

UNDERSTANDING DEMENTIA AMONG THE BANGLADESHI COMMUNITY IN ENGLAND

Muhammad Zakir Hossain

This thesis is submitted in partial fulfilment of the requirements for the award of the degree of Doctor of Philosophy of the University of Portsmouth

August 2017

Declaration of dissemination

I, Muhammad Hossain, confirm that the work presented in this thesis is my own. I declare that the work in this thesis was carried out in accordance with the Regulations of the University of Portsmouth. Where information has been derived from other sources, I confirm that this has been indicated in the thesis. I also declare that none of the work contained within this thesis has been submitted for any other degree at any other university. The contents herein have been composed by the candidate, Muhammad Hossain. Any views expressed in the thesis are those of the author and no way represent those of the University of Portsmouth.

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Abstract

Background: Worldwide, an increasing ageing population means that more people may suffer from dementia. Despite the rapid growth of older Bangladeshi people living in the UK, there is little evidence on how community members understand and view the process of dementia. Bangladeshis have a higher risk of developing type 2 diabetes and heart disease, both of which are important indicators of dementia development in old age. In addition, while Bangladeshis are three times more likely to care for dependent family members than White British (Carers UK, 2011), little is known about the experiences of family carers of people with dementia. There is a paucity of research within the Bangladeshi community on experiences and concerns of Bangladeshi individuals providing care for their relatives with dementia. Therefore, the objectives of this study were to produce new knowledge and understanding of the attitudes, perceptions and beliefs of members of the Bangladeshi community in England about dementia and dementia caregiving, as well as to increase awareness and understanding of dementia.

Methods: The research for this study was gathered in three distinct phases: 1) qualitative meta-synthesis, 2) focus group discussions and 3) semi-structured qualitative interviews. Firstly, a systematic literature synthesis of primary qualitative research studies on South Asian people with dementia and their family carers was conducted. The qualitative meta-synthesis, using the Joanna Briggs Institute's (JBI) technique of meta-aggregation, was completed to consolidate the data and draw together the current evidence base, which informed the development of the interview schedules for phases two and three. Then in phase two, two separate focus group discussions (one male, n=12; and one female, n=9) were held with Bangladeshi people in a large South coast city. Finally, in phase three, semi-structured, audio-recorded interviews were conducted with six Bangladeshi family carers living in London and Portsmouth. All data were analysed using thematic analysis. NVivo 10 software was utilised to simplify thematic analysis, including transcribing, coding, and documenting emergent themes.

Results: One research gap was identified in phase one using the population framework where, despite the increasing number of older people from the Bangladeshi community in England, little or no specific research was carried out on their understanding and management of dementia. Perceptions of the personal ageing process were mostly related to physical decline. Across phases two and three, a lack of knowledge and understanding of dementia awareness was evident, but stigma about dementia was non-existent. Family carers exhibited a strong sense of familism, religious beliefs, and values, which appear to increase interpersonal motive, or obligation, to provide care for their relatives with dementia at home.

Family carers appeared to accept and take for granted the expectations of fulfilling often considerable caregiving roles.

Conclusion: This study provides novel and current research findings on the knowledge and attitudes towards dementia among a Bangladeshi community in England. The findings will help improve the advice, care and support for other Bangladeshi elderly living with dementia and their family carers (as well as healthcare professionals delivering services) outside of the specific context of the research setting. This will also help to better understand the challenges family carers face, the barriers to accessing health and social care services, coping strategies and avenues for future action. In this context, it is vital that future studies highlight the importance of raising dementia awareness and provide more information to Bangladeshi community members about dementia, dementia caregiving and religiously sensitive healthcare services.

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List of Abbreviations

APPG: All Party Parliamentary Group
BAME: Black and Asian Minority Ethnic
BME: Black and Minority Ethnic
BWA: Bangladesh Welfare Association
CAQDAS: Computer Assisted Qualitative Data Analysis
CDW: Community Development Worker
DoH: Department of Health
EPPI: Evidence for Policy and Practice Information and Co-ordinating Centre
GHS: General Household Survey
GP: General Practitioner
JB: Joanna Briggs Institution
JSNA: Joint Strategic Needs Assessment
LGBT: Lesbian, Gay, Bisexual, and Transgender
MCA: Mental Capacity Act
MMSE: Mini Mental State Examination
NHS: National Health Service
ONS: Office for National Statistics

PWD: People with Dementia

QARI: Qualitative Assessment and Review Instrument

QDA: Qualitative Data Analysis

SFEC: Science Faculty Ethics Committee

SHSSW: School of Health Sciences and Social Work

UK: United Kingdom

WHO: World Health Organization

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Outline of the Thesis

This thesis contains six chapters. An introduction can be found at the beginning of each chapter.

Chapter One begins by providing the reader with an overview of dementia and discusses Black and Asian Minority Ethnic (BAME) identities, the Bangladeshi diaspora and their health risk factors, socio-economic and health status in Britain, ageing, and culture. It also explores the definitions and boundaries of dementia and caregiving. Then, the chapter pays particular attention to the rationale and significance of the use of a meta-synthesis, focus group discussions and one-to-one qualitative semi-structured interviews in the study. It determines the research gaps in the previous literature and demonstrates how this study intends to build upon them. The chapter concludes with the research question.

Chapter Two sets out phase one of the study: a meta-synthesis of primary qualitative studies. The goal of this is to comprehensively search the academic literature to find the best available evidence that articulates the experiences of South Asian communities with dementia as well as finding the gaps in the research to explore them in phases two and three of the study.

Chapter Three describes the research methodology for the study. The first half of the chapter describes the research design, epistemology, ontology, and explains the choice of thematic analysis methods. The last part of the chapter then details the procedures used for data analysis, including using NVivo 10 qualitative data analysis (QDA) computer software, the techniques for identifying themes, complex ethical dilemmas, and the difficulties and challenges that are expected to arise while carrying out this research.

Chapter Four describes phase two of the research, where two focus groups interviews with adults of Bangladeshi origin without dementia are conducted to examine their attitudes toward ageing and older people, as well as their knowledge about dementia and caregiving. In both Chapters Four and Five, the population samples, settings, and methods of data collection, are also outlined.

Chapter Five describes phase three of the research, which builds on the findings of phases one and two. This chapter aims to conduct semi-structured audio-taped qualitative interviews with Bangladeshi family carers supporting their relatives with dementia. In particular, this chapter pays close attention to the dementia knowledge of Bangladeshi family carers and their day-to-day caregiving experiences. It also focuses on the perceived barriers and opportunities for improving dementia care and for increasing the awareness and understanding of dementia among Bangladeshi communities in England.

Chapter Six provides a detailed discussion of issues arising from the study as well as a discussion of the findings of the study and their significance to practice and research. This chapter particularly highlights the unique contribution of these findings to knowledge, and also describes the strengths and limitations of the study. Finally, it concludes by returning to the research questions and the aims of the research and demonstrates how the aims have been achieved. It also discusses the contribution of the current study to the current state of knowledge, and the study's implications for further research, practice, and education.

Chapter 1: Background and context

1.1 What is dementia?

The World Health Organisation's International Classification of Diseases (ICD 10) has a more widely used definition of dementia (WHO, 2016). The ICD-10 defines dementia as follows:

Dementia is a syndrome due to a disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.

Dementia is an umbrella term for a decline in mental ability that is severe enough to interfere with daily life. Dementia is not a disease in itself, but a term used to describe a group of symptoms that exist when brain cells die and stop working properly (Alzheimer's Research UK, 2013). Dementia is a progressive disease and the symptoms of dementia gradually get worse with age. Symptoms are likely to include memory loss, confusion, inappropriate behaviour, getting lost, problems with communication or difficulty finding the right words, faulty reasoning, sleep disturbance, hallucination, fainting, and agitation (Alzheimer's Society, 2014). The National Dementia Strategy: Living Well with Dementia defines it thus:

'the term "dementia" is used to describe a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness'. (DoH, 2009)

A person is affected by dementia when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Dementia also leads to a reduction in a person's abilities and skills in carrying out routine activities such as washing, dressing and cooking. Additionally, age is the most significant known risk factor for dementia. Dementia affects men and women in all social groups and therefore, the prevalence of dementia increases exponentially with age (Ott et al., 1995). However, there is no word in South Asian languages that has exactly

the same connotations as the word 'dementia'. Although this can create potential barriers for a discussion about dementia, it is instead sometime explained by using derogatory words, for example, 'madness', 'forgetfulness' or 'losing memory' in old age (Mackenzie, 2006).

1.1.1 Types of dementia

There are many types of dementia, but Alzheimer's disease is the most common cause, accounting for two-thirds of cases in the elderly. Another type of dementia is vascular dementia, which is the second most common type, and which occurs after a series of strokes (post-stroke dementia). Dementia with Lewy bodies is the third most common type of dementia, affecting over 15% of the cases in the United Kingdom (UK). Fronto-temporal dementia is the fourth most common type of dementia and is relatively rare (Alzheimer's Research UK, 2013). There is a plethora of research being carried out on the potential treatments of dementia; however, to date, there are no drug therapies that can cure Alzheimer's disease or any other common type of dementia. However, drugs have been developed for Alzheimer's disease that can briefly lessen the symptoms or slow down their development in some people.

1.1.1.1 Dementia epidemiology and risk factors

There are an estimated 36 million people worldwide living with dementia, and this number is expected to increase to 66 million in 2030, rising by 71% to 115 million in 2050 (Prince, Bryce, & Ferri, 2011). The number of people with dementia in the UK is estimated to be 821,884, representing 1.3% of the population (Luengo-Fernandez, Leal, & Gary, 2010) with about 670,000 family and friends acting as primary carers (Lakey, Chandaria, Quince, Kane, & Saunders, 2012). Dementia can be debilitating not only for the person living with dementia but also for family members. Living with dementia as the condition progresses presents many challenges for both the individual sufferer but also relatives or friends, as deteriorating physical, behavioural, and cognitive abilities require specialised health and social care services and support to meet complex individual needs and maintain quality of life (Royal College of Nursing, 2011). Dementia nonetheless is an expensive condition with considerable care costs to both public and private finances; the current financial cost of dementia care is estimated at £23 billion a year and is born by the NHS, local authorities and families. The care costs are expected grow to £27 billion by 2018 with an increasingly ageing population (Lakey et al., 2012).

1.2 Ethnicity and identity

The Oxford Dictionary defines ethnicity as “the fact or state of belonging to a social group that has a common national or cultural tradition” (Oxford Dictionaries, 2015). The concept of ‘ethnicity’ is complex, and although it is difficult to define accurately, ethnic identity plays a significant role in the lives of people belonging to a certain group or culture in receiving countries. The globalisation of migration and the recent refugee influx has radically increased the scale of ethnic minority populations not only in the UK but also elsewhere in Europe. The number of immigrants is rising and, consequently, immigration has become one of the top agenda items for all political parties in the UK and Europe. Many people are concerned that higher immigration has significantly negative effects on health and social care services, housing, education, as well as lower living standards (Berry, 2014). This is true notwithstanding the fact that the Government’s austerity policies as a whole have more severely affected black and ethnic minority communities, who were already facing inequalities in the UK in terms of housing, health, employment and wealth (Dodd, 2015). Although the issue of immigration and ethnicity are complex and intrinsically sensitive, these areas need to be explored as a first step in order to deepen our understanding about different ethnic groups’ attitudes and knowledge, not only about dementia and caregiving but also for other age-related health issues in the UK.

Black and Minority Ethnic (BME) or Black, Asian and Minority Ethnic (BAME) is the terminology normally used in the UK to describe people of non-white descent (Institute of Race Relation, 2014). Likewise, the ‘BME/BAME group’ refers to non-White communities that originate in South Asia (e.g., those from Bangladesh, India and Pakistan), Africa, the Caribbean, China and, in some cases, Ireland and Poland. On the other hand, strong evidence shows that half of the children of immigrant families, whose parents, or grandparents migrated to Britain from other countries, count themselves as both white and British (McFall, 2012; Nandi & Platt, 2014). Although BME/BAME is a constructed designation, ethnicity is a complex, controversial concept, and it is very hard to define and there is a risk that it may lead to inappropriate generalisations (Botsford, Clarke, & Gibb 2011).

Although ethnic minority populations are brought under the umbrella acronym ‘BAME’, they differ from each other by race, language, culture, and religion. Furthermore, South Asians, Blacks, and other Ethnic Minority groups are not themselves homogeneous (Blakemore & Boneham, 1994; Gill, Kai, Bopal, & Wild, 2004). Hinton (2002, cited in Milne and Chryssanathopoulou, 2005 p. 236) found that the widely held view that culture is a shared set of ideas espoused equally by all members of a specific ethnic group is inaccurate. Even within their own communities, there is tremendous diversity in terms of acculturation, migration, associated patterns of settlement and adaptation, education, income, religious affiliation, and

length of residence in the UK (Milne & Chryssanthopoulou, 2005). However, most ethnic minority groups in the UK tend to confront their health, cultural, and religious issues within their own communities (Ma, Shea, & Yeh, 2012). Though common mental health problems are fairly similar across all BAME groups (Maynard 2008), there are considerable differences in mental health experiences between different BAME groups in the UK. This is one of the most controversial issues in the health variation field (Nazroo 1997). Research shows that people from BAME communities may face increasing difficulties, including higher rates of mental illness in some communities, and subsequent problems with access to the right care and treatment (Rethink 2011).

1.2.1 Diversity in health care

As the diversity of populations continues to grow in most parts of the UK, current and future generations of ethnic minority people with dementia and their family carers are likely to experience complex and unique sets of service needs. Therefore, there is a prerequisite for cultural competency in healthcare service provision for both the people with dementia and their family carers. Understand culture and religion is an integral part of understanding of contemporary social life, health and ageing among South Asians, either in the countries to which they immigrated or in their countries of origin. Religion is a real and continuing social force in the lives of the South Asians, which places great emphasis on their public rituals and festivals. Religion has also a strong influence on public culture and social change in South Asia, including politics, gender relations, socioeconomic inequalities and health. Hinduism and Islam are the two dominant religions in South Asia. Both these religions have common values surroundings such topics as gender relations, dress code and strong family ties. In fact, despite the wide variation of different religious backgrounds in South Asia, cultural values are often shared. For example, most of the South Asian religions, including Buddhism, Hinduism, and Islam have strong culturally based common apprehensions about modesty, especially receiving medical treatment or care from members of the opposite sex (Ehman, 2012). Notwithstanding the role of culture and religion in South Asians' countries of origin, culture and religion also play a vital role in South Asian immigrant communities in the UK and elsewhere.

Researchers have found that for Bangladeshi minorities in the UK, religious beliefs intertwine with their knowledge, perception, and attitudes toward mental health and other health conditions (Dein, Alexander, & Napier, 2008; Rozario, 2008). Religious beliefs about health and illnesses adequately reflect the ethnic and cultural diversity of the Bangladeshi community. There may be some homogeneity within Bangladeshi communities with regard to health beliefs and practices; however, there is much heterogeneity in the understanding of

mental illnesses across South-Asian communities in general (e.g., among Pakistanis or Indians; Ahmad 1996). Therefore, it is important that research focuses on one community alone rather than on all South-Asian communities.

In sum, all participant groups in this study (as determined by religion or ethnicity) exhibited differences in terms of their views and beliefs of illness, health-seeking behaviour, and information-seeking activities related to health issues. Some of these processes may be rooted in cultural practices, and more work is required to further elucidate the factors that impact these different perspectives (Rull, 2011).

1.2.2 The growth of South Asian minority ethnic groups in the UK

The earliest settlement of South Asians in Great Britain is not known. Through the analysis of the records of the British East India Company and the government of India in the Oriental and India Office Collections (OIOC), a researcher discovered that South Asians had settled in Britain since 1600 (Visram, 2002). However, it was not until after the partition of the Indian subcontinent in 1947 that migrants from the South Asia started to arrive in large numbers. There was a shortage of labour in the UK after World War II, and rebuilding post-war Britain was a huge task. Therefore, during the 1950s, further immigration was encouraged by the British government. As a result, for about next 25 years, South Asian workers from East Africa (mainly Sikhs) and India, Pakistan and East Pakistan (later Bangladesh) travelled to work and settle in Britain. Today, the UK is one of most ethnically, linguistically, religiously, and culturally diverse countries in the world (Loftus, 2012; Somerville, Sriskandarajah, & Latorre, 2009; BBC, 2005). It is not always easy to get the exact picture of the ethnic origin of all the population. According to the UK census, the most common ethnicity in the UK is White, followed by Black, Asian and other minority groups (Mateos, Singleton, & Longley, 2009).

It was first recommended that Britain collect ethnicity data in the Census Act of 1920 (Mathur, Grundy, & Smeeth, 2013; Sillitoe & White, 1992). Whilst the decision of capturing ethnic information in the comprehensive population census was a major step forward, it took another 70 years until the 1991 census (Figure 1) before South Asian ethnicity questions were included (Ballard, 1996, 1999; Mathur et al., 2013). Although people from the Indian subcontinent had been coming to Britain en masse since the days after World War II, they were only distinguishable from rest of the population in government records after 1991 due to this census.

11 Ethnic group	
Please tick the appropriate box.	
	White <input type="checkbox"/> 0
	Black-Caribbean <input type="checkbox"/> 1
	Black-African <input type="checkbox"/> 2
	Black-Other <input type="checkbox"/>
	<i>please describe</i>
	<input type="text"/>
	<input type="text"/>
	Indian <input type="checkbox"/> 3
	Pakistani <input type="checkbox"/> 4
	Bangladeshi <input type="checkbox"/> 5
	Chinese <input type="checkbox"/> 6
	Any other ethnic group <input type="checkbox"/>
	<i>please describe</i>
	<input type="text"/>
	<input type="text"/>
If the person is descended from more than one ethnic or racial group, please tick the group to which the person considers he/she belongs, or tick the 'Any other ethnic group' box and describe the person's ancestry in the space provided.	

Figure 1 - South Asian (including Bangladeshi) ethnic group question in the 1991 Census

Adapted from: Ballard, R. (1999). Britain's Visible Minorities: A demographic overview

The 2011 census shows that the number of foreign-born residents in England and Wales rose by nearly 3 million since 2001 to 7.5 million people. Obviously, this is consistent with census findings on international migration, which found that South Asian countries continued to rank highly within the most common non-UK countries of birth (ONS, 2012). The 2011 census records that the combined South Asian (*Indian, Pakistani, and Bangladeshi*) minority ethnic population numbered 3,078,374 (4.9 per cent of the total population), excluding other Asian groups and people of mixed ethnicity. Indian is the largest South Asian group, with 1.4 million people (2.5 per cent) followed by Pakistani (2.0 per cent) and Bangladeshi (0.7 per cent) as shown in Figure 2 below. Significantly, among all South Asian immigrants, Bangladeshis have experienced the greatest increase in numbers since 1991. As of today, the number of Bangladeshis is estimated to be some 451,529 in England and Wales (Jivraj, 2012; ONS, 2013a), which is a 57% increase from the 283,063 recorded in 2001.

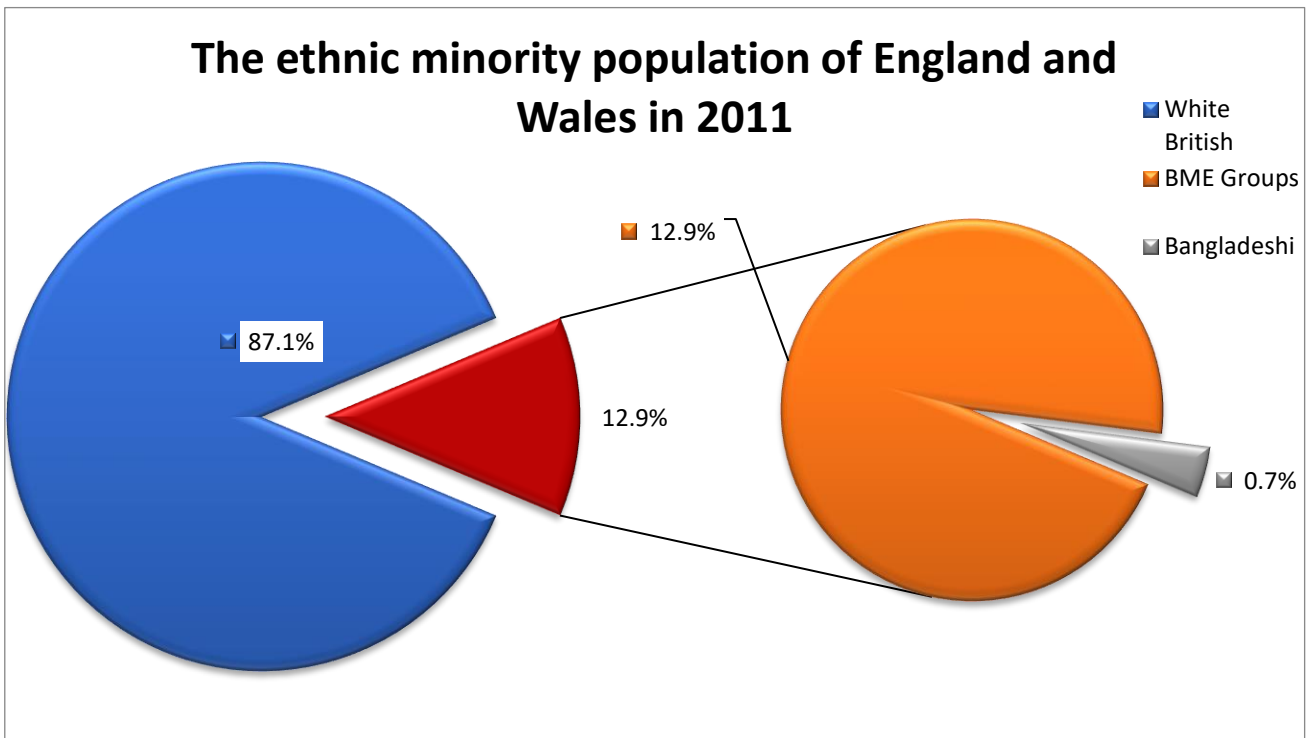


Figure 2 - The ethnic minority population of England and Wales in 2011

Adapted from: ONS, the 2011 Census

[<https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/ethnicityandnationalidentityinenglandandwales/2012-12-11>]

The median age of the largest South Asian group (Indians) is 33, followed by 24 for Pakistanis and 22 for Bangladeshis. The Bangladeshi group has the highest percentage of young people (under 15) within the South Asian groups, amounting to about 38 per cent, whereas the Indian group has highest percentage of over 60 population, amounting to about 11 per cent (Platt, 2009). In addition, the highest numbers of multi-generational households and overcrowding (six or more people per household) was found among South Asian groups. Overall, 14 per cent of all multi-generational households were found to be of the Indian, Pakistani, and Bangladeshi South Asian groups (Smallwood & Wilson, 2007).

1.2.3 South Asians are not a homogeneous group

There are clear differences between South Asians and other BME groups, denoted by class, caste, experiences and time of migration, and origin from urban or rural areas (Bhachu, 1985). Furthermore, Salway, Chowbey, and Clarke (2009), Ali, Kalra, and Sayyid (2006), and Aspinall and Chinouya (2008) argue that many of the ethnicity categories in the UK, including the term “South Asian”, are too broad to be meaningful. They presume homogeneity within populations and neglect the variety of religious, ethnic, geographical or linguistic differences. Despite

searching for studies on seven specifically named countries in addition to studies on South Asians in general, only a small number studies related to the Indian, Pakistani and Sri Lankan communities were revealed. Specific groups, such as the Bangladeshi, Bhutanese, Maldivian and Nepalese communities, have not yet been investigated separately in order to understand their experiences of dementia.

