal with it or not? The same as... I think the only... The only diff-... the only advantage you have with educ-... being educated, you'll understand it a bit more... you'll obviously take them on board..." (FG1 M3)

One family member of a person with dementia shared the difficulties she encountered in having medical knowledge about dementia rather than relying on cultural perceptions of the condition. Issues arose when attempting to get her family to help and support her father, because many family members held beliefs shaped by cultural norms and values. The lack of a shared understanding and knowledge about dementia tainted the entire experience for this participant:

"I'm quite educated where dementia's concerned whereas my family, the rest of them aren't. So to them it's not as important as it is to me. Now, if they were alert on what dementia was about, then they'd probably treat and react to my dad differently because he's still the same person but it's like you have to adapt to their needs, don't you? ... So I think it's things like that that probably my family don't understand because they're not that educated about dementia".

(Family member 1)

This section has explained the importance of community for people of South Asian heritage and how the community's cultural views and beliefs influence a South Asian individual's attitude towards an illness. The next section discusses the South Asian community's worldview of Western culture, mental health, and dementia.

6.2.2 The South Asian worldview of Western culture, mental health, and dementia

As already noted above and in Chapter 3, members of the South Asian community are informed by cultural norms and values embedded in their ancestral Eastern cultural ideology. In this section I reflect on participants' perceptions of how South Asian community culture may differ from UK Western culture, and discuss how a Western notion of dementia and mental illness is viewed from a South Asian cultural ideology, and the potential conflict which may arise as a result.

The participants spoke about the struggle faced by members of the South Asian community following migration to the West, where the lifestyle and culture differ from that of South Asia. Some participants discussed life in their native country, where people live in large extended families. Families depend on each other for strength in hard times. HCPs commented that in South Asian culture there is a “*patriarch[al]* or a *matriarch[al]*” (HCP 7) system, where a person (usually the head of the family) deals with any problems, the family providing strength and emotional support to them:

“Because where they come from, the way that South Asian families are structured, they’re extended and you usually have a patriarch or a matriarch as the head of that family. So when you look at sort of like those people within those age-groups who have a lot to deal with and a lot to worry about.” (HCP7)

Most of the participants compared various elements of South Asian culture and Western culture, noting that Western culture tends to promote self-reliance and individualism; individuals thus often cope with their problems alone:

“I think probably... probably even more so, because I think what’s happened is that a lot of our BME community have come over with a society view and ideas that were maybe twenty,

thirty years behind what we've got in white British culture, like from the '50s, '60s. People have come over and there's more of the extended family... ” (HCP6)

The participants' discussions indicate the differences between the two cultures. They also remarked that South Asian culture emphasises physical work and Western culture emphasises mental work. The participants explained the struggle that people in the South Asian community may experience when they try to conceptualise mental illness and dementia, which have no visible 'physical' manifestation (see the detailed discussion in section 6.2.3). Consequently, dementia and mental illness are unfamiliar concepts in Eastern ideology (see 6.2.2). Family members of people with dementia said that this unfamiliarity with mental illness and, consequently, dementia has resulted in a negative understanding of people living with the condition i.e. they are insane or have lost their mind:

“They don't have an understanding. You know, if they see an ailment which is physical, they show an appreciation and understanding... but if it's a mental illness... they think, oh, it's a case of person is just... lazy... But in the Western world, you are independent, so you deal with difficulties on your own so the... and a lot of the work that you do is more mental so at the tail-end of your life you will get illnesses which reflect the type of work you've done throughout your life... So, where they come from, South... it was more manual work and a bit of... the remedy for a lot of these things is you get a bit of sun on your back, a bit of sweat, and it will... it will... what do you call it... it will rectify itself. Do you know, this is it... this prejudice?” (FG2 M1).

The participants explained how members of the South Asian community rely on their cultural understanding to interpret the symptoms of dementia. All five HCPs of South Asian heritage suggested that cases of dementia with visible behavioural symptoms are described in the South Asian community as the consequence of being possessed by an external power which causes an individual to deviate

from the cultural norms and values (this is explored in detail in section 7.1), as illustrated below. Similar findings were reported by people in the South Asian community in group discussions and interviews with family members of people living with dementia (see section 6.2.4).

“But that’s what the perception was, ‘There’s a jinn [evil spirit] in her that’s making her come home late and hang out with her friends.’ ‘There’s a jinn [evil spirit] in her that’s making her wear those jeans.’ ... and I think those were excuses at that time to deal with cultural problems that people didn’t like. My experience... those issues come up with dementia and a lot of its symptoms which is problematic to their culture, the perceptions is that’s its magic and spirituality and that has an impacting.” (HCP7)

In the group discussions and individual interviews, all the participants used the terms ‘dementia’ and ‘mental illness’ interchangeably, explicitly stating that the community perceives dementia as a mental illness. The participants’ discussions about mental illness informed the researcher’s understanding of the South Asian community’s understanding of dementia, as described by this participant:

“I’m not too sure what it is (dementia), to be honest. I know it’s like a mental illness but apart from that I don’t know.” (FG1 M4)

This section includes a participant’s perception of the south Asian community worldview of the diverse elements of Western culture in the UK, and how this may influence South Asian community perceptions of mental illness and dementia. I explore below how this cultural difference results in the perception of dementia as an unfamiliar illness.

6.2.3 Unfamiliar: “It is something new to our community”

This section explores the concept of dementia as an unfamiliar illness in the South Asian Eastern psyche. Participants discussed how they had observed members of the South Asian community trying to make sense of dementia.

Most of the participants raised concerns that dementia, like many other mental illnesses, is often perceived as a Western notion by individuals who are more devoted to the inherent beliefs of their native culture. Consequently, mental illness is an unfamiliar notion in their native culture, with no comparable terms and definitions to reflect those in the English language. South Asian languages have no term for ‘dementia’, making it difficult to define and even harder to explain and understand, as the following two quotes illustrate:

“I think that all communities, they like this idea of saying... having this one ideology that says I don’t like accepting other ideas to come in so they have sort of comfort that: We think this, we’re not gonna change, and it’s just it’s summat new, that’s alien to us and we’re not gonna really associate ourselves and affiliate ourselves with it. And they’re not going to accept, you know, the science behind it and the reason behind it. That’s what I think anyway.” (FG3 M1)

“I don’t know of a word that’s even in Gujarati that no-one has dementia... known for dementia”. (Family Member 1)

This was further investigated in the individual interviews with HCPs who suggested that, because the concept of dementia is unfamiliar to South Asian community members, they cannot identify with Western notions of mental illness. A person living with dementia is thus commonly referred to as having gone ‘*pagal*’ (insane) or ‘mad’ or ‘having lost their mind’ (HCP7), as illustrated

below. All participants in this study made similar comments. Other HCPs suggested that a dementia diagnosis elicits fear among the family members and individuals who may have adopted native cultural norms or amalgamated their native and Western cultural beliefs because they will be labelled by the community as *pagal* [insane]. The term they used in their mother tongue to communicate the word ‘dementia’ is *yaad shakti* (“memory power”) or *magaj ni bemari*, (literally, “brain illness”).

“I think it’s quite different from the indigenous population, its understanding of the whole mental health issue. It’s not just dementia for the South Asian population, it’s... mental health issue is a big taboo because they don’t want to be labelled with this. I say it’s a very difficult sort of challenge when they start talking about mental health and a lot of time there’s a lot of denial about it and that makes things a bit more difficult”. (HCP3)

“Oh, dementia now is all pagal, pagal and pagal you know. They don’t recognise she’s not pagal...She’s ill, she’s ill. Just like, you know, I’d be ill if I had a stomach ulcer or a colon cancer or something. She’s... it’s an illness”. (FG1 M2)

“Erratic... erratic... Have they personal problems? Is that why they’re reacting like this? Have they lost it? They kind of like label... different label... but not label with the word that, you know, there’s a possibility it could be dementia. But everybody’s dementia’s different, though, isn’t it?” (Family Member 1)

When the family members of people with dementia were asked how they manage this dilemma, they responded that they were unfamiliar with the word ‘dementia’ until a family member was diagnosed, as the family member’s quote below indicates:

“I think because we didn’t know it was dementia... we didn’t know it was dementia. So then when we got the GP out and they actually mentioned dementia I started reading up about things that could happen during dementia, like the mind... you know”. (**Family Member 2**)

One family member of someone living with dementia explained that the South Asian community cultural understanding of dementia regards it as a contagious disease, so people who rely on this community cultural understanding of the condition will try to limit their contact with people living with dementia. The group discussion highlighted this unfamiliarity in terms of the community’s understanding of the causes of dementia. As the quote below illustrates, the participants suggested that dementia is an illness which people can catch:

“Well, I think you’re more likely... there’s a probably chance that, as you’re older, you’ll catch it” (**FG3M3**)

“They don’t want to come near you then because they’re like “Ooh... yeah - what if it comes to us? And I’m like, Oh for the love of God. Are you that thick? Are you that uneducated? Do you not have that understanding that I am telling you it is dementia? I’m just... because they will... they’re afraid to come near her now in case something happens to her. And I’m like, Really? This is what you think? And I’m telling you that it’s this, it’s dementia. It’s just a loss of memory. It’s nothing”. (**Family Member 2**)

A person with early-stage dementia spoke of his difficulty trying to fit the term ‘dementia’ into the South Asian language, expressing his confusion about the term, repeatedly asking during the interview what dementia is. He suggested a lack of confidence in the Western model of health that an illness can manifest without a reason, and gave reasons for his development of dementia. He spoke of his struggle

striving to manage his condition and make his friends and family members in the community understand his illness. They do not believe dementia exists and constantly tell him there is nothing wrong with his memory. His family member expressed sadness that his friends and other family members do not understand his illness. They argue that he is fabricating his illness:

“The meaning of ‘dementia’? What is it? The dementia’s meaning? The dementia is meaning... dementia meaning what?” (Person with dementia)

“For me to be totally... honest, some of them were kind of like saying that he’s fabricating it, the way he’s reacting. Some of them came across like that; some of them are completely ignorant; some maybe with the lack of not understanding, so you get various emotions from people”. (Family Member 1)

6.2.4 Invisible illness: “There is no physical ailment”

This subtheme arose from participants’ discussion of dementia as an unfamiliar illness in the community. They addressed how the visible signs and symptoms of this illness are understood by the South Asian community. Across all three groups a common view was that, unlike other illnesses (such as a broken leg or cancer) with physical symptoms, dementia is a mental illness which cannot be seen - an invisible illness (see the discussion chapter on how similarly views are shared by people in the white British population) - as illustrated in the quote below:

“I think the whole idea of, if there’s an illness that’s not visible, we find it very hard to deal with because we have to be shown to have... like cancer is visible, you know, everyone knows about cancer now, or a broken arm – it’s visible. But when you’ve got depression and dementia, it’s not visible”. (FG2 M1)

This conversation further investigated how the community understands the visible signs and symptoms (such as the behavioural symptoms) of an invisible illness. The group suggested that individuals from South Asian community who lack appropriate understanding of dementia may perceive many visible symptoms of dementia as a normal part of the ageing process. Most participants explained that there is a common understanding in the South Asian Indian and Pakistani communities that dementia is related to ageing. This common knowledge asserts that people who have been diagnosed with dementia are older, vulnerable, and frail, similar to the general perception of ageing. This can be seen from the quotation below. The converse view is that people often associate growing old with memory difficulties, self-isolation, and becoming agitated and aggressive (mood swings):

“I thought, oh maybe it’s something that’s going to happen, it’s normal. And I think because we didn’t know it was dementia, we just kind of took it as part of old age, it’s one of those things, it’s just going to happen and she’ll be fine after a while. But then once she started progressing and getting worse, we thought right okay, I thought to myself this doesn’t seem normal, because I could get her up and we’d be like : come on we’re going to go to the bathroom, and she’d just start hitting me and she’d start kicking off and I’m thinking Gran, it’s me”. **(Family Member 2)**

In the group discussions, participants were asked whether they thought dementia was a normal part of the ageing process. Everyone present was aware that dementia can happen to anyone at any age, making it distinct from normal ageing. Most participants suggested that they thought dementia is something which mostly occurs in older people, over the age of sixty. In the quotation below, one person made an association between dementia and getting old, suggesting that dementia is something one may experience when one grows old:

“Well, I think you’re more likely... there’s probably a chance that, as you’re older”
(FG3M3)

The participants’ discussions indicated that it can be difficult to tell the difference between normal ageing and dementia, especially early-stage dementia:

“To be honest, I thought it was part [of] natural ageing a few years ago. I didn’t think anything about it until... I mean has done a lot of stuff around it” **(FG1F1)**

“It’s a tricky situation that one because a normal person that’s normal, that’s got no dementia, nothing, could forget as well, so early stages you can’t really catch it, it’s quite difficult to catch.” **(FG1M2)**

Interviews with family members of people living with dementia and HCPs clearly indicated that the family members were unaware of dementia until the family member living with dementia was diagnosed. Prior to diagnosis, family members attributed the signs and symptoms of dementia to the normal course of ageing:

“I think other barriers are that they don’t... people are not aware of what dementia actually is. They perceive some of the symptoms as part of getting old and don’t perceive it as an illness necessarily”. **(HCP 2)**

“I think those were excuses at that time to deal with cultural problems that people didn’t like. My experience... those issues come up with dementia and a lot of its symptoms which is problematic to their culture, the perception is that’s its magic and spirituality and that has an impacting. Same with post-natal depression – I’ll give you an example – was perceived as spiritual possession...” **(HCP7)**

Most of the HCPs interviewed in this study stated that this common perception of dementia in the South Asian community – that the symptoms are a normal part of ageing – occurs because the early symptoms of dementia in the Western medical model do not fit South Asian cultural norms of social harmony. One HCP gave an example of social isolation, explaining how this could be perceived as a social rather than a medical problem. The healthcare professionals in this study suggested that the common perception of ageing in the South Asian community is that age brings health problems and physical pain which result in a person socially disengaging with the community and the world. They also suggested that, as the condition and symptoms (especially behavioural symptoms) of dementia progress, this results in a perception that the person has been possessed by an evil power. This is the South Asian community’s way of dealing with things which are not in line with or are problematic in their culture, as illustrated in the quote above. This will be discussed in detail in the next section.

6.2.5 Spiritual causes

Amongst individuals from the south Asian community who identify less with the diverse Western culture, a perception persists that dementia is a condition without physical causes. Thus, their knowledge of the world affects their understanding of the causes of dementia.

Participants in Groups 1 and 3 spoke about the issue of relating dementia to *jinn* (“spirit”). The *jinn* is believed to have ‘possessed’ or ‘taken over’ the person living with dementia’s body, thereby controlling them:

“I think it’s kind of like a curse... the Asian community think of it as a curse, like mental health, so they don’t think of it as scientifically, so because I don’t have that much knowledge on it, so they tend to think of it as a curse or jinns.” (FG3 M3)

“If they think someone has forgotten and someone is behaving inappropriately due to the circumstances, they don’t think that it’s something that can be addressed. They just think jinns [evil spirits] are present.” (FG2 F3)

Similar discussions took place in the interviews with HCPs who spoke at length of the *jinns* being an evil power in the case of individuals with dementia. The community members who adopt the norms of their native group exclude the different element of Western culture, and attribute negative behavioural changes to an evil spirit. One HCP gave an example of behavioural changes which may confirm this existing belief in the community, as illustrated in the quotes below:

“...when their relative who had dementia started to lose any concept of place and was defecating in the kitchen and causing various problems... shouting, knocking on the door.”
(HCP1)

An interview with a family member of a person with dementia spoke about their struggle with people from the community who advised her to go to a religious priest to get rid of the evil spirit:

“I don’t care, I don’t care what the community thinks. They’re not living the life my dad’s living. No, I don’t, I honestly don’t. My priority is my parents, regardless of what the world thinks. If I feel that something is affecting my parents and my dad and I feel that it’s a medical issue, I’m sorry, the doctors are there to treat that. No other person is qualified to treat it. Yes, Allah’s there, yeah... and that’s his final decision what the doctors do, but Allah has created professional people for a reason and that’s what they’re there for and they’re the people to go to – not somebody that has no idea, these... you know, people that live with these faith healers, things and things like that. They’re not educated in what dementia is: they’re just...” (Family member 1)

She said her community believed that the affected individual did not have dementia; instead, they believed that the cause of his socially inappropriate behaviour was black magic. Other participants in the group discussions made a similar point:

“That’s what... that has somebody done any jinn or black magic on them... which is sad because the thing about religion, the most spiritual thing, and doesn’t teach us all that...”

(Family member 1)

“Obviously they know... the first thing they’ll be thinking, it’s like, I don’t know, it’s narrow-minded thinking from the Asian community, it’s like that’s the first thing they’ll... that will go through them – that someone has done black magic on them. They won’t believe that it’s a natural condition. They’ll think: No, it’s not. They’ll try to push it that way as though it’s black magic or something that’s been done.” (FGIM3)

The group discussions and individual interviews indicated that behaviours or actions which do not fit with the community’s norms are attributed to external powers, shifting the responsibility for such behaviour from the individual experiencing dementia, as illustrated in the quote below. Thus, there is a common perception that individuals with dementia are under the control of these external influences and have no control over their behaviour:

“‘We haven’t made a lifestyle change because of that,’ or ‘We never accessed an expert medical opinion because of that.’ It’s much easier then to say, ‘Well, it’s not our fault – it’s a jinn [evil spirit] that is making him or her behave inappropriately.’ (HCP 7)

“It’s black magic; it’s a sort of external... the jinns and spirits and ghosts inside of you... and there’s not, in terms of a scientific point of view, there’s not enough understanding of

mental health and it's often seen as... it's sort of like a stigma and there just isn't enough and the sort of people, they don't understand about mental health, the nature of mental health and what can be done about it and why it happens. And so that then gives way to all these sort of cultural biases and myths for them to sort of answer all these unanswered questions that they don't know about.” (FG3 M2)

6.2.6 Conclusion

In conclusion, the participants' discussions on the South Asian community's understanding of dementia emphasised the difficulties community members experience in trying to understand dementia. They suggested that dementia is an unfamiliar illness in their culture and that the term 'dementia' is not transferable into their own languages. They commented that the South Asian community culture emphasises physicality, either in terms of lifestyle (e.g. manual labour) or health (e.g. a broken leg). It is therefore difficult for them to conceptualise an illness which initially presents with psychosocial symptoms, resulting in the perception that it is a normal part of the ageing process. In the later stages of dementia, where behavioural symptoms of dementia become more prominent, a person living with dementia's behaviour is not regarded as conforming to their accepted cultural values about lifestyle and how to behave. South Asian participants suggested that this may result in a belief that the person with dementia has been possessed by an evil spirit, causing them to deviate from cultural norms and values. The consequences of the South Asian community's understanding of dementia for the lives of people with dementia and their family members are discussed in the Chapter 7.

Chapter 7: Consequences of living with dementia

The South Asian community's widely-held understanding of dementia (see Chapter 6) has consequences for people living with dementia and their family members. This chapter discusses key themes identified from the participants' discussion of the consequences of those beliefs and views about dementia, which may stigmatise the person with dementia (7.1), and how stigmatisation results in the person with dementia being hidden (7.2), when family members and the person living with dementia suffer in silence, managing dementia at home (7.3).

7.1 Stigmatisation of people with dementia

One of the consequences of the South Asian community's understanding of dementia (described in Chapter 6) is that people with dementia experience stigmatisation in the community:

“And I think the stigma is when society or the community or individuals will be prejudiced against someone's [person] beliefs, feelings, statements, solely on the basis that they have been given a diagnosis.” (HCP6)

Participants in all three focus groups (particularly Group 1, whose participants were the middle-aged and of mixed gender) expressed sympathy for people with dementia. When asked why, they referred to an insufficient understanding of dementia in the South Asian community (discussed in 6.2) and because dementia symptoms, especially in the later stages, do not conform to the community's cultural norms and expectations of being perfect, employed, and having high status (all of which are praised and respected). These factors contribute to people with dementia being stigmatised in the community. The participants in Focus Group 1 suggested that the stigmatisation of dementia and mental illness results in families feeling ashamed and too embarrassed to disclose the dementia diagnosis to the

community, even if they identify with the more diverse Western culture. Families are ashamed of stigmatisation, rather than the condition of dementia itself, as the following quotes illustrate:

“It’s the effects on your family, isn’t it, then? Really, if you’ve got dementia, it really affects your family then, doesn’t it?” (FG2 F2)

“And even though they know they’ve got the condition, they think... I think they find it as a... I don’t know, they maybe... I think especially in the Asian community they see it as like as a... an embarrassment or something like, ‘Oh, if someone find out’...” (FG1 M3)

This was confirmed in interviews with family members of people with dementia, who said explicitly said that they did not feel ashamed of their family member’s diagnosis of dementia and asserted that dementia is not something to be embarrassed about. However, some family members admitted that there is, some stigmatisation of dementia in the South Asian community. This results in families becoming fearful of receiving a diagnosis of dementia, because they are afraid to disclose it in the community. One HCP from the South Asian community referred to the fear expressed by the family members of a person with dementia that they will be seen outside the location of dementia services, which discloses to the community that someone in the family has dementia:

“So the perception is that, oh, if we go into a mental health setting or if we go to the GPs or if we drop into a dementia awareness facility or an access point where there’s information on dementia and we’re seen to be doing that, then people will automatically assume that they... there’s an issue of dementia in the family. So that then will spread within the community and that will be a dishonour to our family” (HCP7)

“It’s really horrible to say this... it’s almost as if they’re ashamed of it. And it shouldn’t be because there’s nothing embarrassing about it, it is part of life, you know, I might go through it, you may go through it, my neighbour might go through it. We don’t know who it’s going to hit.” (Family member 2)

Participants recognised the stigma resulting from dementia, commenting that this affects whether or not they decide to access dementia services. Many HCPs suggested that removing the stigma would result in an increased presentation of people from the South Asian community to dementia services:

“The perception and perceived stigma, I think, of mental illness in BME communities – and that doesn’t hold just for dementia, it also holds for other psychiatric conditions. And people will often be presenting late... when it comes to definite diagnosis, I think people don’t seek that because of the stigma.” (HCP6)

Some HCPs discussed the perceived negative effects of the stigma on people with dementia and their family members, saying that it could lead to families isolating themselves due to their fear of being questioned by members of their community, which might result in disclosure of the condition:

“How that person then is viewed in the community, the perceptions around it, how other people are gonna view them, then the stigma and family keeping away from community and not having people visiting... people will probably look at us in a negative light and we don’t want that, we don’t want people finding out, we don’t want people coming to our house and enquiring what’s wrong because naturally, when you come from a community that’s strongly linked, that will happen. People will come in to your domain and enquire about what’s wrong, how everything’s going or ‘Such-and-such saw something today and is everything okay?’” (HCP7)

The next section considers participants' perceptions of the impact of stigma on family members who decide to manage dementia quietly at home on their own, without professional help.