1.2.4 Bangladeshi diaspora in Britain: accuracy and limitations

Bangladeshi diaspora is one of the fastest growing immigrant populations among all major ethnic groups in the UK as well as around the world (Sunder & Uddin, 2007). The popular receiving countries for Bangladeshi short-term labour migrants are Saudi Arabia followed by United Arab Emirates (UAE), and Malaysia (BBC, 2009b; Kapiszewski, 2006; Kibria, 2011b). However, international migrants from Bangladesh are inclined to live permanently in the Western developed world, i.e., the UK followed by United States, Canada, Italy, and Australia and so on. Outside the Middle East, the Bangladeshi diaspora in the UK is one of the largest and fastest growing populations in the world (OECD, 2012).

The earliest records of the Bangladeshi diaspora community first emerged in the UK as early as in the 17th century, and the majority of them arrived as lascars, or merchant seamen (Fisher, 2006). Later, Bangladeshi immigrants began to arrive in large numbers for the first time in the 1970s following the founding of Bangladesh in 1971. Though most of these migrants initially came from three regions of Bangladesh – Sylhet, Chittagong and Noakhali – migrants from Sylhet (in the northeast of Bangladesh) came to dominate the migration flow to the UK, and today more than 90 per cent of Bangladeshi immigrants in the UK have come from Sylhet (Gardner, 1992; Islam, 1995). Bangladeshi immigrants are mostly concentrated in the inner London in boroughs such as Tower Hamlets, Newham, Camden and Southwark. There are also large numbers of Bangladeshi immigrants living in Birmingham, Manchester, Oldham, Luton, Bradford, Cardiff and Portsmouth.

As previously mentioned, the BME/BAME group refers to non-White communities whose roots are mainly in South Asia, Africa, the Caribbean, China, Turkey, and Ireland. Therefore, it is possible that the South Asian population, including Bangladeshi, can sometimes be misrepresented under the constructed designation of BME/BAME. Furthermore, the largest mass migration from Pakistan to Britain was recorded in the early 1960s (Ballard, 1999), at a time when Bangladesh was a provincial state of Pakistan, known as East Pakistan. Hence, even though the last decades have shown that Bangladeshis are a fast-growing ethnic minority, these figures may underestimate the actual number of Bangladeshi immigrants living in the UK to date. Bangladeshis were generally combined into the category 'Pakistani' for

much of the period until 16 December 1971, when Bangladesh won its independence from Pakistan and appeared on the world map. Therefore, it has been argued that the Bangladeshis represent 'a concealed community' (Peach, 1990 cited in Alexander, Firoz, & Rashid, 2005, p. 8). Despite increasing numbers, the immigrant Bangladeshi community often represents the lowest education rates and disproportionately high rates of unemployment, overcrowding, and poorer socio-economic and health conditions among the overall population of the UK (Garbin, 2005; ONS, 2002).

1.2.5 Britain's Bangladeshi ageing population

Worldwide, the number of people aged 65 or older is projected to grow from an estimated 524 million in 2010 to nearly 1.5 billion in 2050, with most of the increase in developing countries (WHO, 2011). In the UK, there were more than 10.8 million people (17% of the UK population) who were over 65 years old in mid-2012, and as of 1996/97, people from Bangladeshi ethnic minority group represented 3% of the total older population (Age UK, 2015b; ONS, 2013b). Another estimate expects the total number of people aged 60 or over to rise up to 20 million by 2030, whereas about 3.8 million from Black and Ethnic Minority groups will reach age 65 by 2051 in England and Wales (Age UK, 2015a; Lievesley, 2010). There are stark differences in the experience of ageing, life expectancy, healthy and disability-free life expectancies between the White British and Bangladeshi ethnic groups compared to other ethnic groups across England and Wales and the broader region. In addition, the life expectancy of White British population is higher than that of the Bangladeshi population: the gaps range from 1.6 years for males to 0.8 years for females (ONS, 2015; Lievesley, 2010). Therefore, in order to understand the experience of dementia among the ethnic Bangladeshi community in England, first it is fundamental to understand their experience of ageing. More than half of UK Bangladeshis were born in Bangladesh, compared with 46 per cent who were born in the UK, and Bangladesh ranks third in the list of countries of birth for Londoners born outside the UK (Piggott, 2004). Realistically, actual birth dates are quite often unknown, because many individuals in Bangladesh do not have an official record of their birth dates. This change reflects the effect of ageing of various cohorts who have arrived in the UK at different times. The percentage of Bangladeshis born in the UK has increased from 35 per cent in 1991 to 51.38 per cent in 2011. Moreover, 10.63 per cent of the Bangladeshi population is aged 50 and over, and 4.25 per cent is aged 65 and over per cent (Lievesley, 2010). Social, cultural, and economic characteristics all have a significant impact on how one experiences ageing.

1.3 Health risk factors among older Bangladeshi

The risk factors for the Bangladeshi ethnic minority, which is also a socioeconomically disadvantaged group in the UK, that interfere with successful ageing include smoking, diabetes, high blood pressure, heart disease, stroke, and depression. Mainstream research highlights that the connections between ethnicity and ageing is central to understanding what it means to grow old in a Western society. Data on the Bangladeshi community is largely descriptive and provides information about the size and age profile of the population, its health problems and, to a lesser extent, its lack of access to health care services. There is very little research about the health risk factors of the Bangladeshi ageing population in Britain and therefore there is limited understanding of its problems. Being aged can mean isolation from society, even within one's own community and family. There is a gap in research in relation to the diversity of meanings attached to the way in which concepts like quality of life and empowerment differ across cultures (Wray, 2003). Cross cultural gerontology focuses on ageing in relation to culture, ethnicity, the experiences of ethnic minorities, and the migration of older people (Torres, 1999 cited in Wray, 2003, p. 516). Although this field of study has provided insights into other South Asian groups which are fairly similar to the Bangladeshi community, there is a need to investigate the experience of Bangladeshi older people in particular: what barriers they face, and what being old in Britain means for them.

By analysing six years of the UK General Household Survey (GHS) 1991-96, Evandrou (2000) found that older people from the Bangladeshi ethnic minority group experience a disproportionate degree of socioeconomic and health disadvantages. Bangladeshis aged 60 years old have the highest rates of poor health of all ethnic minority groups in the UK. In addition, the 2001 census data found that while 27% of people over 50 years old in the UK mentioned that they suffer from limiting long-term illness such as diabetes, hypertension or stroke, 54% of the Bangladeshi over 50 population reported this (ONS, 2001). There is a substantial amount of literature on the determinants of dementia and the links between diabetes, hypertension, stroke, depression and dementia. Dementia has profound implications for the Bangladeshi community in how it affects the family carers and cared for persons, as well as other family members. It is important to ensure that Bangladeshi immigrants living in the UK have a good understanding of dementia and that families are not left isolated and unsupported.

1.4 Dementia in South Asian communities

There is little research on dementia in BME groups. This is not surprising, given the younger age profiles of the oldest migrant communities (median ages around 35 years), from India, Pakistan and the Caribbean. There is no specific discussion about any South Asian ethnic minority community and dementia in the literature and there are no exact figures regarding the prevalence of dementia in BME groups in the UK. In addition to this, dementia has been characterised as a 'hidden problem' for South Asian people (Brownlie, 1991; Wilkinson, 2002) and South Asian people with dementia are a considerably marginalised group who remain excluded from literature commenting on service use or on the experience of people living with dementia (Wilkinson & Bowes, 2003). However, the number of older people from South Asian communities is rising, as those who came to the UK between 1950 and 1970 (for seeking work) are now ageing, and, as such, the risk of dementia in South Asian communities is increasing. South Asian people are less likely to engage with services, and for various cultural reasons, may be less willing to talk about dementia. Rates of dementia diagnosis are disturbingly low – at around 45% in the general population – and, therefore, for various cultural, institutional, and informational reasons, are likely to be much lower in BME communities (APPG, 2013; Truswell, 2014). Estimates of people from BME groups with dementia ranged from 11,000 in 2004 (Dementia Advocacy Network, 2009) to 15,000 in 2009 (DoH, 2009), representing 1.7% of all people with dementia in the UK. It is acknowledged that these figures are likely to be a considerable under-representation (Knapp et al., 2007) and are set to rise. Furthermore, a very recent estimates suggest that there are almost 25,000 people with dementia from the African-Caribbean and South Asian communities in England and Wales, and the figure is predicted to grow to 50,000 by 2026 and 172,000 by 2051 (APPG, 2013; Truswell, 2014).

Estimates on how many live with dementia vary and are likely to be unreliable, as the high incidence of cardiovascular disease, heart disease, stroke, and diabetes in these communities impacts the prevalence of dementia. A recent study from Lancet Neurology revealed seven potentially variable dementia risk factors such as diabetes, mid-life hypertension, mid-life obesity, smoking, depression, low educational attainment and physical inactivity (Barnes & Yaffe, 2011). More evidence suggests that people with diabetes have an increased risk of developing dementia in later life (Bruce, Harrington, Davis, & Davis, 2001; Peila, Rodriguez, & Launer, 2002; Stewart & Liolitsa, 1999). Four out of seven of these principal risk factors have been identified as having an important association with developing dementia, which is disturbingly common among BAME communities. Type 2 diabetes is up to six times more common in people of South Asian descent and up to three times more common among people of African and African-Caribbean origin than it is among the White British population (Diabetes

UK, 2012). In fact, many people in the South Asian community attribute pre-dementia symptoms to diabetes or strokes (Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007; Mukadam et al., 2011; Uppal et al., 2013). Moreover, doctor-diagnosed diabetes is almost four times as prevalent in Bangladeshi men, and almost three times as prevalent in Pakistani and Indian men compared with men in the general population (HSCIC, 2006). Among women, diabetes is more than five times as likely among Pakistani women, and at least three times as likely in Bangladeshi women. In addition, according to the Health Survey for England 2004, children of South Asian origin were more than 13 times more likely to have Type 2 diabetes than White British children. Nonetheless, Pakistanis and Bangladeshis have the highest rates of self-reported smoking, whereas Bangladeshis have the highest rate of chewing tobacco compared to the national average and other ethnicities. Despite the high prevalence of diabetes and smoking rates in the South Asian older population in the UK, which may cause cognitive deterioration, the role of diabetes mellitus (DM) and smoking as risk factors for cognitive decline in later life has received little epidemiological attention in the UK (Stewart & Liolitsa, 1999). Therefore, it is suggested that the above estimated number of people with dementia does not accurately represent the South Asian and other BME communities.

1.5 Dementia in the Bangladeshi community

It appears, therefore, there is evidence that some research has been carried out on older people in the wider South Asian immigrant community in the UK as well as in other countries. In particular, a very small portion of this research utilises qualitative methodology as an appropriate approach to seek answers to questions about experiences, attitudes toward diagnosis and treatment, barriers and enablers to service use and support. The little qualitative research that has been conducted on dementia research among ethnic minority people has been conducted within a relatively confined paradigm. This confined paradigm of research lacks, first of all, a coherent definition for individual South Asian communities such as the Bangladeshi community; secondly, there is a lack of data on culturally appropriate service targets in South Asian people with dementia and their family carers; finally, there is a lack of theoretical and empirical inquiry.

Nonetheless, the most significant gap in the previous primary studies about South Asian people with dementia as well as their family carers is that there is only a handful of such studies, and none of these studies attempted to understand the views, knowledge and experiences of dementia of the Bangladeshi community. It appears that the prevailing paradigm for dementia research among ethnic minorities focuses more on overall all BME groups by ignoring the needs of any particular community (APPG, 2013; Butt, 2006). The lack

of culturally congruent research methods is also limited in the existing literature, e.g., participants' involvement in the research design about how the research materials should be prepared or who should interview who, given priority to the language matching with the participants. To date, there have been no qualitative studies conducted with people living with dementia from the Bangladeshi community in England. Moreover, almost two decades ago, Patel (1998) argued that the mainstream academic study of dementia has been 'colour blind' while the mainstream academic study of minority ethnic ageing has been 'dementia blind'. South Asian communities and the Bangladeshi community may face additional burdens accessing the British health care system. Some barriers may arise out of their religious and cultural beliefs and practices, other barriers may relate to the complexity of the health care system. In some cases, there may be a need to integrate cultural considerations into service to support appropriate care and access to services.

1.6 Who are carers?

'A carer spends a significant proportion of their life providing unpaid support to family and potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has a mental health problem or substance misuse problems' (DoH, 2008). However, research suggests that the English term 'carer' has no single or forthright definition (Clements & Francis, 2012; Rethink Mental Illness, 2013) and there is no such word as 'carer' in South Asian languages (Godfrey & Townsend, 2001). The identity of a carer can vary from person to person and culture to culture. Family members and friends sometime find the word 'carer' incongruous with their actual identities, and that it cheapens their natural relationships with the persons they cared for (Hughes, Locock, & Ziebland, 2013). Maybe the distinction between 'carer' and 'family carer' should be made to differentiate those with paid from those with unpaid caring roles. To date, carers in the general population across the UK number around seven million and will increase to nine million by 2037 (Carers UK, 2015). As the aim of this study is to explore how the Bangladeshi family carers of people with dementia experience their caring role and support in England, in this chapter I will only focus on family carers.

1.6.1 Bangladeshi family carers

There are many Bangladeshi family carers who do not recognise themselves as carers but classify themselves as husbands, wives, sons, daughters, daughters-in-law, parents or friends. The 2001 census statistics revealed that family carers from South Asian (Indian, Pakistani and Bangladeshi) communities provide higher levels of care than any other group in England (ONS, 2001). In addition, Bangladeshi men and women are three times more likely

to be carers than White British men and women (Yeandle, Bennett, Buckner, Shipton, & Suokas, 2006). Despite all of this, Bangladeshi family carers are the most deprived, neglected and effectively hidden group. Hidden carers do not recognise themselves as carers. They identify themselves as fulfilling family duties and do not associate this with caring (CCG, 2011). They are unknown to the service providers because they do not present themselves for services for various reasons in England.

1.7 Rationale for this study

There is little dementia research in the UK that specifically looks at BAME groups. However, what research has been carried out to date has been predominately in the USA. A thorough search of the literature has revealed that few previous primary studies have been conducted, and the majority of these are US-based studies mainly focused on African American, Hispanic, Black Chinese, Chinese American, Korean, Korean American, Latino, White and US-based European Union carers of people with dementia (Botsford, Clarke, & Gibb, 2011; 1997; Connell, Janevic, & Gallant, 2001; Daker-White, Beattie, Gilliard, & Means, 2002; Milne & Chryssanthopoulou, 2005; Mukadam, Cooper, & Livingston, 2011; Regan, Bhattacharyya, Kevern, & Rana, 2012). One systematic review comprising a mixture of both qualitative and quantitative international literature looking at dementia from the patients' perspectives was conducted by de Boer et al. (2007) in Netherlands. Although fifty international studies met the inclusion criteria, none of these represented the perspectives of South Asian patients. Hence, there is a pressing need for further research to be conducted within the South Asian communities. As was acknowledged earlier, the concept of ethnicity is complex, and there is a risk that it may lead to inappropriate generalisations. However, future research needs to take ethnicity into account while ensuring that worsening factors, including socio-economic, housing, education and health are not ignored and that ethnic labels are used sensitively and appropriately (Botsford et al., 2011).

In the light of all of this, in the UK and elsewhere, there has been little quantitative research done on the prevalence of dementia in South Asian ethnic minority communities. First, a prevalence study was conducted among ethnic elders of South Asian origin in the inner city of Liverpool that used the Hindi translation of the community version of the Geriatric Mental State schedule (GMS-A) diagnostic tool to identify dementia (Bhatnagar & Frank, 1997). Their study suggested that vascular dementia is much more common among South Asian people than dementia of the Alzheimer's type. A decade later, another quantitative study conducted among the Indian population in Manchester focused on knowledge about some basic aspects of dementia such as prevalence, risk factors and symptomatology (Purandare, Luthra,

Swarbrick, & Bums, 2007). This study found that Indian people have poor knowledge about dementia. In addition, another quantitative study also conducted in Leicester among the Indian Gujarati population (Shah, Lindsay, & Jagger, 1998) and a few more quantitative studies conducted in India (Pinto & Seethalakshmi, 2006; Shaji, Promodu, Abraham, Roy, & Verghese, 1996) used survey methods and depended on local modified versions of the Mini Mental State Examination (MMSE) method for the diagnosis of dementia. However, few qualitative studies have also examined the knowledge, attitudes and experiences of living with dementia in South Asian older people in the UK (Adamson 2001; Godrey and Townsend, 2001; Bowes and Wilkinson, 2003; Mackenzie, 2006). All were restricted to a small number (4 to 16) of South Asian people who were caring for a relative with dementia. There was a need to synthesise this work to provide a coherent critical summary of it. This might reveal additional understanding and provide a focus for future research. Therefore, the initial rationale for the research was to conduct a qualitative synthesis under phase one of this study.

Secondly, despite the increasing number of older people from the Bangladeshi community in England, little or no specific research has been carried out on their understanding and management of dementia. Yet, as part of ageing, South Asians have more heart disease than Europeans and among South Asians, Bangladeshis are thought to be at greater risk of developing heart disease (Bhopal et al., 1999; Patel & Bhopal, 2004). Type 2 diabetes is markedly higher for Bangladeshi immigrants among South Asian and all other ethnic minority immigrants in the UK (Diabetes UK, 2010). The principal risk factors of diabetes and heart disease have been identified as important indicators of developing dementia. Diabetes increases dementia risk (Bruce et al., 2001; Peila et al., 2002; Stewart & Liolitsa, 1999) and a joint research between the University College London and the French National Institute of Health and Medical Research (INSERM) has found that heart disease patients are likely to develop dementia which will be expressed through problems with reasoning, vocabulary and verbal fluency (Singh-Manoux et al., 2008). In addition, in England, Bangladeshi communities have been shown to have lowest education rates, the highest smoking rates, the poorest socioeconomic conditions and the worst health positions, the most risk factors for underdiagnosis, and the poorest access to healthcare services and support (Garbin, 2005; HSCIC, 2006; ONS, 2002).

As a result of little primary research in the area, and to explore further, there was a need to conduct a primary qualitative study among the Bangladeshi elderly community and to provide a coherent critical description and interpretation of their knowledge about, experiences with, and perceptions of dementia. It is believed that this research will reveal additional understanding and provide avenues for future research. Therefore, qualitative focus groups interviews were conducted in phase two of this research study. Phase two aimed to explore

perceptions across the Bangladeshi community about ageing, caring for older people, mental health, dementia diagnosis and management, before going on to explore the reality of those living and coping with dementia from within these communities. It was important to study people without dementia among the Bangladeshi community first in order to raise awareness about dementia and about how to improve their access to local services. This was the first step to knowing whether or not Bangladeshi people without dementia were aware of dementia and of early diagnosis, so that they could help their family members or community members who might be suffering from dementia symptoms. It was also important to know what others perceive as barriers to dementia services, and whether this would be the same for those who were coping with potential symptoms of dementia.

Lastly, the rationale for interviewing Bangladeshi family carers in phase three was to gain a view of their personal experiences with their care recipients. Despite the growing interest in family carer's roles in family support and needs among BAME communities in Western Europe and America, there is a dearth of published research about carer's burden, physical health, psychological health, economic situation and quality of life in the UK (Milne & Chryssanthopoulou, 2005). The qualitative synthesis (in Chapter Two) shows that there have been very few qualitative studies carried out among the family carers of dementia from South Asian backgrounds and no studies on family carers from the Bangladeshi community specifically. Further research is required to explore and understand Bangladeshi family carers' experiences, feelings and the ways they cope with their caregiving roles. Since Bangladeshi people with dementia and family carers have been categorised under the South Asian hidden population with dementia, capturing the lived experiences of the family carers of people with dementia would not be easy.

Therefore, qualitative semi-structured interviews were also conducted in order to inform action and to better understand the personal and social barriers and coping strategies of Bangladeshi family carers. Nonetheless, to my best knowledge, this is the first primary research of ageing and dementia among Bangladeshi elderly people in the UK utilising a qualitative methodology. The purpose of this research was to inform action and to produce new knowledge that will be applicable outside of the context of the research setting, with implications for other UK Bangladeshi elderly persons living with dementia, their families and health care professionals. Therefore, this research will seek to contextualise its findings within the larger body of research and its results will have implications for policy. It was also hoped that this study would explore the concept of dementia in depth and examine the impact of stigma on individuals, family carers, and wider communities.

1.8 Research questions

Taking into account the background and context of the study, the rationale for the study, the overarching research question that guided the study was:

- What are the levels of awareness and understanding of dementia among the Bangladeshi community in England?

The key research questions and aims were as follows:

Research question for phase one:

- What are South Asians' views and experiences of dementia?

The aims of phase one were to undertake a qualitative meta-synthesis to gain an understanding of the experiences and views of South Asian people with dementia and their family carers. The intention of this phase was to inform the development of the focus group and interview schedules for phases two and three.

Research question for phase two:

- What are the Bangladeshi adults' knowledge and attitudes toward dementia?

The aims of phase two were to conduct two focus group discussions with adults of Bangladeshi origin without dementia to understand their perceptions, knowledge, and attitudes toward ageing and dementia. Phase two of the study also informed the development of the interview schedules for phase three.

Research question for phase three:

- What range of experiences and knowledge do Bangladeshi family carers have about dementia?

The aims of conducting face to face interviews with the family carers of people with dementia from the Bangladeshi community were:

- To explore their experiences of caring for someone with dementia
- To better understand their coping strategies
- To better understand their cultural and religious barriers to using services
- To inform future action

1.9 Summary

The aim of this chapter was to present an overview of the research entitled 'Understanding dementia among the Bangladeshi community in England'. The chapter offered an elaboration of the background and rationale of conducting this study. The chapter provided a brief overview of dementia by introducing a definition of dementia, and considered dementia's aetiology and risk factors. The chapter also provided a short history of the immigration of South Asians as well as Bangladeshis to the UK and their settlement. The chapter ended by providing the research questions.

The next chapter will synthesise the empirical qualitative literature investigating the awareness, knowledge and experience of dementia among the South Asian people with dementia and their family carers. As there was currently no research that focused on the Bangladeshi community per se, the chapter reviewed other South Asian studies to consolidate and draw together the current evidence base which informed the interview schedules for phases two and three.

Chapter 2: Awareness and understanding of dementia in South Asians: A synthesis of qualitative evidence

2.1 Qualitative synthesis

A synthesis of qualitative evidence is a transparent review of previous research on a specific topic. 'Qualitative synthesis' is a general term used to describe the 'pooling together' of a body of research on a particular subject. The current qualitative synthesis followed a carefully organised protocol, a detailed plan about its objectives, concepts, and methods that was set up at the beginning (Saini & Shlonsky, 2012). The aim of this current qualitative synthesis was to describe, combine and analyse the literature for common meaning to draw conclusions on the state of previous research, in order to inform the focus, methodology and direction of the current study (Ring, Ritchie, Mandava, & Jepson, 2011).

The importance of synthesizing the best available qualitative studies to support decision-making at the policy and practice level is increasingly recognised across the health and social care sectors. For example, experiences of dementia, diagnostics, treatment and care management may vary across ageing South Asian populations due to physiological, psychosocial, religious and culturally sensitive issues. Many qualitative studies have sought to understand the experiences of people with dementia and their formal and family carers. However, because individual qualitative studies are context specific and have produced different findings, which may or may not contradict each other, a synthesis can summarise common meaning and provide an overview to give a sense of the whole. The current qualitative synthesis combined all the similar studies and was carried out by methods that allowed me to produce a transparent, consistent, and comprehensive interpretive rendering of the current body of knowledge (Sandelowski & Barroso, 2003).