7.2 Hiding the person with dementia

The stigma attached to dementia results in family members trying to avoid disclosure by hiding the person with dementia.

Participants spoke about the difficulties people in the south Asian community experience in trying to keep information private from the community. All participants commented on the ripple effect which sometimes occurs in the community i.e. gossip - participants described this as, "people gossip" (FG1 M3) - which spreads knowledge of an individual's problems throughout the community. Two participants in the group discussion thought this could also have a positive effect in certain situations, for example in cases where a family would receive support from the community and where individual problems become community problems. However, most participants in the group discussion participants and the HCPs spoke at length about the negative effects of such gossip on family members of people living with dementia. In most cases, family members tend to hide the dementia in the family:

"If someone finds out the word will go round, and it's like people come back to us, 'Oh, like... fancy your house, this person got dementia.'" (FG1 M3)

"I think that, with family mem-... with, when my grandma, it wasn't dementia. She... was pretty ill, but my granddad was like, 'No, we don't want to tell anyone.' Just say, 'Oh, she's gone on holiday,' or 'She's just not around, that's why she's not coming out.' But they don't tell anyone she's ill. So I think with dementia as well that it could be pretty similar that we don't want people to know that, okay, we've got someone ill." (FG1 M4)

When asked to explain this concept, participants indicated that the word dementia has a negative connotation in the community, and is often seen as representing weakness and failure. Families therefore try to maintain their status in the community by hiding or avoiding disclosure of dementia, fearing judgment, discrimination, and alienation from the community:

“It’s like people would stop going to their house or like just complete like kind of cut off ties with them because they might be scared that, oh, if they’ve got it, it could be contagious or we don’t want anything to do with them.” (FG1 M4)

“Weakness is perceived as negativity. So if someone’s not strong and they’ve not got a great memory, there’s a negative perception around that that person’s not really, you know, a good-standing member of the community.” (HCP7)

All participants in the group discussion and most HCPs spoke at length about the perceived implications of stigmatisation for people living with dementia and their family members. They suggested that the family’s efforts to hide dementia often results in the family either “brushing it under the carpet” or “denying” it (FG1 M3), which can lead to a delay in diagnosis, causing further pain and suffering to people with dementia:

“I think they tend to brush it under the carpet in that sense, thinking that, if no-one knows about it, they’ll treat me... like they’ll treat me day-to-day basis, with... before knowing that I’ve got this condition.” (FG1 M3)

Family members of people living with dementia denied that they were hiding their family member’s dementia diagnosis from the community. However, they also acknowledged that hiding dementia is

prevalent in the South Asian community. They suggested that they had not themselves felt affected by judgments from the community or by the community's perceptions of dementia:

“Because they don't want other people to find out, they don't want people to talk and they don't want anyone to know because they are embarrassed by it. It could be because they do begin to treat people differently... we became outcasts... You know, we were looked at... we were looked down upon. You know, frowned upon, we were a disgrace... and I thought to myself ‘Why don't you come and help? Instead of making comments like that. I know what I'm doing for my Gran, how dare you say something to say that I'm not doing a good enough job? You're not there! You come for five minutes every month, and that's what you get.’” (Family member 2)

The next section considers participants' perceptions of how people living with dementia and their families “suffer in silence”, and manage dementia at home without professional help or treatment, and the impact this strategy has on people living with dementia and their family members.

7.3 Suffering in silence: Managing dementia at home

Hiding dementia is associated with South Asian families' cultural expectation of striving to endure and manage illness in private, therefore a person with dementia should be cared for at home.

The participants' use of the term ‘manage’ suggests only the delivery of physical care. This was clear in discussions about the effect that the home-management of dementia has on the lives of people living with dementia and their family members. Participants suggested that families would be willing to provide physical care to people living with dementia, but would not address their psycho-social needs:

“...rightly says those people themselves – and there’s evidence of this – actually get ill looking after people who are ill and this, when it comes to things like dementia, what happens is here, somebody can be left alone for a considerable... because it’s just a husband and wife maybe looking after an elderly parent, one elderly parent, they may just leave that person thinking we just feed them... we just feed them, take them to the toilet, feed them, take them to the toilet... and not really conversing with them.” (FG1 M2)

The HCPs shared their observations of how families in the South Asian community try to stay strong and manage dementia at home without professional assistance. They observed that families often continue to manage the condition until a crisis-point is reached, for example when the behavioural symptoms of dementia become difficult to manage. They then seek assistance from dementia services at a late stage in the trajectory of the illness. Some HCPs stated that, in their experience, families in the South Asian community continue managing dementia at home even after receiving a diagnosis, accessing dementia services on a limited basis only (see section 8.1):

“I think from experience mental health issues in the Asian community is kind of dealt with in their community... They tend to manage somebody ill with things themselves and seek support when they’re absolutely desperate for support.” (HCP4)

“The family tend to keep it amongst themselves and only when the problems start to become unmanageable at home do they present to the services, that is when due to the advanced dementia people start to present with behavioural problems.” (HCP1)

Interviews with the family members of people with dementia confirmed this: they said they felt it was their responsibility to look after their family members, and that they had no other option. Family

support was regarded as more important in managing dementia than professional help. A family member described their limited interest in using dementia support services:

“When you’ve got two people under the same roof who are struggling, we haven’t got any support and we’re relying heavily on our... it’s so tough for us as a family that the amount of arguments we as a family will have because we haven’t got an outlet, we haven’t got anywhere to go to let it out so we take it out on each other. But then it’s your family so you think oh, okay, I can scream and shout at them but they’re still going to talk to me because that’s my brother, that’s my sister, that’s my Dad.” (Family Member 2)

Participants in all three group discussions expressed the view that their cultural norms and values had taught them to care for their older family members. They frequently and explicitly stated that they would never put their parents in a care home, as they felt it was their duty and moral obligation to “look after their own” (FG3 M2):

“No, I wouldn’t put my...No, never put my family members in a care home... Because I’d want to be there with them and I wouldn’t want them to be... I guess it’s someone... it’s like, because I’m their child, sort of like my responsibility to look after them when they’re older, so I feel as though I shouldn’t throw away my responsibility and...” (FG3 M2)

Family members of people living with dementia and participants in the group discussion all emphasised the idea of a family sticking together, underlining the importance of strong family ties and support compare to strong community ties or serving the community. Family members suggested the need to stay strong together to look after their family. They considered it their familial responsibility and moral duty to care for the ill and older members of their family which, according to their faith, means they will receive a better life in the next world (“paradise” - Family Member 2). One family

member of a person living with dementia shared their experience of how the South Asian community's cultural values and beliefs place expectations on the family unit to endure and provide care to older family members. Thus, when her family decided to seek professional care, the community perceived them as having "failed" (Family Member 2) in fulfilling this responsibility:

"People were like 'Oh, they can't even care for their Gran, they've got carers coming in.' and I thought to myself 'Why don't you come and help, instead of making comments like that? I know what I'm doing for my Gran, how dare you say something to say that I'm not doing a good enough job? You're not there! You come for five minutes every month, and that's what you get.'" (Family Member 2)

"Get some stuff together and really work together, but we've had to do it as a family... and kind of rely on each other and kind of go off my Gran and see what we can pick up. So it's not really a lot of support from outside, it's more of what we've been able to do for her... My Dad took on the feeding role, my Mum did the cooking, we all kind of job-shared, you know." (Family Member 2)

One Group 2 participant discussed the implications of managing dementia at home in terms of the wellbeing of the carers, who might themselves have limited expertise in this area:

"They don't feel that they should seek assistance even though it's pushing them on to the edge. It pushes them to the edge. And they don't often have... well almost exclusively they don't have the expertise in this area – that's most important. You know, you can't have just an ordinary family lay member trying to muddle through and look after somebody who's just suffered: it's quite a complex area." (FG2 M1)

Participants said “enduring in silence” has become a cultural norm for members of the South Asian community caring for people with dementia. They explained that the family members of a person living with dementia often do not speak openly about the condition, carrying the burden of managing dementia at home for as long as they can. They added that South Asian Indian and Pakistani families do not tend to seek professional help until the dementia symptoms become severe and difficult to manage on their own:

“They only go when they’re falling off the rails, yeah. Yeah, forget the doctors, but especially with dementia, if I know there’s nothing they can do about it, so I just... as a family we try and deal with it, look after the person behind closed doors – that’s what we normally do as Asians. That’s my experience anyway.” (FG1 M2)

Four people in Group 1 empathised with such families. They felt they could understand why a family might decide to manage dementia at home without a diagnosis, perhaps because there is currently no cure available for dementia and doctors cannot really do much to actively help the person with the illness. Most participants identified family support as the most important value for people in the South Asian community when caring for a relative with dementia:

“There is no cure for dementia, there’s nothing you can do for it. So I think that element you’d end up where somebody just thinks: You know what, what’s the point in telling anybody? With cancer or other issues you can maybe, you know, get rid of some of it by discussing it with people, but with dementia you just know.....it’s progressive, there’s nothing they can do so they will continue managing on their own...” (FG1 M3)

7.4 Conclusion

The consequences of how participants saw their community's beliefs and views of dementia affected how family members contained dementia in the community, and their unwillingness to disclose the illness to others. Family members of people living with dementia expressed their view that the community's beliefs and views of dementia tend to be negative, resulting in stigmatisation. This was perceived to result in broader experiences of family members' shame and embarrassment about their relative's dementia. Consequently, families frequently avoided disclosing dementia, and were described as going to great lengths to hide the dementia diagnosis, fearing that the family's standing in the community might be affected. Families of people living with dementia tended to manage/contain their relative at home, which the participants perceived as having a negative impact on the wellbeing of all concerned. As a consequence of having a family member with dementia, the family experiences discrimination and may become alienated from the community, with a potential loss of their sense of belonging.

Chapter 8: Provision of health and social services

Chapter 7 considered participants' discussions about how family members of people living with dementia need to overcome cultural community barriers when they choose whether or not to access dementia services. However, when those services are accessed, many service-level barriers may add to the difficulties experienced by the person living with dementia and their family members. This chapter considers some of those barriers.

The participants' discussions considered the different aspects of the term 'access', which can either mean choosing not to use the services at all or that services are not readily accessible because South Asian cultural needs differ from those of the indigenous population. The first section considers participants' discussions and their perceptions about why members of the South Asian community choose to use dementia services or not (see section 8.1). The second and third sections explore participants' perceptions of whether or not dementia services are accessible in terms of meeting the South Asian community's cultural needs. The second section explains how people in the South Asian community are both integrated in and yet segregated from dementia services (Section 8.2). This is followed by consideration of the participants' perceived unmet needs in the community, addressing how current dementia health promotion strategies fail to take into account the needs of the South Asian community (Section 8.3). The final section of the chapter outlines participants' perceptions of how dementia services could be improved (Section 8.4); and concludes by summarising the key findings from the themes revealed by discussions about access to dementia services.

8.1 Being invisible: accessing dementia services by the South Asian community

This section explores how often people in the South Asian community access dementia services, using the qualitative perspectives of HCPs, people with dementia and their family members, and the South

Asian community discussion about the point at which a South Asian person with dementia and their family may decide to seek professional help.

All HCPs in the study said they had observed a low number of people from the South Asian community seeking dementia services. This suggests that, compared with other ethnic groups, this community is underrepresented in the use of such services. HCPs at the memory clinic shared their experiences of working in dementia services, stating that the South Asian community forms approximately twenty-two per cent of the population of this service area. However, from one HCP's observation, around five to ten per cent of people in the South Asian community presented at dementia services after referral to the clinic:

“Certainly in my experience running the Memory Clinic for [Area 1, where approximately twenty-two per cent of population is of South Indian background, I do not see the similar... similar presentation statistically coming to the Memory Clinic. So I would say roughly about five to ten per cent of my patients at the Memory Clinic are from a South Asian background. The rest are mostly Caucasians.” (HCP1)

When seeking help for these conditions, families in the South Asian community will first try to manage the dementia at home (see 7.3) until they reach a crisis point at which they can no longer manage their relative's care. At this point the family members of someone living with dementia will decide to seek professional help to obtain a dementia diagnosis, which is usually at a late stage in the progress of the person's dementia, as described by healthcare professionals below.

“Yes, because as I said we notice some changes rather than they notice some changes to come to GP, and I've not seen anybody coming to me and saying, ‘My parent or my family member etc., ...’ So it's late presentation – definitely late presentation.” (HCP3)

“...someone is very tolerant in a close family sometimes of really quite severe dementia: they just muddle through and accept it as normal ageing possibly, or something they’ve just got to deal with, or whether there’s a stigma attached to it. I mean I had a case where the family had really presented very, very late and when you did her six CIT screening for dementia...”

(HCP6)

Most participants commented that families usually access dementia diagnostic services only when behavioural symptoms (aggression and violence) become unmanageable without professional help, as the next quote illustrates. A family member of a person living with dementia stated that they accessed dementia services because of their relative’s violent behaviour, which had become difficult to manage, prompting them to approach the family GP:

“Yeah, they indeed are quite reluctant. The first part of the question, what are the issues that they come up with: it’s mainly around behavioural difficulties that they have on a day-to-day basis and find it difficult to manage with them. If I’m allowed to give an example, one family member only approached the Memory Assessment Service when their relative who had dementia started to lose any concept of place and was defecating in the kitchen and causing various problems... shouting, knocking on the door. So it was only at that stage that she [sought] some help....” **(HCP1)**

“But then once she started progressing and getting worse, we thought right okay, I thought to myself this doesn’t seem normal, because I could get her up and we’d be like : come on we’re going to go to the bathroom, and she’d just start hitting me and she’d start kicking off, and I’m thinking Gran it’s me. You know, what’s wrong? And I would think that something was wrong, like something maybe going on and she was trying to tell me something. Nobody... we didn’t

know it was dementia. So then when we got the GP out and they actually mentioned dementia...” (Family Member 2)

Most HCPs interviewees felt firstly that people in the South Asian community will only seek help to obtain a dementia diagnosis in order to start medical treatment. Secondly, they felt that South Asian community members use support or care services related to dementia only to a limited extent. One HCP stated that over the years she has seen only one person from the South Asian group attending a dementia support group. The participants suggested that people in the South Asian community may not want to share their diagnosis of dementia with the community because of stigmatisation, as it is considered personal to them (see section 7.2):

“I mean things like dementia cafés and carers’ groups and activities that would, you know, be... could be beneficial that are available in the community for more of the earlier to moderate phase of dementia. I have only seen mixed-race couples... I see a few mixed-race couples, and I’ve only really seen them access those services of ours which I was really, really pleased about. Yeah. But not... I’ve only had one person attend a carers group once from the South Asian community.” (HCP5)

Thus, the participants perceived that the South Asian community, despite comprising a large number of people who have lived in Blackburn with Darwen for decades, is underrepresented in using dementia services. The next section discusses another limitation of access to dementia services which may act as a barrier to people in the South Asian community choosing to access this specialist healthcare service.

8.2 Integrated yet segregated in services: a lack of culturally sensitive services

People of South Asian heritage feel that service providers want equal representation from the South Asian community at dementia services (integrated), but their needs are not equally met in dementia services which currently lack a culturally sensitive approach to people in that community (i.e. segregated). This section examines the perceived cultural biases of using cognitive testing to diagnose dementia, and the importance of healthcare providers adopting a culturally appropriate approach when engaging with South Asian community service users.

All the participants discussed the lack of culturally sensitive service provisions for people living with dementia in the South Asian community. HCPs spoke at length about the lack of cultural appropriateness of using the current cognitive testing as one of the tools used for diagnosing dementia. All HCPs in the study referred to its failure to take into account the cultural and historical background of the South Asian community in the UK. Participants said that many of the questions in the cognitive test are about significant events in UK history, and many first-generation South Asian immigrants in the UK who have since developed dementia may have insufficient knowledge of UK history to complete the test:

“It’s very difficult because with a cognitive test there are certain questions, like when you start asking who was the Prime Minister here, then they will not remember who was the fifth Prime Minister from now – and things like that. So it’s... it’s... and again some of the elderly people in Asian community...They’ve come from another country and that history is not there... yeah, the history is not there, of course.” (HCP3)

One HCP in the South Asian community related her father’s experience in completing the cognitive test. She addressed the limitations of cognitive testing with people in the South Asian community, emphasising that it is designed in a manner which results in failure for them. She gave an example of

one such question: her father was required to name an animal shown in a picture; in his native country, he did not have these animals on his farm, so he answered the question incorrectly. She suggested developing culturally sensitive diagnostic material, which takes a holistic view of the South Asian community's culture and heritage:

“When my dad, for example, had it, speaking from experience, he couldn't do some of that test because he'd never heard of those words. He's never seen those pictures. When he grew up his heritage is Pakistani, he'd never seen those animals. They don't live on his farm, they don't exist, so he failed half of that test because of that. They're not culturally sensitive. We need much better materials, we need better testing kits, they need to be around... you need to be looking at more universal tools and there needs to be other ways of testing people that doesn't involve remembering in English learning.” (HCP 2)

She reflected on the stress her father experienced when asked to complete the cognitive test, adding that he had never been to school and had never even held a pencil. When asked to complete a cognitive test, she could see his hands shaking:

“He can understand English but he's never been to school, couldn't pick up the pencil. I could see his hand shaking doing the test because it was like a proper test: had a drawing section in it and all these things. Found it difficult.” (HCP2)

Other HCPs agreed, saying that many first-generation South Asian immigrants may not have attended school or may have had no education at all, so it is unfair to expect them to “sit and do a test”(HCP4). The participants added that, when designing a dementia diagnostic tool, it is necessary to take into account the cultural heritage of people in the South Asian community:

“...if somebody hasn’t been to school – which is often the case, there’s no schooling, no education – how can you expect somebody to sit and do a test when they’ve not had education or schooling? It’s unfair to put somebody through that and I wouldn’t do that.” (HCP4)

Participants suggested that a single, one-size-fits-all cultural approach to dementia services, treating everyone the same, may not be appropriate when working with the South Asian community. Participants said culture is a factor in the South Asian community’s understanding (see Chapter 6) and their approach to health differs (see Chapter 7). It is therefore necessary to provide cultural awareness training to HCPs about South Asian culture and heritage, to enable HCPs to provide culturally sensitive services to people in the South Asian community who are living with dementia:

“...Might be one thing that’s right for me, not right for bhai [Brother]. But you know they think... they think that we all people just came from one stencil and they can treat everyone the same. How? They all individual. They got their own issues, the thing... and they should have a sensitivity, that awareness and that understanding and cultural and religious understanding as well because... especially our health, it’s very much to do with...” (FG2 F3)

Participants agreed that another key issue was HCPs’ lack of cultural awareness. The family members of people living with dementia reported that the HCPs involved in dementia services lacked a culturally sensitive approach when engaging with service users from the South Asian community. One family member related that her relative who was living with dementia as a result of a stroke had no translator present at the cognitive assessment appointment. She was dissatisfied with the HCP’s lack of cultural awareness for thinking that everyone using dementia services would be fluent in English, and said that the HCP failed to take into account the language barrier faced by first-generation South Asian immigrants when they choose to use dementia services. She said she understood the assumption that, if you live in the UK, you are expected to know English, but that this is not always true for first-

generation South Asian immigrants. She suggested that HCPs working with the South Asian community should have a cultural awareness which would enable them to adopt a nurturing attitude towards the people in that community who are living with dementia. This would give the dementia service users in this community a more positive experience.

“And there’s nothing there. I understand why they say ‘Well, you live in England and you should know English’ and stuff, but that generation doesn’t, you know. So you have to kind of still be a bit more compassionate towards them, have to have something in place to support them. If I ask for an Asian translator all I ever get is ‘Oh, we’re sorry, we don’t have one available.’ So then what do you want me to do? You’re not going to let me sit in, you want her to go in and speak to her but you don’t want me to say anything, but you couldn’t provide me an Asian translator. What are you going to get out of her?” (Family Member 2).