2.1.1. Rationale for qualitative synthesis

Despite the increasing number of older people from Bangladeshi community, it appeared that little or no specific research had been carried out on their understanding of dementia. However, some research had been carried out within South Asian communities more broadly. Therefore, it was necessary to synthesise the primary qualitative studies on this topic area to identify clear gaps in the current literature. The qualitative synthesis informed the research questions and direction of the second and third phases of the study: a focus group study on adults of Bangladeshi origin, and semi-structured qualitative interviews with Bangladeshi family carers of their relatives with dementia respectively. Figure 3 sets out the steps of the approach to meta-aggregation that has been adopted.

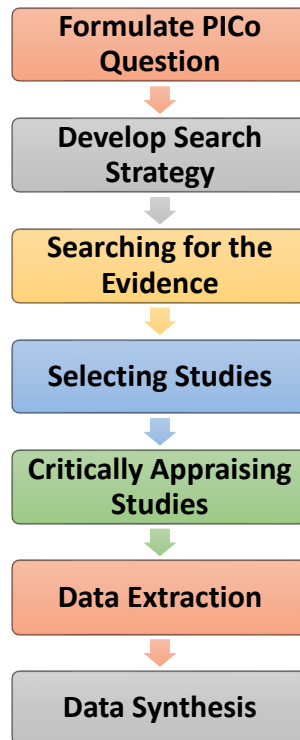


Figure 3 - Qualitative synthesis process

Source: Pearson, Robertson-Malt, & Rittenmeyer, 2011

2.2 Objectives

The objective of this review was to appraise and synthesise the best available qualitative evidence to provide a better understanding of the experiences of South Asian people with dementia and their family carers.

2.3 Methods

A qualitative synthesis of primary studies was conducted using a meta-aggregation method guided by the JBI approach. The meta-aggregation method of qualitative synthesis is one of the first to provide a robust framework for qualitative synthesis designed to model Cochrane's process for systematic reviews whilst being sensitive to the nature of qualitative research and its traditions (Pearson, 2004). The JBI approach comprises a number of set stages: a comprehensive search of the literature, a critical appraisal of potential studies using a suitable criteria-selection tool, synthesis of the findings from the included studies (meta-aggregation), and finally, creating a "line of argument" output that can serve as a basis for evidence-based practice. The meta-aggregation procedure involves the following three steps (Figure 4).

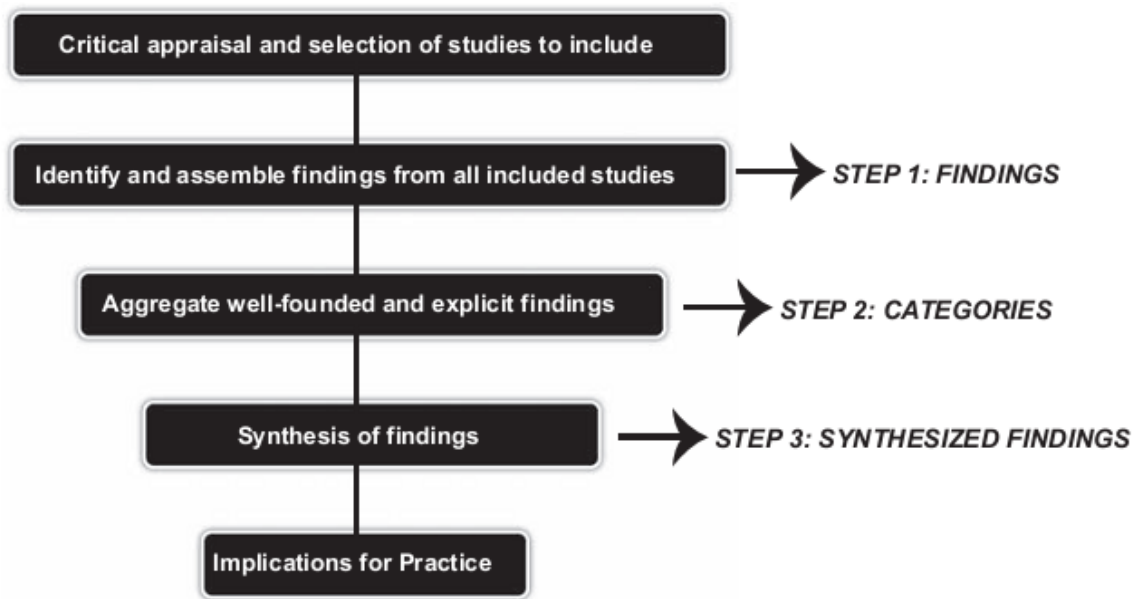


Figure 4 - Steps in meta-aggregation

Source: Pearson, Robertson-Malt, & Rittenmeyer, 2011

2.3.1 Search strategy

The considered qualitative interpretive studies drawing on the experiences of South Asian people with dementia included, but were not limited to, methodological approaches such as phenomenology, grounded theory, ethnography, action research, and feminist research. The search strategy aimed to find both published and unpublished studies. The three step search strategy depicted above was adopted. An initial limited search of MEDLINE and CINAHL was undertaken, which included searching for words contained in the title and abstract, as well as for the index terms used to describe the article. A second search using all identified keywords (Table 1) and index terms across all relevant databases was then undertaken, covering the period between 1970 and 2014, such as the Web of Science, MEDLINE (Web of Knowledge), CINAHL, E-Journals, SocINDEX, eBook Collection, PsycINFO, MEDLINE (ProQuest), British Library EThos, JSTOR, Social Care Online, and Science Direct. An additional search was also carried out via relevant websites and gateways (e.g., Age UK, Alzheimer Europe, Alzheimer Scotland, Alzheimer's Research UK, Alzheimer's Society, Alzheimer's Association, Alzheimer's Disease International, British Medical Association, Dementia Friends, MIND, Rethink Mental Illness, and Time to Change). Thirdly, a search of the reference lists of all identified reports was also carried out to incorporate additional studies. The search was not limited to nationality or language, as the search strategy aimed to find international qualitative studies written in English and in other languages. Non-English studies were subsequently translated into full-text articles, if it was possible to do so using translation tools, such as Google Translate. In the event that translation was not possible, the primary authors were

contacted to provide additional details about their study. If the author could not be reached, and if the document could not be translated, the article was subsequently excluded from the study. In addition, grey literature was sought, and a hand search of relevant journals was also conducted (Figure 5). Attempts were made to contact the authors, experts, and groups that might have access to relevant data (both published and unpublished). Some, however, did not respond to these emails.

2.3.2 The initial search terms included

Keywords:

The initial search was not limited by the methodology to assure the maximum article retrieval from the databases. The keywords were organised into six groups, as follows (Table 1):

Table 1- Keywords used in the search

Keyword groups	Keywords/terms
Keyword group 1: Phenomenon of interest	Attitudes, barriers, experience*, impacts, issues, opportunit*, understanding
Keyword group 2: Dementia	Alzheimer's disease, creutzfeldt-jakob disease, delirium, dementia, dementia diagnos*, dementia with lewy bodies, early onset dementia, fronto-temporal dementia, cognitive impairment, huntington's disease, korsakoff's syndrome, memory loss, parkinson's disease, vascular dementia
Keyword group 3: Older people	Age*, elder* geriatric, later life, older adults, patients, pensioners, seniors
Keyword group 4: Carers in context	Care*, carer, community care, family members, formal care, informal care, primary care, service, spouse, support,
Keyword group 5: South Asians	Asian, Bangladesh*, Bhutan, black and minority ethnic groups, bme, ethnic*, immigrants, India*, Maldives, migrants, Nepal*, Pakistan*, south Asia, Sri Lanka
Keyword group 6: Qualitative approaches	Action research, conversational analysis, descriptive qualitative research study, discourse analysis, ethnograph*, exploratory stud*, focus groups, grounded theory, interview*, narrative* observational method*, participant observation, phenomenology*, qualitative, qualitative research method, qualitative study, qualitative synthesis, thematic analysis

2.3.3 Inclusion criteria

The PICO mnemonic was used to construct clear and meaningful questions for this systematic review protocol of qualitative evidence (Booth, 2004).

Population: (1) South Asian people with a diagnosis of any type of dementia; and (2) formal and family carers.

Phenomenon of interest: the range of knowledge, views about dementia, perceptions, beliefs, and experiences of older people from South Asian communities living with dementia, as well as their formal and family carers.

Context: communities and primary care settings, both in South Asian countries and abroad.

Outcome: it was hoped that the outcomes of this review would help to identify the various themes embedded in the qualitative studies that fully describe the primary outcomes of South Asian people with dementia and their family carers, as well as their families in their countries of settlement and in their countries of origin. Secondary outcomes for carers would be included, such as each carer's burden, their dementia-associated stress and health experiences, their physical health, the resultant economic impact, and their quality of life.

2.4 Data screening

Following the search, 2,515 papers were identified. After removing duplicates, 1,267 papers were entered into the EPPI-Reviewer database. The screening process was conducted in three stages, as studies were included or excluded based on the following: (1) the titles alone, (2) the abstracts, and (3) reading of the full texts. The reasons for each article's inclusion or exclusion were documented to include descriptive and evaluative codes, descriptions of each included study, and the data used and produced during synthesis (Rees, Oliver, Woodman, & Thomas, 2011). Each stage was independently assessed by two reviewers. Where an agreement could not be reached, a third reviewer was involved.

2.5 Data extraction

2.5.1 Study details

A total of 187 papers were examined in depth. Seventeen studies were selected for retrieval for this review. Four of these studies were then excluded based on the assessment of their methodological quality, which meant that 13 studies met the inclusion criteria (Figure 5). All included studies were published between 2001 and 2013, and all were scientific research papers apart from one (Jutla, 2011), which was a PhD thesis. The analytical methods of all 13 studies that were finally included in this analysis were described as grounded theory (n=4), thematic analysis (n=4), content analysis (n=2), and ethnographic analysis (n=2); one study's adopted methodology was generic qualitative or unclear (n=1). Most studies (n=10) used interviews as the primary method of data collection, while two studies combined both interviews and non-participant observation methods, and one study combined both interviews

and focus group discussions. The qualitative papers selected for retrieval were assessed by two independent reviewers for methodological validity.

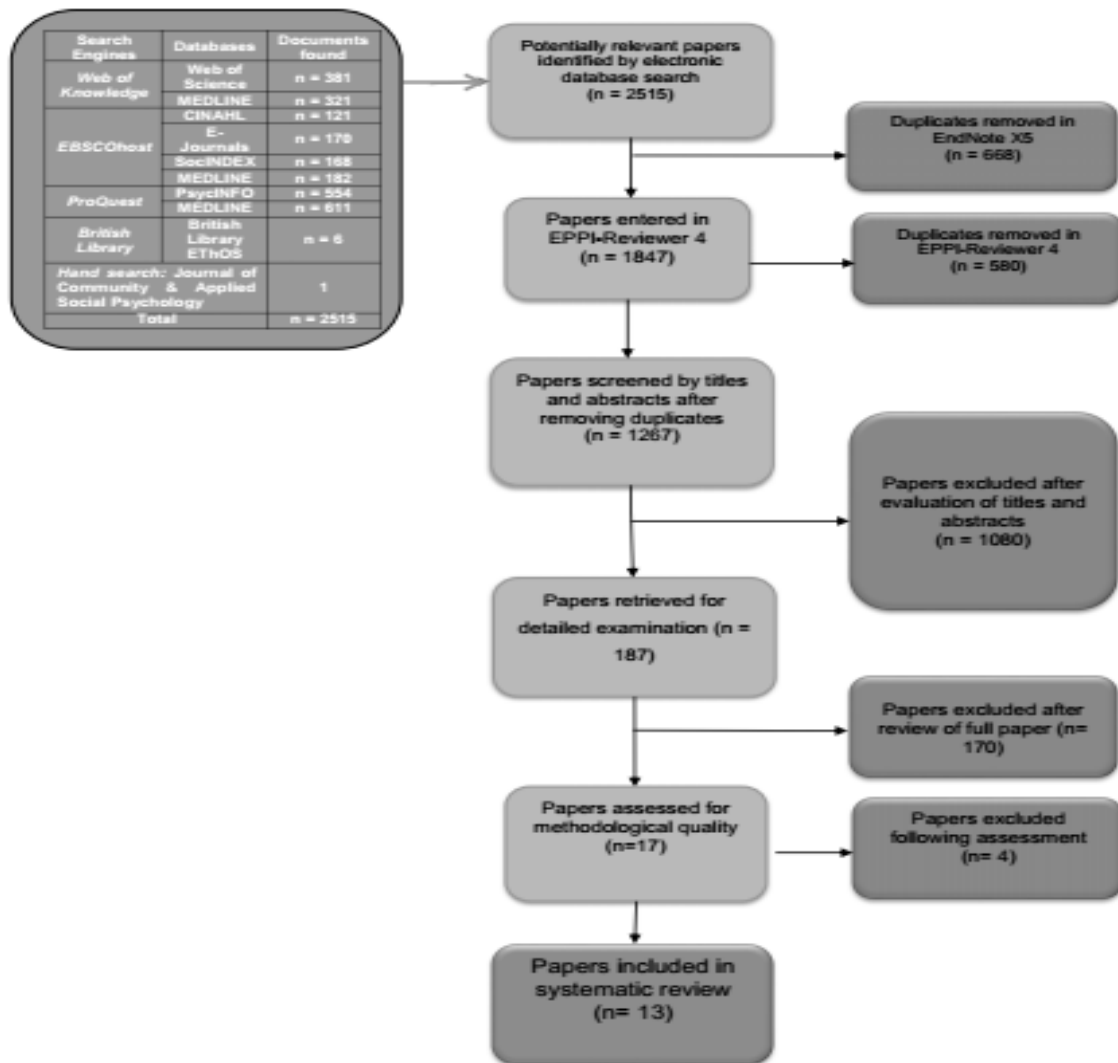


Figure 5 - A flowchart of search results

2.5.2 Assessment of methodological quality

An assessment of the methodological quality of each paper was performed prior to inclusion in the qualitative synthesis; the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI QARI), a standardised critical appraisal instrument tool was used to achieve this aim (JBI, 2011), as shown in Table 2 below. Data were then extracted from the included studies using the standardised data extraction tool, JBI QARI.

Table 2 - JBI QARI Critical Appraisal Checklist for Interpretive and Critical Research

Reviewer _____ Date _____
 Author _____ Year _____ Record number _____

	Criteria	Yes	No	Unclear
1	There is congruity between the stated philosophical perspective and the research methodology.			
2	There is congruity between the research methodology and the research question or objectives.			
3	There is congruity between the research methodology and the methods used to collect data.			
4	There is congruity between the research methodology and the representation and analysis of data.			
5	There is congruity between the research methodology and the interpretation of results.			
6	There is a statement locating the researcher culturally or theoretically.			
7	The influence of the researcher on the research, and vice-versa, is addressed.			
8	Participants and their voices are adequately represented.			
9	The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval an appropriate body.			
10	Conclusions drawn in the research report appear to flow from the analysis or interpretation of the			
	Total			

Overall appraisal: Include: Exclude: Seek further info.

Comments (Reasons for inclusion or exclusion)

Source: JBI, 2011

2.5.3 Study setting and participants

The included studies were conducted in a variety of countries: the UK (n=9); India (n=2); Canada (n=1); and Pakistan (n=1). Most studies (n=8) were part of a broader BME investigation and included African-Caribbean, Irish, Eastern European, and White British populations. The South Asian studies relied on fairly small sample sizes, but they reported that most of their participants were from the general region of 'South Asia'. Across the 13 studies included in the analysis, there were 214 participants, most of which were family carers (n=145) (in 12 studies). Importantly, no formal carers were identified in those included studies, although the perspectives of service providers (n=53) were assessed in three studies, and three studies examined the experiences of people with dementia (n=16). Those studies that examined one's perspectives between his or her country of origin or his or her country of settlement concentrated on two countries (India and Pakistan). The majority of participants across the 13 studies were of Indian background, followed by those of Pakistani background, while very few were Sri Lankans. Missing were the perspectives of those from Bangladesh,

Bhutan, the Maldives, and Nepal. A small number of studies (n=2) referred to specific religious groups, such as Sikhs, or to people from particular geographical areas, such as the Punjab. Moreover, nine UK studies included immigrants from India and Pakistan; there was also one Canadian study that included immigrants from India and Sri Lanka alone. As part of the large BME groups, two UK studies also included immigrants (n=5) from Bangladeshi communities (1 immigrant and 4 immigrants, respectively). However, Bangladeshi immigrants and their voices were not adequately represented in those two studies. Further details are provided in Table 3 below. Furthermore, despite their inclusion, the voices of the people with dementia were also not satisfactorily characterised in either of the two reviewed articles.

Table 3- Summary of reviewed articles

Studies conducted in SA immigrants' countries of settlement					
References	Methods	Phenomenon of Interest (Purpose)	Setting (Country)	Cultural	Participants
Adamson, J. 2001	Exploratory; in-depth, semi-structured interviews; thematic analysis and coding	Awareness, recognition and understanding of dementia	Primary care based settings, informants' homes (England)	SA and African/Caribbean heritage in the UK	N=30 carers of a person with dementia, 18 African/Caribbean and 12 SA (Pakistan, India and East Africa)
Adamson, J and Donovan, J. 2004	Exploratory; in-depth, semi-structured interviews; constant comparison methods, analytical headings and topic guides coding	Experience of African/Caribbean and SA carers caring for older family members with dementia	Primary care based setting; research participants' own homes (England)	African/Caribbean and SA heritage in the UK	N=36 carers; 21 African/Caribbean and 15 SAs/ older family members
Bowes, A. Wilkinson, H. 2003	Exploratory; semi-structured interviews, case studies; thematic analysis	Understanding the dementia experiences	Primary and community based (Scotland)	SA	15; 11 service providers and 4 case studies with people with dementia and their families
Godrey, M & Townsend, J. 2001	Exploratory; In-depth interviews, individual and focus group interviews; nothing mentioned about the data analysis	Understanding of the barriers to respite care services experienced by SA families caring for a relative with dementia	Local offices and day centres; home-based respite services (England)	SA, East African Asian	N=12 carers; Pakistani 7, Indian 3, Bangladeshi 1 & East-African Asian 1
Jutla. K. 2011	Constructed grounded theory; in-depth narrative interviews; conceptual framework analysis	This study highlights the importance of the migration experiences and personal histories of carers, and the extent to which those experiences influence the perceptions and experiences of formal and informal care services amongst Sikh carers in Wolverhampton, particularly among those caring for an older person with dementia	Primary care settings at carers' homes (England)	Sikhs, Indian	N=12 Sikh carers
Lawrence, V., Samsi, K., Banerjee, S., Morgan, C., Murray, J. 2010	Grounded theory; in-depth individual interviews; thematic analysis	Individual experience or subjective reality of living with dementia	Primary care based settings, such as participants' homes or community based settings e.g. at day centres (England)	Three of the largest ethnic groups; Black Caribbean, South Asian and White British	N=30 people with dementia; 11 Black Caribbean (3 male and 8 female), 9 SA (5 male and 4 female), and 10 White British (5 male and 5 female)
Lawrence, V., Murray, J., Samsi, K., Banerjee, S. 2008	Grounded theory; in-depth individual interviews; thematic analysis	Attitudes, experiences, and needs of family carers of people with dementia	Primary care based settings as participants' homes (England)	Three of the largest ethnic groups; Black Caribbean, South Asian and White British	N=32 carers of people with dementia (10 Black Caribbean, 10 SA, 12 White British)
Mackenzie, J. 2006	Phenomenology; semi-structured interviews; thematic content analysis	Stigma and care giving experiences of dementia among carers	Primary and community care-based settings (England)	East European and SA	N=21 carers; Pakistani carers 11, Indian carers 5, Polish carers 4 and Ukrainian carer 1
McCleary et al. 2012	Descriptive research methodology; in-depth, semi-structured, and face-to-face to interviews; qualitative content analysis	Experiences of a diagnosis of dementia	Primary and community care-based settings (Canada)	SA; Indian and Sri Lankan	N=14; 6 people with dementia (3 Indian and 3 Sri Lankan) and 8 carers
Mukadam, N., Cooper, C., Basit, B., Livingston, G. 2011	Demographic study; semi-structured interviews; thematic analysis	Attitudes towards dementia diagnosis pathways	Home and healthcare settings (England)	White, SA and Black Caribbean cultures	N=18 carers; 4 White UK carers, 5 SA, 5 Black African/Caribbean, 1 White Irish, 1 White other, 1 Asian other, and 1 Chinese
Studies conducted in SA immigrants' countries of origin					
References	Methods	Phenomenon of Interest (Purpose)	Setting (Country)	Cultural	Participants
Brijnath, B. 2011	Ethnography; semi-structured interviews, observation; field notes, deductive and inductive coding, thematic coding, NVivo 9	Examine how care is understood cross-culturally by providing different types of food and how food can maintain positive relationships	Home and institutional settings (India)	Indian/ SA	N=20 carers 9; 3 men and 17 women; 21 key service providers
Brijnath, B & Manderson, L. 2011	Ethnography; in-depth, semi-structured interviews, observation; data were transcribed and coded thematically, inductive and deductive, NVivo	Biomedical technologies, MRI scans for dementia diagnosis	Home, hospital, and community (India)	Indian, SA	N=20 carers; spouses n=10, daughters n=6, daughters-in-law n=4. And 21 Key Service Providers
Qadir, Gulzar, Haqqani, & Khalid. 2013	Exploratory; in-depth, semi-structured interviews; thematic analysis	This study explores awareness among carers, their attitudes toward family members suffering from dementia, and their experience of burden	Hospital settings (Pakistan)	Pakistani	N=12 Carers

2.5.4 Quality of included studies

The methodological quality of the included studies was assessed by two reviewers using the assessment tool from the JBI, known as QARI (Table 2). The quality scores for the included studies were calculated by weighing the studies according to the QARI assessment tool's 'yes', 'no', or 'unclear' values. The studies were appraised according to each QARI question and they were given a score of 1 for one satisfactory 'yes' answer, and a score of 0 was given for a 'no' or an 'unclear' answer. The final score was obtained after adding the values assigned to each question. A cut-off point of answering 'yes' to six out of the 10 questions was agreed upon and implemented by all reviewers. Only one study had a maximum score of 10, while four studies failed to make the cut-off point of six 'yes' responses; these four studies were then excluded from the synthesis. The qualitative studies that scored lower than six points typically did not provide sufficient information on QARI questions 6, 7, 8, and 9. For example, some of these studies lacked clarity regarding the researchers' values, beliefs, and their potential influence on the research. In addition, an absence of participant validation of the research findings (by providing verbatim quotations of participants' voices, for instance) was apparent in the study. Therefore, the reviewer searched for and included participants' direct quotations from the studies. This was a significant step when assessing the study quality during data extraction, as it helped the reviewer to establish the degree to which the findings were genuinely characteristic of the data (Pearson, Robertson-Malt, & Rittenmeyer, 2011). Also, studies from South Asians' countries of settlement suffered from an unclear sampling strategy and difficulties with recruitment; hence, these works failed to represent the individual target South Asian populations.

2.6 Synthesis of findings

The meta-synthesis of studies included in the review generated three meta-synthesized findings; furthermore, this synthesis was derived from 186 study findings that were subsequently aggregated into seven categories, as shown in Figure 6 below.

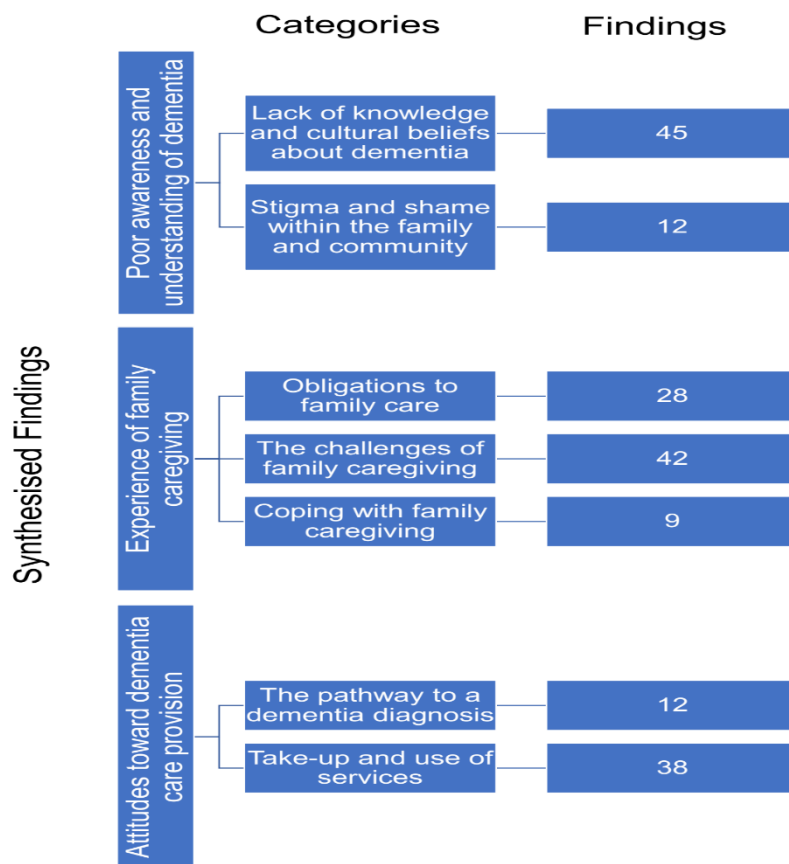


Figure 6 - Relations of synthesis topics, categories, and findings

2.6.1 Meta-synthesis 1. Poor awareness and understanding of dementia

One of the most significant synthesis findings of this review was the lack of knowledge and understanding of dementia among South Asian family carers who were taking care of their relatives with dementia. Eleven of the 13 included studies highlighted this issue. Within this first meta-synthesis theme, two categories emerged: lack of knowledge and cultural beliefs about dementia, and stigma and shame within the family and community.

2.6.1.1 Category 1.1. Lack of knowledge and cultural beliefs about dementia

Across the groups, most people with dementia and their family carers consistently acknowledged their lack of knowledge about dementia. Moreover, various studies assessing the differences between immigrants in their countries of origin or countries of settlement generally revealed that family carers had difficulty recognizing dementia symptoms. Even when the symptoms of dementia were detected, they were not seen as problematic; rather, they were regarded as consistent with the normal ageing process. The studies conducted on South Asian people with dementia in England and Canada demonstrated that memory loss

and dementia were seen as part of the normal ageing process rather than symptoms of a degenerative disease of the brain that becomes worse over time (Lawrence, Samsi, Banerjee, Morgan, & Murray, 2010; McCleary et al., 2012). In particular, those people with dementia in the UK and Canada were unaware about their earlier cognitive changes, and those fluctuations did not warrant alarm until a family member drew attention to them.

Adamson (2001) interviewed 12 immigrant South Asian family carers of relatives with dementia in the UK. She found that most of the family carers lacked knowledge about the signs and symptoms of dementia before their relative was diagnosed. Family carers linked dementia to a wide range of psychosocial, physical, and mental problems including diabetes, excessive tension or depression, sadness, anxiety, fear, social withdrawal, isolation, and loneliness (Brijnath & Manderson, 2011; Jutlla, 2011; McCleary et al., 2012; Mukadam, Cooper, Basit, & Livingston, 2011). Family carers' religious beliefs also informed their understandings, and some believed that dementia was a punishment resulting from something the individual had done wrong (Adamson, 2001; McCleary et al., 2012).

Rather, he referred to his mother as 'mad' and said his mother was paying for something bad she had done earlier in her life. Nasreen explained that the lack of understanding about dementia results in family members bringing their own beliefs, for example, on religion, into their explanation for the symptoms. In this case her father felt, from his interpretation of the Koran, God was making his mother pay for punishing his sister for running away from an abusive marriage his mother had encouraged. (Case study 2: p. 394 in Adamson, 2001)

However, family carers in Pakistan described that dementia was a medium through which one's relationship with God deepened, and not a punishment from God (Qadir, Gulzar, Haqqani, & Khalid, 2013). Most studies conducted in the immigrants' settlement countries reported that dementia was regarded as 'madness', and that understanding of this disease was not just an individual issue, but it was also important within families and the wider community (Adamson, 2001; Bowes & Wilkinson, 2003; Brijnath & Manderson, 2011; Godfrey & Townsend, 2001; Lawrence et al., 2010; Mackenzie, 2006). In India, Brijnath and Manderson (2011) found that the symptoms of dementia were seen as part of the normal ageing process rather than mental illness, until the people with dementia suffered from incontinence and also developed paranoia and delusions, and showed violent behaviours. Moreover, given that service providers often use jargon, and since there are no meaningful words for dementia in their own languages, family carers sometimes confused their understanding of dementia with other diseases, such as cancer, acquired immunodeficiency syndrome (AIDS), depression, or schizophrenia.

Most importantly, research conducted in Scotland and Canada reported that a visit to a general practitioner (GP) or hospital for trauma or another acute medical problem for people with dementia were regarded as the first tangible signs of a dementia diagnosis among immigrant South Asian family carers (Bowes & Wilkinson, 2003; McCleary et al., 2012). Family carers did not recognise the symptoms of dementia prior to the traumatic events, as the presence of these symptoms only became clear when doctors referred people with dementia for cognitive testing. Before these traumatic events and early dementia symptoms, the family carers attributed any physical or psychosocial problems to the normal ageing process; these were not considered serious by them.

In addition, a study conducted in India by Brijnath and Manderson (2011) showed that family carers had little knowledge about the support and treatment available for people with dementia, which was not confined to members of the public. Of the eleven key service providers (GP, community psychiatric nurses, and consultants) in Scotland who participated in the research, three participants believed that there was no treatment available for people with dementia (Bowes & Wilkinson, 2003). Although family carers thought memory problems and dementia were a normal part of ageing, they felt that dementia-associated problems could be prevented by changing the lifestyles of the people with dementia (Brijnath & Manderson, 2011). There is a belief that the people with dementia may be deliberately difficult, rather than acknowledging that their memory problems might be caused by a disease process.

Nonetheless, the service providers working with immigrant South Asian people with dementia reported that perceptions of dementia as 'memory loss' have created fear among South Asian community members in Scotland (Bowes & Wilkinson, 2003). The service providers argued that the term 'memory loss' alone is not quite capable of defining dementia; rather, it confuses and worries people, particularly since many people experience memory loss issues and they do not suffer from dementia-associated problems. Hence, the service providers explained why it is important to use the word 'dementia' rather than 'memory loss' to increase the knowledge of carers and people with dementia.

2.6.1.2 Category 1.2. Stigma and shame within the family and community

Seven studies reported that various cultural and religious factors influenced the level of stigma associated with dementia among the South Asian communities. Mackenzie (2006) explored the causes of stigma among immigrant family carers of Indian and Pakistani origin living in England. The study discovered how the different perspectives of the stigma associated with dementia were rooted in both religious and supernatural explanations among immigrant Pakistani Muslim families. Family carers and their relatives with dementia were stigmatised

through being perceived by the wider Muslim community members as being cursed or possessed by evil spirits. Perhaps they had not been strongly faithful Muslims, or they did not pray enough to keep the dementia away. Thus, dementia was regarded as a punishment from God that ultimately brought shame upon the entire family. Another study found that people with dementia felt stigmatised about their deteriorating cognitive state (memory loss, speech impairment) and their declining ability to participate in activities with their families or in the broader community; they thus withdrew, which in turn affected their lives and led to a loss of self-esteem and loneliness (Lawrence et al., 2010).

I can't talk well, I can't figure out the sums you see, taking 8 from 12 is difficult for me, changing, getting the change if I go to the shops, I don't go now. So it has affected my life very badly. I avoid going to people, especially former friends, unless I go to places where everyone has Alzheimer's. (p. 8)

However, three UK studies demonstrated that the stigma about dementia in the South Asian community interferes with the willingness or ability of people with dementia and their family members to participate in the community (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Juttla, 2011). Two UK studies found that South Asian immigrant families felt socially excluded by having a relative with dementia, and they tried to hide the person from visitors (Adamson & Donovan, 2005; Mackenzie, 2006).

Before we used to invite people for dinner and I had to do a lot of cooking. We were going to other people's houses for parties and dinner before. But now we have to stop that and I can't go in the evening because I can't leave my husband home and I can't take him – nobody invites us anymore. Two years back, some people were inviting us even still but now everybody has stopped inviting us because he can't... So they don't invite us anymore. (p. 44 in Adamson & Donovan, 2005)

Brijnath and Manderson's (2011) study conducted in India produced results contrary to those reported by the above studies (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Juttla, 2011), as family carers were more likely to report stigma associated with managing incontinence among people with dementia, rather than experiencing stigma with any of the other symptoms. The tendency to associate the symptoms of dementia with mental illness was also considered as a barrier to arranged marriages within some South Asian communities, as reported in one study (Bowes & Wilkinson, 2003). Specifically, if there was dementia in the family, it was kept secret for fear that a marriage would not take place if this information was disclosed. Thus, notions of stigma permeate cultural and religious perceptions of dementia in South Asian populations at every stage of this disease, starting from the initial recognition of memory problems and extending to an official diagnosis and beyond.

On the other hand, not being able to care for a person with dementia within the family was another potential source of stigma in South Asian communities. Regardless of any physical or mental illnesses, caring for an ageing parent at home, rather than putting them in a care home, is traditionally considered a strong cultural and religious duty (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Juttla, 2011). The moral obligation to care for an ageing or disabled elder is strictly and solemnly observed by the wider South Asian community. Some studies reported that immigrant family carers felt they were under pressure from various community members to look after the people with dementia within the family because of the stigma associated with not meeting family obligations to provide care (Juttla, 2011; Adamson & Donovan, 2005; Godfrey & Townsend, 2001). Seeking external help or sending the people with dementia to a day centre or care home was reported as bringing shame upon the family.

South Asian groups varied in their understanding and experiences of the social stigma related to dementia. However, social stigma was also associated with contemptuous attitudes and misconceptions among service providers. Bowes & Wilkinson (2003) found that service providers made generalisations about the stigma faced by South Asian communities, believing that families did not want to disclose dementia problems outside the family. However, case study findings revealed that family carers actually wanted to receive help from service providers in order to cope with their loved one's dementia, but they rarely asked for this assistance (Bowes & Wilkinson, 2003). Participants felt that none of the existing services were responsive enough to people's needs and that the needs of South Asian people were particularly neglected.

2.6.2 Meta-synthesis 2. Experience of family caregiving

This theme refers to the family carers' experiences of caring for their relatives with dementia. Eight of the 13 studies included herein reported the obligation to provide care, the practical and emotional challenges of family caregiving, and how these carers managed their situations.

2.6.2.1 Category 2.1. Obligations to family care

This category explored the key factors that were associated with the constructs of one's obligation to provide care for a person with dementia. Family carers described a mix of filial and moral obligation, as well as reciprocal love and respect toward their older parents. Some expressed a belief that if adult children cared for their elderly parents, then one day, their children would also look after them when they were old (Godfrey & Townsend, 2001). While there was a tendency to focus on the problems associated with family care, the analysis showed that caring for an elder with dementia was often seen in a positive light. In India,

Brijnath & Manderson (2011) found that once a relative received a diagnosis of dementia, it served as an opportunity for family carers to prepare themselves for care rather than to seek treatment. Conversely, in England, Godfrey and Townsend (2001) reported that grandchildren caring for a grandmother with dementia described reciprocity, love, respect, and duty as the main reasons for providing care. Furthermore, a wife believed that caring for her husband with dementia made her a good wife, and she was thus happy to undertake this role (Godfrey & Townsend, 2001). Likewise, daughters' or sons' attitudes toward caregiving were reciprocal, as they stated they were giving back to their older parents who gave them life and provided care when they were younger; now it was the children's time to provide care for their parents (Lawrence, Murray, Samsi, & Banerjee, 2008).

You know as Indians, we always look after our parents. Yes, I am the sole carer, I have no brothers and I just... my father he looked after me when I was young and he has done lots and lots of things for me so it's my turn to look after him. (p. 241)

In the studies, all immigrant family carers living in the UK did not seem to perceive caring for one's parents or grandparents as a pleasant task, but rather as a religious duty or cultural obligation (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Jutlla, 2011; Lawrence et al., 2008; Mackenzie, 2006). Religious and cultural obligations to provide care are highly influential among South Asian communities. Religious beliefs offer family carers a sense of internal personal support and peace of mind throughout the difficult journey of caring for their loved ones with dementia (Adamson & Donovan, 2005; Bowes & Wilkinson, 2003; Godfrey & Townsend, 2001; Lawrence et al., 2008; Lawrence et al., 2010; Mackenzie, 2006; Qadir et al., 2013). One study showed that living with and caring for ill husbands constituted one of the core teachings of, and an established practice in Hinduism. An immigrant Hindu wife in England, who was the family carer of her husband with dementia, stressed her religious duty to provide care for her husband (Adamson & Donovan, 2005). Similar research was conducted in both the immigrants' country of origin and in their country of settlement in Pakistan and England, respectively (Adamson & Donovan, 2005; Qadir et al., 2013). These studies revealed that while Pakistani Muslim family carers feared retribution from Allah for not providing care, they regarded providing care for their parents with dementia as virtuous deeds and as a blessing to be rewarded in the afterlife. Family carers believed that by providing care, they were fulfilling their religious duties toward their elderly relatives, as well as toward God, which was expected from a truly religious person. Where there were strong religious and cultural pressures to care for people with dementia, there was a persistent faith in God that supported families when caring became difficult. Thus, there was an expectation that adult children would provide care for the people with dementia. However, parents sometimes felt that the care they

received from their children was less than their contribution to their children (Lawrence et al., 2010). If they received good care, it was seen as the children paying them back.

2.6.2.2 Category 2.2. The challenges of family caregiving

Although the previous category highlighted the cultural, religious, and filial obligations to provide care, ten out thirteen studies in this category reported that the caregiving situation created greater challenges for the family carers. Most studies stated that caring for people with dementia was mostly a family-based task, and that the majority of the family carers were daughters-in-law or unmarried daughters, who engaged in intense hard work on a daily basis (Adamson & Donovan, 2005; Bowes & Wilkinson, 2003; Godfrey & Townsend, 2001; Lawrence et al., 2008; Mukadam et al., 2011). The reviewed studies described how the symptoms of dementia affected people with dementia, and how this severely impacted the family carers' psychological and physical health, as well as their finances, employment, and practical daily living.

The lack of knowledge about how a person may change as a direct result of dementia impacted every family member, including children. Family carers were worried about their children, as they did not understand the features of dementia and found it hard to accept the fact that the person with dementia was exhibiting unusual behaviour (Godfrey & Townsend, 2001). Another study found that living with a person with dementia also had a negative effect on one son's mental health, as he was simultaneously coping with frustration and anger (Adamson & Donovan, 2005). A lack of knowledge about the symptoms of dementia made children perceive that the people with dementia were responsible for their illness. In addition, the stress of family care had a negative impact on family relationships, especially on marital satisfaction, as couples were often unable to spend time together (Godfrey & Townsend, 2001; Lawrence et al., 2008; Qadir et al., 2013). Several studies further found that husbands were complaining that their wives – who were acting as family carers for their parents – did not spend intimate time with them, as the wives were rather busy with their caregiving duties (Godfrey & Townsend, 2001; Qadir et al., 2013). Thus, in addition to the physical pressures of meeting the needs of a person with dementia, there were also psychological and emotional factors and consequences.

Godfrey & Townsend (2001) found that South Asian immigrant family carers commonly had to deal with the people with dementia's behavioural difficulties, sleep disturbances, as well as night-time waking. Some family carers were subjected to abusive or threatening behaviours by their relatives with dementia, including wives who described how on several occasions, their spouses (with dementia) became aggressive. Moreover, in Pakistan, Qadir et al., (2013)

found that those family carers who were under intense emotional and physical pressure wanted to escape, and some even prayed for the person's death. Half of the male family carers reported that the caregiving burden triggered anger, resentment, and guilt as, on several occasions, they had used physical force on their relatives with dementia.

Behaviours such as sleeplessness, agitation, and incontinence caused severe disruptions to family life which, as shown in an Indian study, indicated that family carers' experience of depression and anxiety was strikingly evident when the people with dementia stopped eating (Brijnath, 2011). Particular difficulties that family carers faced included the struggle to manage the people with dementia's personal hygiene, which was very difficult and embarrassing for the family members to accomplish. Only a few studies discussed how carers dealt with the unpleasant and difficult experience of handling the issues associated with urinary or faecal incontinence. In fact, a few studies have reported that family carers' need to deal with the people with dementia's incontinence was the most upsetting and humiliating act for the people with dementia, and it was also stressful for the carers themselves (Bowes & Wilkinson, 2003; Brijnath, 2011; Godfrey & Townsend, 2001). In devout Muslim households, faecal incontinence meant that the people with dementia and the carers could not pray in the house, nor could they go to mosque (Bowes & Wilkinson, 2003). The whole house had to be washed for purity before praying. One family had to move to a bigger house so that the people with dementia could have a separate flat for this very reason.

Although family carers were the around-the-clock care providers for the people with dementia, they received little attention or support directed toward the needs associated with their vital role. The current review found that when family members had recognised the symptoms of dementia, and it was followed by an official diagnosis, the interests of the people with dementia came before those of the carers. For instance, in Godfrey & Townsend's (2001) study, a daughter-in-law described how it was her duty to look after her mother-in-law, as she did not have any other choice. In line with the various original studies that were conducted to assess the experiences of immigrants in their countries of origin or settlement, the current review also revealed that daughters-in-law in South Asian households played three different challenging roles, as rooted in time and relationship demands. They were expected to care for their husbands, their young children and, additionally, their parents-in-law (Godfrey & Townsend, 2001; Jutlla, 2011; Lawrence et al., 2008; Qadir et al., 2013).

You don't put yourself first. In fact, sometimes you don't even put the children first. Looking after the children is done around that of caring for elderly parents. We have put our careers on hold to look after them. It is stressful. There is a stress on

relationships. Like we can't go out like a normal couple when we want to. (p. 37 in Godfrey & Townsend, 2001)

However, family carers described how their hard work was unnoticed and unappreciated, and they felt neglected despite their very hard work. The nature of the caregiving role changed due to the increasing demands within the family environment, and the family carers reported feeling 'invisible' in the family. As a result, those family carers caring for a person with dementia neglected their own health and wellbeing (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Jutlla, 2011). Nonetheless, despite these findings, immigrant family carers also mentioned that they found it hard to express the details of their caregiving burden to health professionals and others in the community (Bowes & Wilkinson, 2003; Godfrey & Townsend, 2001).

2.6.2.3 Category 2.3. Coping with family caregiving

Although most of the research reviewed in this report has focused on the knowledge of dementia and the burdens of being a family carer, only a few studies have focused on which coping strategies were used by family carers. To minimise the level of disruption to their own lives, family carers in India coped by consulting Ayurvedic, allopathic, and homeopathic doctors, as well as traditional practitioners and transcendental healers when seeking assistance for their relatives with dementia; family carers often received suggestions about different foods and lay remedies to use (Brijnath, 2011). On the other hand, regardless of their religious identities, the majority of immigrant family carers used prayers and continuous faith in God as religious coping mechanisms (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Mackenzie, 2006; Qadir et al., 2013). This was also the case for Pakistani family carers in their home country (Qadir et al., 2013).

I satisfy myself by assuring time and again that troubles are from Allah (God) and he does not burden one more than his capacity. I cannot think of any other way out but to offer namaz (prayer) regularly. (p 236)

Family carers generally believed that dementia was God given, and that He did not trouble anyone beyond their abilities. Despite the burdens and strains of caring, many family carers described the positive aspects of being a carer, such as the blessings that were bestowed upon them, which would provide them with earthly and heavenly feelings of satisfaction (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Mackenzie, 2006; Qadir et al., 2013). The participants explained that although caring was a stressful and burdensome role, they believed that it would bring rewards from God one day. Many also relied on their extended family to help with various activities, such as housework and emotional support, which helped

relieve the family carers' stress (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Qadir et al., 2013).

2.6.3 Meta-synthesis 3. Attitudes toward dementia care provision

This theme examined South Asian family carers' knowledge and attitude toward the current and future provision of dementia healthcare services. Despite the limited evidence in the reviewed research, these investigations also explored the various cultural and religious issues that affected the accessibility of dementia care services in South Asian family carers' countries of settlement and in their countries of origin. This theme included the two following categories:

2.6.3.1 Category 3.1. The pathway to a dementia diagnosis

Overall, six studies reported on the process of achieving a dementia diagnosis (Bowes & Wilkinson, 2003; Brijnath & Manderson, 2011; Lawrence et al., 2010; Mackenzie, 2006; Mukadam et al., 2011) among the South Asian communities. Almost all of the family carers included in these studies recognised delays associated with seeking their relative's dementia diagnosis. Unlike White and Black African Caribbean groups in those studies, the main causes of delay among the South Asians included a lack of knowledge, confusion about the early signs, fear and stigma. The numerous barriers to a prompt or accurate diagnosis of dementia prevented family carers and people with dementia from getting the best possible treatment; this influenced their attitudes toward seeking help from service providers.

He is 75 years old, he has a few memory problems. It isn't anything that serious. So he goes out and forgets a bit, even I do. (p. 5 in Lawrence et al., 2010)

Bowes and Wilkinson's (2003) study discussed that South Asian people with dementia were not getting a dementia diagnosis, due to such factors as poor medical communication or language issues. Moreover, a lack of dementia awareness was found among three out of eleven professionals. That study also reported that overall professionals' specific knowledge about dementia in South Asian communities was essential to improving services. Similarly, immigrant family carers blamed the hospital staff for providing a delayed diagnosis of dementia (Mukadam et al., 2011). Family carers expressed several concerns, as hospital staff members appeared to be disorientated and failed to differentiate their older relative's significant physical health problems from the potential signs and symptoms of dementia. Another key issue that emerged from the study conducted by Mackenzie (2006) was that there was an overwhelming sense of fear and embarrassment among immigrant family carers and their family members in the South Asian community. Family members were fearful of the stigma associated with

being diagnosed with dementia, as a diagnosis of dementia could result in condemnation of the family.

In India, Brijnath & Manderson's (2011) study explained that poverty, structural weaknesses, and a lack of mental health professionals were the main reasons underlying the barriers faced when obtaining a dementia diagnosis. Other studies reported that a dementia diagnosis was often incidental, as it came about when visiting doctors for other physical problems (Bowes & Wilkinson, 2003; McCleary et al., 2012). McCleary et al. (2012) found that immigrant South Asian Canadians initially normalised the symptoms of dementia, attributing them to other causes and echoing the findings of Mukadam et al., (2011). The average length of time between recognizing the early symptoms of dementia and finally seeking professional help was four years (Mukadam et al., 2011; McCleary et al., 2012). However, if families did recognise the symptoms of dementia, they often delayed seeking help for an official dementia diagnosis, which was another major problem. Cultural beliefs and expectations act as barriers to seeking and accepting help. The family carers initially sought help from friends and families instead of obtaining help from social services.