Having explored some of the cultural barriers faced by people in the South Asian community when they chose to use dementia services, the next section considers how the participants discussed the perceived barriers to raising awareness of dementia in health promotion materials for the South Asian community.

8.3 Unmet needs: communicating health information, and literacy levels in the South Asian community

Improvement is needed to communicate health information – particularly dementia awareness - to older people in the South Asian community who may have lower English literacy.

All the participants expressed perceived limitations about mainstream health promotion materials, including health promotion techniques to raise awareness and educate the community about an illness with paper leaflets. The participants suggested that, although leaflets are an effective way of raising

awareness of and educating the community about an illness, it may not be an appropriate technique for educating the South Asian community about dementia, even when translated into South Asian languages:

“...again people think leaflets is the ultimate, but as I said, some of the people they can't even read in that language so leaflets are quite... sometimes useful for the people who can read, but if they can't read it, that leaflet is not important. Because the third generation, they can't read Urdu and the first generation, some of them, they can't read it, so what the leaflet is for? It's just there, sitting there, doing nothing. Maybe a couple of people they pick up and then they say, 'Right, this is a good read etc.'” (HCP3)

The HCPs said that many older people in the South Asian community speak their own language but are illiterate in that language. One HCP raised this issue, suggesting that some people who cannot read and write may avoid the topic out of embarrassment. A health promotion strategy needs to be developed for people who are illiterate in the South Asian community. One HCP suggested that audio recordings could be used to communicate with and educate older people in the South Asian community about dementia:

“I don't think leaflet is as good as something audio because audio is more like... you can listen to it so you don't have to read it or write it or get embarrassed – that's the thing, when something is written and you don't know how to read it, you don't touch it. So what you do is you just avoid it. Yeah? But if it's something in audio form it's pretty easy because you can't avoid it.” (HCP3)

One family member of a person living with dementia discussed how the prevalence of illiteracy in the South Asian community will influence the effectiveness of conveying health promotion messages.

They suggested that a better form of communication is needed with the older South Asian generation. Other relatives discussed the need to educate people with dementia, who are illiterate in their mother tongue, about their illness by using an accessible format which is easy for them to understand. One relative remarked that an appropriate technique for delivering information on dementia would require more than a translated written document, and that audio recordings in different South Asian languages would be a more effective method:

“We need something in different languages, not something just in written languages but something more audio recording which will... or radio...you use that machinery as well at the same time, but if you give 'em a piece of paper that's in, say, Gujarati, depending on what your mother's tongue is...” (Family Member 1).

The participants suggested that using leaflets translated into a South Asian language is a great “mistake” (FG2 F1) as it does not effectively convey the message to many of the South Asian community, who are not educated even in their mother tongue. A Group 2 participant explained the danger of this, adding that in her experience of working with the South Asian community, many who cannot read in their own language look at the translated leaflets and dissociate themselves, if they cannot relate to the leaflets. She suggested that leaflets are problematic because of an expectation that people will take the leaflet and read it by themselves. However, a poster with an interesting picture or pictures and some writing will appeal to people. In her experience, illiterate people can relate to the poster pictures and ask someone to explain the writing:

“They are not educated in their own mother tongue either and when you give them written stuff they can't read it. I've worked in the community and I've made that mistake and they sort of look at it and say, 'I don't want to' but if they see kind of a poster with images and Asian

language written on it, they will ask somebody and say, 'What does that say?' because they know that it's for them." (FG2 F1)

Participants' discussions about how to improve dementia health promotion materials suggest that they are keen to raise awareness about and educate the South Asian community about dementia. The next section sets out participants' thoughts about how best to bridge the gap between Western services and the South Asian community.

8.4 Looking to the future: bridging the gap between dementia services and the South Asian community

Participants offered suggestions about methods which might improve access to dementia services by those in the South Asian community who adhere to their traditional cultural beliefs, values and practices, but are excluded from Western information. Suggestions included forming what could be described as a 'bridge of knowledge'. The term 'bridge of knowledge' in this context refers to finding a shared platform or common place which individuals from the south Asian community (who do not identify with Western culture) can access and Western health service providers can operate from directly. This could hopefully bridge the gap between individuals with a more traditionalist South Asian cultural outlook and the Western service outlook on dementia.

All participants noted a lack of knowledge of dementia in the South Asian community because of a reliance on the Western medical model of dementia (see Chapter 6). Participants explained the need to educate the community about the medical aspects of dementia, to encourage a more positive view of the causes of dementia, emphasising the concept that seeking help early can be beneficial, in accessing available help and support:

“To show them that it’s real, it’s in the world, and that it’s just one of them things that happens and that there’s no... there’s none of this sort of black magic or that sort of mystical side of it and that it’s just as you get a ’flu, as you get broken legs, it’s an illness just like that but only of the mind... Because it’s mental they can’t see that so you’ve got to sort of disseminate the information and sort of show them that it actually does impact people’s lives and that it actually is a problem and to...” (FG3 M2)

Participants in the group discussions and family members of people with dementia expressed their views on normalising dementia, suggesting that it is necessary to promote the view that dementia is an illness, like any other physical illness. However, they agreed that it would take time for perceptions to change for individuals who identify more with their native culture, to alter their beliefs about mental illness and dementia (see Chapter 6):

“They don’t understand dementia in that... in that way, so that’s one of the stumbling blocks you have to overcome in trying to explain dementia in a normalised way to the South Asian community that... it’s an illness like... like other physical illness, like cancer... you know what I mean.” (FG2 M1)

All the participants agreed that a good place to start this change is by educating the third- and fourth-generation South Asians about dementia. Raised in the Western world, they are more open to Western ideology than their older relatives, so if they are provided with appropriate information and education, they can form a useful bridge in bringing their newfound knowledge to the community:

“...as the generation gets more and more, there are going to be more and more older people.....to look after, right. The younger generation, if they know what’s going on, they know what to do, how to access the services, and then they can help and they can use the help

themselves... I think we approach them at High School level, but not at 13, 14... I would be told 15, 16... 17, 18... College levels.” (FG2 F2).

“When you look at the demography of our society in [Area], there’s a lot of children, you know, who are BME Asian... we’ve got to find a way of making sure that they are well-educated on it – and I think generally they are. I mean I think you’ve also got to look at how you communicate with communities and we’ve mentioned sort of education globally, we’ve mentioned the internet. I think technology’s a very good way of communicating with BME teenagers especially because they’ve very IT-literate as a sub-group. I think also, you know, to normalise it, to make it part of every-day understanding, and to reduce the stigma.” (HCP6)

HCPs emphasised the need for sensitivity to South Asian cultural and traditional values whilst also trying to show them the medical model of dementia, commenting that the community feels a Western worldview is imposed on them. Group 3 participants considered how this could be minimised: by using experts - South Asian language speakers - to educate the community in person, to facilitate the process of educating and integrating the medical model of dementia in the South Asian community:

*“If people are not aware of stuff like dementia and the symptoms and the causes and the reasons, then they’re not gonna do anything... If there’s no communication and there’s no understanding, if there’s no knowledge, then they won’t do that: they won’t... they’ll just think of it as *summat*, you know, natural... you know, you could have people volunteering that know about dementia to go to, let’s say, houses and, as I said, have that sort of dialect of them speaking Urdu, you know, for them to be more comfortable.... if people are coming to them, you know, making them feel special, they’ll probably think: Oh, yeah, you know what... I’m in my own home, I’m comfortable here, I’ll listen to you about it.” (FG3 M1)*

8.5 Conclusion

In conclusion, all HCPs suggested that access to dementia services by people in the South Asian community living with dementia is limited, only taking place in the later stages of their dementia illness. The participants from three focus groups, HCPs and people with dementia and their family caregivers all discussed how health and social services are provided indicated that, when services are accessed by people from the South Asian community, culturally inappropriate tools and resources are often used in their treatment and diagnosis. HCPs discussed using cognitive diagnostic tools, suggesting that this method fails to take into account the cultural diversity of people living with dementia who are tested. The family members of people living with dementia expressed their hope that a culturally competent service for people in the South Asian community could be established which would promote diversity in its approach to its engagement with service users. They suggested that, in order to achieve this, cultural training is needed among health professionals about the historical background and cultural heritage of the South Asian community. This would help them understand and respect the needs of the community, especially first-generation South Asian immigrants living in the UK. Conversely, the majority of participants agreed on the need to educate the South Asian community about the presence of dementia by using appropriate health promotion approaches. Currently, these approaches fail to take into consideration that many people in the South Asian community cannot read or write even in their mother tongue. Face-to-face communication or audio recordings on dementia in South Asian languages would be more effective, methods which would facilitate the process of educating the community about the Western medical model of dementia.

Chapter 9: Discussion

This research has sought a deeper understanding of dementia in the broader context of community, health, and illness. The qualitative approach enabled me to explore and explain my understanding of the sociocultural issues underpinning the processes of accessing dementia diagnoses and support services in the South Asian population in Blackburn with Darwen. I have drawn on Habermas's theory of communicative action and Goffman's theory of stigma, which enable an understanding of socio-cultural issues, here specifically how the dementia diagnosis is made and how related support administrations are accessed by the South-Asian Indian and Pakistani populations.

Chapters 6, 7 and 8 interpret the findings of how the South Asian population accesses dementia services, the consequences of living with dementia, and community health services provision. This chapter describes the findings more comprehensively, taking account of the wider literature including material introduced in Chapters 2, 3, and 4. I also develop a conceptual model which summarises the relationship of the key research themes, consider the strengths and limitations of undertaking this research, and outline my experiences while undertaking the study.

9.1 Developing understanding

The research process confirmed my initial perception that South Asian culture has caused some people with dementia, and their families, to experience stigmatisation, contributing to their delay in accessing health services. Findings in Chapters 7 and 8 indicate negative cultural aspects associated with dementia, which proscribe the level of engagement with and provision of health services. However, most participants interviewed in this qualitative research suggested that this may be due to a lack of knowledge of the differences between normal healthy ageing and age-related illnesses such as dementia. Figure 9.1 outlines a conceptual model illustrating diagrammatically how cultural

perspectives, a lack of knowledge, and a lack of culturally sensitive services influence South Asian people to seek professional help for dementia.

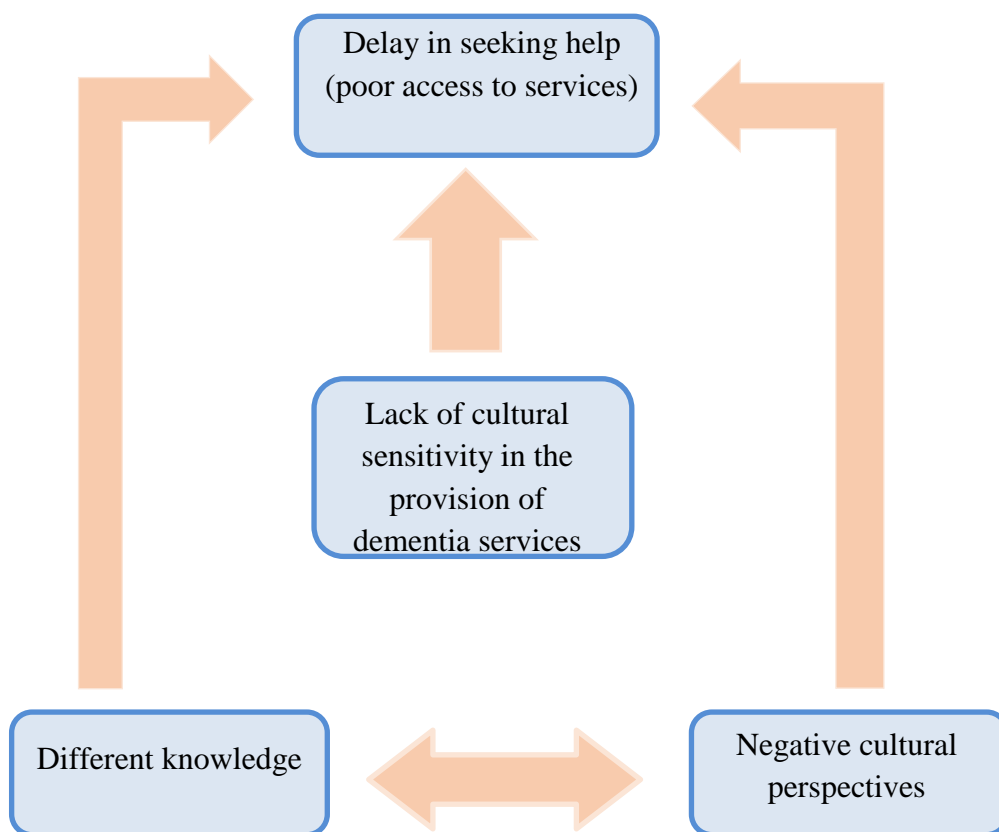


Figure 9.1: The delay in service and lack of cultural sensitivity in the provision of dementia services.

Figure 9:1 shows how poor access to dementia services, coupled with different knowledge and negative cultural perspectives, together result in South Asian people adhering to cultural norms which discourage them from seeking medical services at an early stage of dementia. The negative labelling attached to individuals with dementia because of cultural norms leads to cognitive separation, which in turn causes social withdrawal and rejection. A negative perspective on dementia may prevent people with dementia or family caregivers from seeking health services or providing support to individuals from an early stage of dementia. As the research findings confirm, the broadly quite negative perceptions in the South Asian Indian and Pakistani community of people with dementia may compromise the delivery of such services to those affected. Seeking help at an early stage of dementia

means appropriate support and information can be given to the person, helping them to make decisions as to whether they would like an early or timely diagnosis (see section 1.1. for a detailed discussion).

Literature cited in Chapter 3 emphasises how a lower level of acculturation shapes the perception and knowledge of dementia, through the culturally associated beliefs and values assigned to dementia by the South Asian community (Adamson and Donovan 2005). Hailstone et al. (2016) argue that culture has a profound effect on the knowledge and subsequent decisions made by individuals about seeking healthcare services. The lack of information about dementia in the South Asian community is a factor in the decision to delay seeking healthcare assistance. Habermas's Theory of the communicative action, draws on colonisation of lifeworld by the system world is the critical theory underpinning the research findings. Habermas's theory implies that a lack of appropriate interaction in the South Asian community (see section 9.2) causes people from that community to seek a diagnosis of dementia at a late stage when the illness has become unmanageable in the family. Goffman's Theory of Stigma, moreover, amplifies the shame attached to mental illness in the South Asian community, illuminating how persons with dementia and their families face stigma in the South Asian community. Incorporating these two theories enables a broader understanding of the reasons for the South Asian community's poor access to health services for individuals with a different knowledge of dementia, and a lack of cultural sensitivity in the provision of dementia services and literacy issues.

9.2 Poor access to health services

The study's findings attribute poor access to health services to the inadequate knowledge of and negative cultural perspectives on dementia which make South Asian people adhere to cultural norms, discouraging them from seeking medical services in the earlier stages of dementia. Drawing on the underlying cultural aspects noted by Goffman (1963) and the communicative model of Habermas (1984 and 1987) may explain the social and cultural reasons for poor access to dementia services for people from the South Asian community. According to Goffman, society often tends to look down on

individuals with mental illnesses, regarding them as not 'normal.' As already noted in Chapters 6 and 7, many in the South Asian Indian and Pakistani society attribute mental illnesses and dementia to madness or 'craziness', or believe the condition has a spiritual origin. This confirms a previous study by Adamson (2001) who found a similar association with dementia; this causes stigma, an issue which deters individuals from seeking healthcare at the appropriate time. These cultural factors evidently determine whether or not a person with dementia would seek health services.

The findings from this research imply that in the South Asian Indian and Pakistani community, the underlying cultural factors, such as cultural beliefs, customs, and practices, result in associating dementia with spiritual origins, which makes the South Asian community view individuals with dementia differently – and in turn, an individual with dementia will behave differently to conceal their condition. This reflects Goffman's theory of stigma, particularly the concept of back-stage and front-stage, which are discussed in more detail in Chapter 4. For instance, the study findings suggest that individuals with dementia in the South Asian community may take a back-stage position about seeking help when in the public domain. 'Back-stage' here implies that an individual with dementia may shy away from seeking health services because of the stigma associated with the disease in their community. They do not seek help from society or health professionals, resorting instead to seeking help from their family. Individuals with dementia visit clinics and other healthcare services only when the symptoms worsen and eventually become unmanageable without professional healthcare experts' assistance. Attempting to manage dementia without professional support can cause severe suffering for individuals with the disease and their relatives. In Goffman's model, such individuals put on a 'face' to conform to community expectations, only presenting their true self in private.

Habermas's theory incorporates aspects of 'lifeworld' into society's social activities (Habermas, 1984), contending that the system-based governance structure in the healthcare sector accords the healthcare professionals the power to colonise the lifeworld of individuals. Chapter 8 discusses how people manage dementia in the community, feeling unable to access professional support because of

unintentionally biased non-inclusive healthcare policies. System-based governance thus disrupts the communicative action between individuals with mental illnesses, such as dementia, and the healthcare professionals.

Habermas asserts that communicative action holds the key to harmonious interdependence between healthcare professionals and people with dementia. The distortion of the communication process thus implies that the healthcare professionals have authority over the lifeworld of individuals with dementia, thereby creating medical dependence. While the healthcare professionals have good intentions and motives to help people with dementia, they are part of the system which suppresses such healthcare delivery, as the study findings indicated (Chapter 8). Habermas' theoretical perspective posits that communication is critical in creating rationality and establishing a participatory democracy in which the formal system and individuals living with dementia correlate harmoniously (Habermas 1984). Policy-makers and the community can reach a consensus on healthcare for individuals with dementia from the South Asian community through participatory means, including the communication process. Through communication, healthcare professionals can develop a fundamental cultural knowledge of the South Asian community, which will enable them to offer substantive healthcare to individuals with dementia without challenges.

9.3 Different knowledge of dementia in the South Asian community

This study interviewed healthcare professionals (HCPs) and people with dementia and their family members to explore the understanding of dementia in the South Asian Indian and Pakistani community. Knowledge of dementia is important because having appropriate understanding will enable family members to accept that their relative has dementia and seek the support and services needed to manage the condition. A knowledgeable community is an empowered community (Purandare et al., 2007). Education about dementia can equip members of the community with the necessary crucial information. Despite increasing knowledge of dementia, the findings revealed that

most in the South Asian community tend to perceive dementia differently from the Western view of the disorder. The people from the community relied on experience knowledge (lifeworld) while managing the dementia condition, but had limited cognitive knowledge (system medical knowledge). However, the person with dementia continues to be viewed by family members and the community in a way which reflects their experience knowledge (after being given appropriate information). Experience and knowledge encompasses the personal experience of caring for people with dementia, including understanding how to manage dementia at home without engaging healthcare professionals. Cognitive knowledge, however, includes the awareness to seek dementia services, ideally drawing on evidence and information. Jutlla (2015) asserts that the rising numbers of people living with psychological illness in South Asian communities in the UK mean that this marginal population does not have the cognitive knowledge, which is detrimental to good management of dementia.

Healthcare professionals and participants from the South Asian community who participated in the study were of the opinion that the situation is changing for the better because of improving education across our society. People who have benefited from higher education, according to the HCPs, perhaps unsurprisingly tend to be more informed about dementia compared to a member of the South Asian community with little education. Giebel et al. (2015) support these findings, asserting that a lack of information can delay seeking a diagnosis for dementia, as it shapes an alternative interpretation, explanation, and meaning of the illness. Giebel et al. (2015), even after controlling for education level, found that dementia caregivers from Asian, African, and Hispanic families still conceptualised dementia differently from the biomedical model. It is therefore important to understand the cultural meanings, beliefs, and values associated with dementia, which can delay diagnosis and impact the quality of life for people with dementia from the South Asian population.

Culture affects individuals' knowledge of medical problems (Purandare et al., 2007). Dissimilarities are evident between Western culture and that of the South Asian communities; the majority of the community respondents referred to the challenges members of the South Asian community faced after

migrating to the West, as Western lifestyle and culture differ from the lifestyle and culture of South Asia. The majority (over seventy-five per cent) of South Asian respondents said they regarded dementia as a mental illness, and that it is often perceived as a Western notion since the community is devoted to the inherent beliefs of their native culture. As the concept of dementia is unfamiliar to South Asian community members, they cannot identify with Western notions of mental illness. One respondent indicated that dementia, like other mental diseases, is regarded as a taboo because no-one wants to be labelled with such a disease. Some respondents attested that they regarded dementia as an invisible illness, like cancer, and all agreed unanimously that dementia occurs in old age. HCPs reported a common perception of dementia in the South Asian community that the symptoms are a normal part of ageing – a perception which arises because the early symptoms of dementia in the Western medical model do not fit South Asian cultural norms and social harmony. According to Purandare et al. (2007), some Asian groups regard dementia and cognitive decline as a common disorder of old age. Accordingly, changes in memory - including dementia symptoms - are seen by family members as among the usual changes attributed to old age. Some respondents in this study who do not understand the illness related dementia to either a spirit or a curse. Attributing such a serious medical condition to a spirit affects people's attitudes, particularly if they have someone with dementia in their family.