Finally, once the person was diagnosed with dementia, the family carers regretted blaming the person for his or her behaviours and symptoms, which would not have occurred if the diagnosis had been made earlier (Godfrey & Townsend, 2001). Moreover, an earlier diagnosis would have helped family carers to better prepare for and handle the situation. One of the most difficult and distressing challenges that immigrant family carers faced was to make decisions related to the dementia for their relatives with dementia. However, family carers were not always able to make these decisions for the people with dementia. A diagnosis of dementia meant that the people with dementia would rely on the individual or individuals who had decision-making power within the family unit. The family hierarchy clearly played a vital role, where male members had the authority over decision-making processes, including those related to healthcare (Godfrey & Townsend, 2001). As the head of the family, a son or husband plays a dominant role in healthcare decision-making. Godfrey & Townsend (2001) found that whilst the daughter-in-law primarily provided everyday caregiving for the people with dementia, it was the son who was the decision maker for the people with dementia's care, while ensuring the well-being of his ageing parents, whether with respect to dementia or any other sickness. Any requests for help to care for the people with dementia would need to be approved by the family carer's husband or father-in-law.

2.6.3.2 Category 3.2. Take-up and use of services

As the current review findings previously showed, female family members, such as daughters-in-law, provided the majority of care in the South Asian communities. Several studies also revealed that South Asian women's significant caregiving obligations are well rooted in tradition, culture, and religion. Nonetheless, since the majority of immigrant family carers perceived potential dementia symptoms as part of the normal ageing process, carers continued their care duties as an extension of their current caregiving obligations for their relatives with dementia (Adamson & Donovan, 2005; Lawrence et al., 2008). Thus, following a diagnosis of dementia, family carers accepted their new roles and showed fewer expectations related to seeking and using external help.

The eldest son is [responsible] and their daughter-in-law. It comes down to the daughter-in-law, not to the oldest son, it's very rare [that] you see an oldest son doing it, it's always his partner who takes over the role... it's the wife that does it. (p. 40 in Adamson & Donovan, 2005)

Notwithstanding this, immigrant family carers were also unhappy with the services on offer, and access to services was particularly difficult, as there was a lack of information about these services provided in the family carers' respective languages. Furthermore, family carers were profoundly frustrated by the complicated and untrustworthy GP services, and they also reported that hospitals did not have enough facilities to provide the appropriate services for their relatives with dementia (Mukadam et al., 2011). Several family carers further expressed deep resentment, as they had experienced discrimination from the rigid service providers and blamed the government for ignoring the needs of South Asian groups in the UK (Jutlla, 2011).

Perhaps not surprisingly, almost all immigrant family carers in this review mentioned that their relatives with dementia preferred to remain at home. Due to the excessive caring responsibilities and the lack of support being provided by the extended family network in some cases, a few immigrant family carers wanted respite support at home. However, respite services were not fully understood by these immigrant family carers, and they were reluctant to receive care in their homes due to shame and privacy concerns. In addition, they did not wish to welcome strangers into their homes, and they were equally concerned about confidentiality even if the care workers were from the family carers' own communities (Jutlla, 2011; Godfrey & Townsend, 2001). Moreover, when help with personal care was needed, there were concerns about support being provided by younger people, particularly those of the opposite sex (Godfrey & Townsend, 2001).

It is when Mum comes in and does the home care role. She bathes her and clears her room. Things like that I can't do for her in the Sikh culture, I cannot bathe her. (p. 41)

The reviewed evidence concerning family carers' attitudes with respect to turning toward care home services for people with dementia were limited and conflicting. South Asian immigrant communities appeared to be greatly concerned about the cultural appropriateness of care homes. They had concerns about language issues, the availability of South Asian care staff, access to South Asian food, and the level of respect for cultural and religious beliefs. However, many participants did not actively look for culturally appropriate services because they felt ashamed of doing so, or they feared that others in the community would think that the family members of people with dementia were unable to care for them (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Jutlla, 2011). Similar to what was noted for home respite services, another barrier to seeking out residential care was the issue of intimate care being undertaken by young health workers, particularly those of the opposite sex (Godfrey & Townsend, 2001). To date, however, only Godfrey & Townsend's (2001) study has specifically investigated issues related to personal care being provided by opposite-sex health workers. Many major factors also compounded the reluctance of immigrant South Asian older people with dementia to seek care from their children at home, as well as to seek admission to mainstream care homes. Despite the fact that care is typically offered by the people with dementia's children, in Godfrey & Townsend's (2001) study, it appeared that some older people with dementia did not want any support from their children whatsoever. Older people realised that providing care is a very difficult undertaking; hence, they did not want to be a burden on their children, and they thus preferred to go to a care home. In addition, it is apparent that there is a need for more culturally appropriate healthcare services. Moreover, since few professionals are working with immigrant South Asian people with dementia and their family carers, it is important to incorporate various culturally-appropriate services within the currently available healthcare system (Bowes and Wilkinson, 2003).

2.7 Discussion

This synthesis of the findings of the included studies that explored the experiences of South Asian people with dementia and their family carers revealed three meta-synthesis themes. First, the theme of "poor awareness and understanding of dementia" appeared to be central to the experiences of South Asian people with dementia and their family carers. The evidence reviewed in this synthesis showed that one's knowledge of dementia is of great importance; in fact, possessing knowledge about dementia ultimately shaped the quality of the course of care, and also affected the support provided to people with dementia and their carers across the journey of care. Since the participants' experiences of dementia and the caregiving journey were viewed through the lens of the South Asians' lack of knowledge about dementia and their cultural beliefs related the condition, the subsequent themes that emerged from these primary

themes were thus interrelated. Obviously, knowledge is powerful because it controlled the immigrants' or homeland family carers' intentions to seek and access help and support from care facilities.

Consistent with the findings of a previous review that focused on Black African, African Caribbean, Chinese, and South Asian populations (Milne & Chryssanthopoulou, 2005), the current synthesis also revealed that the majority of family carers regarded the early symptoms of dementia as part of the normal ageing process. The findings from the current synthesis were also in line with those of a previous study by Botsford, Clarke, and Gibb (2012), which found that potential early symptoms of dementia, such as memory impairment, were viewed as part of the normal ageing process, which subsequently affected help-seeking behaviours among family carers. Their study only highlighted two ethnic minority communities in London: the Greek Cypriot and the African Caribbean. However, current study findings differed from most of the White populations who believe that dementia is caused by a physical, organic disease, yet signalling a much clearer understanding about dementia than South Asian communities (Turner et al., 2005).

When examining the results of this synthesis in greater detail, similar themes emerged in a recent review that was conducted to examine the role of religion, spirituality, and culture in the understanding of dementia among the South Asian communities in the UK (Uppal & Bonas, 2014). However, in that review, some limitations were noted, including the fact that only five studies were included. Two of those five studies (Fontaine et al., 2007; Turner et al., 2005) did not recruit any participants from either the people with dementia or family carer groups; hence, the findings of that review may be constrained by their limited sampling strategy. Moreover, that particular review combined both qualitative and quantitative studies, where the latter were not wholly capable of examining the complex nature of ethnicity and dementia issues (Botsford et al., 2011; Curry, Nembhard, & Bradley, 2009). Conversely, the current review adopted a purely qualitative method in an attempt to clarify the deeper meanings and understandings of dementia among South Asian people with dementia and their family carers. Perhaps qualitative methods have a greater capacity to elucidate the complex aspects of healthcare and ethnicity, to uncover participants' knowledge and beliefs about dementia, and to capture essential aspects of dementia caregiving from the perspective of South Asian communities (Berkwits & Inui, 1998; Malterud, 2001; Milne & Chryssanthopoulou, 2005).

The authors of the papers reviewed here have drawn the tentative conclusion that dementia awareness should be increased among South Asian communities in the UK and elsewhere. Without exception, all of the authors of the included studies acknowledge that dementia was under researched among South Asian communities (Milne & Chryssanthopoulou, 2005;

Botsford et al., 2011). Knowledge and understanding of the various symptoms, causes, and treatments of dementia are more limited among South Asian communities than they are among White British communities in the UK (Turner et al., 2005). South Asians' understanding and knowledge of dementia is limited by the lack of an equivalent term for 'dementia' in their native languages. Knowledge and understanding of dementia, of course, is not constrained by language among the White British. Secondly, cultural norms, values and religious beliefs shape the meaning of dementia as well as influence the caregiving responsibilities among South Asian communities (Seabrooke & Milne, 2004). The White British population is more influenced by Western philosophical thoughts, where understanding of dementia is mostly dominated by biomedical models that consider dementia a pathological entity affected by neuronal and neurotransmitter failure (Turner et al., 2005). It was clear from this synthesis that the experiences, diagnostics, treatment, and care management of dementia varied across the ageing South Asian populations due to physiological, psychosocial, religious, and culturally sensitive factors. There was a lack of understanding and a failure of the individuals or family members to seek a diagnosis, usually by failing to recognise or ignoring the symptoms of dementia (which were considered to be a part of the normal ageing process). This resulted in family members expressing their anger and frustration, and ultimately blaming the people with dementia for both the causes of dementia and for any related inappropriate behaviour.

Most of the studies focusing on South Asians found that many individuals have negative attitudes toward dementia, and that there is also a high degree of stigma associated with it. However, dementia-related stigma exists in all other communities as well (APPG, 2013), although South Asians' cultural and religious diversity means that this stigma manifests itself differently. For example, Mukadam et al. (2011) found lower levels of stigma among whites and South Asian in England, where McCleary et al. (2012) did not find any stigma at all associated with dementia among immigrant Indians and Sri Lankans in Canada. Unlike other studies, South Asian immigrant family carers in both McCleary et al.'s (2011) and Mukadam et al.'s (2011) studies did not conceal their relatives' symptoms of dementia from outsiders, and they enthusiastically shared their experiences with the researchers; however, in the latter study, the stigma associated with dementia and the negative experiences related to the available health services were only mentioned by Black and African family carers. Thus, notions of stigma permeate cultural and religious perceptions of dementia in South Asian populations at every stage, from the initial recognition of memory problems, to diagnosis and beyond.

Although levels of stigma were hard to gauge from the included studies, it could be argued that the stigma associated with dementia may not necessarily constitute stigma about the disease itself. It is possible that the stigma is rooted in prejudices involving migration,

education, ageing, ethnicity, poverty, illnesses, gender, and language barriers (Fisher & Ragsdale, 2006). In fact, stigma may not solely be associated with dementia; South Asian immigrants may think that there is a stigma associated with being old in Britain, or that there is a stigma pertaining to their ethnic identities (Derose, Escarce, & Lurie, 2007). In addition, if dementia was to be understood as 'cognitive impairments' or 'a disease of the brain' rather than 'madness' or the 'effect of bad spirits', any of the associated stigmas would be reduced (Innes, 2002). Appropriate language use can combat the misunderstandings and resultant stigmas associated with dementia. Stigma will probably persist among the South Asian and other BME communities until proper education has been provided and an understanding of dementia has established (WHO, 2001). Therefore, family and community members need to be made aware of the various related consequences that stigma can have on the quality of care that people with dementia and their family carers receive. Families, communities, and healthcare settings need to work together to tackle stigma by raising awareness about dementia. In order to raise this awareness to reduce stigma while maintaining successful communication between South Asian service users and service providers, emphasis should be placed on recruiting more culturally and linguistically trained staff or staff members from South Asian ethnic backgrounds. Furthermore, service providers should also work with South Asian religious leaders (e.g., imams from the mosques, Hindu temples, and Gurdwaras) in order to challenge this stigma and to maintain a better understanding and acceptance of the available services.

Existing research about the burden of caregiving comes from White and Afro-Caribbean backgrounds in the USA (Daker-White et al., 2002; Milne & Chryssanthopoulou, 2005; Botsford et al., 2011), but the caregiving experience in South Asian communities differs from this in many ways. The primary reasons for these huge differences in dementia caregiving experiences between White, Black, and South Asian backgrounds are socio-economic, cultural, and religious issues, which remain understudied. Despite the importance of caregiving roles in the South Asian communities and the scarcity of current knowledge about dementia, research has thus far provided little evidence to illuminate how caring for persons with dementia relates to burdens or blessings that underlie the obligation to care. Most studies to date have shown how families are the source of caregiving in the South Asian communities. Perhaps not surprisingly, one prominent theme that emerged from the reviewed studies was how the expectations of dementia care provision among the South Asian community mainly fell upon the daughters-in-law. These findings were also in line with those of previous reviews, which discovered that BME carers were generally culturally obliged to provide care for the people with dementia in the family (Milne & Chryssanthopoulou, 2005; Botsford et al., 2011).

To date, most research on filial responsibility has specifically looked at Chinese communities (Chiu & Yu, 2001; Milne & Chryssanthopoulou, 2005). Not much research has discussed the filial obligation to care for elderly parents in the South Asian community. Further research is needed to examine various sensitive issues that remain unexplored, such as how there are many problems concerning the South Asian community that are not talked about, including the idea that older people believe that their families do not care, or that they are being treated harshly by their children. Evidence shows that numerous traditions, such as the strong sense of extended family, living with and looking after the elderly, and being cared for by relatives, are breaking down in South Asian communities because of numerous socio-economic and demographic changes (Evandrou, 2000). For example, the role of South Asian women in the family is changing as more women are participating in the labour market than ever before (Wilson, 2006). However, the realities faced by South Asian families include the fact that adult children want to look after their older parents, but they have other priorities (Hossain, 2012) such as, balancing work and family commitments. Therefore, the older people's expectations and understandings are changing day by day as well. The adverse mental health impacts of poverty and poor housing, a lack of education, unemployment, and low income are not unusual problems. These are some of the issues that have not yet been addressed by research teams, and our understanding of these factors will benefit from an exploration of these issues.

Although daughters-in-law perform most of the caring duties in the family, today, few empirical data are available on how the carer's role is perceived, and on the relationship between daughters-in-law and mothers-in-law in South Asian communities. The relationship between a daughter-in-law and her mother-in-law in South Asian communities is not always perceived as a positive and pleasant one to discuss. A daughter-in-law is always regarded as one of the weakest members of the family, although she gains some empowerment when her children grow up. It is very important for South Asian families to make sure that the daughters-in-law serve their parents-in-law, irrespective of whether or not they have dementia (Godfrey & Townsend, 2001; Gupta & Pillai, 2002). When considering the status of women in the household, the distribution of power amongst them is very complex. A few studies have been conducted around how family carers are being motivated or forced to provide care for their parents-in-law (Dasgupta & Rudra, 2011; Godfrey & Townsend, 2001; Jutlla, 2011). There may be many reasons underlying this caregiving role within extended families, including moral, cultural, religious, or family pressures, especially pressure from the carer's husband or mother-in-law. However, their White counterparts may not experience such stressful caregiving roles (Dykstra et al., 2006). White groups may not be obliged to provide care to the same extent as is commonly associated with the South Asian community's expectations, and neither do they

have to live in overcrowded, poorly maintained houses with their extended families as many South Asians do.

A dementia diagnosis is, of course, a paramount issue among all South Asian communities, which is why clear research on the barriers to a dementia diagnosis among the South Asian population is needed. Until there is a much better understanding of the obstacles to a dementia diagnosis among South Asian communities, it would be tough to understand South Asian individuals' experiences of dementia. Previous evidence has found that South Asian family carers tend to access various healthcare services, or they seek help in response to a major illness or, in some cases, to deal with other symptoms, such as those associated with stroke, diabetes, and heart disease. A dementia diagnosis is significantly uncommon not only among the South Asian communities in the UK, but also among the entire UK population, regardless of ethnicity. More than 800,000 people with dementia are currently living in the UK; however, it has been estimated that only 48% of those individuals ever receive a dementia diagnosis (Alzheimer's Society, 2014). The financial cost of a timely diagnosis of dementia may be a significant barrier for those in developing countries like India, Pakistan, Sri Lanka, and other South Asian countries (Brijnath & Manderson, 2011; Patel, Joshi, Suthar, & Desai, 2014). However, why do South Asian older people remain under diagnosed when they live in England or Canada, and why are they instead labelled as a hidden population (Brownlie, 1991; Wilkinson, 2002)? In the UK and Canada, the available health services are adequately capable of diagnosing dementia. However, South Asian older people are frequently not diagnosed with dementia. None of the studies available thus far has addressed these issues. Inadequate English proficiency may render South Asian older people a hidden population, as majority of older people cannot communicate and express their problems in English. Language barriers and a low level of education can thus prevent South Asian individuals from seeking help for a dementia diagnosis (Alagiakrishnan, 2008; Schmand, Lindeboom, Hooijer, & Jonker, 1995; Schmand et al., 1997). Importantly, none of the published research has highlighted this issue as a barrier specific to South Asian communities. Moreover, researchers specifically identified that among this population, help-seeking behaviour is limited to friends and families. Again, Brijnath & Manderson (2011) found that when dementia-related healthcare problems arose, family members spoke to various doctors in India. This may be one of the reasons why this population did not experience any language or cultural barriers in India when seeking help. However, in the UK, language and cultural barriers are definitely present when South Asian people ask for help. Perhaps this is why they are more comfortable discussing their health problems with their families and friends, as there are no cultural or linguistic differences within these groups. The lack of appropriate cultural and linguistic support is a pertinent issue for South Asian immigrants in the UK, as this not only presents difficulties for South Asians when

they seek help, but it is also very challenging for the GP and clinicians (Fazil, Bywaters, Ali, Wallace, & Singh, 2002). However, to date, no research data are available related to self-reported memory problems or changes prior to the dementia diagnosis.

Healthcare decision-making power is significantly important in South Asian families. However, only one study thus far has specifically focused on this issue in the UK; it shows that due to a lack of knowledge about dementia and its diagnosis, decision makers in South Asian families are typically unable to make any decisions on where to seek help (Godfrey & Townsend, 2001). Despite this, they put more pressure on family carers to look after the elderly. Further research that focuses on how personal caregiving provided by the opposite sex is a barrier to receiving institutional care will also be beneficial. Subsequent research initiatives need to focus on alternative solutions to help those in South Asian communities when seeking a diagnosis of dementia, as well as when receiving healthcare services. South Asian communities sometimes obediently comply with the instructions given to them by their doctors or mosques' imams. Therefore, perhaps the decision makers could be found from outside the family among experienced professionals, like GP, psychiatrists, mosques' imams, or other religious leaders.

2.8 Limitations

There are some limitations of this systematic review. First, meta-aggregation is a new approach that has received little attention worldwide when compared with other systematic review methodologies. Despite using broad terms in the search strategy, it might be possible that my systematic searches still missed some sources due to methodological quality. For example, if there were no direct quotations from the participants, those studies were excluded from this synthesis. Secondly, the scope of this synthesis was limited in terms of its ability to compare South Asian immigrants' experiences of dementia in their countries of origin and in their countries of settlement, especially since the majority of studies included in this synthesis were conducted in the participants' countries of settlement. The current understanding of dementia within the South Asian countries of origin is, therefore, a relatively neglected area that remains to be explored.

2.9 Summary

The findings of this synthesis highlighted the various characteristics associated with the understanding and experiences of South Asian people with dementia and their family carers. Three themes emerged that provided a general description of these individuals' experiences

with and understanding of dementia, which include the following: (1) a poor awareness and understanding of dementia, (2) the experience of caregiving, and (3) the attitudes toward dementia care provision. A consistent message that emerged from this qualitative synthesis was that there was limited knowledge and understanding of dementia among the South Asian population. Symptoms of dementia such as 'memory loss' were believed to be a part of normal ageing. The themes mostly represented the family carers' experiences of caring for the people with dementia from the perspectives of the burdens or blessings of family caring, the family carers' coping mechanisms, and the family carers' attitudes to the current and future provision of dementia care services. These findings also illustrated the various causes and principles used by these family carers to cope with their stressful situations while they provided care to their loved ones. However, the South Asian culture and its associated religions are complex and unique in many ways, particularly as there are many sub-cultures within the South Asian population. These individuals have many different forms and levels of expression. Therefore, it would be a grave mistake to make any broad generalisations or assumptions about South Asian communities and their culture. For example, the numerous and varied foods, religions, languages, educational systems, employment situations, gender rights, castes, and social statuses distinguish each South Asian community from the others, which poses a significant challenge for any researchers or policymakers who wish to explore these issues in greater detail.

The next chapter will discuss the methodology employed and describe how the research was carried out. It will provide a justification for the methodology chosen and a rationale behind the chosen approach is provided. Ethical considerations and sampling procedures for both the interviews and focus groups will be discussed.

Chapter 3: Research methodology

3.1 Background

This chapter will address the choice of methodology used in this programme of research, covering the philosophical perspectives underpinning the studies and the most suitable approach to data collection and analysis. This chapter will first discuss the philosophical perspectives that form the basis of the research, provide my ontological and epistemological position, and justify the choice of qualitative methodology.

In the subsequent sections of this chapter, ethical considerations for both phases of the research are presented because the choice of methodology and ethical consideration are often closely intertwined (Thomas & O'Kane, 1998). Clear procedures for obtaining ethical approval were followed for both phase two and phase three of this research. Both phases used many similar procedures in attaining ethical approval from the same Science Faculty Ethics Committee of University of Portsmouth; therefore, they are discussed together in this chapter.

In both phase two and phase three of the study presented in this thesis, the lived experiences of Bangladeshi people are explored by using qualitative methodology. The data analysis methods and findings for each of the phases' research questions will be presented and discussed in more detail separately in their respective chapters (Chapter 4 and 5 respectively). While the philosophical approach drove the direction of the research, it should be noted that I utilised examples from the research findings to better explain the approach and how it was put into action.

This chapter concludes with an explanation of the extensive use of QSR NVivo 10, a Computer Assisted Qualitative Data Analysis Software (CAQDAS), in the context of qualitative methodology and the process of thematic analysis. In Section 3.7, some basic tasks that were undertaken using NVivo 10 are illustrated to show how NVivo was used to organise phase two and phase three of this thesis. The use of inductive thematic analysis to interpret the raw data collected from focus group discussions and one-to-one semi-structured interviews (phase two and phase three respectively) is then described and justified. I used Braun & Clarke's (2006) thematic analysis approach for both phases of this study; a detailed step-by-step process of thematic analysis is presented later in this thesis (Chapters 4 and 5).

3.2 Philosophical perspectives

Selecting a research paradigm is one of the first tasks a researcher needs to do for establishing a research methodology (Doyle, Brady, & Byrne, 2009). There are many definitions of a paradigm. One is that is a “basic set of beliefs that guides action” (Guba, 1990, p. 17). Lincoln & Denzin (2011, p. 13) define paradigm as “the net that contains the researcher’s epistemological, ontological, and methodological premises”. A paradigm is a set of ideas or theory chosen by the researcher about the world and how it should be understood and learned. In a research context, a paradigm is a worldview or a set of ideas used to generate knowledge. It is a set of assumptions, research strategies, and criteria for rigour – a researcher must adopt what assumptions are suitable and applicable for their research topic’s interest. A particular philosophical approach and potential methodologies are essential in order to gain insights into a research problem. There are three major philosophical paradigms to structure qualitative research by; the first is the positivist paradigm, which is mostly associated with quantitative research, whereas the last two, the interpretive and critical paradigms, are principally related to qualitative research. Each paradigm has three major dimensions e.g. ontology (what is the nature of ‘reality?’), epistemology (how do we know something? what is the relationship between the ‘knower’ and the ‘known?’), and methodology (how should the researcher go about finding out knowledge?) (Denzin & Lincoln, 1994; Guba, 1990). The interpretive research paradigm was chosen for the framework of this current study. In the interpretive paradigm, theory is inductive and concerned with exposing implicit meaning. The interpretive paradigm aims to understand the phenomenon under study.