The difference in perception and knowledge of dementia exemplifies what Habermas outlines in his communicative action theory. The communicative action indicates that the lifeworld of the South Asian community requires social and mutual understanding to minimise the effect of dementia services designed to serve the system world. Through the communication process individuals in a community can comprehend issues in their society through consultation and argumentation. Individuals often engage in argument during a communication process, which forms the basis of rational communicative rationality and consensus, particularly concerning a society's behaviour and practices. People in a community often have differing opinions on particular issues, and try to convince others that their

viewpoint is correct through argumentation (Hahn, 2000), often reaching a consensus through the argumentation process. The theory posits that individuals will always vindicate or criticise a contentious issue - as witnessed in the South Asian community - including the concept of dementia (Hahn 2000). Criticism of dementia is useful in establishing the facts underlying the causes or management of the disease. In this case, a communication space is required between the healthcare professionals and the people with dementia and their family members.

Habermas's concept of the lifeworld posits that social and mutual understanding among groups is established through face-to-face interaction occurring over time (Habermas, 1984), which results in the formation of groups of people with shared norms, values, and practices who form families or create communities. Habermas suggests that different cultures have distinctive aspects and that practices, values, and beliefs adopted by individuals often depend on the level of attachment to their culture (Habermas, 1984). Individuals with devoted beliefs and strong attachment to their cultural practices often display behaviour and practices which align with those cultural practices. The South Asian culture, like the British Western culture, has a broad range of cultural elements, encompassing different elements. Habermas proposes that a key component of the lifeworld is that individuals may relate to each other through shared mutual understanding of a particular situation (Hahn, 2000). The suggested lower number of people from the South Asian community accessing dementia diagnostic service may be attributable to the lack of social and mutual understanding of dementia; lack of broader understanding among the people of South Asia limits the opportunities for establishing social relations, and affects how dementia services are delivered.

Most of the study's respondents agreed that unity of community and family is a strength to overcome various challenges. As Jutlla (2015) asserted (see Chapter 3), the strains of dealing with individuals with dementia lead to emotional issues for the individual and their family. Victor et al. (2012) noted that with the caregiver and family's support a person with dementia can manage their condition and understand their symptoms. La Fontaine et al. (2007), however, argue that Asian caregivers experience

shame in having a family member with dementia, as they fail to maintain social associations in a socially expected way. The assertions of La Fontaine et al. (2007) concur with the study's findings that the majority of family members attested that they prefer concealing their relative's dementia to avoid being rejected and isolated by the wider community. This can result in further stigmatisation, which may worsen the situation. In Goffman's theory of stigma, a person with dementia may become stigmatised through a negative labelling process, which may make the person with dementia withdraw from social activities and interaction before losing status in the community. South Asian community or family members of individuals with dementia thus play an important role in determining the stigmatisation of people with dementia. The wider South Asian community and family members of people with dementia need to avoid negative stereotypical views and labelling to avoid stigmatisation.

Goffman's (1963) work supports the findings of this study by indicating that what is categorised as stigmatising by a particular group or community is developed and maintained through the process of a social construct. According to Goffman's concept of stigma, stigmatisation arises when there is a discrepancy between the virtual social identity and the actual attributes individuals possess. In his theory of stigma, Goffman points out that certain characteristics are regarded as honoured or dishonoured, depending on the nature of the illness or the historical and social context, particularly when it involves understanding stigma within a racial or cultural group. An individual may, for instance, identify a perceived risk or situational indications. People develop a collective knowledge of negative stereotyping and cultural views about mental health, identifying those which could dishonour their character - individuals thus strive to maintain their social identity. Where possible, most people with mental illness will typically try to avoid potentially demeaning situations; Goffman's theory of stigma posits that social actors will behave differently depending on the familiarity of the setting, where they are, whom they are with, and what role they play.

Purandare et al. (2007) support the current study's findings, asserting that when people with mental illness (a non-visible stigma) understand the social viewpoint (cultural understanding) of what it might

be like to live with mental illness within a community, they and their family members will be afraid to disclose their illness or diagnosis to the community. Such fear may be attributed to a fear of losing status or even rejection. The family may experience embarrassment and discrimination in the community because their relative's mental illness leads to the family feeling shame or becoming fearful of talking about mental illness. To avoid this, the study's family member interviewees who were affected by the dementia condition agreed on the societal acceptance and support. The respondents stated strongly that community support is key to ensuring unity, a sense of identity and feeling love. Rejection from the community would make the family of a person with dementia feel both vulnerable and unprotected. To ensure the wellbeing of people with dementia, therefore, it is important to enhance community integration. Avoidance of negative stereotypical views and negative labelling among the South Asian community and family members of people with dementia can lead to a diagnosis of dementia at an early stage.

9.4 Negative cultural perspectives

As with most communities, South Asian people are influenced by cultural background because a person's identity, personality, education, socioeconomic status, and experience are all derived from the immediate community. The findings indicate that individuals with dementia from the South Asian community are likely to approach their health practitioners for support with physical ailments rather than mental disorders, because of the various cultural issues which inhibit them from seeking healthcare services. Many such people hold the deeply-ingrained cultural belief that general practitioners respond only to physical ailments and not mental illnesses, including dementia. The findings indicated that this belief derives from the spiritual perspective of South Asian cultures which associates dementia with spiritual possession, rather than regarding it as a disease. The study findings also allude to the South Asian community's inclination to the cultural belief which associates dementia with shame – which leads to a reluctance to seek professional help - rather than regarding it as a

neurodegenerative disorder. This study also confirms previous findings by La Fontaine et al. (2007) (see Chapter 3).

Most members of the South Asian community believe that families should take care of individuals with dementia, and that therefore no additional care from healthcare professionals is needed. This was evident as the study participants attested that they always prefer to take care of individuals with dementia at home rather than bring them for effective treatment by professional caregivers. The majority asserted that home-care is preferable, since the disorder is associated with spiritual factors. Purandare et al. (2007) support this finding by arguing that family members of individuals with dementia often prefer to avoid staying in hospital to recover. Purandare et al. (2007) also put much emphasis on the lack of cultural adaptation. The study's findings revealed that unlike the dominant Western culture, which elevates individualism, the South Asian cultures tend to promote collectiveness and the pursuit of communal activities. The cultural arguments are distinct in both the Western and South Asian cultural backgrounds. As noted in section 6.2.5, the dominant cultural beliefs in the South Asian community result in a perception that individuals with mental disorders, including dementia, are "possessed" or "taken over" by spirits, which control their bodies. The perception and belief imply that the management of dementia is spiritual, so the professional and scientific approach to managing dementia is largely discounted. Many members of the South Asian population do not share the dominating Western understanding of dementia. Western cultural belief embraces healthcare intervention in tackling dementia, asserting that any contrary perception is likely to hinder the management of the mental disorder.

The different cultural perspectives on dementia illustrate Habermas's view of cultural modernity. Habermas argues that the system fails to provide adequate understanding of illness to patients without taking into account traditional norms, cultures and most importantly religious beliefs. His theory implies that cultural undertones affect the South Asian community's understanding of the causes and therapies for dementia and other mental illnesses. From the Habermas (1984) theoretical perspective,

the members of a society pursue certain social actions as a result of mutual understanding and co-operation, as encompassed in the 'lifeworld' concept. The theory also attributes lifeworld to a shared cultural system of meaning and institutional order which underpins certain patterns of social actions and personality structures, as witnessed in various social settings, including school, family, neighbourhood and the religious setting. No matter how effective the healthcare professionals may try to be, the South Asian cultural and belief systems usually curtail their harmonious relationship with people with dementia, thus interfering with healthcare access (Habermas, 1984). The Habermas model posits that individuals often achieve friendly relationships and mutual understanding through the communication process. However, the cultural system exercises power over the lifeworld of individuals, such as facilitating negative cultural perspectives about dementia, thereby disrupting effective communication and understanding between the community and the healthcare professionals. As noted in the findings of this study, the lack of common belief between Western and South Asian cultures results in difficulties in diagnosis which lead to poor administration of appropriate care.

Individuals with dementia always experience emotional, social and psychological consequences because of negative cultural perceptions about the disorder. Karim et al. (2010) suggest that the impacts of the disorder on individuals with dementia are not confined to the physical symptoms, but also encompass the psychological and emotional attributes. The individual with dementia's family members may exhibit feelings, responses, and thoughts which are detrimental to mental and emotional wellbeing. Responding to and addressing an individual's needs is critical in managing dementia. Adamson (2001) stated that a person with dementia may be prone to mood changes and irritability. The community and family members of people with dementia influenced by cultural norms may negatively label someone with dementia as insane, possessed by evil spirits or suffering from infectious disease. This leads to loss of self-esteem and community status, resulting in withdrawal and stigma. As a result of stigmatisation, in Goffman's theory the individual no longer seeks healthcare support from the professionals, or shares their challenges and encounters openly with other community

members. Instead, they rely on family members for support, which may compromise both the professional healthcare support and their social health.

Living with dementia can have a tremendous impact on a person; stigmatisation and discrimination are attributed to insufficient understanding of dementia in the South Asian community and the perception that dementia symptoms, especially in the later stages, do not conform to the community's cultural norms and expectations of being perfect and having high status. Goffman's theory of stigma posits that the front-stage interaction and behaviour of someone with an illness will be informed by how it is reflected in the setting and how they may be expected to behave. Lawrence et al. (2010) assert that the act of stigmatising someone is deeply rooted in cultural understanding.

9.5 Cultural sensitivity in the provision of dementia services

As already discussed in this chapter, Western and South Asian cultures are diverse, and the level of attachment individual members of society have to their culture may impact on the decision to seek healthcare. Individuals who have a strong attachment to their culture which perceives dementia as normal ageing are unlikely to seek immediate healthcare or contact their GP for urgent treatment. Conversely, individuals less strongly attached to that culture are likely to forego the cultural belief and seek healthcare support for mental illness. A South Asian member with dementia often seeks family help without contacting a professional caregiver, only seeking professional help when the condition worsens (Adamson, 2001). Western culture – unlike South Asian culture - advocates immediate healthcare support to individuals with dementia once signs and symptoms become apparent. Chapter 8, however, indicates that not everyone from different cultures will seek healthcare at the onset of the disease.

That most South Asian members usually seek help from the family without contacting professional caregivers can be attributed in part to the lack of culturally sensitive approaches. Cultural sensitivity is

imperative because of the reduced awareness of dementia in certain cultures. It is important therefore that the community is offered access to knowledge about dementia which respects their culture and faith. Habermas's theory implies that individuals involved in the provision of healthcare services to people with dementia should be culturally sensitive (Habermas, 1984). Two people from different cultural backgrounds may misjudge each other's actions because of differences in their cultural practices. Both individuals will present divergent and culturally prescribed viewpoints on various issues, including communication patterns, problem-solving, and etiquette, among other potentially contentious issues. The theory suggests that the communicative process enables individuals from different cultural worlds (here, healthcare professionals and people with dementia) to interact and understand each other on various platforms. However, the system often exercises power, using such resources as money to disrupt the communication between such individuals. In so doing, it marginalises people with dementia by imposing unfavourable healthcare policies, such as a shortened duration of professional healthcare assistance and other potential deterrents. People with dementia require an intervention which both reflects their culture and provides timely medical attention. HCPs should be able to distinguish between the needs of the broader community and those of particular cultural groups. The next section will focus primarily on how literacy levels influence access to and delivery of dementia services.

9.6 Literacy

In the modern world, global literacy levels play an instrumental role in almost all aspects of a person's life and in community wellbeing. The findings of this research suggest that the literacy levels seen in the South Asian community have contributed adversely in dementia management in the community. Respondents attributed the lack of awareness of dementia and inadequate health information among the older to low literacy levels. All the respondents mentioned high illiteracy rates in the South Asian community, particularly among the older who often cannot understand written health information.

With low literacy levels, individuals may lack vital knowledge about dementia, which affects their healthcare decisions, including the need to access healthcare in health facilities. It is challenging for those with scant knowledge of dementia to both understand and relay information to others about how to manage dementia, and here the South Asian community is not exceptional. The findings revealed that the older generation's fluency in their language does not necessarily imply they are literate in communicating dementia treatment information to other people in the community, even in their mother tongue. Some people may be fluent but lack the capacity to convey valuable relevant information to the targeted audience on various topics, including dementia.

The Habermas (1984) theory advocates adult education as one of the core initiatives needed to increase people's literacy levels and awareness of dementia treatment and management. Equal inclusive rights to education were proposed, and equal access to the opportunities adult education can provide (Hahn, 2000). Improved education revitalises the public political sphere, enabling an emancipatory and participative society. Education equips people with adequate and reliable information relevant to making appropriate political and social decisions, promoting democracy in society and giving everyone an equal right to be heard and to participate in the decision-making process and other initiatives (Hahn, 2000). An educational initiative could improve South Asian community members' literacy levels, particularly in understanding and addressing dementia and associated factors. The Habermas model implies that enhanced literacy levels are critical in revitalising the political, cultural, social, and political systems in both the South Asian region and the world as a whole (Hahn, 2000). It also enhances cultural sensitivity as people become aware of others' cultural background, thereby offering effective and appropriate healthcare services to individuals with dementia irrespective of their cultural background.

9.7 Finding common ground

The discussion above clearly illuminates the sociocultural issues underpinning the processes of accessing dementia diagnoses and support services in the South Asian community. Figure 9.2 can help find the common ground about the South Asian Indian and Pakistani community experience of dementia through the application of Habermas and Goffman theories.

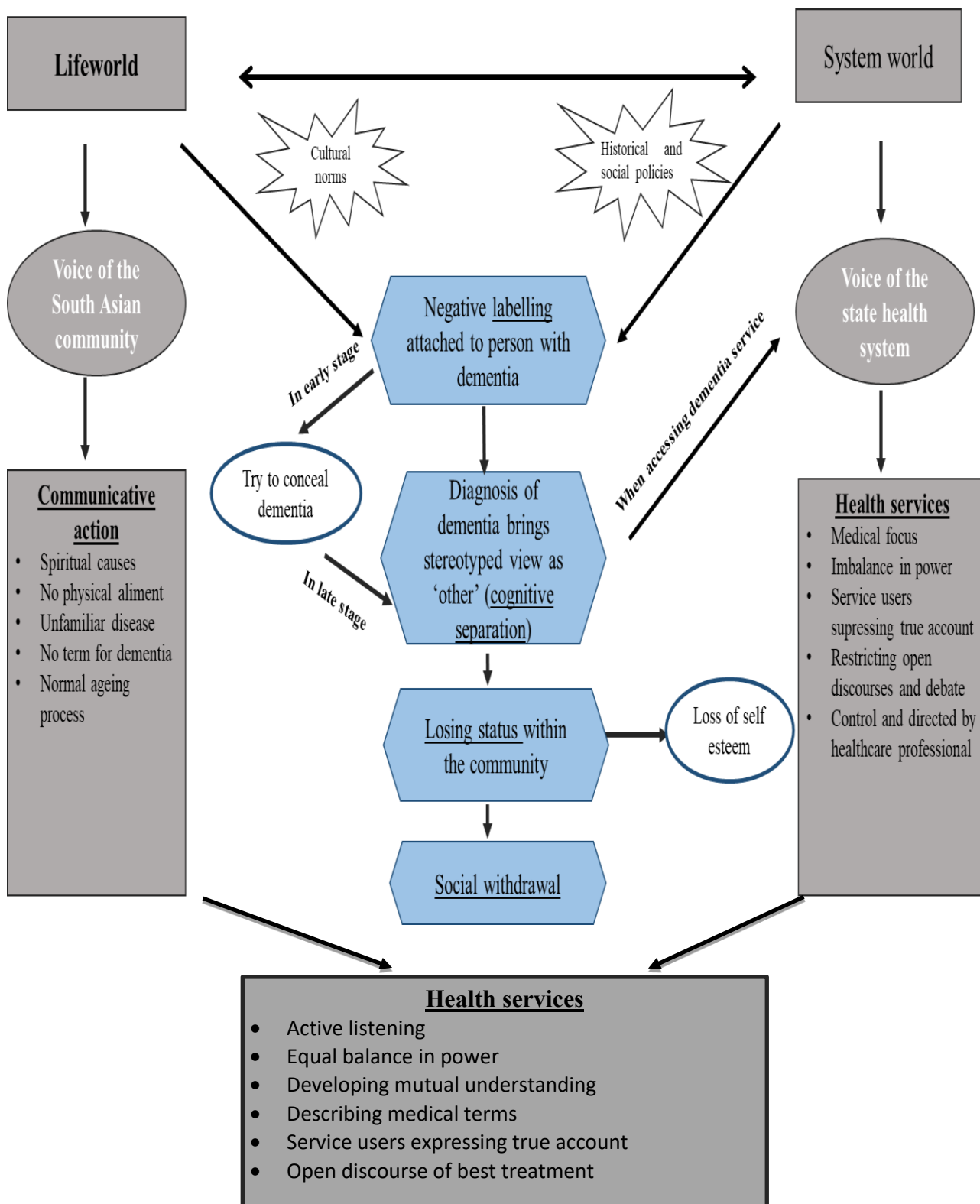


Figure 9.2: Applying the theories of Habermas (in grey) and Goffman (in blue) to better understand the South Asian community's experience of dementia

Figure 9.2 illustrates the concept of communicative action, proposing that the lifeworld of the South Asian community requires social and mutual understanding in order to ensure healthcare services

engage more effectively with this community. Habermas emphasises lifeworld as a setting where people can discuss and deliberate reflectively on social goals through communicative action (Hahn, 2000). Language is regarded as critical in reducing the necessary action of the system world over the lifeworld of modern society (Hahn, 2000). While lifeworld encompasses the private sphere, Habermas argues that system world involves the public space where individuals share opinions and ideas on a societal platform, emphasising that the system often takes advantage of its authority to colonise the lifeworld. In the delivery of healthcare to the South Asian community, for instance, the system world often imposes restrictions and conditions on those seeking dementia services through the healthcare professionals.

Chapter 4 discussed how healthcare professionals are bound by existing healthcare policies, which in many cases favour the professionals over the community. Healthcare policies - such as short-duration GP appointments as the first contact with a healthcare professional - often limit the potential for someone with dementia to access quality services, including referral to the memory clinic for further healthcare assistance. The lifeworld in the Habermas theoretical model is a social context where individuals share their problems through mutual understanding (Hahn, 2000).

The South Asian Indian and Pakistani community lifeworld encompasses their shared values, customs, and cultural practices. Their shared cultural identity is established through shared interactions and maintained through collective action. In such communities, shared cultural identities may negatively perceive issues such as dementia (see section 9.5), and the South Asian culture has labelled such individuals (see Chapter 7), leading to heightened stigmatisation of individuals with the disease (Hahn, 2000). Figure 9.2 illustrates how the negative perception of individuals with dementia may result in social stigmatisation, which arises when the society perceives an individual as 'not normal' compared to other members of the society. The social stigma may lead to self-stigma, resulting in social withdrawal (Hailstone et al., 2016). Thus an individual subjected to social stigmatisation by the

community is more likely to conceptualization of poor mental wellbeing such as become depressed and develop self-stigma or deteriorated self-esteem.

Individuals with dementia often disengage from 'normal' members of their community (Victor et al., 2012, P.86), especially when social stigmatisation sets in, as demonstrated by Goffman's theory. This study's findings confirm that individuals with dementia often shy away from the public and from seeking healthcare support, particularly when they experience social stigma from community members who view them as not 'normal' (Giebel et al., 2015, P.377). Withdrawal often occurs when such individuals succumb to negative stereotyping and feel inferior to other members of their community. The Goffman stigma model emphasises how society stigmatises individuals they perceive as having disgraceful or dishonourable characteristics, and in so doing, society labels individuals it considers lack qualities and characteristics which make people 'normal'. Integrating Goffman's social stigma theory and Habermas's theoretical models enhances the understanding of cultural knowledge's relevance in the pursuit of collective understanding.

Based on Goffman concept, individuals from south Asian community develop a collective knowledge of negative stereotyping and cultural views about mental health, identifying those that could dishonor their characters; in this fashion, individuals strive to hide their status and do not seek medical services. Therefore, any individual who is developing a dementia will have knowledge of how other members of the community might stigmatize them and their families. Habermas' theory of communicative action implies that people from a South Asian community need to engage in an open, shared space where individuals come together and discuss their opinions and societal problems freely. Nevertheless, people from a South Asian community may experience stigma in the cultural context because the services and health policies do not conform to their cultural understanding. This limits the influence of the system on the colonisation of their lifeworld through communicative action; in practice, by expressing their disagreement to the healthcare professional.