This qualitative research uses an interpretivist-constructionist position where the subjective experiences and meanings of the world are understood to be multiple and contextual and influenced by the researcher’s involvement (Finlay 2006, 2011). Although this research is not largely a phenomenological study, some of its aspects are supported by the phenomenological ideologies that emphasise exploring and articulating the important characteristics of a defined phenomenon. The phenomenological approach is contingent with the research aims of the second and third phases of the study, in which I was paying attention to how dementia is perceived and portrayed among Bangladeshi community members in the UK. Phase two aimed to explore the views of Bangladeshi people without dementia and how they perceive dementia. The focus of this study was how Bangladeshi people socially construct meaning and how they make sense of dementia. In phase two of this study, female participants spoke about how they were affected by interactions with older people without dementia, about their existential fears, and about their personal experience of caring for a relative without dementia. The interviews took this disclosure to a deeper level in phase three with actual dementia family carers. This does not encapsulate the aim of phenomenological research, which focuses on

the lived experience of individuals and is much more about their inner worlds. Interpretivists are believed to base their position on phenomenology and hermeneutics, and concentrate on how people interpret and make sense of reality (Miller & Crabtree, 1999). Interpretivists consider experiences to be contextual, temporal, and subjective (Holloway 2008), with “our situatedness determining our understanding” (Finlay 2006 p19). In the interpretive paradigm, theory is inductive and concerned with exposing implicit meaning with the aim of gaining understanding.

3.2.1 Ontological position

Ontology is about the nature of social reality; it is a certain way of looking at a phenomenon that exists. This current research stems from an ontological paradigm, which identifies a socially constructed, fragmented, and convoluted world where the number of older Bangladeshi people is continuously increasing in the UK but their dementia experience remains under researched and poorly understood. In this research, my ontological position was that of a relativist and social constructivist. Bangladeshi people’s experience and knowledge of dementia is considered a reality built within their own mental constructions through interacting and reflecting within the world in which they live. The way Bangladeshi people without dementia and Bangladeshi family carers of people with dementia interpret their lived experience reflects their construction of social reality. There was the reality of Bangladeshi peoples’ ageing experience, their dementia knowledge, and there were the underlying causes of dementia that they never learned directly, but which were the sources of their ageing experience. In addition, the social reality of Bangladeshi family carers of people with dementia who are involved in 24-hour caring duties and their caring experiences were considered one of the social realities of this study. Therefore, remembering the ontological position is important in this study in order to understand their knowledge of dementia and caring experience, which is based on their social belief and reality.

3.2.2 Epistemological position

My epistemological position was subjectivist – the relationship of the inquirer (researcher) to the target of inquiry was inductive, interpretive, and influenced by social constructivism. From the subjectivist and interactional stance, I designed the fieldwork, which involved seeking, acknowledging, recognizing, and interrogating the knowledge about dementia among the Bangladeshi community. This information will help to increase knowledge among the wider research community and policy makers about what dementia and care mean to Bangladeshi ethnic minority population in the UK. Through a constructivist methodology and this

epistemological position, I developed an intimate relationship with the data that emerged from the study, and I was very cautious about developing a general theory (Strauss, 1987). The knowledge obtained in this research comprises of Bangladeshi adults' perceptions of dementia and Bangladeshi family carers' experiences for Bangladeshi people with dementia living in the UK. This knowledge not only represents their understanding of dementia, but also their socio-cultural, and religious background in the UK. Given the paucity of knowledge about dementia among the Bangladeshi ethnic minority community, new knowledge has been discovered in this current research through the interaction between the participants, and myself. Through its interpretivist-constructivist methodology, this research explored specific knowledge about the Bangladeshi community members', as well as Bangladeshi dementia family carers' social reality by collaborating with them during the course of the research process.

3.3 Ethical considerations

The process of gaining ethics approval is an essential step in conducting research. The UK is a multi-ethnic society home to many diverse racial, cultural, religious, and linguistic groups, which raises complex and difficult questions about research ethics issues (Nazroo, 2006). However, despite an increasing demand for social research among the UK's multi-ethnic society population, very few studies discuss how ethnicity affects research ethics (McLean & Campbell, 2003; Salway et al., 2009). The Department of Health (DoH) guidelines for researchers who are interested in conducting research among ethnic minority suggest that:

Research, and those pursuing it, should respect the diversity of human society and conditions and the multicultural nature of society. Whenever relevant, it should take account of age, disability, gender, sexual orientation, race, culture and religion in its design, undertaking, and reporting. The body of research evidence available to policy makers should reflect the diversity of the population. (DoH, 2005, p. 8)

Racial, ethnic, linguistic, cultural, and religious factors affect research ethics. Moreover, a review of ethical and scientific evidence on ethnicity found that many studies warned that researchers should not conduct research studies if they are not culturally competent, experienced, or unaware of the limits of their own knowledge (Salway et al., 2009). Research also suggests that building a good relationship with the participants may help the researcher obtain consent more easily (Nygård, 2006). Therefore, having a researcher and known gatekeepers who were from the same community, spoke the same language and shared the same culture as the participants, helped to create good relationships among the Bangladeshi community and encouraged participation in the research study. In addition, Bangladeshi

community members felt themselves as valued persons in the wider community as the researchers showed an interest in them.

Due to the possible consequences of exploring sensitive topics among potentially socially disadvantaged family carers from ethnic minorities, ethical protocols were carefully examined and adhered to during all stages of the research. Therefore, in addition to the DoH guidelines, other fundamental ethical principles included gaining ethical approval from the ethics committee at the University of Portsmouth, as well as adhering to the code of ethics of the World Medical Association (Declaration of Helsinki 2000). The main principles that were considered included obtaining informed consent, protecting the participants, and ensuring participant confidentiality, anonymity, and safety. Copies of the Science Faculty Ethics Committee (SFEC) application letters detailing the study's final approvals can be found in the appendices (Appendices A & B).

3.3.1 Informed consent

Information sheets and consent forms were supplied to each of the potential participants who were interested in taking part in this study. Participants were asked to complete a consent form before the focus group discussion and interview began, which also provided details of the study. The consent forms outlined issues such as the purpose of the study, confidentiality, data storage and protection, how the results would be presented and the participants' right to withdraw. Bengali versions of the leaflets, invitation letters, participation information sheets, and consent forms used in this investigation were provided alongside their respective English versions. Each participant received a copy of the signed consent form; one copy of this consent form was placed in my file, which was stored in a locked cabinet in my university office.

3.3.2 Privacy and confidentiality

In line with the ethical compliance of the study, the privacy and confidentiality of the participants, gatekeepers such as local community leaders, community development workers, local charity groups, and religious leaders involved in the study were strictly protected. Participants were assigned a unique study code number to identify them. All audio recordings of focus group discussions and interviews were stored on an encrypted computer, and destroyed once the transcriptions had been completed and fully written up. Only I heard the recordings, read the transcripts, or viewed the accompanying field notes.

3.3.3 Participant welfare

No known serious adverse effects or risks have been previously identified for participants taking part in focus group discussions or semi-structured interviews. However, some minor potential risks were identified (e.g. some of the topics might be emotional or cause the participants distress due to reliving personal memories during the interviews). If the participants found some of the issues upsetting, the interview would be brought to an end to give them time to compose themselves or withdraw from the interview, and a box of tissues was available for them. It was anticipated that time could be a potential burden. In order to prepare participants, the information sheet suggested that between 30 minutes to one hour would be required to take part in the interviews; depending on what they wanted to share of their experiences, this could be longer or shorter. However, participants were informed that participation was voluntary and they could withdraw at any time with no consequences.

3.3.4 Researcher's safety

A risk assessment was carried out to identify any risks to myself while carrying out the focus group discussion in the mosque or one-to-one interviews in the participants' homes. I was aware of and adhered to the University lone working policy. This ensured both maximum access to the community and minimised misunderstandings and expectations. Throughout the research, and particularly when attending to participants' own homes, I was aware of any possible unforeseen risks. As such, I always carried a fully charged mobile phone and ensured that a member of the administration staff and the first supervisor at SHSSW had been informed of where the interview will take place, the expected time of return, and I provided them with relevant contact telephone numbers.

3.3.5 Debriefing and feedback

At the end of each focus group discussion and semi-structured interview, participants were given an opportunity to ask any further questions after the recording equipment had been switched off. Additionally, all participants were asked if they would like to receive a full report or summary of the research upon completion of the study and would be informed when this was ready for distribution.

3.4 Qualitative research methodology

The mounting recognition of qualitative methods is a result of the fiasco of using quantitative methods used to deliver insights about the attitudes, beliefs, motives, or behaviours of people,

for example in understanding the emotions, perceptions and actions of people who suffer from health related issues (Wong, 2008). Qualitative research aims to discover the values and differences in human experiences of a particular topic, where explicit methods are used to investigate how participants view and experience the world (Miller & Crabtree, 1999). Qualitative research and qualitative data allowed me to investigate Bangladeshi people's experiences and the socio-cultural elements of dementia phenomena despite their individual or collective origin. In the health and social care contexts, qualitative research 'seeks to understand and interpret personal experiences, behaviours, interactions, and social contexts to explain the phenomena of interest, such as the attitudes, beliefs, and perspectives of patients and clinicians; the interpersonal nature of carer and patient relationships; the illness experience; or the impact of human suffering' (Wong, Wilczynski, & Haynes, 2004, p. 311).

As there is currently no dementia research among the Bangladeshi community in the UK, qualitative research was utilised. Qualitative research is particularly useful for exploratory research where little previous research has yet been undertaken to capture the meaningful experiences and life values, explore the attitudes, and perceptions of persons with dementia and their family carers (Beuscher & Grando, 2009). In addition, qualitative research starts from the assumption that one can obtain a profound understanding about people and their worlds from ordinary conversations and observations. Its empiricism is grounded in the everyday data of experience (Gubrium and Sankar, 1994). Qualitative research, despite linguistic and cultural differences, can elicit grief, joy, sadness, anger, and other strong emotions from the gestures and talk of individuals. Therefore, a qualitative approach was the most suitable for this investigation because it focused on people's feelings, meanings, experiences, and perceptions; it was also essential to conduct the study within three primary ethical principles: 'beneficence', 'respect for human dignity', and 'justice' (Polit-O'Hara & Hungler, 1995). The overriding concern was to protect those involved from harm and distress.

The current study utilised qualitative methods to collect data, firstly using focus group discussions to explore the perception of ageing and dementia from the wider Bangladeshi community, followed by one-to-one semi-structured interviews with Bangladeshi family carers of people with dementia. Qualitative interviews, for example, one-to-one interviews and focus group discussions, provided an opportunity for me to discuss and inform the participant about the research issues. Furthermore, in the qualitative interviews I was able to use my research skills, techniques, and instruments (focus group and interview questions) during the interviews. Qualitative methodology allows inductive, exploratory research to provide a detailed description of how different ethnic groups feel about dementia and what paths they take to access health and social care services for people with dementia. This approach is

appropriate to exploring complex personal narratives and experiences of accessing services for ethnic minority people (Mukadam, Cooper, Basit, & Livingston, 2011).

3.5 Data collection methods

This research was designed to have three closely interlinked phases. The first phase involved a qualitative synthesis (Chapter Two) of the studies conducted on South Asian people with dementia and their family carers; the second phase involved two focus group discussions among Bangladeshi people without dementia, and the third phase focused on Bangladeshi family carers of people with dementia by involving them in one-to-one in-depth qualitative interviews. For phases two and three, data collection methods will be addressed in the following sections, as well as the thematic analysis method including sections about recruiting participants, sample size, data management in this chapter.

3.5.1 Focus group discussions

Prior to the late 1970s, focus group methods were predominately used in market research; they were widely overlooked in academic research (Merton, 1987). In recent years, focus groups have become progressively more common as a primary data collection approach in both health and social care research. Although focus groups have gained ever-increasing popularity in social sciences research, there is a paucity of focus group research in the context of cultural differences. Focus groups are thought to be the perfect technique for research studies that explore socially marginalised community members and their individual understandings of health, well-being, or disease-related matters (Kitzinger, 1994; Wilkinson, 1998).

For cultural and religious reasons, the male and female focus group discussions were conducted separately. My discussions with the CDW, the mosque committee, and the Imam revealed that the use of separate groups (i.e., female-only and male-only groups) encourages diverse attendance; it was also preferred by the members of the local community. The use of separate male and female interviews is often suggested among Bangladeshi or other Muslim communities for religious reasons, but it may be an indication of personal or male decision makers' preferences as well. In Islam, there is a strict and rigid rule prohibiting unrelated men and women from attending face-to-face meetings or sitting together in the same place unless they are husband and wife (BBC, 2009a; Islam's Women, 2014). As such, I led the male focus group discussions, as well as organised both groups, while a trained and experienced female research assistant facilitated the focus group discussions with the female participants. A

bilingual (English and Bengali) trained female research associate was recruited from the community in order to interview the female participants from the Bangladeshi community. Immediately after the focus group discussions were held, reflexive field notes that provided initial reflections describing the setting as well as any interactions that were not captured through the audio recording were made. As such, the field notes helped to obtain a detailed chronicle of various events, conversations, and behaviours, to support the later analysis and write up of data (Bryman, 2004).

3.5.2 Semi-structured interviews

The data collection in phase three of the study was based on in-depth semi-structured qualitative interviews. Using one-to-one semi-structured interviews as a data collection method is ideally suited to obtain relevant stories with meaning, distinctiveness, and contexts associated with the participant's background. Semi-structured qualitative interviews typically involve a context in which the interviewer has a series of topics to guide the interview process, but the sequence of topics is not set and the participant is encouraged to introduce new topics, deviate, and provide a context relevant to the purpose of the research study. An interview schedule was developed to guide the process. In semi-structured interviews, the interview schedule provides flexibility and allows researcher to probe and expand interesting ideas arising from the stories the participant wishes to share during the interview. The topics and questions in the interview schedule provided a frame of reference, rather than an inflexible structured process (Bryman, 2004).

3.6 Sampling strategy

Conducting this study among Bangladeshi community presented significant challenges for recruiting potential participants. The Bangladeshi community is often reported as a hidden population in the UK (Alexander et al., 2005), whereas Bangladeshi family carers are the most deprived and hidden group among them (Tasker, 2011). As with phase two and three of this research study, therefore, purposive and snowball sampling were used to collect data from the community members (who were not affected by dementia), and family carers of people with dementia. A combination of purposive sampling (selection based on predefined inclusion and exclusion criteria) plus snowball sampling (where those recruited suggested others who might be interested as well as potentially eligible to take part in the study) were particularly useful for dealing with the underprivileged, geographically dispersed and hard-to-reach Bangladeshi community in Portsmouth and London, where no usable sampling frame exists (Eland-Goossensen, Van-De-Goor, Vollemans, Hendriks, & Garretsen, 1997).

Given that the participants were harder to reach than expected, I originally planned to recruit no more than eight respondents for each of the focus groups. Also, at one point, I expressed doubts as to whether recruitment of the target numbers could be achieved. However, despite reservations that participants would not be willing to take part, the final number attending (n=21) exceeded expectation. Two separate focus group discussions (one male, n=12; and one female, n=9) were held with Bangladeshi community members in Portsmouth.

Furthermore, contacts were made with 20 potential participants; I contacted family carers directly or via a male family member or a guardian of a female family carer. A total of 12 family carers expressed an interest in the research. However, the number that finally agreed to participate was lower than had been anticipated. A sample of five family carers refused to attend the interviews due to the gender differences between them and myself. Two potential participants were referred through snowball sampling procedures; in both cases, the interviewed person provided the referral facilitated in communicating the potential participants. However, one participant met the inclusion criteria and other was excluded from the study. The research thus proceeded with six Bangladeshi family carers, living either in Portsmouth and London. Half of the respondents were female and half were male.

3.7 Data management and analysis methods

3.7.1 Data management

Miles and Huberman (1984) expressed concern that qualitative data analysis techniques could hardly show readers to follow how an analysis reached a conclusion. A well-planned research data management is a vital part of a good qualitative data analysis. Data management is defined as 'the operations needed for a systematic, coherent process of data collection, storage, and retrieval' (Huberman & Miles, 1994, p. 428) and it ensures that the readers follow how the qualitative analysis reached a conclusion (Miles & Huberman, 1984). In this research phase, to aid transparency, systematic tasks are necessary in the data analysis process. Systematic tasks include: how the data was collected, organised, sorted, how the data was stored and retrieved, as well as how the data was made visible and accessible for readers to judge the process completed. As with phase two, I used the NVivo 10 data management programme to manage data in phase three of this study. First, I systematically organised the audio recordings and interview transcripts into the NVivo structural folders. Although the NVivo data management programme is no substitute for the researcher's judgement in managing data, NVivo allowed me the flexibility to record my ideas on the research findings as they emerge, as codes, sub-themes, and themes. NVivo facilitated the control of data versions and provided accessibility for storage and recovery when necessary for the thematic analysis.

When I began the process of writing the report, I was able to go back and forth to confirm emerging themes, strengthen the rigour of the research process, and enhance the validity of the findings (Bazeley, 2007). I applied the NVivo qualitative data analysis technique to simplify the thematic analysis, including transcribing, coding, and documenting emerging themes from the interviews.

NVivo has been helping research communities worldwide to accurately and transparently represent data, while also providing an audit of the qualitative data analysis process as a whole — which has not always been possible in qualitative research before the software was developed (Welsh, 2002). There is a common understanding that using computerised data analysis packages such as NVivo can help enhance reliability and ensure rigour in the qualitative research analysis process by applying the techniques built into the software. However, it is also acknowledged that NVivo does not make any decisions by itself, or carry out the analysis for the researcher, but heavily relies on the researcher's input in the software. It provided me with a sophisticated workstation which enabled me to do the thinking, gather information, organise data in a deliberate way, generate transcripts, codes, and auto-codes, create themes, analyse and visualise, and report the results in a way which is thorough, transparent and transportable (Bisit, 2003; QSR International, 2013). The advantages of using NVivo are manifold; a major advantage of using NVivo is that it can handle large amounts of text efficiently by providing easy access to the transcripts and coded materials (García-Horta & Guerra-Ramos, 2009). One of the main disadvantages of the programme was that I had to invest a significant amount of time and effort to learn NVivo proficiently (MacMillan & Koenig, 2004; Thompson, 2002). So far, the advantages have outweighed the disadvantages.

3.7.2 Recording and transcribing

Both focus group discussions and all interviews were digitally recorded with the participants' permission. Two Olympus digital recorders, DS 200 and DS 400, were used to ensure adequate audio recording of the interviews. The audio recorder allowed me to concentrate on interview management as well as engage in a more comprehensive conversation (Edwards & Skinner, 2010; Noor, 2008). However, brief field notes were also taken during the interviews which allowed the interviewer to accurately capture periods of silence, and take notes on body language and facial expressions that a digital recorder could not capture. Whilst all participants could have opted out from being recorded, nobody did. I transcribed the interview recordings verbatim and I extensively used the NVivo 10 computerised software to produce accurate interview transcriptions. Five interviews were conducted in English and one in Bengali. I

translated and transcribed the Bengali interview recording and checked the interview transcription against the tape recorder. In addition, a local trained and experienced bilingual research assistant checked the Bengali interview transcription against the tape recorder for double accuracy.

Transcription is a crucial visible feature of qualitative analysis and a vigorous act of data portrayal. It was argued that transcription should closely linked to the research design and methodologies rather than a backstage analysis method (Oliver, Serovich, & Mason, 2005). I wanted to ensure I produced an accurate transcript; producing transcript is a time consuming task as a one-hour interview can take up to seven hours to transcribe (Britten, 1995). Although transcribing interviews was a laborious process, it was incredibly helpful in that I remained closely familiar with the data (Crouch & Pearce, 2012). In fact, the first data analysis process started from interview transcription as I was able to develop themes and sub-themes during listening and transcribing the recording data. Detailed transcripts enabled me to organise and prepare the transcriptions for member checking.

3.7.3 Member checking

In order to establish trustworthiness and credibility for this study, I utilised the member checking technique. Member checking has been considered the “most crucial technique for establishing credibility” (Lincoln & Guba, 1985, p. 314). It is a participant validation technique to help improve the accuracy, credibility, and transferability of the research (Creswell, 2009). Member checking was utilised once the transcripts had been generated from the interviews and examined thoroughly by me. I was aware that participants might be confused, distressed, or embarrassed after reading their interview transcripts (Kvale, 1996). Most importantly, participants were cautioned that the transcripts were written in their spoken languages, hence, any fragmented sentences or grammatical errors in their transcripts verified that the transcripts accurately conveyed their responses in the study.

When I telephoned the participants about focus group discussions’ transcripts validation, most of the male and female participants had negative responses toward reading the individual transcripts; however, a few female participants showed interest in reading the final written report. One participant from the male focus group had email access, so he reviewed his interview transcript data via email correspondence. Although the majority of the focus group participants did not have email access, nearly all of the male participants had WhatsApp messaging applications installed on their mobile phones. Furthermore, out of six interviewees, two reviewed the transcripts from their interview data through email correspondence, and three reviewed them via the Whatsapp text messaging application. However, one participant

did not have email or the Whatsapp mobile application, hence, the interview transcript was delivered to the interviewee by post. The participants were asked to check the accuracy of their interview content, and were given the opportunity to clarify, add, or delete any information they considered appropriate. The participants were given two weeks to read through the transcripts and notify me if there were any misinterpretations in the transcripts. All of the participants confirmed that the transcripts were accurate and truthfully represented their opinions in the interview.

Salam, Mr. Md. Hossain

I hope you are all well. Thank you for that, it is interesting, it looks alright. Good.

Text box 1 - Focus group participant's comments after reading the transcript

"Thank you I did read all your transcripts it like all my life is there in what you have written so thank u."

Text box 2 - Family carer's comments after reading her interview transcripts

3.8 Thematic analysis

Thematic analysis was chosen as the most appropriate method to analyse and interpret the data obtained during this research project. Thematic analysis has been regarded as a better-fit approach to qualitative data analysis since about 1940. In 1945, anthropologist Morris Opler developed three key steps when using thematic analysis to analyse culture: identifying the appearance of themes, the expression of themes, and the interrelations between themes (Opler, 1945). Since the 1940s, many researchers have been identifying various ways to represent themes during the research analysis processes; however, they have used different terms to express their views, such as categories, codes, labels, incidents, segments, chunks, units, concepts, and so on (Ryan & Bernard, 2003). Despite its frequent use, thematic analysis has not been well defined; instead, thematic analysis has been criticised as being too vague and lacking depth and transparency with respect to its theme development methods (Attride-Stirling, 2001; Holloway & Todres, 2003). Although other qualitative approaches are incredibly diverse, complex, and nuanced, Braun and Clarke's (2006) thematic analysis method is useful for rich, detailed, and complex data, given that qualitative data is diverse and complex in nature. In addition, thematic analysis is reasonably suitable for hard-to-reach populations or where qualitative researchers use relatively small sample populations (Joffe & Yardley, 2004). Thematic analysis can be used with a relatively small sample size and can gain insight without

further intrusion into that hidden population (Fugard & Potts, 2015). Therefore, thematic analysis was selected as the most suitable analytical method for this research, as it fit well with the primary research purpose: to identify congruence between the knowledge of, experiences with, and perceptions about ageing, dementia, caregiving among male and female participants in the focus group discussions. The breadth and scope of this method allowed me to draw unequivocal themes from both focus group discussions and semi-structured interviews, which is consistent with the aims of the current research. The data collected from both focus group discussions and semi-structured interviews were subjected to inductive thematic analysis, in line with my ontological and epistemological position. Using this inductive but flexible approach to thematic analysis process, I felt able to incorporate the realities of Bangladeshi community members' understandings of dementia and experiences of caregiving to try to reach a better understanding of the phenomena explored.