Applying Goffman's theory (1963), the South Asian community in BwD could be said to experience 'group association stigma', whereby they cannot seek assistance because of the shame and the cultural differences which exist in the recognition of mental health care and mental illness. This means that ethnicity and culture are the key aspects which should be taken in account when applying effective approaches and treatment strategies (Habermas, 1984), particularly at earlier stages before the illness progresses. People with dementia and their family members can, by socialising within the community, identify cultural cues about what it means to live with or have a family member suffering from dementia within that community. However, Habermas's (1984) theory suggests that the system may generate the opinion that the only way to manage this condition is by medical dependence. Giving power to healthcare professionals (a component of the system-operated health setting) colonises the lifeworld of the people using dementia services through economically-driven health policies (for example, through five-minute appointment times with GPs). This limits the opportunities for communicative action between healthcare professionals and people with dementia or at best, access to resources available to the individual. This particular pattern of communication within a person's lifeworld arguably then allows healthcare professionals to maintain their power, by dominating communication and exerting medical interventions, resulting in a missed opportunity for a more culturally sensitive interaction; and thus not allowing the person with dementia to give a true account of their condition (service users suppressing the account). Integrating Goffman's social stigma theory in Habermas' theory of communicative action will help provide new knowledge and insight into the empirical social world of the South Asian community. This enhances the understanding of cultural knowledge's relevance in the pursuit of collective understanding.

9.8 Strengths and limitations of this study

The strengths and limitations of this study are discussed in this section.

9.8.1 Strengths

When this research was initially conceived, little was known at policy and research level about the South Asian population's understanding of dementia. More recently, (see Chapter 2), there has been increasing interest in understanding the societal and community responses to dementia and people living with dementia (DH, 2012). This research is the first locality-based study to explore the socio-cultural issues underpinning the process of accessing dementia diagnoses and support services in the South Asian population in Blackburn with Darwen.

Various aspects of qualitative research informed the methodological approach adopted by the researcher, to understand why accessing and delivery of healthcare among individuals with dementia in the South Asian community is typically delayed. The study used primary data collected through interviews, and a literature review to thoroughly understand the factors behind the variables in the research. This research has addressed a gap in the literature and provides a comprehensive understanding of how dementia is perceived by the South Asian community living in an ethnically diverse locality, and the impact of this understanding on people living with dementia and their family members. Adopting a qualitative data collection approach has enabled the study to establish an in-depth understanding of South Asian community experience of dementia. The use of qualitative interviews and focus groups has allowed the researcher to explore the factors that may influence these choices or opportunities of access to existing services. The qualitative aspect enables a researcher to acquire rich data about participants' emotions, personality characteristics and human behaviour.

Cross-cultural working raised certain language constraints which have impacted on the data. A key strength of the study is the researcher's multi-lingual fluency and knowledge of the South Asian culture, which have been invaluable in limiting translation difficulties and improving the quality of the

translated data (Temple and Young, 2004). The researcher's fluency in Gujarati made it possible to translate interviews with those with dementia through a literal translation of the data. Secondly, belonging to the South Asian culture made it possible to have an insight and be tuned into how someone from the South Asian culture might speak English, where individuals' levels of English fluency varied.

9.8.2 Limitations

The research participants might have had a greater knowledge of or interest in dementia than those who declined to take part. Even allowing for this selection bias in recruiting people from the South Asian Indian and Pakistani community (people who were not healthcare professionals) for the qualitative phase of the research, the findings have nevertheless deepened an understanding of the issues. It would have been interesting to explore the characteristics of those approached during recruitment who declined to take part.

All the community members in the focus groups and the individual interviews with persons with dementia and their family members were from a Muslim background. The participants are therefore not representative of the religious diversity of the South Asian Indian and Pakistani community. However, this study reflects the experience of dementia for people with a South Asian background who are Muslims (see Chapter 3).

While the South Asian community is a complex, heterogeneous group, with different cultural values and traditions, this research narrowed the focus to the South Asian Indian and Pakistani group. South Asian Indians and Pakistanis are arguably heterogeneous groups but, drawing on my own experience of belonging to both communities, this thesis suggests that there are more shared cultural values and norms than differences between the two groups, which were evident in the focus groups, where Indian and Pakistani members took part together in the group discussions. Habermas's theory suggests, furthermore, that individuals from homogeneous groups may differ in the relationships they share with

their community's norms and values (see 9.2). Another limitation of the study is that although it adopts Habermas's theory, which discusses the level of acculturation (social, psychological and cultural modification an individual or group adopt as a result of blending between cultures), I chose not to measure this among the participants, which in light of the findings it would have been useful to explore, to achieve a deeper insight into the meaning and extent of acculturation among the South Asian community.

Another limitation is that the study falls short of looking into aspects of social care for people from South Asian community. While the study placed emphasis on healthcare, particularly among individuals with dementia, it did not address social care issues. It would be necessary to identify the social care needs of individuals with dementia before adopting a comprehensive social care plan to tackle such needs. While most people easily pursue daily activities, individuals with dementia may feel uncomfortable in accomplishing daily chores (Hailstone et al., 2016).

Despite these limitations, the study's findings form the base line and initial work of the experience of dementia of people from the South Asian community, to help identify ways to improve access to dementia diagnosis and healthcare services by people from the South Asian Indian and Pakistani community. The evaluation of dementia services may be subject to the findings about the effects of cultural factors on the access and delivery of healthcare services to individuals with the disorder. The application of the study is discussed in detail in section 10.3.

This section has considered the practical strengths and limitations of the study which may have affected the findings. The next section reflects on how the presence of the researcher may have influenced the study design and findings.

9.9 Personal reflection

My previous professional and personal experience of engaging with members of the South Asian community affected my perception of the Western understanding of dementia. As I look back to this, I

can see that this study similarly cross the personal and professional boundary by using Habermas's lens of lifeworld and system world. However, this study in its entirety is based on the lifeworld and system world; several entries in my reflective dairy highlight the personal struggle I encountered during my PhD research journey. From a Habermas's (1984) perspective I was trying to find a balance between life and system world as a member of the South Asian community, with a multi-faceted experience of being a family caregiver to a person with mental illness (the lifeworld), and also a researcher who was looking to answer the system world questions regarding access to dementia services by people from the South Asian community. This tension between the two worlds was evident during the construction of interview/focus group questions and in obtaining the data collection. I have tried to discover a balance between these two worlds; firstly by ensuring that my lived experience of (a) being from the south Asian community and (b) being a family caregiver of someone with mental illness did not influence the construction of questions and the direction of the interview/focus group. In other words my experience were not affecting or directing the needs and experiences of my participants as a result of the type of questions asked. The effect of my experience on the research process was minimised by acknowledging the tension and conflict through active discussion with my supervision team and by keeping a reflective critical journal of my thoughts and impressions which surfaced during the research, particularly during the preparation of interview/focus group questions and obtaining the data collection. This helped to acknowledge any unclear or unrecognised thoughts, feelings and impressions which might have led to bias in the study, if unchecked.

Secondly, I tried to ensure that the preparation of the questions and the direction of the interview/focus group were shaped by the literature review and scoping exercise. This was reviewed by the research team which consists of: my supervisors at Lancaster University, public health specialists from Blackburn with Darwen Council, members of the advisory group, and NHS Research Ethics Committee. However, upon reflection, the research enquiry arose from the system world as it was informed from within the system, to answer public health question from where this study originated.

Furthermore, it was reviewed and developed according to guidance from people working within the system; therefore, the study is primarily focused on access to services. Despite this I did end up exploring the lifeworld and that added great insight and richness to my understanding of the lived experiences of people with dementia from South Asian community such as stigma. As a researcher, I did attempt to balance between my lived experiences of the south Asian community and staying in researcher role while attempting to answer the questions proposed by the system. However, this did make it harder to capture the more positive aspects of the collective South Asian community, such as the advantage of a family caring for its own members. This was evident in the designing, developing and reviewing of the research which tended towards interviews with professionals and NHS data. However, I did attempt to address this by recruiting people from the community in focus groups, as the recruitment issues made it very difficult to interview more than two families and a person with dementia. This also reflects on my position and the tension I encountered in finding a balance between a lifeworld and a system world.

Most participants rarely shared personal experiences with me, but used terminologies and expressions I was familiar with, thereby helping me to understand them better. My position as a woman from a South Asian background may arguably have had an adverse impact on the study, as most of the participants may have decided not to share their personal experiences. I noticed that focus group participants made little or no reference to their experiences, although one member had a grandmother living with dementia. While the findings concurred with Purandare et al. (2007), the concealment of difficulties is an integral aspect of South Asian cultural norms.

Several entries in my reflective diary acknowledge that the participants responded to me as a member of the South Asian community rather than as a researcher who wanted to understand the South Asian community's experience of dementia. Being from the same community, I integrated effectively in the research by engaging them well in various issues about the disorder. This was evident in their use of

South Asian terminology, e.g. in using the term '*pagal*' (insane) when describing how the South Asian Indian and Pakistani community regards people with dementia and mental health issues.

Given the difficulty and length of the research, it took time and patience to recruit people with dementia and their family members. I also chose to interview healthcare professionals who provided insight into the dementia diagnostic pathway process. One health professional spoke about the nine different types of information persons with dementia receive on diagnosis. Healthcare professionals varied when describing the dementia diagnostic pathway, in contrast to how the service users and their family members described their experience of using and engaging with the dementia diagnostic services.

Although the experience of engaging with members of the South Asian Indian and Pakistani community, and with persons with dementia and their families, was challenging, it has provided me with a unique understanding of the realities of individuals living with dementia from the South Asian Indian and Pakistani community and how this may affect their family members.

9.10 Conclusion

The access to and delivery of healthcare services for individuals with dementia in the South Asian community hinges on a range of factors. By analysing qualitative data, it became evident that dementia is notable in the UK's South Asian community. Applying Habermas's communicative action model and Goffman's social stigma theory illuminated that management of dementia faces certain barriers ranging from cultural barriers to literacy levels. Stigma about dementia is common in the community, and is an impediment to successful management of dementia. It is important to avoid discrimination in the South Asian community to eliminate the possibility of fear leading to hiding dementia. A culturally sensitive approach is needed to ensure effective management of dementia in the South Asian community in the UK.

Chapter 10: Conclusion

This study explored the social and cultural issues relating to the process of accessing a dementia diagnosis and support services in the South Asian population in Blackburn with Darwen. The qualitative approach was used to consider the wider context of the South Asian community's experience of dementia and engagement with the dementia services (discussed in Chapter 5). This chapter summarises the key findings, outlines the contribution to knowledge, and makes recommendations for future practice and possible future research.

10.1 Summary of the study findings

This study sought to identify the sociocultural issues underpinning access to dementia diagnosis and support services in the BwD South Asian population. A qualitative methodological approach was used and the findings indicated that, most people from the South Asian Indian and Pakistani community struggle to understand dementia, and the study discovered a range of understandings of dementia in the South Asian community. The community's diverse understanding leads to different views and beliefs about dementia, some of which result in stigmatisation of those who have dementia, and shame and humiliation in the family. However, as some participants noted, there is an enduring view that dementia is somehow a culture understanding for the ageing population. The various understandings of dementia tend to influence access to healthcare services in the South Asian community. Healthcare professionals indicated that few people from the South Asian community access dementia services and most do not seek medical support until the later stages of the illness. This may be due to diverse understandings, negative perspectives, and variations in knowledge about dementia may constitute barriers in the community to accessing appropriate support for people with the illness. The study also indicates (Chapter 9) that service level obstacles - including the lack of culturally-sensitive provision of dementia service - influence the access of healthcare services in the South Asian community.

The interpretation of the study findings drew on Habermas' theory of the colonisation of the lifeworld by the system, in conjunction with Goffman's theory of stigma. Habermas' theory, when applied to the field under study, suggests that the lack of social interaction in the South Asian community (between HCPs, people with dementia, and their family caregivers) causes people with dementia and their family caregivers not to seek a diagnosis of dementia at an early stage. Based on Habermas' concept of communicative action suggest that there is a lack of social and mutual understanding of dementia among people with dementia, and their family caregivers. A lack of common understanding in the South Asian community restricts the opportunities to establish social relationships and interactions, affecting how dementia services are delivered. The study, through the lens of Habermas's theory, further indicates that lack of social and mutual understanding both increases the sense of isolation and alienation and minimises people's capability to take charge or control their actions in managing dementia. People who have dementia and their family members feel unconnected to the social context, unable to communicate effectively with others about their condition; this therefore calls for the need to improve awareness in the community to support people with dementia. Although awareness may not instantly eliminate bias or lead to rational social understanding, negative communication can, over time, improve through interaction, to enhance the South Asian community's moral, practical and cultural values, by opening a public space which enables the South Asian voice to be heard and incorporated.

Goffman's Theory of Stigma helped to illuminate the vulnerability to stigma and shame attached to mental illness (dementia) in the South Asian Indian and Pakistani community. Goffman's theory implies that an individual with dementia symptoms - such as memory loss - may become stigmatised by a negative labelling process, which may affect the person's social activities and interaction, leading to diminished social status. The South Asian community family members of people with dementia face much stigmatisation because they are negatively labelled. Family members of individuals who have dementia will attempt to conceal the condition to maintain their status in the community, making it

even harder to deal with dementia in the family. Goffman's theory also implies that the usually supportive South Asian community will offer strength and assistance only to those who observe the community's cultural values. Those who fall short of the accepted values are regarded as being possessed by spirits, in their retreat from the cultural standards. It is therefore vital to consider cultural perspectives in the context of access to and delivery of dementia services.

Every culture has a unique and characteristic view of dementia. The study findings indicate that South Asian people believe dementia is a natural condition and see no purpose in approaching general practitioners, and other cultures believe that individuals with dementia are either abnormal or obsessed by evil spirits. Such cultural beliefs can create barriers, making it challenging for people with dementia to access medical services. The majority of South Asian families find it difficult to seek appropriate health and social care services because no culturally-sensitive approaches are offered to them, which leads them to feel they cannot seek medical services because of cultural differences. The study indicates that the dominating Western understanding of dementia as an illness is not shared by many Asian people, who view people with dementia as outcasts who bring stigma and shame. The people with dementia from the South Asian community reported that they feel unwelcome when they use mainstream services, and a lack of common cultural belief hinders the diagnostic process, leading to social isolation and poor delivery of healthcare services. In short, the various cultural perspectives on dementia can directly and indirectly cause emotional changes characterised by fear, disbelief, grief, and humiliation.

Adult education is important in the South Asian community (see discussion in Chapter 9) as it can ensure equity in service provision, particularly healthcare services, to people with dementia. Habermas theory implies that education in a community offers greater equality of access to prospects offered by the political, social and economic institutions (Hahn, 2000). A low literacy level – evident in the South Asian community - hinders effective communication and interaction between social groups). The study's findings indicate that many of the challenges to accessing medical services may be attributable

to the low literacy level of many South Asian Indian and Pakistani people. Provision of adequate education facilitates social interaction and enhances the participative community, enabling a society of cultural critics and social activists; when people understand dementia better, they will be able to engage more fully with improved culturally sensitive dementia services.

10.2 Contribution to knowledge

This thesis offers a unique insight into the South Asian population's experience of dementia. In acknowledging the sociocultural issues underpinning the process of accessing dementia diagnosis and support services by the South Asian population, the thesis innovatively draws together knowledge from Habermas' theory of communicative action and Goffman's theory of stigma to illuminate the nature of living with dementia. My understanding has been deepened and improved by the subjective process of answering the research question, and through describing and interpreting the main themes. The origins of the research lie in the perception that the South Asian community's blinkered cultural view of dementia – known in the existing literature but little explored - leads to people with the disorder becoming stigmatised, which in turn contributes to their delay in accessing health services. The thesis contributes new knowledge: a deeper understanding, through reflection on the socio-cultural issues influencing access to dementia services in the South Asian community, to inform understanding and practice and stimulate new interpretations.

Although the existing literature offers evidence of the experiences of various populations living with dementia, few researchers have conducted studies with the South Asian Indian and Pakistani community. Mukadam et al. (2015) note the South Asian community's lack of knowledge about dementia, which inhibits them from differentiating between the initial symptoms of dementia and the more typical conditions of the later stages. Mackenzie (2006) also found a negative perspective of dementia in the South Asian community, most of whom believe the behavioural symptoms of dementia are triggered by the individuals themselves, possessed by evil spirits, the symptoms the

consequence of their sins. The literature described and interpreted here converged with an assertion that poor understanding and negative perceptions of the causes of dementia can lead to a delay in seeking healthcare services. Through understanding the literature, this study has bridged the gap in knowledge, presenting new data and applying various theoretical frameworks to interpret it, exposing how the diverse socio-cultural issues underpin the process of accessing dementia diagnosis and support services by South Asians resident in Blackburn with Darwen, UK.

10.3 Recommendations

The literature and findings indicate that people from the South Asian community are under-represented in service use and are consequently typically diagnosed at a later stage of the illness, or not at all. Families of individuals with dementia experience feel shame because of their loss of status in the community. The provision of culturally appropriate services and support can help to ensure that individuals can access the assistance they require. Practical recommendations can be a gateway to minimise the prevalence of undiagnosed dementia and enable people to plan for the future. I will now outline various recommendations for current practice and future research, including preventative ways to reduce the burden of dementia in the South Asian community.

Reviewing the findings helped the researcher to recognise the barriers preventing this community from accessing dementia-related services. The next step is to consider these findings to provide explicit, practical, useful and achievable recommendations for improving access to dementia-related services, to ensure those services are openly accessible to the Blackburn and Darwen South Asian community. These recommendations are tabulated in Table 10.1, which will be discussed in more detail in section 10.3.1 and 10.3.2. It is also hoped that the following recommendations will have a potential impact on improving the wider South Asian Indian and Pakistani community's knowledge and perceptions of dementia, thereby improving their access to dementia-related services in the earlier stages of the disease, rather than when a crisis-point is reached.

Table 10.1: Recommendations for practice and future research

Recommendations for Practice	Recommendations for future research
Increase provision of culturally-sensitive dementia services for people from the South Asian community	Socio-cultural factors influencing access to dementia service among other ethnic and cultural groups
Pilot campaign to educate people with dementia and their families from South Asian community	Construction of dementia across other south Asian sub groups such as Bangladeshis, Sri-Lankans and Nepalese
Raise awareness of dementia among members of the South Asian community, through a more focused educational campaign and health promotion tailored to the needs of the community i.e. literacy level.	Role of acculturation in influencing individuals' experiences of dementia
Develop outreach programme with children and young people from the South Asian community	Influence of gender on the experience of dementia among members of the south Asian community
Health services to provide an open, shared space where people from South Asian community can discuss their concerns regarding dementia	Cross-cultural differences in the conceptualisation of mental health
Recruitment of professionals who are skilled at working with people from the South Asian community	
Form effective partnerships with faith leaders	
Provide cultural sensitivity training given to staff and HCPs	

10.3.1 Recommendations for Practice

Local service delivery for people with dementia and does not adequately meet the needs of individuals from the South Asian, Indian and Pakistani community. Families of people living with dementia may not look for support, fearing community rejection or loss of status. There is poor awareness of how services may help them or of how they can obtain these services, and a lack of culturally-sensitive dementia services. Many families are reluctant to use services that do not correspond to their religious

or cultural needs and attempt to continue unsupported. A broad range of actions is needed, to ensure that every person with dementia and their families can access appropriate high-quality individually-centred support.

It is important that individuals in the South Asian community who have dementia, and their families, develop improved understanding and knowledge of the disease, so a pilot campaign should be developed to educate people about dementia. A more focused dementia education campaign, specifically tailored to the South Asian community, could potentially enable more people to accept others with dementia, which their cultural values currently often appear to tolerate. Such a campaign should be informed by research which takes into account whether the community requires a particular approach. Information, transmitted through a range of audio and visual media, could raise awareness and educate the community about dementia. People with dementia and their families in the South Asian community could be involved in planning a targeted campaign to raise understanding and awareness of dementia, aimed at older adults. The campaign should adopt a strategy which targets people with all levels of literacy, so offering Asian language tuition would be imperative in the provision of care services. Language is the key to raising awareness and educating people, so a community dementia education campaign could provide much-needed crucial information. More people would be receptive to and satisfied by the available services because they would understand the importance of diagnosis and the need for treatment. HCPs, GPs, and carers managing individuals with dementia could work together with the South Asian community and media outlets, to raise awareness of dementia among South Asian people through print and broadcast media channels. This approach would be enhanced by hiring primary care teams familiar with the community to distribute information booklets or leaflets.

Furthermore, long-term health promotion is needed to educate the South Asian Indian and Pakistani community, particularly in overcoming the myths about the causes of dementia. This may remove the negative stereotypes often experienced by people who have been diagnosed with dementia. The

educational programme could enlist the assistance of faith leaders, and hold a day fair (Mela). It would be necessary to inform the community about where to obtain help, the benefits of obtaining a diagnosis, and the pharmacological and non-pharmacological help available for people diagnosed with dementia and their family members.

The younger age-group may be the future carers or children/grandchildren of people who have been diagnosed with dementia. An outreach programme is recommended, to educate children and young adults in BwD about the biomedical model of dementia, to help overcome the myths about its causes. Education is needed to raise awareness of how to identify dementia, how it differs from the normal ageing process, and how to seek help from dementia-related services when there is concern about a family member.

GPs and HCPs should ensure that their services are perceived as being a safe place where this population will feel welcome and be encouraged to discuss their concerns about dementia. Dementia café and different health centres around Blackburn should be facilitated to share expertise among the South Asian community to enhance the community's confidence in the capacity of mainstream dementia services. These services should be culturally sensitive and enable the community to support individuals with dementia better. It is also important to form partnership with care providers who work with this community, to ensure that they offer effective support to people with dementia. It is necessary to consult and work with people who have been diagnosed with dementia and their family members in the South Asian Indian and Pakistani community, to ascertain what type of support network they would like to be available for them.