In this current study, NVivo 10 provided the best option for coding themes directly within digital audio files, focus groups and interview transcripts, and field notes. NVivo is specifically designed for the thematic analysis of qualitative data, with theory-building capabilities (Lapadat, 2009). I used inductive coding within NVivo to facilitate the thematic analysis of this research. The features of NVivo, including coding, linking, searching, and model building, to facilitate rigorous and sophisticated thematic analyses, have been outlined in the following sections. After the data were collected from the audio files of both focus groups and interviews, and transcripts entered into the QSR NVivo 10 data management program, a comprehensive process of data coding and theme identification was undertaken. I repeatedly read the transcripts to identify a number of recurring concepts, generating initial codes which developed until primary recurrent themes emerged by using an adaptation of Braun and Clarke's (2006) six step data analysis method steps. The aims and description of each step are described in Table 4 below.

Table 4 - The six phases of Braun and Clarke’s (2006) thematic analysis

Phases of thematic analysis	Description of the process
Familiarizing yourself with your data:	Transcribing data within NVivo, reading and re-reading the data, noting down initial ideas.
Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. Giving full and equal attention to each data items, and identify interesting aspects in the data items that may form the basis of repeated patterns (themes) across the data set.
Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme. NVivo will use tree maps to create flexible mind-maps to generate the initial thematic map at this early stage.
Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a final thematic ‘map’ of the analysis.
Defining and naming themes:	On-going analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Thematic analysis delivered an efficient component to data analysis that allowed me to extensively understand the phenomena under investigation. Furthermore, thematic analysis was a recursive, rather than linear, process where I moved back and forth as needed throughout the six phases. To provide consistency, Braun and Clarke’s (2006) detailed six step thematic analysis process has been discussed extensively in chapters four and five.

3.8.1 Validity of the thematic analysis

I followed Braun and Clarke’s (2006) criteria for performing good thematic analysis by using a 15-point checklist to ensure that the thematic analysis processes were thorough, plausible, and of high quality.

Table 5 - 15 Point Checklist of Criteria for Rigorous Thematic Analysis

Process	No	Criteria	Criteria achieved through
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'	I transcribed all the focus group discussions and semi-structured interviews within the NVivo 10 software and checked transcriptions against the recordings.
Initial coding	2	Each data item has been given equal attention in the coding process	Considerable amount of time was given for each focus group discussion and semi-structured interview; equal attention was paid to each data by reading and re-reading the transcripts for each focus group discussion and semi-structured interview carefully.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.	During the coded process in Phase 5, themes were thoroughly generated by reviewing the coded extracts. Essence of codes or more than one example for each code was included.
	4	All relevant extracts for all each theme have been collated.	In Phase 5 all relevant extracts were collated by sorting them out into initial groups relevant to their theme.
	5	Themes have been checked against each theme have been collated.	Data analysis involved re-checking all the collated themes against the original data set by checking their relevancy to the theme.
	6	Themes are internally coherent, consistent, and distinctive.	Through reviewing the themes numerous times against the original data set, consistency was ensured.
Analysis	7	Data have been analysed –interpreted, made sense of -rather than just paraphrased or described.	In this stage, I identified stories in their themes rather than paraphrasing or describing it.
	8	Analysis and data match each other – the extracts illustrate the analytic claims.	I followed these steps by moving back and forth between themes, coded extracts and the original data set so that the analysis and data replicated each other.
	9	Analysis tells a convincing and well-organised story about the data and topic.	I made sure that the analysis was well organized, coherent, and easy to follow. I also wrote each theme story as an essay so that reader can understand the whole story and learn more without knowing the details of analysis process.
	10	A good balance between analytic narrative and illustrative extracts is provided.	Identified themes and sub-themes were supported by clearly selected quotes.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.	I planned this research analysis time adequately so that analysis took place over a period of time without rushing a phase which allowed me to interact with the data. This also allowed me to reflect over a period of time.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.	My assumptions were clearly explicated because I followed the step by step process of the thematic analysis and I had a clear understanding of the procedure goals.
	13	There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported analysis are consistent.	I clearly wrote the method section when I was conducting the research analysis and writing up a clear report.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.	I used the language which was easily understood by the reader and to easily identify the concept of the analysis. It was also aimed to provide reliable and consistent evidence of concept of the analysis throughout this research report.
	15	The researcher is positioned as active in the research process; themes do not just 'emerge'.	I was alert to the technique in which I could become passive during the analysis of focus group and interview data. I overcame this by a continual process of reflection throughout data analysis.

Source: Braun & Clarke, 2006, p.96

3.9 Summary

This chapter has described the philosophical paradigm utilised in the research and how computer assisted qualitative data analysis software NVivo was used. NVivo was found to be a good data management and thematic analysis tool. This chapter also described the methods used to discover the views of Bangladeshi people without dementia and Bangladeshi family carers of people with dementia, and examine the themes to explore the existing research gaps in literature as well as possible areas that would benefit from future investigation.

Chapter Four will discuss the findings from the focus group discussions conducted among the Bangladeshi community members who were not affected by dementia and thematic analysis. This data will be used to identify core themes and sub-themes. The chapter aims to explore and analyse the perceptions, knowledge, and attitudes of ageing and dementia among the Bangladeshi community.

Chapter 4: Perceptions and attitudes toward ageing and dementia among the Bangladeshi community in England

4.1 Background

In this chapter, the research question “what are the participants’ knowledge and attitudes toward dementia?” is addressed. Based on the current gap in the literature, and to achieve the aims (as already stated in chapter one) of phase two of this study, two qualitative focus groups interviews were held that explored the Bangladeshi community’s perceptions toward ageing, caring for older people, dementia, and the management of dementia (with the aim of identifying who was responsible for this task), before going on to explore the realities of those living and coping with dementia from within these communities. It was hoped that conducting this investigation would help to explore individuals’ knowledge, perceptions, and attitudes toward ageing and dementia in order to compare these views with those of the individuals who have dementia or that are caring for somebody with dementia. In addition, the findings from these focus groups would further inform the development of the interview schedule for phase three, one-to-one semi-structured qualitative interviews with Bangladeshi family carers, who play an important role in supporting an older person living with dementia.

The main methodological and ethical issues have already been discussed in the previous Chapter Three. This chapter and the following chapter, therefore, do not seek to report all the methodological and ethical issues but rather aim to provide the reader with an overview of the specific methodological and ethical issues which are only relevant to their respective parts of the study.

4.2 Eligibility criteria for the focus group discussions

The following eligibility criteria were employed during recruitment:

- Individuals of Bangladeshi origin residing in Portsmouth;
- Adults 18 years of age or older;
- No personal experience of living with dementia or caring for a person with dementia in the last 5 years; and
- Individuals who were able to provide written informed consent to participate in the study.

Prospective participants were informed from the outset that they might not be selected to participate in the study. However, all potential participants were thanked for their interest in the study and offered a summary of the research findings upon their request.

4.3 Recruitment of participants

The first issue to address in fieldwork was getting permission to conduct the research study (Bogdan & Biklen, 1992). Portsmouth was intentionally selected as the proposed research area. Portsmouth is a city that is home to the single largest number of people of Bangladeshi origin living in the south-eastern region of England outside of London (Khan et al., 2007; Portsmouth City Council, 2011). Current research reveals that the Alzheimer's Society and other voluntary organisations overwhelmingly focus on London's inner city, while very few initiatives have been extended to the Asian communities outside of London.

In order to access potential participants, a local Community Development Worker (CDW) was approached and agreed to act as a gatekeeper. The CDW facilitated effective communication between me and prospective participants from the Bangladeshi community in Portsmouth. She handed out research packs, which included an invitation letter (Appendix C), the participant information sheet (Appendix D), the participant consent form (Appendix E), and a reply slip (Appendix F). After receiving and reviewing the research information pack, potential participants could indicate whether they wished to take part in the focus group discussions. If they were interested in doing so, they were asked if their contact details could be passed on to me. They were also given the choice of contacting me directly, depending on whichever option worked best for them. Potential participants would then be contacted by me to discuss their study participation. I ensured that the participants met the eligibility criteria.

Secondly, after an initial meeting with a local mosque's Imam as well as the mosque committee, they agreed to act as gatekeepers for the recruitment of potential participants. Mosques' imams are highly respected spiritual leaders in any Muslim community. Therefore, it was believed that the mosque's imam would act as one of the key community gatekeepers from the Bangladeshi community in Portsmouth. Both the imam and the mosque committee agreed to display the study's advertisement (Appendix G) on the mosque's notice boards. Furthermore, at the end of Friday sermons (just before the weekly big prayer held each Friday), the imam made a brief announcement about the research study and introduced me. Therefore, based on the information disseminated at the Friday sermon and on the notice board study advertisements, potential participants were encouraged to contact either the imam or me directly. After providing a brief verbal explanation of the study, potential participants were given a research information pack. At the same time, potential participants who were interested in taking part in the focus groups were asked to contact me by either telephone or email; I did not initiate any direct contact with any prospective participants. Those who did not have internet access or who used pay-as-you-go mobile phones were asked to leave their telephone numbers if they felt comfortable doing so. Thus, I was able to contact these individuals directly to further discuss their participation in the study.

4.3.1 Venues

The male focus group discussion took place in a local mosque (Appendix P) and the female focus group discussion took place in a local community centre in Portsmouth. Both venues provided a quiet, private, inclusive, non-threatening environment that enabled rich discussions. A notice stating 'Interview in progress, do not disturb unless there is an emergency' was hung on the door. Light refreshments and water were supplied at the venues.

4.4 Data collection

As already stated in the methodology and design chapter (Chapter Three), this qualitative research uses an interpretivist-constructionist position, with data being collected by one-to-one interviews and focus group discussions; this phase of the study used the latter.

4.4.1 Focus group topic guides

Prior to the focus group discussions, I developed a focused interview schedule (Appendix H) following the detailed analysis of the studies that were included in the qualitative synthesis from phase one, as well as after holding discussions with my supervisors. The focus group discussion schedule was followed to ensure that critical topics related to the research questions were covered, while also allowing additional issues to be raised, as needed. After an initial introduction and details of the study were provided, the topics that were explored included participants' perceptions and attitudes toward ageing and older adults; participants' knowledge and perceptions of dementia; the stigma associated with dementia; gender and care issues; and carers' strain.

4.4.2 Use of vignettes

Vignettes are "short stories about hypothetical characteristics in specified circumstances, to whose situation the interviewee is invited to respond" (Finch, 1987, p. 105). Vignettes have traditionally been used to pursue and understand people's attitudes, perceptions, beliefs, and norms within health and social care, regardless of the interviewee's ethnic background (Finch, 1987; Gourlay et al., 2014; Hughes & Huby, 2002). Vignettes were used in this study to examine the extent to which participants from the Bangladeshi community understood and perceived dementia (text boxes 3 and 4 below). Two vignettes were used in this study; they provided culturally impartial scenarios related to issues that are complex, sensitive, and under investigation among the Bangladeshi community in the UK. The vignettes were adapted from vignettes that were previously tested and used for their cultural appropriateness in studies

conducted among South Asian communities (Fontaine et al., 2007; Lawrence et al., 2010; Patel & Prince, 2001; Uppal et al., 2013). The term 'dementia' was not stated in the vignettes; however, they featured an older hypothetical woman named 'Mrs. Parul', who was of Bangladeshi descent (in terms of both her cultural and religious background). The vignettes first depicted how she was suffering from symptoms that corresponded to mild to moderate dementia, and then symptoms that corresponded to severe dementia. After the first vignette, the participants were asked the following questions: 'what do you think about Mrs. Parul in this vignette?'; 'Why was she behaving this way?'; 'What were her problems?'; and 'What would you call that problem or symptom?' Then, at the end of the second vignette, participants were asked the following: 'what do you think of her situation now?'; 'What could be the reasons behind this?'; 'What should be done now?'; 'How would you care for this person?'; and 'Who should you ask for help at this point?'

Mrs Parul is 70 years old. She was diagnosed with diabetes last year. A few months later, family members began to notice that she was becoming more forgetful; for example, she confuses people's names, even her own family members' names. She forgets the Namaz (prayer) time and if she cooks sometimes she forgets to turn off the stove. She is unable to remember an event from last week but clearly remembers what happened 40 years ago in Bangladesh. Family members noticed the problem more than one year ago and it has been gradually getting worse day by day.

Text box 3 - The first vignette about mild dementia that was used in the focus group discussion

Mrs Parul is now 74 years old. Now she has difficulties recognising her own daughter or other close family members. She repeats herself in a conversation. She is becoming moody and feels anxious, withdrawn, isolated, depressed or angry for no apparent reason even with the grandchildren. Not only Namaz (prayer) time is forgotten but now she needs to be reminded to go to the toilet or take a bath; and she finds it difficult to make her way to the toilet. She also has difficulty to remembering where the toilet is situated. She sometimes wakes up in the middle of the night, insisting that it is morning. Moreover, she does not go out, but spends whole days in her room without doing anything in particular. The family is struggling to cope.

Text box 4 - The second vignette about severe dementia that was used in the focus group discussion

4.5 Data analysis

For the data in this chapter and the next chapter, thematic analysis was chosen for my data analysis method; it has already been presented and justified in the previous chapter.

4.5.1 Thematic analysis procedures

Here, the six step process is described alongside the qualitative research software NVivo 10 as a systematic, and transparent method for coding, analysing, and storing the data.

Phase one: Familiarizing oneself with the data

The familiarisation process began with the transcription of the data from the audio recordings within NVivo. I transcribed and generated codes from the audio files using the 'play', 'pause', 'skip back', and 'skip forward' buttons in NVivo, or by using keyboard shortcuts. Although the transcription process was time consuming, difficult and, at times, an exasperating experience, the task of identifying initial themes during the early stages of the audio tape transcription process proved invaluable for me (Braun & Clarke, 2006; Ryan & Bernard, 2003). Following this, I also exported the transcripts from NVivo to Word documents where hard copies were read through several times, extracts of interest highlighted, and my initial thoughts on them were recorded (Appendices N & O). Revisiting, by double checking the transcripts through a review of both the NVivo and hard-copy versions, I tried to ensure that all the focus group data represented the participants' accounts as accurately as possible in terms of both content and meaning.

Phase two: Generating initial codes

Initial coding determines the qualities in the text that were of interest with regards to the research questions (Braun and Clarke, 2006). During qualitative research, coding is a primary process where text excerpts (usually a word, terminology, short phrases, sentences, paragraphs, or metaphors) are pulled out from the participants' accounts and assigned to a feature of the data defined as having some common meaning or relationship to a phenomenon (Boyatzis, 1998; Carpenter & Suto, 2008). Furthermore, each code can be used as a label or category, which may be useful for further data exploration. The coding categories used in the present study were initially constructed in light of the research questions, focus group discussion schedules, the pertinent literature, and the overall theoretical and methodological perspectives in this subject area. Therefore, I derived the initial codes on the basis of the main study objectives: the knowledge, attitudes, and beliefs of Bangladeshi immigrants toward

ageing and dementia. These issues were fragmented, so I used the heading styles that were applied to the paragraphs in the transcripts to automatically code the text in paragraphs while following those headings (in other words, the program automatically created nodes based on the heading text). The initial coding procedure comprised an open auto-coding process in NVivo of all the responses each topic posed in the focus group discussions, which created a node for each topic and the relevant data was coded accordingly. I then applied headings to the focus group discussion questions, to the names of the participants, or to headings in research journals; the text beneath these headings was auto-coded with ease, so that I was able to quickly obtain an overview of the form of the data segment, and to filter, for example, a specific research question or participant. To illustrate, I created the heading 'knowledge of dementia' for a focus group topic; then, any text under that heading was auto-coded in NVivo. As a result, case nodes (coding containers) were made and were ultimately used to code what each focus group participant said about the topic 'knowledge of dementia'.

Auto-coding provides a fast way to organise data into nodes, which are a collection of references about a specific theme, place, person, or other area of interest. Later in the project, I collapsed or combined these nodes with other nodes and attributes to create a really focused analysis of the research data. Followed by the initial auto-coding process, each participant's transcript was coded line by line, and also into 'chunks' of meaningful text, where the connotation or significance of a statement only appeared to clear within the context of further responses. These extracts of text were given a label or 'code'. This was a recurring process; when codes were developed in one transcript, I re-read the transcript data segments linked to the new code. With the help of NVivo, initially 191 codes were generated; this was a time-consuming process and it mostly involved careful scrutiny during 'recontextualisation' of the data to discover new meaning. Some excerpts of the transcript were given more than one code such that I tried to make sure that each extract from the transcript was given equal attention by re-checking the assigned codes. The developed codes were then checked against the research questions and interview schedules to confirm that only those codes that meaningfully contributed to the research aims were followed.

Phase three: Searching for themes

During this phase, all of the data had been read, re-read, initially auto-coded, re-coded, and collated, and a long list of the different codes was created for the entire data set. After the initial coding process, all data were assembled into potential themes (Braun and Clarke, 2006). During this stage, I critically scrutinised the data, considered how the different codes could be combined, and identified issues that seemed familiar and common to create overarching

themes. Themes were developed separately for the male and female focus group participants. Once the focus group discussions had been coded, I broadened the thematic analytical process by identifying the emerging themes in a hierarchical manner and exploring their relationship to each other. Subsequently, I discovered the potential connections between the themes, as some were sub-themes of broader themes. The essence of this choice was a collection of excerpts as direct quotations from the participants that demonstrated the principal relationship and characteristics of that code.

For these focus group discussions, the 191 initial codes generated in the previous stage were collapsed into ten key themes after reading and re-reading the codes in aggregation with the documents and my notes. During the thematic analysis, the recurrence of the semantic content of the codes within the individual transcripts this directed me to deeply explore their meaning. After logically categorizing of all the themes, I discussed the initial themes and sub-themes that were starting to emerge with the supervisory team to gain their input. Furthermore, I drew a preliminary thematic map (illustrated in Figure 7) of this early stage in order to explore the relationship between codes, themes, and different levels of themes (e.g., main overarching themes and the sub-themes within them) (Braun & Clarke, 2006, pp. 89–90). NVivo 10 easily facilitates the reorganisation of codes into various groupings, and also delivers a model representation of the themes and their corresponding codes by providing a hierarchical structure of the data. During the later stages of qualitative data analysis, I noted that some of the themes overlapped, as they were similarly coded; also, I coded excerpts that did not seem to be useful. Following Braun and Clarke's (2006) suggestions, I did not discard any of the codes at this stage; they were kept instead for further consideration in the upcoming phases of analysis.

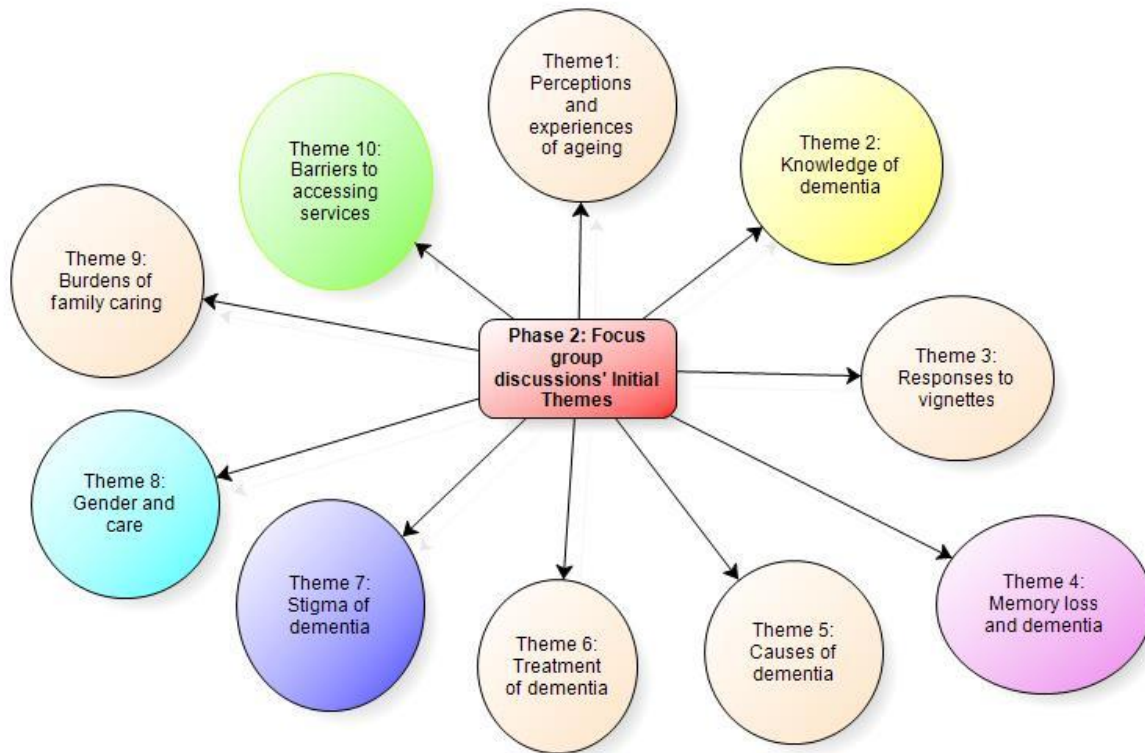


Figure 7 - Initial thematic map

Phase four: Reviewing themes

This phase involved reviewing and refining the themes developed in the third phase. This is an essential step, as the themes that previously emerged are scrutinised to make certain that the themes were amalgamated and ultimately became broader once the coded extracts from the focus group transcripts were incorporated. At this stage, reviewing the themes required an assessment of whether the data within the themes cohered in a meaningful way, and whether there are clear and identifiable distinctions between themes (Braun and Clarke, 2006, p. 91). Based on these guiding principles, I began the process by returning to the entire data set, where I reread the focus group transcripts, field experience research log book (which included direct observations during the focus groups), as well as my reflexive journal. I also read the data excerpts for each theme to ensure that there were coherent patterns within the themes; if there were no clear or identifiable distinctions between themes, I discarded those data extracts. Through this review process, I made a number of changes when reviewing the main themes and sub-themes. I discarded a few sub-themes and codes that were not frequently found or that were absent in other focus group transcripts. For example, 'financial tensions were causing the memory losses was removed as a sub-theme, as there was insufficient evidence for this. Additionally, I identified data excerpts that appeared to be related to the

individual codes, and I then went back to the original codes to further review and refine them to conclude whether a theme actually existed there. This phase came to a close when I was able to determine that the individual themes and initial thematic maps were reflective of meanings in the entire data set, as well as strong enough to characterise recurring and unifying ideas of overarching themes. Following the thorough examination of themes and coded extracts, the ten themes were reduced to three, and various sub-themes were also developed. Therefore, at this stage, the initial thematic map was ultimately developed into a final thematic map, which provided a big-picture overview of the research findings (see Figure 8).

Phase five: Defining and naming themes

The process of defining and refining themes involves capturing the essence of what each theme is about and what aspect of the data each theme encompasses by organising data extracts into a coherent and internally consistent account (Braun & Clarke, 2006). A thematic map was developed in the previous phase facilitated the process of defining, refining, and naming the various themes at the start of this fifth phase. This stage also entailed refining the themes into concise and easily understood labels which I revisited and reread the themes numerous times, to ascertain whether the story told within the themes was clearly defined and reliable. Once these steps were taken for each theme, I devised names for each theme, most succinct and appropriate, and that instantly conveyed the subject matter to the reader (Braun and Clarke, 2006). Although the initial thematic map showed ten themes and sub-themes, it was then condensed and refined to form a full-story representation of the analysis so that the final thematic map was distilled into three main themes and several sub-themes were finally developed and illustrated (Figure 8). The three main themes are: (a) perceptions of ageing and older people, (b) knowledge and perception of dementia, and (c) perceptions of caring for people with dementia (see Section 4.7 for details).