Organisations which provide services to people with dementia and their family carers should actively approach different audiences when advertising volunteering opportunities and employment prospects. By adopting this approach, qualified and experienced staff can be recruited who have the skills to recognise the early stages of dementia and/or facilitate effective support for older people with

dementia in the South Asian community. Early diagnosis of dementia is instrumental in offering the necessary support, to avert the pitfalls associated with delayed diagnosis.

The voluntary sector should form a network from the South Asian Indian and Pakistani community, which should include faith leaders, with whom they can work in partnership, to improve the community's access to dementia-related services. The statutory sector must recognise the voluntary sector's role in providing a meaningful partnership with the community, so should invest financially in work undertaken by this partnership. Better communication between the voluntary and statutory sectors would improve working relationships between dementia-related services' commissioning managers and the community. This would help to develop, design, and implement dementia-related services with community input.

It is crucial that those responsible for training the staff involved in the support and care of people with dementia ensure that training programmes include the topic of culturally-sensitive care. It is important that the community learns about dementia without it infringing on their faith values. More people will be likely to approach their GP if they are confident that medical assessments do not counteract their beliefs. Furthermore, GPs should receive guidance on improving diagnosis rates among South Asian people thought to have dementia.

These recommendations can be implemented to some extent in the BwD South Asian population. The recommendations have financial benefits and conform to the UK Prime Minister's 2020 plan for the delivery of dementia-related services open to people of all ethnicities. The recommendations conform to the Borough's plan to commission better dementia-related services, in order to improve access for all ethnic minority groups, particularly South Asians. It may also be appropriate to extend the recommendations to other ethnic groups.

10.3.2 Recommendations for future research

From a qualitative standpoint, there is little research about the experiences of people with dementia in the South Asian community. The findings of this study emphasise the impact of both social and cultural factors influencing the South Asian community's experience of dementia and access to dementia services. Although this research is limited to the South Asian Indian and Pakistani group, in light of the increasing diversity of communities living in the West, future research with other cultural groups would be useful. This could contribute to providing better support, both to people with dementia and those involved in improving access to dementia services for all ethnic, cultural groups living in the West.

This study also raises the important question of dementia as a global condition. It would be beneficial to conduct further research with heterogeneous South Asian groups: Indian, Pakistani, Bangladeshi, Sri Lankan and Nepalese. A qualitative approach could be used to discover how cultural constructs of dementia may vary across different cultural groupings.

Another gap in the current research, already briefly mentioned in this study, is the role of acculturation in determining individual experiences of dementia diagnosis, treatment and care, which may influence inequalities in diagnosis. This could have important consequences for planning, policy and strategy developments involving access to dementia diagnosis and services. More research could be conducted on both the process of cognitive ageing and various risk aspects of dementia, to identify the unique risk factors at the initial and late stages of dementia.

Current research indicates the marginalisation of women by men in group conversations, where men often dominate the discussion by talking continuously. Few published studies currently offer gender-sensitive responses which consider the experiences and challenges encountered by older people. An exploration of the cultural, religious/spiritual and gender values about dementia in the South Asian community could contribute to an enhanced understanding of how individuals conceptualise

difficulties related to their specific roles in the family and community, by allowing the research to identify how this influences the decision to seek help and access dementia diagnostic services.

Cross-cultural work is now an integral part of the role of psychologists and consultant psychiatrists. Since their ethos is to work holistically, further research could be undertaken to better understand the cross-cultural conceptualisations of mental health. Research in this area emphasises the importance of encompassing the individual and cultural differences which arise in our work, and the process of being critical of diagnoses and any related assumptions they may bring.

10.4 Concluding remarks

This study identifies the South Asia community knowledge about what dementia is, what causes it, and how it is distinct from healthy ageing. There is a negative attitude towards dementia in the South Asian, Indian and Pakistani communities, together with a lack of knowledge of dementia. This may result in the family perceiving dementia as a social rather than a medical challenge. The community's understanding of the causes of dementia reflects South Asian native and ancestral cultural understanding of mental illness, historically regarded as a spiritual disorder. Cultural understandings can lead to stigmatisation of individuals living with dementia and their family members, which may in turn deter the family from seeking medical help for fear of the diagnosis. It is evident that stigmatising dementia is common in the community, which acts as an impediment to successful management of the disease. The study recommends the importance of avoiding discrimination in the South Asian community to eliminate the possibility of fear and of concealing the dementia condition.

The South Asian Indian and Pakistani community's understanding of and attitudes towards dementia have been influenced by poor knowledge coupled with deeply-held cultural beliefs about dementia which may lead to families' resistance to seeking help. Education about dementia in the community may help equip community members with the necessary crucial information. However, when people

from the South Asian Indian and Pakistani community decide to access dementia services, they often find there is no culturally-sensitive approach to assessing, diagnosing, and treating a person with dementia. The lack of sensitivity towards South Asian cultural and traditional values in dementia-related services causes the community to feel the imposition of a Western worldview, making them reluctant to access dementia services. This challenge may hinder the process of accessing dementia assessments and support services in the South Asian population in Blackburn and Darwen, indicating that a culturally-sensitive approach is required to ensure effective management of dementia in the UK's wider South Asian community.

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Appendix 1 Method for estimation of the number of people from the South Asian community accessing dementia diagnostic services in Blackburn with Darwen

This appendix outlines a method used to identify the number of people from the South Asian community accessing dementia diagnostic services in Blackburn with Darwen (BwD). To do this I used data from the East Lancashire Memory Assessment Service (MAS) database. Firstly, this section describes the data abstraction. Secondly, the quality of the data was assessed, followed by a description of the process by which diagnosis, patient postcode, and age, gender and ethnicity variables were categorised. Lastly, a detailed description is provided of the statistical analysis performed using the categorised variables to achieve the overarching quantitative aim as stated above.

1.1 Data Abstraction

The primary source of data about the number of diagnosed dementia cases in Blackburn with Darwen was the East Lancashire Memory Assessment Service (MAS) database, which is a part of the Lancashire Care NHS Foundation Trust (LCFT). The MAS database records information for analytical purposes on characteristics of all patients from East Lancashire, including BwD, who have accessed their service. A request was submitted to the MAS for an anonymised dataset on each individual diagnosed with dementia at the East Lancashire MAS and who were resident in BwD at the time of diagnosis (see Table 1 which illustrates the requested list of preferable variables and the back-up list of variables).

Table 1: Requested list of preferable variables and back-up list of variables

Variables – preferred list	Variables – back-up list
Unique ID – generated by provider	Unique ID – generated by provider
Age in calendar years at diagnosis	Age in calendar years at diagnosis
Year of birth	
Gender	Gender
Date of diagnosis	Date of diagnosis
Diagnosis by broad type – Alzheimer’s, Frontal lobe disorder, Vascular dementia, Dementia with Lewy bodies	Diagnosis of Vascular dementia or Alzheimer’s
Ethnicity – ONS classification	Ethnicity – ONS classification
Geographical locator variable – 5-digit postcode or LSOA	Geographical locator variable – MSOA
Geographical locator variable – GP practice name/postcode	Geographical locator variable – GP practice name/postcode

Over a period of several months, a team of LCFT technical analysts abstracted the data from the LCFT operational database. The data were specifically extracted and integrated for the purpose of the researcher’s request (see Table 1), aggregated and recorded in an Excel spread sheet.

The dataset was sent in October 2015 in a password-protected email from the MAS, which was downloaded and saved onto a password-protected computer using the Trust’s and Lancaster University ethical guidelines and governance requirements on data protection and storage.

The anonymised dataset comprised 2,225 rows, each row relating to an individual. Each individual had been diagnosed with some type of mental, behavioural or neurodevelopment disorder between September 2007 and July 2015 (as illustrated in Table 2). Diseases had been coded according to ICD-10 (International Classification of Diseases, 10th revision).

Table 2: Type of diagnosis with ICD-10 code and number of cases diagnosed in the dataset in BwD between September 2007 and July 2015

Type of diagnosis	ICD-10 code	Number of cases
<i>Dementia in Alzheimer's disease</i>	F00	1,348
<i>Vascular dementia</i>	F01	181
<i>Dementia in other diseases</i>	F02	43
<i>Delirium</i>	F05	5
<i>Korsakoff's dementia</i>	F10	4
<i>Schizophrenia</i>	F20.9	2
<i>Persistent delusion disorders</i>	F22	2
<i>Bipolar disorder</i>	F31	2
<i>Depression</i>	F32	49
<i>Recurrent depressive disorder</i>	F33	3
<i>Other anxiety disorders</i>	F41	1
<i>Other mood disorders</i>	F38	1
<i>Other anxiety disorders</i>	F41	1
<i>Generalised anxiety</i>	F41.1	4
<i>Chronic mixed anxiety and depression</i>	F41.2	2
<i>Reaction to severe stress/adjustment</i>	F43	1
<i>Adjustment reaction and adjustment disorder</i>	F43.2	1
<i>Mild mental retardation</i>	F70	1
<i>Not known</i>	No code	574
Total		2225

The following variables were included in the data (see Table 3).

Table 3: list of variables received in the data

1. Patient ID
2. Year of birth
3. Gender
4. Ethnicity
5. Age at diagnosis
6. The services at which they were diagnosed i.e. East Lancashire MAS
7. 3- to 5-digit postcode of the patient
8. GP practice code
9. GP practice name
10. GP practice postcode
11. Clinical Commissioning Group (CCG)
12. ICD-10 code for the diagnosis
13. Name of the type of diagnosis
14. Any additional text about the diagnose
15. Description or information recorded by the professional carrying out the diagnosis
16. The numerical date format
17. Time of the assessment
18. Month and year of the assessment
19. The year the assessment was conducted

1.2. Data Quality

The data was then reviewed for its completeness (see Table 4).

Table 4: shows the variables with missing data and the number of missing data in each variable in the dataset between September 2007 and July 2015

Variables	Number of individuals with missing data
Patient's year of birth	1
Ethnicity	2
Age at diagnosis	1
Patients' postcode	54
Patients' GP code and GP practice name	330
CCG	339
Type of diagnosis <i>not known</i>	575

The data was checked for duplicate entries to determine whether individuals had multiple entries in the dataset as a result of repeat visits to the clinic.

The aim was to assess the number of cases of dementia by age, gender, ethnicity and type of diagnosis in the residents of BwD, as the data quality assessment revealed incompleteness and visible non-uniformity in the following variables: age, gender, ethnicity, type of diagnosis and patient postcode. Data cleaning of these variables would correct, where possible, any missing or unknown values and to an appropriate structural format.

The dataset contained information on those individuals diagnosed with a range of mental, behavioural and neurodevelopment disorders, including dementia. The dataset also included data on people from the geographical area served by the memory clinic - the administrative district of East Lancashire. It was not exclusive to people with dementia living in BwD. The data was restricted on population of people with dementia diagnosis and a home address in BwD.

1.3 Categorisation of Diagnosis

Diagnosis was recorded in two related variables: ICD10 code for the diagnosis and a variable containing the name of the diagnosis, including clinicians' notes and text on the diagnosis, e.g. Alzheimer's disease with cerebral vascular disease or Korsakoff's dementia (F10.7). There were 1,576 cases of dementia in the raw data.

For the purposes of this study, dementia was defined as a diagnosis of Alzheimer's, Vascular dementia, Dementia in other diseases, Unspecified dementia and Korsakoff's Dementia (ICD F00, F01, F02, F03 and F10). Where a patient had a diagnosis with an ICD10 code of F00, F01, F02, F03 or F10, the description matched the diagnosis. However, a number of people who had been assigned a diagnosis of dementia in the description column were recorded as *not known* in the ICD column.

Where a description of the diagnosis of dementia was given in the descriptive column but *not known* was recorded in the ICD 10 column, I assigned an appropriate code for dementia according to the following protocol: a diagnosis of dementia was assigned in the ICD column where it was clear from the description column that a diagnosis had been made. A manual using the ICD-10 code and description as guidance was developed by the research team to help assign a diagnosis code to the *not known* value using the clinicians' descriptive text as a guideline. The manual contained the following instructions:

- Mixed Alzheimer's and vascular dementia or mixed vascular and Alzheimer's type of dementia (F00.2 MIXED TYPE) and Alzheimer's disease (AD) with cardiovascular disease (F002) was given a value F00 '*Dementia in Alzheimer's disease*'.
- Vascular dementia, mixed Lewy bodies and vascular dementia was given a value F01 '*Vascular dementia*'.
- Frontal lobe disorder, front temporal dementia, Parkinson's disease dementia (F02.3) and Lewy bodies dementia (G31.8) was given a value F02 '*Dementia in other diseases*'.
- Dementia, probable vascular dementia, dementia (difficult to formally assess memory), dementia with depression still under investigation (F03) and mixed dementia was given a value F03 '*Unspecified dementia*'.
- MCI and cognitive impairment was given a value F06 '*Other mental disorders due to known physiological condition*'.
- Organic personality disorder was given a value F07 '*Personality and behavioural disorders due to known physiological condition*'.
- Symptomatic mental illness and unspecified mental disorder was given a value F09 '*Unspecified mental disorders due to known physiological condition*'.
- Additional comments – probable dementia is coded to a diagnosis, anything with '?' in front, not coded to a diagnosis, i.e. ? vascular dementia – still under investigation.

A separate column variable ‘*DI_ICD_ID_1_2*’ was added which was labelled ‘*recoding of DI_ICD_ID_1*’ to categorise the *not known* value in the *DI_ICD_ID_1* (type of diagnosis) column using the manual. The consistency and validity of the manual was obtained by researching using the manual to complete the categorisation of a *not known* diagnosis, which was then repeated individually by my supervisor.

286 individuals in the dataset were designated unknown but had a described diagnosis of dementia in the description column. Of there, 242 were re-categorised to a diagnosis of dementia using this manual as shown in Table 5 below.

Table 5: The re-categorised cases of *not known* to a dementia diagnosis (2007- 2015)

Name of dementia diagnosis with ICD-10 code	Number of cases re-categorised
<i>Dementia in Alzheimer’s disease</i> (F00)	59
<i>Vascular dementia</i> (F01)	52
<i>Dementia in other diseases</i> (F02)	14
<i>Unspecified dementia</i> (F03)	114
<i>Korsakoff’s dementia</i> (F10)	3
<i>Total</i>	242

The process by which the *type of diagnosis* column variable was categorised and labelled in a more meaningful format was described in this section. A similar process performed to categorise the patient postcode is discussed in detail in the next section.

1.4 Categorisation of Patient Postcode

The dataset was further appraised to remove people who did not reside in BwD. The BwD postcodes - BB1, BB2 or BB3 - were used to select individuals for inclusion in the analysis. The dataset contained individual data from twenty-eight different localities in and around BwD (see Table 6 below); in most cases the individuals had a different CCG and GP practice to BwD.

Table 6: List of postcodes based on region in the dataset between September 2007 and July 2015

<u>Postcodes</u>	<u>Label given to each postcode based on region</u>
BB1-BB3	BwD
BB10-BB12	Burnley
BB18, BB8-BB9	Pendle
BB4, OL13	Rossendale
BB5-BB6	Hyndburn
BB7	Ribble Valley
BD16	Bingley
BD23	Craven
BL0, BL8	Bury
BL6 5, BL7 0	Bolton
DN16	North Lincolnshire
FY8 1, FY8 2, FY8 5	Fylde
L39 1, WN8 0, WN8 7	West Lancashire
LA4 6	Lancaster
LN12	East Lindsey
M34 5	Tameside
M40 1	Manchester
ME12	Swale
NE62	Northumberland
NG32	South Kesteven
OH13, OL12, OL16	Rochdale
OL14	Calderdale
PO12	Hampshire

PR1-PR5	Preston
RG8 9	South Oxfordshire
SY10, SY12	Shropshire
WF7 6	Wakefield
WN2 5	Wigan

After completing the categorisation of type of diagnosis and postcode (described above), a filter was added to include all those with a diagnosis of dementia, including F00, F01, F02, F03, F04 and F10 (see Table 5) and those who were also a resident of BwD (Postcode 1, as illustrated in Table 6). This resulted in 462 cases of people with a dementia diagnosed living in BwD postcodes with no missing data on ethnicity, gender and age. The 462 cases of diagnosed dementia was achieved after removing fifty-six multiple cases entries, and a further fifty-four patient records were removed because of missing postcode data. Of 286 individuals in the dataset designated unknown with a described diagnosis of dementia in the description column (as discussed in section 1.3), forty-four individual cases were removed as there was insufficient information to re-categorise them to a diagnosis of dementia.

1.5. Categorisation of Age, Gender and Ethnicity Variables

1.5.1 Age at diagnosis

Both age at diagnosis and date of birth are important for this research and were recorded in the dataset. For the purpose of this study, the age of 65 was selected as the cut-off for young onset dementia as described in the Alzheimer's Society report (Knapp and Prince, 2007) and other research into dementia (Licht et al., 2007; Koedam et al., 2010). Age at diagnosis was categorised into young onset < 65 years and late onset \geq 65 years.

1.5.2 Categorisation of Gender

The gender of those with a dementia diagnosis, also an important variable, was categorised as male or female.

1.5.3 Categorisation of ethnicity

The individuals with a confirmed diagnosis of dementia were from the following ethnic groups: Asian British – Indian, Asian British - any other Asian, White - any other White, White – British, White – Irish, Any Other Ethnic Group, Not Known/Specified, Not Stated.

Given the small number of people in ethnic groups such as Asian British Indian and White Irish, the ethnic groups were grouped and categorised into Asian British, White British and other (which consisted of these groups: Any Other Ethnic Group, Not Known/Specified and Not Stated re-categorised into other).

The next section describes in detail the statistical analysis conducted using the variables of age, gender, ethnicity and type of diagnosis.

1.6 Statistical methods

The quantitative dataset provided information on the overall number of cases of dementia, which were classified according to age, gender, ethnicity, type of diagnosis and patient postcode. Ethnicity data, including ethnic group classifications, are similar to those used in current data supplied by the ONS (Office for National Statistics, 2016). Patient postcodes were classified using Postcode Finder (Postcode Finder UK, 2016).

Statistical analyses were conducted on these categories using the Statistical Package for Social Science (SPSS) computer software package, version 22 (Bowling, 2002). SPSS enabled descriptive statistics to

be obtained on the frequency of dementia by age, gender, ethnicity and type of diagnosed dementia within the Blackburn with Darwen population. The incidence of dementia in each ethnic group (Asian, White British and others) by gender is illustrated in chapter 2, Table 2.3.

APPENDIX 2 Databases and search terms

Table 1: Database and search terms

Databases	Search terms
EMBASE	<p>Dementia OR "Frontotemporal dementia" OR "Multiinfarct dementia " OR Alzheimer* OR "Lewy dody" OR "Cognitive defect" OR Memory OR Forget* AND</p> <p>Asian* OR "South* Asia*" OR India* OR Gujrat* OR Hind* OR Nepal* OR Pakistan* OR Punjab* OR Urdu OR Muslim OR Bangladesh* OR Bengal* OR Sri Lanka* AND</p> <p>Spiritual* OR Cultur* OR Ethnic* OR Religio* OR Community OR Understand* OR Coping OR Impact OR Living OR Experience* OR Perspective* OR Belief* OR Attitud* OR Perception* OR Awareness OR Recognition AND</p> <p>Diagnosis OR "Health care utili*" OR "Health service utili*" OR Service* OR Pathway* OR Engag* OR Consult* OR Involv* OR "Illness representation*" OR "Decision making" OR Participation AND</p> <p>Limit to English, between 2000- 2017</p>
PubMed	<p>Dementia OR "Frontotemporal dementia" OR " Frontotemporal Lobar Degeneration" OR Alzheimer* OR "Vascular dementia" OR "Lewy body disease" OR "Cognitive dysfunction" OR Memory OR Forget* AND</p> <p>Asian* OR "South* Asia*" OR India* OR Gujrat* OR Hind* OR Nepal* OR Pakistan* OR Punjab* OR Urdu OR Muslim OR Bangladesh* OR Bengal* OR Sri Lanka* AND</p> <p>Spiritual* OR Cultur* OR Ethnic* OR Religio* OR Community OR Understand* OR Coping OR Impact OR Living OR Experience* OR Perspective* OR Belief* OR Attitud* OR Perception* OR Awareness OR Recognition AND</p> <p>Diagnosis OR "Health care utili*" OR "Health service utili*" OR "Health care use" OR "Health service use" OR Service* OR Pathway* OR Engag* OR Consult* OR Involv* OR "Illness representation*" OR "Decision making" OR Participation AND</p> <p>Limit to English, between 2000- 2017</p>
Scopus	<p>Dementia OR "Frontotemporal dementia" OR "Frontotemporal lobar degeneration" OR Alzheimer* OR "Vascular dementia" OR "Lewy body" OR "Cognitive dysfunction" OR Memory OR Forget* AND</p> <p>Asian* OR "South* Asia*" OR India* OR Gujrat* OR Hind* OR Nepal* OR Pakistan* OR Punjab* OR Urdu OR Muslim OR Bangladesh* OR Bengal* OR Sri Lanka* AND</p> <p>Spiritual* OR Cultur* OR Ethnic* OR Religio* OR Community OR Understand* OR Coping OR Impact OR Living OR Experience* OR Perspective* OR Belief* OR Attitud* OR Perception* OR Awareness OR Recognition</p>

	<p>AND</p> <p>Diagnosis OR "Health care utili*" OR "Health service utili*" OR "Health care use" OR "Health service use" OR Service* OR Pathway* OR Engag* OR Consult* OR Involv* OR "Illness representation*" OR "Decision making" OR Participation</p> <p>AND</p> <p>Limit to English, between 2000- 2017</p>
Web of science	<p>Dementia OR "Frontotemporal dementia" OR "Frontotemporal lobar degeneration" OR Alzheimer* OR "Vascular dementia" OR "Lewy body" OR "Cognitive dysfunction" OR Memory OR Forget*</p> <p>AND</p> <p>Asian* OR "South* Asia*" OR India* OR Gujrat* OR Hind* OR Nepal* OR Pakistan* OR Punjab* OR Urdu OR Muslim OR Bangladesh* OR Bengal* OR Sri Lanka*</p> <p>AND</p> <p>Spiritual* OR Cultur* OR Ethnic* OR Religio* OR Community OR Understand* OR Coping OR Impact OR Living OR Experience* OR Perspective* OR Belief* OR Attitud* OR Perception* OR Awareness OR Recognition</p> <p>AND</p> <p>Diagnosis OR "Health care utili*" OR "Health service utili*" OR "Health care use" OR "Health service use" OR Service* OR Pathway* OR Engag* OR Consult* OR Involv* OR "Illness representation*" OR "Decision making" OR Participation</p> <p>AND</p> <p>Limit to English, between 2000- 2017</p>

APPENDIX 3 CCAT Form 2012 and User Guide

Crowe Critical Appraisal Tool (CCAT) Form (v1.4) Reference

Reviewer

This form must be used in conjunction with the CCAT User Guide (v1.4); otherwise validity and reliability may be severely compromised.

Citation			Year

Research design (add if not listed)	
<input type="checkbox"/> Not research	Article Editorial Report Opinion Guideline Pamphlet ...
<input type="checkbox"/> Historical	...
<input type="checkbox"/> Qualitative	Narrative Phenomenology Ethnography Grounded theory Narrative case study ...
<input type="checkbox"/> Descriptive, Exploratory, Observational	A. Cross-sectional Longitudinal Retrospective Prospective Correlational Predictive ...
	B. Cohort Case-control Survey Developmental Normative Case study ...
Experimental	<input type="checkbox"/> True experiment Pre-test/post-test control group Solomon four-group Post-test only control group Randomised two-factor Placebo controlled trial ...
	<input type="checkbox"/> Quasi-experiment Post-test only Non-equivalent control group Counter balanced (<i>cross-over</i>) Multiple time series Separate sample pre-test post-test [no Control] [Control] ...
	<input type="checkbox"/> Single system One-shot experimental (<i>case study</i>) Simple time series One group pre-test/post-test Interactive Multiple baseline Within subjects (<i>Equivalent time, repeated measures, multiple treatment</i>) ...
<input type="checkbox"/> Mixed Methods	Action research Sequential Concurrent Transformative ...
<input type="checkbox"/> Synthesis	Systematic review Critical review Thematic synthesis Meta-ethnography Narrative synthesis ...
<input type="checkbox"/> Other	...

Variables and analysis			
Intervention(s), Treatment(s), Exposure(s)	Outcome(s), Output(s), Predictor(s), Measure(s)	Data analysis method(s)	

Sampling					
Total size	Group 1	Group 2	Group 3	Group 4	Control
Population, sample, setting					

Data collection (add if not listed)	
Audit/Review a) Primary Secondary ... b) Authoritative Partisan Antagonist ... c) Literature Systematic ...	Interview a) Formal Informal ... b) Structured Semi-structured Unstructured ... c) One-on-one Group Multiple Self-administered ...
Observation a) Participant Non-participant ... b) Structured Semi-structured Unstructured ... c) Covert Candid ...	Testing a) Standardised Norm-ref Criterion-ref Ipsative ... b) Objective Subjective ... c) One-on-one Group Self-administered ...

Scores				
Preliminaries	Design	Data Collection	Results	Total [/40]
Introduction	Sampling	Ethical Matters	Discussion	Total [%]

General notes	



Crowe Critical Appraisal Tool (CCAT) :: Version 1.4 (19 November 2013) :: Michael Crowe (michael.crowe@my.jcu.edu.au)

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Appraise research on the merits of the research design used, not against other research designs.

Category Item	Item descriptors [Present; Absent; ■ Not applicable]	Description [Important information for each item]	Score [0–5]
1. Preliminaries			
Title	1. Includes study aims <input type="checkbox"/> and design <input type="checkbox"/>		
Abstract (assess last)	1. Key information <input type="checkbox"/> 2. Balanced <input type="checkbox"/> and informative <input type="checkbox"/>		
Text (assess last)	1. Sufficient detail others could reproduce <input type="checkbox"/> 2. Clear/concise writing <input type="checkbox"/> , table(s) <input type="checkbox"/> , diagram(s) <input type="checkbox"/> , figure(s) <input type="checkbox"/>		
			Preliminaries [/5]
2. Introduction			
Background	1. Summary of current knowledge <input type="checkbox"/> 2. Specific problem(s) addressed <input type="checkbox"/> and reason(s) for addressing <input type="checkbox"/>		
Objective	1. Primary objective(s), hypothesis(es), or aim(s) <input type="checkbox"/> 2. Secondary question(s) <input type="checkbox"/>		
Is it worth continuing?			Introduction [/5]
3. Design			
Research design	1. Research design(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of research design(s) <input type="checkbox"/>		
Intervention, Treatment, Exposure	1. Intervention(s)/treatment(s)/exposure(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Precise details of the intervention(s)/treatment(s)/exposure(s) <input type="checkbox"/> for each group <input type="checkbox"/> 3. Intervention(s)/treatment(s)/exposure(s) valid <input type="checkbox"/> and reliable <input type="checkbox"/>		
Outcome, Output, Predictor, Measure	1. Outcome(s)/output(s)/predictor(s)/measure(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Clearly define outcome(s)/output(s)/predictor(s)/measure(s) <input type="checkbox"/> 3. Outcome(s)/output(s)/predictor(s)/measure(s) valid <input type="checkbox"/> and reliable <input type="checkbox"/>		
Bias, etc	1. Potential bias <input type="checkbox"/> , confounding variables <input type="checkbox"/> , effect modifiers <input type="checkbox"/> , interactions <input type="checkbox"/> 2. Sequence generation <input type="checkbox"/> , group allocation <input type="checkbox"/> , group balance <input type="checkbox"/> , and by whom <input type="checkbox"/> 3. Equivalent treatment of participants/cases/groups <input type="checkbox"/>		
Is it worth continuing?			Design [/5]
4. Sampling			
Sampling method	1. Sampling method(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of sampling method <input type="checkbox"/>		
Sample size	1. Sample size <input type="checkbox"/> , how chosen <input type="checkbox"/> , and why <input type="checkbox"/> 2. Suitability of sample size <input type="checkbox"/>		
Sampling protocol	1. Target/actual/sample population(s): description <input type="checkbox"/> and suitability <input type="checkbox"/> 2. Participants/cases/groups: inclusion <input type="checkbox"/> and exclusion <input type="checkbox"/> criteria 3. Recruitment of participants/cases/groups <input type="checkbox"/>		
Is it worth continuing?			Sampling [/5]
5. Data collection			
Collection method	1. Collection method(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of collection method(s) <input type="checkbox"/>		
Collection protocol	1. Include date(s) <input type="checkbox"/> , location(s) <input type="checkbox"/> , setting(s) <input type="checkbox"/> , personnel <input type="checkbox"/> , materials <input type="checkbox"/> , processes <input type="checkbox"/> 2. Method(s) to ensure/enhance quality of measurement/instrumentation <input type="checkbox"/> 3. Manage non-participation <input type="checkbox"/> , withdrawal <input type="checkbox"/> , incomplete/lost data <input type="checkbox"/>		
Is it worth continuing?			Data collection [/5]
6. Ethical matters			
Participant ethics	1. Informed consent <input type="checkbox"/> , equity <input type="checkbox"/> 2. Privacy <input type="checkbox"/> , confidentiality/anonymity <input type="checkbox"/>		
Researcher ethics	1. Ethical approval <input type="checkbox"/> , funding <input type="checkbox"/> , conflict(s) of interest <input type="checkbox"/> 2. Subjectivities <input type="checkbox"/> , relationship(s) with participants/cases <input type="checkbox"/>		
Is it worth continuing?			Ethical matters [/5]
7. Results			
Analysis, Integration, Interpretation method	1. A.I.I. method(s) for primary outcome(s)/output(s)/predictor(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Additional A.I.I. methods (e.g. subgroup analysis) chosen <input type="checkbox"/> and why <input type="checkbox"/> 3. Suitability of analysis/integration/interpretation method(s) <input type="checkbox"/>		
Essential analysis	1. Flow of participants/cases/groups through each stage of research <input type="checkbox"/> 2. Demographic and other characteristics of participants/cases/groups <input type="checkbox"/> 3. Analyse raw data <input type="checkbox"/> , response rate <input type="checkbox"/> , non-participation/withdrawal/incomplete/lost data <input type="checkbox"/>		
Outcome, Output, Predictor analysis	1. Summary of results <input type="checkbox"/> and precision <input type="checkbox"/> for each outcome/output/predictor/measure 2. Consideration of benefits/harms <input type="checkbox"/> , unexpected results <input type="checkbox"/> , problems/failures <input type="checkbox"/> 3. Description of outlying data (e.g. diverse cases, adverse effects, minor themes) <input type="checkbox"/>		
			Results [/5]
8. Discussion			
Interpretation	1. Interpretation of results in the context of current evidence <input type="checkbox"/> and objectives <input type="checkbox"/> 2. Draw inferences consistent with the strength of the data <input type="checkbox"/> 3. Consideration of alternative explanations for observed results <input type="checkbox"/> 4. Account for bias <input type="checkbox"/> , confounding/effect modifiers/interactions/imprecision <input type="checkbox"/>		
Generalisation	1. Consideration of overall practical usefulness of the study <input type="checkbox"/> 2. Description of generalisability (external validity) of the study <input type="checkbox"/>		
Concluding remarks	1. Highlight study's particular strengths <input type="checkbox"/> 2. Suggest steps that may improve future results (e.g. limitations) <input type="checkbox"/> 3. Suggest further studies <input type="checkbox"/>		
			Discussion [/5]
9. Total			
Total score	1. Add all scores for categories 1–8		
Total [/40]			

APPENDIX 4: Papers selected for inclusion in the systematic literature review

<u>Author, date and country</u>	<u>Aim of study</u>	<u>Sample</u>	<u>Study design; data collection methods; data analysis</u>	<u>Key findings</u>	<u>Limitations/use of theory?</u>	<u>Relevance to your study</u>
1. Adamson and Donovan (2005) UK (Total score 32)	Examines the meanings of being an informal carer of an older family member for South Asian and African/Caribbean carers.	21 African/Caribbean and 15 South Asian carers.	Qualitative design; interviews	The experience of informal care has many similarities with the experience of chronic illness.	Whilst the caregivers had a tendency to interpret their caring experiences as part of their cultural heritage as individuals from UK South Asian group, this is not to say that such notions of caring as 'the norm' are either unique to South Asian and African/Caribbean carers, nor by any means universal.	The paper provides the relationship between individual experiences, cultural factors and macro-social structures, which align with the aim of the current study.

<p>2. Lawrence et al., (2008) UK (Total score 35)</p>	<p>Explores the caregiving attitudes, experiences and needs of family carers of people with dementia from the UK's three largest ethnic groups.</p>	<p>32 carers of people with dementia (10 Black Caribbean, 10 South Asian, 12 White British).</p>	<p>A qualitative study; Interviews</p>	<p>Carers were identified as holding a 'traditional' or 'non-traditional' caregiver ideology, according to whether they conceptualised caregiving as natural, expected and virtuous.</p>	<p>Although the study took place in south London, participants were recruited from areas where there is socio-economic diversity; hence, it was difficult to generalize the findings.</p>	<p>The study suggests that specific cultural attitudes towards the caregiving role have important implications for how carers can best be supported.</p>
<p>3. Adamson (2001) UK (Total score)</p>	<p>Explores awareness, recognition and understanding of dementia symptoms in families</p>	<p>30 carers of a person with dementia of South Asian and African/</p>	<p>A qualitative study; In-depth, semi-structured interviews</p>	<p>Most participants were aware of the condition of dementia, but used different terms to describe the</p>	<p>There was no clear elaboration of the understanding of dementia symptoms in families of each ethnic minority group.</p>	<p>This research highlights the importance of raising dementia awareness and emphasises the importance of the provision of clear and understandable information, from health and social service providers.</p>

24)	of South Asian and African/Caribbean descent in the UK.			disorder.		
4. Victor , et al., (2012) . UK (Total score 28)	Explores participants' understandings and experiences of care and support in the context of their family lives and social networks	20 older Bangladeshi and Pakistani women and men aged 50 years and older	A qualitative study; semi-structured pilot interviews	The family remains central in the provision of care and support for these South Asian older people	The reliance on field notes for this article inevitably introduces limitations to the depth of data used and analysis. Interview notes lack the level of detail and richness of recorded interviews and are mediated through the researcher and their recollection and interpretation of the participant's responses.	The study identifies Pakistani and Bangladeshi communities as being in greater need of care and support in older age. This helps to understand the needs and experiences of South Asian communities.

<p>5. Giebel, et al., (2015). UK (Total score 32)</p>	<p>Investigate how South Asians with self-defined memory problems, with and without GP consultation, construe the symptoms, causes, consequences and treatment of the condition.</p>	<p>33 (18 M, 15 F) older South Asians aged 65 or over</p>	<p>Qualitative and mixed method design; in-depth interviews</p>	<p>Perceptions of dementia varied by GP consultation for memory problems. A greater proportion of older adults without a consultation considered memory problems to be given by God, saw acceptance of fate as an alternative treatment and did not identify medical support as appropriate.</p>	<p>The sample sizes of both groups were small, so statistical analyses for differences in perceptions remain tentative. Further research should also adjust for level of education, which was not considered feasible in this exploratory study.</p>	<p>The variations reported on a small scale in this pilot study suggesting the need to explore the impact of perceptions on rates of GP consultation, to improve timely diagnosis and access to appropriate services.</p>
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<p>6. Puran dare et al., (2007) . UK (Total score 32)</p>	<p>Examines knowledge of dementia in South Asian older people, as compared with Caucasian older people.</p>	<p>191 Dementia Knowledge Questionnaire (DKQs) from Indians and 55 DKQs from Caucasians</p>	<p>Quantitative study; survey and questionnaire</p>	<p>Knowledge of dementia was poor in both Indian and Caucasian older people, especially so in the former.</p>	<p>The brevity of the questionnaire was probably the main limitation of the study although it might have helped the response rates. The inadequate time given to answer the questions may have affected the key findings.</p>	<p>The study implies that Indian older people in Manchester (UK) have insufficient knowledge about dementia, which may explain their relative absence in the local dementia treatment clinics.</p>
<p>7. Shaji, et al., (2002) . UK (Total score 29)</p>	<p>Explores care arrangements for people with dementia and the strain experienced by their family caregivers.</p>	<p>17 South Asian caregivers</p>	<p>Qualitative study design; interviews</p>	<p>The majority of caregivers were young women, often daughters-in-law of women with dementia. The principal sources of caregiver strain were behavioural</p>	<p>The statistical analyses for differences in perceptions remain uncertain in this study.</p>	<p>It is noted from the study that South Asian societies are characterised by low levels of awareness of dementia as a chronic degenerative brain syndrome, and by an absence of supportive health and welfare services. This contributes to the key objective of the current study.</p>

				problems associated with the dementia syndrome, and incontinence.		
8. Katbama et al. (2001). UK (Total score 28)	Explores the role of the primary healthcare team (PHCT) in supporting carers from British South Asian communities.	4 South Asian communities in Leicestershire and West Yorkshire	Qualitative study; in-depth interviews	While some carers were positive about the PHCT role, the main weaknesses concerned poor consultation, PHCT attitudes towards carers, and access to appropriate services.	South Asian carers' experiences largely parallel those of others, but some issues are distinct: language and communication barriers, culturally inappropriate services, and implicit or explicit racism.	It is noted from the study that South Asian societies are characterised by low levels of awareness of dementia as a chronic degenerative brain syndrome, and by an absence of supportive health and welfare services. This contributes to the key objective of the current study.

<p>9. Turner, et al., (2005) . UK (Total score 34)</p>	<p>Investigate s whether there were difference s in views about the nature, causes and treatments for dementia, and who participant s believed should provide care.</p>	<p>96 South Asian and 96 white older people (age range 58–85 years)</p>	<p>Qualitative study; semi-structured interviews</p>	<p>South Asian older people had much less specific knowledge about dementia and were much more likely to see it as part of the normal ageing process.</p>	<p>Further research should also adjust for level of knowledge, which was not considered feasible in this exploratory study.</p>	<p>This study has furthered understanding as to why South Asians are under-represented in mental health services, and revealed the areas of hindrance which need to be targeted to change this representation in services for older people with dementia.</p>
<p>10. Mackenzie. (2006) . UK (Total score 34)</p>	<p>Develop and deliver culturally appropriate support group materials for South Asian and</p>	<p>167 people and agencies</p>	<p>Qualitative study design; interviews</p>	<p>Stigma in the South Asian group tended to be linked to religious and ‘magical’ explanations for the onset of dementia. These</p>	<p>There was a tendency in both the Eastern European and South Asian case study groups to try to conceal a relative’s dementia from others in the community. This prevented effective delivery of group</p>	<p>The study gives insights into how understandings of dementia in different cultural contexts can become operational through stigma processes and in turn influence how people with dementia and their family carers engage with formal and informal support.</p>

	Eastern European family carers of relatives with dementia living in the UK..			explanations ranged from being understood as a punishment from God, to dementia symptoms themselves being seen as evidence of a powerful curse.	materials in this research.	
11. Hailstone et al., (2016) . UK (Total score 27)	Devise and validate a theory of planned behaviour questionnaire to measure attitudes that predict medical help-	37 South Asian older adult	Quantitative study; survey and questionnaire	The strongest predictor of willingness to seek help was perceived social pressure from others around help-seeking; these attitudes were associated with beliefs about the	The researchers found frequent favourable attitudes and willingness towards help-seeking for memory problems, which may also be because they interviewed a self-selected sample consisting of a relatively high proportion of individuals who had	The research presents a valid and reliable measure of attitudes which influence help-seeking for dementia in people in the UK from South Asian backgrounds: an ethnic minority group which presents relatively late to dementia services.

	seeking for UK-based South Asian people, to assess the effectiveness of future interventions promoting earlier help-seeking.			views of family members and embarrassment around help-seeking.	cared for someone with dementia. This may limit the generalisability of the findings.	
12. Karim, et al., (2010). UK (Total score 36)	Explores at the possible differences in the symptomatology of Alzheimer's disease (AD) in	Two groups of people with AD (45 in each group) were recruited at the two sites	Qualitative study; semi-structured interviews	Compared to people from Manchester, the Pakistanis had lower literacy levels but similar cognitive deficits when the Mini Mental State	The research did not take into account service and care needs when developing culturally sensitive instruments for assessing cognition, psychiatric symptoms, personality changes and daily activities.	The study illustrated many possible cultural differences in affective symptoms, personality changes and every day activities. It highlights the need for developing mental health services for older people in Pakistan and making UK services more accessible for this growing community.

	people from Manchester, UK and Rawalpindi, Pakistan.	(90 South Asians and 90 British).		Examination (MMSE) scores were adjusted for education		
13. Lawrence et al., (2011) UK (Total score 28)	Examines the subjective reality of living with dementia from the perspective of people with dementia within the 3 largest ethnic groups in the UK.	11 Black Caribbean, 9 south Asian, and 10 White British older people	Qualitative study; in-depth interviews	The key theme that emerged was “threat to valued elements of life.”	The heterogeneity of the sample also made it difficult to fully examine how characteristics such as gender, socioeconomic status, and age might influence the individual’s experience	The findings outlined in this paper provide understanding on the need for culturally sensitive approach in delivery of dementia services.

<p>14. Mogra bi, et al., (2012) . UK (Total score 20)</p>	<p>Investigate s the frequency of unawareness of memory impairment in dementia, exploring regional differences and sociodemographic and health status correlates in large population-based surveys.</p>	<p>15,022 participants from three world regions (Latin America – 5,654, China - 4532, and India - 4836)</p>	<p>Qualitative study; standardised interviews, diagnostic algorithms, and neuropsychological memory assessment.</p>	<p>Regional differences in frequency of unawareness were found, from 63% in China to 81% in India.</p>	<p>The researchers had to create a variable to quantify unawareness, as this was not specifically measured in the source surveys. Because of power considerations in the analysis, the researchers did not consider information on subtypes of dementia.</p>	<p>The frequency of unawareness found in the sample suggests this is an aspect to be included in epidemiological studies, perhaps using specific questionnaires covering different levels and objects of awareness.</p>
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<p>15. La Fontaine, et al., (2007) . UK (Total score 26)</p>	<p>Explores perceptions of ageing, dementia and ageing-associated mental health difficulties amongst British people of Punjabi Indian origin.</p>	<p>49 English-, 26 Hindi- and 23 Punjabi-speaking British South Asians, aged 17–61 years</p>	<p>Qualitative study; A focus-group interview</p>	<p>Ageing was seen as a time of withdrawal and isolation, and problems as physical or emotional; cognitive impairment was seldom mentioned. There was an implication that symptoms of dementia partly resulted from lack of effort by the person themselves and possibly from lack of family care.</p>	<p>The focus was on one particular community which limits transferability and generalisability of the findings.</p>	<p>People from ethnic minorities are often under-represented in mental health services. This study informs the need for awareness and conceptualisation of dementia in South Asian communities.</p>
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<p>16. Muka dam et al., (2011) . UK (Total score 32)</p>	<p>Explore the link between attitudes to help- seeking for dementia and the help- seeking pathway in the minority ethnic (ME) and indigenous population .</p>	<p>18 South Asian family carers</p>	<p>Qualitative study; semi- structured interviews</p>	<p>ME carers, in contrast to the indigenous population, tended to delay help- seeking until they could no longer cope or until others commented on the problems.</p>	<p>The researchers did not formally control the socioeconomic status of the participants, as it is possible that differences between groups are attributable to socioeconomic and educational as well as ethnic differences. Also this study was carried out in inner city boroughs of London which may limit its generalizability to other settings.</p>	<p>The study gives a detailed picture of how different ethnic groups feel about dementia and what paths they take to access mental health services.</p>
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<p>17. Mukadam et al., (2015) . UK (Total score 29)</p>	<p>Determine s the barriers to timely help-seeking for dementia among people from South Asian backgrounds and what the features of an intervention to overcome them would be.</p>	<p>53 English or Bengali speaking South Asian adults</p>	<p>Qualitative study; focus groups and individual interviews.</p>	<p>Participants identified four main barriers to timely diagnosis: barriers to help-seeking for memory problems; the threshold for seeking help for memory problems; ways to overcome barriers to help-seeking; what features an educational resource should have.</p>	<p>While this relatively large qualitative study gave rich in-depth information about the views of 53 participants, it is not necessarily representative of that entire community.</p>	<p>The study created an intervention to encourage more help-seeking in South Asian communities, which has not been done before.</p>
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<p>18. Bowes, and Wilkinson. (2003). UK (Total score 35)</p>	<p>Examines some experiences and views of dementia among older South Asian people, and their caregivers and families, and explores central issues of service support.</p>	<p>11 professionals working with South Asian people with dementia</p>	<p>Qualitative study; interviews</p>	<p>The researchers noted a strong demand for services, a need to develop awareness and knowledge about dementia in South Asian communities, and a need to promote more culturally sensitive, individually responsive services.</p>	<p>The researchers focused on one specific community and the sample was small, which limits transferability.</p>	<p>This study is relevant to the current research as it suggests that there is little knowledge and experience of dementia in South Asian communities. It will strongly link up with the research objectives.</p>
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<p>19. Jutlla. (2015). UK (Total score 31)</p>	<p>Explores experiences of caring for a family member with dementia for those from South Asian communities living in the UK.</p>	<p>8,000 South Asian caregivers</p>	<p>Quantitative and Qualitative study: In-depth interviews</p>	<p>Experiences of South Asians are influenced by: cultural norms associated with roles and positions in South Asian families; dementia being understood as a mental illness and its associated stigma and prior experiences of health and social care services.</p>	<p>There was a tendency in the participants to try to conceal a relative's dementia from others in the community. This affected the collection of precise data from the respondents.</p>	<p>This study further elaborates on the experiences of South Asian communities in the UK, offer a great insight to the current research.</p>
<p>20. Bamford and Bruce (2000)</p>	<p>Identifies the desired outcomes of communities</p>	<p>176 South Asian participants</p>	<p>Qualitative study; dialogues and interviews</p>	<p>Despite a notable overlap in the outcomes identified by</p>	<p>The study did not elaborate on the impacts of how dementia services are delivered. This creates</p>	<p>The study provides perceptions about the process of dementia diagnosis and engagement with health services.</p>

<p>UK (Total score 28)</p>	<p>y care of older people with dementia.</p>	<p>(carers and older people with dementia)</p>		<p>people with dementia and their carers, there were several limitations of depending solely on carers were identified.</p>	<p>a gap between the study and the current research.</p>	
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APPENDIX 5 Interview questions with people with dementia and their family caregivers

Experience of dementia

1. Could you tell me about your memory problems?
2. How do these problems affect you in your everyday life?
3. Have you been forgetful (or had memory problems) for some time? / roughly how long do you think this has been a difficulty ?
4. Were there any difficulties that you and your family experienced?
5. Do you have a specific word in your language by which you refer to memory problem or forgetfulness?
 - How is dementia referred to in your language

Knowledge of dementia

6. When were you diagnosed with dementia?
7. Can you tell me how you found out that you had dementia?

Interview prompts:

- How long did this take, including getting a diagnosis?
- How did this make you feel?

Experiences, stories about their memory loss and the diagnosis will be explored

South Asian Attitude

8. Could you tell me the reaction of people around you about your diagnosis or memory loss? Explore the belief and attitude around memory loss/ dementia by using words like Why? When? Who? What? Why?
9. How did that make you feel about your memory loss or dementia diagnosis? Explore their feelings and emotions.
10. What influenced the decision-making process regarding the choices you made?

Dementia services

11. What was the process of being diagnosed like?

Prompt:

- What were the positive and negatives?
- How easy was it to get a GP to refer you to another service eg the hospital, memory clinic or psychologist?

12. Can you tell me what information and help you got?

Interview prompts:

- Was this easy to get?
- Was this useful?
- Were there other things you would have liked?

13. And what help and treatment do you get now?

Interview prompts:

- Have these been easy to get?
- Have these been useful?
- Who helped, eg family, friends, professionals?
- Are there other things you would have liked or want for the future, eg advocacy?
- What helps you the most?

14. What would you say has changed for you having dementia?

Interview prompts:

- What changes in your life have you made?
- Have you made any plans for the future?

15. Do you have any suggestions for development of the current dementia diagnosis service?

16. What do you think will improve the service for people from the South Asian community?

17. Is there anything I haven't asked you about that you want to tell me

APPENDIX 6 Interview questions with Healthcare professionals involved in dementia diagnosis pathways in Blackburn with Darwen

A. Experience of supporting diagnosis and access to treatment in South Asian population

1. What is your experience of working with and supporting those from the South Asian population with a dementia diagnosis and access to services by the South Asian population and their families?
 - What sort of challenges do these patients and their families appear to have and/ or report?
 - Prompt – What proportion of your patients are South Asian?
 - Do you think there are differences in the length of time people from different ethnic communities take to seek diagnosis?
 - If fewer South Asian patients than you would expect accessing get service early in their dementia / cognitive impairment what factors do you think affect this
 - Can you describe what is it like using cognitive test
 - What is the role of the interpreter – how often are they used in the service?
2. What sort of barriers or challenges if any do you observe for South Asian patients seeking help or accessing memory services?
 - Prompt – Language barriers – Are there any differences in the way South Asian persons with dementia express their symptoms?
 - What is the South Asian community's views/persepctives toward the dementia services (cultural issues)?
 - Do you observe any variation in the level of knowledge / or understanding about dementia/ or memory loss as you move down the generations; e.g., first generation migrant in comparison to the third generation?
 - How do you see South Asian patients and their families coping with these problem?
 - What sort of issues do they report and how much help do they seem to heave from within their community / how much help from outside I.e. Local support charities or care agencies / agencies etc

B. Improvement

3. How do you think the service Could improve or be more supportive for people from the South Asian community?
 - What are the key areas you could see might better address the challenges to these South Asian patients and their families?

C. Process of diagnosis

4. Using this template how might you describe the “timeline” of the dementia diagnosis pathway
 - What sort of help or information about other services do patients receive when first diagnosed?
 - How much help do South Asian patients and families report actually taking up and what do they tell you about those services?

APPENDIX 7 Focus group questions

1. What is dementia?
2. Is dementia a normal part of ageing which all older people will develop as they age
3. Is decline in memory due to ageing same as dementia?
 - Prompt: what is the difference
4. How does one develop dementia?
 - Clarify- what causes dementia?
5. What are the signs and symptoms of dementia?
6. From your current knowledge and understanding about dementia do you think the person with dementia diagnosis should be concern
 - Prompt- Why should they be concern about what is to come?

Attitude

7. If you have dementia, what you would like to know.
 - Prompt- would you seek help
 - Clarify- would you get a diagnosis?
 - If no, Why?
8. Would you make plans for the future (for yourself and family) if diagnosed with dementia?
9. If you or your family member have dementia, would you be happy to tell others in your community know
10. If you or your family member have dementia, you would be ashamed or embarrassed to tell everyone in your community

APPENDIX 8 AtlasTi. Coding list Output

Code-Filter: All

HU: Dementia project 20.5.2016
File: [C:\Users\Documents\MAARIA\ATLAS TI\Dementia project 20.5.2016.hpr7]
Edited by: Super
Date/Time: 2016-05-20 14:14:27

---+{} SEEKING SERVICES BY THE SOUTH ASIAN COMMUNITY

--+{} South Asian community's perception of seeking services

1 -...{} First point of contact

- ..+{} Alternative approach over mainstream
- ..+{} Faith healers
- ..+{} GP
- ..+{} Homeopathic practitioner

2-+{} Community's Perceived Needs

2a-+{} ...Community level

- ++{} ...Training carers / family
- ++{} ..Changing mindset regarding myths around dementia
- ++{} ..Providing the person with dementia and their family with some insight into dementia
- ++{} ..Raising awareness

2b-+{} ..Service level

- ++{} .Culturally sensitive services (If they were geared towards helping them in an appropriate way culturally, sensitive and... then maybe they would be more ready to go and get that help).
- ++{} .Effective health promotion
- ++{} .Services needing to be person-centred

3-+{} Crisis Point (They only go when they're falling off the rails)

- ++{} Family Managing
- ++{} No cure
- ++{} Services not meeting their needs
- ++{} Source of knowledge

--+{} Family members' and the person with dementia experience of seeking services

1-...{} First point of contact

- _+{}]GP

2-+{} Family Members' and the Person with Dementia Perceived Needs

2a-+{} ...Community level

- ++{} ... Educating community about dementia
- ++{} ..Providing insight into the diagnosis

2b-+{} ..Service level

- ++{} Culturally sensitive services
- ++{} Support group for people with dementia: 'It would be nice if they met up with people who have similar problems as them, such as dementia, so they feel better and they don't feel that they're the only one that's going through this'
- ++{} Minimising the timespan it takes to access services

3-+={ „FM- Point of seeking services

- ...{} When first symptoms of dementia appear, to the point of seeking services
- ...{} For behaviour difficulties
- ...{} For memory difficulties

4-+={ („...Diagnostic Pathways by FM

- ++={ („...FM-Presented to GP services
- ++={ („...FM-Referral to memory clinic

5-+={ { „...FM-Experience of engaging with the services

- ++={ { „...FM- Have to keep chasing: 'if you don't attend they don't chase you up – you've got to be on the ball to chase them up'
- ++={ { ... Lack of communication from memory services

-++={ („... Healthcare Professionals' (HCP) perception on access to services by South Asian community

1-++={ („...Diagnostic Pathways by HCP

- ++={ („...HCP- Presented to GP services
- ++={ („...HCP-Referral to memory clinic if suspected dementia
- ++={ („...HCP-Referral to supportive services if diagnosed

2-++={ („HCP-Presentation to services

- ++={ („HCP- At late stage
- ++={ („HCP- Late-For behavioural difficulties
- ++={ („HCP- Late-For chronic pain
- ++={ („HCP- Limited access

3-++={ („, HCP- Barriers when service are accessed by South Asian community from HCP perspective

3a -++={ („, HCP- Service level barriers

- ++={ („...HCP- Lack of communication within services
- ++={ („...HCP- Lack of culturally sensitive services in dementia diagnostic pathway
- ++={ („...HCP- Lack of person-centred approach

- ++=(..HCP-(Somatisation) Difference in expression of dementia symptoms
- ++=(..HCP- Language difficulties
- ++=(..HCP- Use of family members as interpreters
- ++=(.. HCP- Diagnostic tools
- ++=(.. HCP- Staff's attitude
- ++=(.. HCP- Supportive services
- 3b-++=(./ HCP-Community level barriers**
 - ++=(./ HCP- Family dynamic
 - ++=(./ HCP-Negative connotations of dementia within the community
 - ++=(./HCP-Lack of awareness around dementia within the community
- 4-++=(HCP- Importance of building good therapeutic relationship with South Asian community**
- 5-++=(HCP Perceived needs of people with dementia from HCP perspective**
- 5a-++=(.,, HCP-Community level needs**
 - ++=(.,, HCP-Educating the community about dementia
 - ++=(.,, HCP-Promoting positive perceptions of dementia
 - ++=(.,, HCP-Providing the person with insight into their diagnosis
 - ++=(.,, HCP-Raising awareness
- 5b-++=(= HCP-Service level**
 - ++=(HCP--Health promotion
 - ++=(HCP--Representation of South Asian population
 - ++=(HCP--Techniques for health promotion
 - ++=(HCP- One local Health and Social Care website, even for professionals
 - ++=(HCP-Community engagement in service designing
 - ++=(HCP-Consistency across services
 - ++=(HCP-Culturally sensitive services
 - ++=(HCP-Forming a partnership with dementia-related services
 - ++=(HCP-More community-based services
 - ++=(HCP-Recruiting and training people from the same community
- 6-++={ ...HCP-South Asian community engagement with the services from HCP perspective**
 - ++={ ..HCP- with GP services
 - ++={ ..HCP- with memory services
 - ++={ ..HCP- with social care services
 - ++={ ..HCP- with supportive services
 - ++={ ..HCP-Family managing at home
- 7-++={ ##HCP-Preferable methods of treatment**
 - +={ #HCP-Faith Healers
 - +={ #HCP-Medication
- 8-++={ ,,HCP- Point of seeking services by South Asian community**
 - +={ ,HCP-Crisis point
 - +={ ,HCP-Family unable to manage

###--= SOUTH ASIAN CULTURAL PERSPECTIVES OF DEMENTIA (we have so many cultural biases on so many levels)

###--Community reported culturally transmitted perspectives of dementia

1##'..[]Responses

1a #''..Of People with dementia and their families toward dementia

- #''..Stigmatising (it's sort of like a stigma and there just isn't enough and the sort of people, they don't understand about mental health)
- #''..Bezati ho jayegi [Dishonour]
- #''..Denial

1b#''[]Community responses toward people with dementia and their families

- #''[]Failure
- #''[] Pagal [Insane]
- #''[] Punishment from god for their evil sins
- #''[] Discriminate the family

2#--...Services

- #--Care home
- #--Hospital care
- #--Living at home (expectation to care, we can look after our family)

3#--..Future Care Planning

- #--..Good to plan ahead
- #--..Role of family
- #--..Take each day as it comes
- #--..Unaware

###—Family and the person with dementia lived experience of culturally perspective of dementia

1#''..[]Responses

1a #''.. Experiences of responses of family members of people with dementia

- #''.. FM-Approaching the person differently
- #''..FM-Frustrated
- #''..FM-Protective
- #''..FM-Worried
- #= FM- 'Some people get labelled as well, you know, and that's the biggest concern in South Asian community'

1b #''.. Family member experience of community responses toward people with dementia and their families

#"[] FM-'Are they possessed?'
#"[] FM- Lost it
#'.FM- 'There is nothing wrong with him...he is fabricating it'

2#--..FM-Services

#--FM-Care home

#--FM-Living at home (expectation to care, we can look after our family)

#='.... Healthcare professionals' perception of South Asian cultural perspectives of dementia

1# = ... HCP-Responses

1a # = ... HCP- PwD responses of person with dementia

= ... HCP-PwD does not want to burden the family

1b # = ... HCP-Responses of family members

= ..HCP- How will we be perceived by the community?

= ..HCP- Stigmatising

= ..HCP-Denial

= ..HCP-Dishonour

= HCP-Alienate the family

1c# = HCP-Community towards people with dementia and their families

= HCP-Failure

= HCP-Pagal [Insane]

= HCP-Taboo

/'----SOUTH ASIAN COMMUNITY KNOWLEDGE OF DEMENTIA (they sort of come out of phases of their lives)

/'----South Asian Community perception on traditional community understanding of dementia

1/'---\$\$Signs and Symptoms

/'--\$ Behaviour form of communication

/'--\$ Disorientated

/'--\$ Memory difficulties

2/'--Cure

3/'--Services

4/'--.Dementia vs Ageing (it is difficult to define the person who has dementia)

/'-Ageing

/'-Person with dementia

5/'[]-Cause (I could see families not understanding is it mental health? I could even see them thinking: there's some possession)

/'[]Biopsychosocial model

/'[]Spiritual

/'----Family Members of people living with dementia understanding of dementia

1/'---- Family members' perception on person with dementia; knowledge of dementia

/'-- PwD knowledge-memory loss

2/'--- Family members' knowledge of signs and symptoms of dementia

/'-- FM-\$ Memory difficulties

/'--FM-\$ Behaviour form of communication

/'--FM-\$ Deteriorate over time

3/'-- FM- No word for dementia

4/'--.Dementia vs ageing (it is difficult to define the person who has dementia)

/'-Ageing

/'-Person with dementia

5/'[]-Cause (I could see families not understanding is it mental health? I could even see them thinking: there's some possession)

/'[]FM-Biopsychosocial model

/'[]FM- Spiritual

/'== Healthcare professionals' understanding

1/'==Dementia vs ageing (it is difficult to define the person who's got dementia)

/'==Person with dementia

/'=Ageing

2/'=HCP-Lack of understanding of signs and symptoms

3/'=HCP-Services available

/'HCP-memory

/'HCP-supportive services

/'HCP-whom should be first point of contact

4/''=HCP-Cause

///'=HCP-Biopsychosocial model

///'=HCP-Spiritual

~ CASE CODES

~ FG1_Female 1

~ FG1_Male 1

~ FG1_Male 2

~ FG1_Male 3 Personal experience of Dementia

~ FG1_Male 4

~ FG2_Female 1

~ FG2_Female 2

~ FG2_Female 3

~ FG2_Male 1
~ FG3_Female 1
~ FG3_Male 1
~ FG3_Male 2
~ FG3_Male 3
~ Interviewer
~HCP1
~HCP2 Personal experience of dementia
~HCP3
~HCP4
~HCP5
~HCP6
~HCP7
~HCP8-Responded 1
~HCP8-Responded 2
~ PwD 1 Living with dementia
~Family Member 1 of PwD Personal experience of dementia
~Family Member 2 of PwD Personal experience of dementia



Health Research Authority
National Research Ethics Service

NRES Committee North West - Lancaster

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03 February 2015

Miss Maaria Atcha
358 Derby Street
Bolton
Lancashire
BL3 6LS

Dear Miss Atcha

Study title: Facing the Dementia Challenge: A mixed methods study exploring access to a dementia diagnosis and support within an ethnically diverse communities in Blackburn with Darwen.
REC reference: 15/NW/0049
Protocol number: N/A
IRAS project ID: 159606

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Mrs Carol Ebenezer, nrescommittee.northwest-lancaster@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the

study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants	1	22 December 2014
Covering letter on headed paper	1	22 December 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Certificate of Employer's Insurance]	1	22 December 2014

GP/consultant information sheets or letters [Letter to the GP]	1	22 December 2014
Interview schedules or topic guides for participants [Interview questions for Participants with dementia and their family member]	1	22 December 2014
Letter from sponsor [Letter from Sponsor]	1	22 December 2014
Letters of invitation to participant [Appendix 2 Advertisement Flyer]	2	28 January 2015
Other [Appendix 1]	1	22 December 2014
Other [Expression of interest form]	1	22 December 2014
Other [Consent form for family member taking part]	1	22 December 2014
Other [Participants detail form to fill]	1	22 December 2014
Other [Transcriber Confidentiality Form]	1	22 December 2014
Other [Interpreter Confidentiality Form]	1	22 December 2014
Other [Semi- structured interview questions for healthcare professionals involved in dementia diagnosis pathways in Blackburn with Darwen]	1	22 December 2014
Other [Participant information sheet (for health professionals)]	1	22 December 2014
Other [Assessment of Capacity Form]	1	22 December 2014
Other [Public Insurance Indemnity]	1	22 December 2014
Other [Professional Indemnity]	1	22 December 2014
Other [Amanda Bingley CV]	1	05 January 2015
Other [Katherine Froggatt CV]	1	05 January 2015
Other [Thomas Keegan CV]	1	06 January 2015
Other [Appendix 3 Expression of interest]	2	28 January 2015
Other [Participants detail Questionnaire]	2	28 January 2015
Participant consent form [Consent form]	2	28 January 2015
Participant information sheet (PIS) [Participant information sheet for people with dementia]	2	28 January 2015
Participant information sheet (PIS) [Participants Sheet for carers]	1	28 January 2015
REC Application Form [REC_Form_06012015]		06 January 2015
Research protocol or project proposal [Research Proposal]	1	22 December 2014
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	22 December 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/NW/0049	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Lisa Booth
Chair

Email: nrescommittee.northwest-lancaster@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Ms Deborah Knight, University of Lancaster*
Ms Beverley Lowe, Lancashire Care Foundation Trust