Phase six: Producing the report

As suggested by Braun & Clarke (2006), I need to make an argument for the findings in relation to the research questions and the existing literature reviewed such that the final report delivers a succinct, comprehensible, coherent, and interesting account of the findings (Braun & Clarke 2006). Therefore, the final stage of the thematic analysis and write-up of the findings report not only provided a descriptive story through the various themes but also provided an analysis of each theme. Quotations and coded extracts were used to demonstrate the key characteristics of each theme, as justified, exemplified, and illustrated within the six phases.

4.6 Findings

Three main themes were discovered within the thematic analysis, and these will be detailed below using participants' direct quotations as data extracts to demonstrate the themes. Some extracts overlapped across several themes. The participants' responses from the discussions were not changed. Therefore, any grammatical or unusual wording is an accurate reflection of what the participants said during the discussions. I chose these specific extracts based on their significance to the main themes and sub-themes.

4.6.1 Demographic characteristics

The participants' demographic information was captured on a reply slip, which served as a questionnaire, prior to the formal focus group sessions (see the reply slip in Appendix F). A total of twenty-one adults of Bangladeshi origin across all age groups (18 years or older, with no upper age limit) and socio-economic backgrounds took part in two focus group discussions (twelve men were in the male focus group and nine women were in the female focus group). The average age of the participants was 50.66 years (range: 25–77 years). All participants were born in Bangladesh, except for one male participant who was born in England. The participants' primary languages were a mix of Sylheti (a Bengali dialect), Bengali, and English and all males were competent in the English language. All participants were Muslim; no one was recruited from the Bangladeshi Hindu community. The anecdotal evidence suggest that Bangladeshi Hindus' have a lack of presence in the UK or they were less visible where the recruitment took place, notwithstanding that the actual number of Bangladeshi Hindus was not recorded in the census data (Berkeley, 2006). Participants' educational qualifications were subdivided into four categories: those participants that did not have any formal educational background; those participants that had completed some form of secondary school; those that completed a higher secondary school education; and those that had some type of university qualification. Two of the nine women who attended the female focus group discussion did not have any formal education, and two male participants chose not to disclose their educational achievements. All nine women participants had never worked outside their homes. Eight out of twelve male participants were working full-time, three were not working and one was retired.

Table 6 - Demographic characteristics

	Total number
Gender	
Men	12
Women	9
Age groups (years)	
21-30	1
31-40	4
41-50	8
51-60	5
61-70	0
71- 80	3
Country of birth	
Bangladesh	20
UK	1
Education attainment	
No formal education	2
Prefer not to say	2
Primary school or less	2
High school or less	7
Some college levels	4
Bachelor's degree or more	3
Madrassa (Arabic/Islamic qualification)	1
Marital status	
Single	1
Married	18
Widow	2
Time of UK residency (years)	
01-10	5
11-20	4
21-30	1
31-40	7
41-50	2
51-60	2
Employment	
Working	8
Not working	13

4.7 Main themes identified

A complete list of major themes and sub-themes that emerged from the data is illustrated below in Figure 8; a bulleted list has also been provided for clarification purposes. Figure 8 shows the three main themes and sub-themes that had been identified in relation to the research questions presented earlier. The main themes were:

- Perceptions of ageing and older people,
- Knowledge and perceptions of dementia, and
- Perceptions of caring for people with dementia.

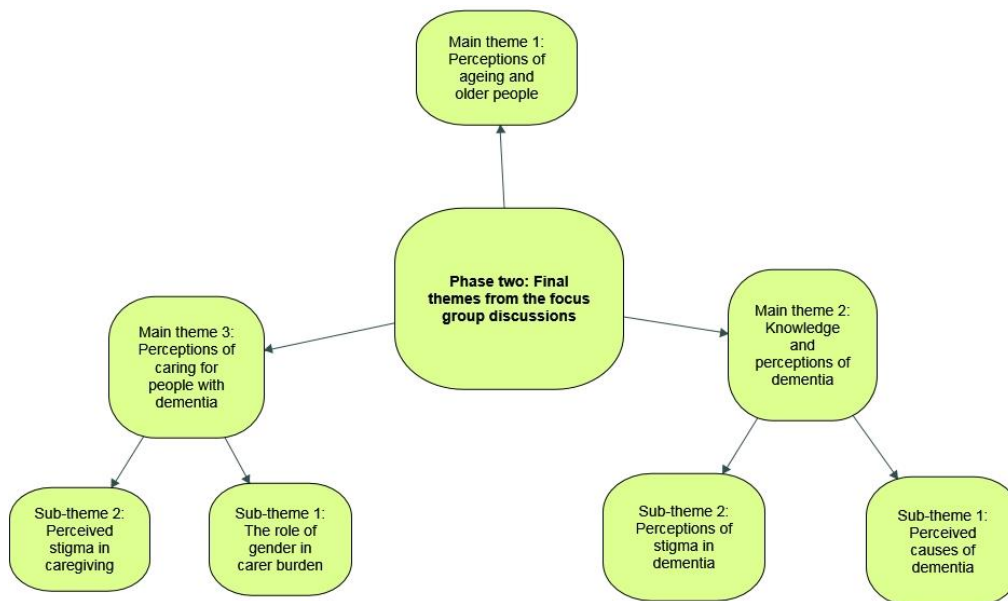


Figure 8 - Main themes and sub-themes

The themes and subthemes are defined below and are also demonstrated by a collection of stories and quotations that were present in the transcripts to further validate the relationship between the data and the themes.

4.7.1 Main theme one: Perceptions of ageing and older people

During both of the focus group discussions, the participants were first asked to express their perceptions about ageing and older people. It was important to examine what factors influenced the Bangladeshi community members' perceptions of the aged and ageing in the UK before exploring the following theme, which pertained to their knowledge and perceptions of dementia.

The focus group transcripts revealed that most of the participants generalised their perceptions about ageing and older people, and these were primarily driven by traditional Bangladeshi family values. The majority of the participants described their perceptions and attitudes toward ageing and older people by unambiguously referring to their own older family members and their own experiences. Although ageing is a biological process, the perceptions of ageing and older people among the Bangladeshi community members were highly variable. Their understanding of ageing encompassed a mix of biological, psychological, and socio-economically constructed meanings. Participants were asked about their perceptions of ageing and older people, I revealed that the male and female participants regarding ageing and older people in positive, negative, and neutral ways. Positively, older adults were seen as active members of the community who were valued, sociable, and knowledgeable. However, the females tended to hold more negative perceptions than the males. For example, overall, older people were categorised as having poor health and poorer memory; conversely, they regarded older males as annoying, complaining, temperamental, dominating, unhappy, and lonely. In addition, most of the female participants described their own ageing experience as involving increased fatigue and a lack of energy, having to live with chronic pain, feeling stressed, and worrying about their own future.

Focus group members, particularly the female participants, tended to speak of having less energy, and feeling constantly exhausted and tired; however, this was not the case with male participants. The findings also suggest that three out of the nine female participants, who were in their forties, felt older than their actual ages:

I am becoming tired day-by-day, physical pain, and pain in my leg. I don't like to work, don't like to cook. I am worried about my future. I will be weaker as days have gone by... I don't know. (Woman, 46 years)

The following woman was 47 years old and she described herself as 'an old woman':

I feel really sorry about my age as I am getting old. I just think how quickly my life is getting over as I am an older person and thinking about my death. (Woman, 47 years)

These two quotations illustrate how even though these women were in their forties, they already viewed the ageing process somewhat negatively by citing their own insecurities and worries.

The findings also revealed that men were less apprehensive about ageing than women. However, males still held concerns about their physical weaknesses, but the males tend to be more preoccupied with this in later stages of their lives as compared to women. It appears that

men perceived themselves to be aged if they were older than 60, whereas women regarded being old as being in their forties.

Like my forefathers, I am mentally and physically OK. I can remember whatever I had done in my childhood. Everything I know about my childhood/teen age. (Man, 77 years)

Some participants also generally believed that a person's old age is affected by a number of health-related conditions, and that many of these occur more frequently with advanced age. These included diabetes, high cholesterol levels, strokes, and heart attacks. In a similar vein, one man (who was a decade older than the two women quoted above) reported that his perceived physical deterioration made him upset and frustrated:

I am already 60 years old, and the various problems I am suffering from for example, I have diabetes, cholesterol and these are causing me trouble. (Man, 60 years)

Likewise, some additional factors influenced the focus group participants' perceptions of ageing and older people, such as gender, the participant's level of engagement with the elderly, and age, as well as cultural and religious aspects. The participants' gender also influenced their attitudes toward ageing and older people. The majority of the female participants showed less favourable attitudes, especially toward older men. These views may have been shaped by their first-hand experience of family members' deterioration.

The female participants provided real-life examples of their husbands' ageing processes; they discussed how they noticed changes in these males' behaviour with advanced age. The female participants also reported that older men in particular seemed increasingly angry, short-tempered, conflictive, and intolerant, and that these moods were getting worse over time. Notwithstanding, as mentioned before, I observed that the female participants who were living with an ageing spouse generally held negative perceptions toward older people and ageing. This may be a reflection of the women's excessive caring experiences for their elderly husbands in the family, while they were also ageing at the same time.

"Short fuse" ... yes I have noticed older people (my husband) is getting angry very easily nowadays. Although they get angry very easily for a minor reason in their old age. It's funny now they get angry, get annoyed for no reason. (Woman, 50 years)

Another woman participant talked about her perceptions of older people in general by citing a traditional stereotyped Bangladeshi saying about older people as intolerant and bitter:

Because there is a proverb in Sylhet, Bangladesh that 'Mango is sweeter when ripe and men get bitter as they age'. Well, that was a proverb they used to say about becoming older and annoying. (Woman, 43 years)

It was evident that a steep decline in physical activity was perceived as being old. However, most of the male participants (7 out of 12) and only a few of the female participants (3 out of 9) regarded ageing and older people as being associated with a diminishing mental capacity. Unlike the female participants, some male participants commonly mentioned how mental abilities decline in old age. They described how cognitive deterioration was inevitable among older people, even though these participants were unfamiliar with dementia. The findings revealed that the female participants were more distressed and worried about their memory than men as they were getting old. The participants believed that parts of their memory had been affected by various ageing-related factors; for example, some talked about tension, while others were distressed about their loneliness.

I am worried about my memory as I am growing old. I don't remember now, I am losing memory, I don't remember where I put things. (Woman, 60 years)

It is general that older people make mistakes, cannot remember etc. these are normal when people get older. (Man, 77 years)

The participants quoted above discussed their perceptions of ageing, and they reflected on how they had experienced memory difficulties in their sixties. From the findings above, it is clear that both male and female participants perceived old age as being associated with some degree of memory problems. However, it seemed that the female participants were more worried about their age-related memory issues than the male participants were. The findings showed that women were more likely to associate memory impairment with negative implied attitudes toward old age than men.

In addition, many participants also reported that they perceived old age to be accompanied by loneliness, a sense of being trapped in the family, feeling stressed, and facing problems and a lack of support within the family in the UK:

My perception of ageing is all about stress, family stress all around... Well, lots of stress, family stress, family problems in this country. (Woman, 50 years)

The older people who are living in this country are lonely. (Man, 47 years)

One widow described her loneliness and deep concerns about her future care arrangements. This immigrant widow, who came to England after her husband passed away, inevitably suffered from loneliness and isolation. England, to her, represented an entirely different environment where the cultural norms, values, and beliefs were not in line with those of her culture and religion, and, as such, had created a real sense of anxiety for her and her own ageing, especially as she was living alone.

I think every Bangladeshi older people worried about their old ages in this country. I see other older people are suffering and that made me very worry. I pray that Allah (God) will look after me. (Woman, 60 years)

In addition to the feelings of loneliness, another participant added that fear of falling and concerns about decreasing mobility were major issues for a lonely older person. A fear of falls negatively impacted this person's confidence to leave the house, which severely affected her mobility. She kept saying that older people tend to converse less and become quieter and unobtrusive in old age due to bodily weaknesses.

Falls and mobility are the main problems when an older person is living alone. When nobody is around to that older people they become more vulnerable and more risks to fall. (Woman, 43 years)

One younger participant envisioned that future Bangladeshi generations would inevitably suffer from isolation and loneliness in this country. The perceptions of ageing and older people reflect their recognition of the changing nature of the family structure and relationships within the Bangladeshi community in the UK. They perceived that the current generation (rather than the older generation) has become more integrated into the British culture and less interested in extended families. Thus, some expressed a fear of isolation and loneliness that emerged among the participants; even a participant in her thirties worried about her inescapable future grief in the UK.

I think we will be going in the same direction when we will be older. I don't know how it will be in this country. I feel trapped after staying all day at home in this country. Pressure and tension at home my mind is unrest. (Woman, 37 years)

Despite the stereotyped perceptions and attitudes toward ageing and older people among most of the participants, one discussed her sense of optimism that being happy, healthy, and living without psychological distress, uncertainty, or tension would help individuals to age successfully.

If older people are happy and live without tension then they have healthy mind and good memory. However, the older people who are under pressure and living with everyday tension then their mind and memory become weaker and weaker. Their heads don't work properly, they lose memories. (Woman, 43 years)

With respect to this main theme, the findings suggest that the majority of male participants (8 out of 12) felt they possessed good overall physical and psychological well-being, particularly when compared with the female participants' perspectives. The findings also revealed that most women (6 out of 9) reported experiencing psychological discomfort and physical ill-being.

In the current study, it is important to note that there were more men than women; similarly, the men were also older (in terms of their maximum age) than the women. Of the twelve male participants, seven were above 50 years old (the oldest was 77 years), whereas three of the nine women were above the age of 50 years (the oldest was 60). However, the findings revealed that, despite the women's younger age, they were more likely than men to perceive ageing as a time of decreased physical and psychological well-being. The women tended to be more adversely expressive of their perceptions and attitudes toward older people and ageing as compared to the men. Perhaps the participants' gender roles and subjective well-being influenced their own perceptions that ageing is a negative experience in the UK.

4.7.2 Main theme two: Knowledge and perceptions of dementia

The second primary theme, the participants' knowledge, perceptions, and attitudes toward dementia presents the most striking findings revealed in the focus group discussions. This theme involved presenting two hypothetical vignettes (see section 4.4.2) about dementia. The first depicted an older woman with the symptoms of mild to moderate dementia, while the second was about the same older woman with the symptoms of severe dementia.

The word 'dementia' was not revealed in the vignettes presented during the focus groups discussion. After hearing the vignettes, the participants were questioned about what they thought about the woman, and they were asked to name the illness of the hypothetical patient presented in the vignettes. The findings revealed that the participants used a number of Bengali terms to understand dementia; however, these terms took on more positive connotations, e.g., *smorok sokti thakena* means 'memory loss', which is a term they used to mean short-term memory loss; the participants said this type of cognitive issue is common regardless of age. In addition, the participants used the Bengali term *smoron sokti harano*, meaning 'lost memory', which is generally used for someone who has completely and permanently lost her/his memory. Other words that were used for short-term memory loss included *mon vula*, which means forgetful mind. This term is used to describe those who are unable to temporarily remember something, but who regain their memories after some time. However, the participants described people who were unable to remember again with various Bengali terms such as *smoron sokti hariye jawa*, meaning 'lost memory'; this referred to those people who have lost their memories permanently. All of the Bengali terms were expressed as non-stigmatizing words from the Bengali language.

None of the participants mentioned the word 'dementia' until this was brought up by me at the end of the second vignette, which implied that the participants did not have prior knowledge of dementia. As soon as the participants heard the term 'dementia', the majority of them were

very keen to learn more about it. As a result, they asked us multiple questions to find out more about the disease.

We don't understand dementia, what is dementia? I want to request if you please tell us, explain to us what is dementia. So that we can increase our knowledge. (Man, 76 years)

Following the presentation of both vignettes, a female participant asked this question during the focus group discussion:

Does this disease affect older people or younger people? (Woman, 43 years)

Following this participant's question, another participant in the female focus group tried to answer it by herself: she assumed that young people are the ones who normally suffer from dementia. Furthermore, another participant mentioned that they were aware of mental health, but not dementia:

I don't know, I can't say. We have heard of mental health but we never heard of dementia. (Woman, 56 years)

Two following sub-themes emerged from this predominant theme, such as the perceived causes of dementia and the perception of stigma about dementia; these concerned the participants' knowledge, perceptions, attitudes, and awareness of dementia.

4.7.2.1 Sub-theme one: Perceived causes of dementia

Many participants, however, were able to identify and make sense of the dementia vignettes. The collective perception among both male and female focus group participants was that the imaginary person in the dementia vignettes was experiencing a normal ageing process. Also, most of the male and female participants commonly and consistently mentioned that the hypothetical woman in the vignettes was suffering from memory problems that were part of the natural ageing process.

When someone gets old then they behave like Mrs Parul (vignette character). When you become old, after eating you'd say no I didn't eat, after namaz (prayer) you'd say no I didn't say my namaz. These are various problems older people are going through when they become old. (Woman, 60 years)

In the old ages, people tend to forget all because they are getting old. (Man, 56 years)

The participants enthusiastically participated in the group discussions; the vignettes encouraged them to discuss their perceptions with other group members and with us. For example, some male and female participants were able to recognise their own family members' behaviours while reading about the vignette character; several participants even offered conceivable examples of their own family or community members' attitudes and perceptions in connection with the hypothetical person from the dementia vignette:

This is because of her age. My grandfather/grandmother forget every day. My grandfather is 93 years old and this is because of his age. They are in good health but they forget sometime. Maybe he is 93 and that is why he is forgetting. (Woman, 37 years)

Another participant made a sweeping assumption about Bangladeshi community members' perceptions and attitudes toward ageing and memory loss. That participant also provided a reason for his assumption. For example, the participant stated that people lose their memory when they become old. According to that participant, there appears to be an interconnected and inverse relationship between increased age and decreased memory:

In Bangladeshi community, what people think about older and memory loss are in similar ways. Because generally people lose memory when he or she becomes older. So the term older and memory loss are related to each other. But we cannot take out the term memory loss from the term older. It's related. (Man, 75 years)

Although all of the participants were more likely to understand dementia and memory loss as part of the normal ageing process, the male participants were more expressive than the female participants about wanting to distinguish between dementia and memory loss caused by the normal ageing process. Although not widely agreed upon among the participants during the focus group discussions, one female participant's opinion diverged in her perception of ageing and memory loss. The participant thought that the 'memory loss or forgetting' disease is caused by a genetic disorder and not by ageing alone, which is inclined to pass on through families:

Maybe it is family related 'forgetful' disease. I think it is a disease about "forgetfulness" which runs in the family. (Woman, 43 years)

Apparently, forgetfulness or memory problems are not as visible as other types of physical illness. One participant described that forgetting or memory loss was not a serious health issue; rather, it was an age-related issue. Forgetfulness and memory loss were viewed as common symptoms among older people, and the participant believed that serious conditions did not cause these symptoms for the woman presented in the vignettes. Thus, the participant

explained that since those symptoms were not serious physical health problems, people should not be concerned about their memories or forgetting things as they age:

I think it's forgetful, whatever reasons behind it. But as it is a general thing as it happens as you grow older. Then we should not worry too much about memory because it is an age matters. (Man, 76 years)

Contrary to the male participant's beliefs described above, a female participant noted that forgetfulness or memory loss among older people can cause frustration, anger, and resentment among family members. She added that older people with memory problems have great difficulty dealing with others in the family, which prompted anger and annoyance. Perhaps the memory lapses were invisible or unclear to the family members, and identifying such changes within the older person intensified the family members' anxiety.

Yes lot of people get angry when older people behaving like a child, don't remember, keep forgetting that make other family members upset, that triggers anger. Feel that behaviours as annoying. (Woman, 46 years)

However, despite all of the general perceptions toward ageing and memory loss, one male participant believed that the same hypothetical character in the second vignette needed medical support. Although the participant described that the first vignette scenario was indicative of the normal ageing process, he reported that the woman in the second vignette was experiencing issues that were not part of the normal ageing course; specifically, she was facing a serious medical condition:

I think this time now she (vignette character) needs medical counselling. Because she is not just sick or behaving that because she is just above 70 years old. But I think there is something else and she needs medical counselling for that. Because I don't think only because of her age everything is happening. Maybe something affecting her in the head, it is the reason. (Man, 77 years)

The participants generally mentioned that most of the people have busy lives in the UK, and that they have little time to spend with their older relatives. As a result, older people feel isolated from their own family members, which causes tension and dementia. The participants in the focus group discussions also described old age and dementia as a result of social withdrawal and isolation. The participants attributed loneliness and isolation to memory loss and suffering from dementia in old age. This situation can heighten the feelings of loneliness and isolation among older Bangladeshi people in the UK, as this may lead older people to suffer from dementia:

Many older people living in this country are lonely because we cannot give them company. They are suffering from diabetes, blood pressure in their old ages. These factors may affect them for losing their memories. (Man, 47 year)

Correspondingly, the majority of female focus group participants attributed anxiety, depression, and tension to be the primary cause of the second women's behaviour. Women were more expressive than men about their understanding of the deterioration/symptoms displayed, particularly with respect to how tension and worrying too much about their family problems can lead to dementia:

Too much tensions reason to forget things, losing their memories. It's depression. (Woman, 43 years)

While most of the female focus group discussants explicitly linked family tension and worry to their understanding of dementia, a male participant portrayed the symptoms described as resulting from physical decline and financial hardships in old age:

Financial tensions, health tensions are causing the memory loss. (Man, 77 years)

In summary, across the groups terms frequently used to find out the causes of the vignette character's unusual behaviour were depression, stress, tensions, anxiety and loneliness.

4.7.2.2 Sub-theme two: Perceptions of stigma in dementia

In the focus groups of the present study, the participants' perceptions of stigma associated with dementia were explained within the context of madness or possession by a *jinn* (a life-form created from fire which belongs with the angels) or *bhuta* (a malicious spirit of a dead person). The participants explained that madness, dementia, and memory problems are not representative of the same phenomenon. The participants further described that madness or bad spirits that haunt a person speak rubbish or show deviant behaviour, which can cause stigma within the family and community. However, the participants did not believe that the hypothetical character in the vignettes – or any other persons suffering from dementia or memory problems – was experiencing madness or stigma at all. Since dementia or memory problems are caused by ageing, and given that people generally suffer from memory problems when they become older, the participants clarified further.

No stigma related to the lady (in the vignette) we don't think so. But there is a category. If we say my mother or son or brother became 'mad' then it is a stigma. In Bangladesh people use stigmatised word when a person haunted by a ghost then we called that

person 'bhuta dhorse' (Bengali terms of haunted by a ghost or bad spirit) that is stigmatised word (Man, 76 years)

Subsequently, I asked the participants why they did not feel that stigma was related to dementia. The participants spontaneously rejected the general views about dementia held by other South Asians, and they strongly noted that there is no stigma associated with dementia:

That's not true what other Muslim community or Pakistani community believe about stigma of dementia. (Man, 58 years)

The participants also described that dementia in old age is a sign of forgiveness and blessings from God. More than half of the participants (12 out of 21) in this research shared a general belief that age-related dementia was given by Allah (God), and it was a form of mercy and served as a way to atone for one's sins. They believed that the hypothetical character in the vignette will be rewarded after death for her suffering in old age and emphasised that people should not worry about dementia in old age, which comes as a blessing from God.

No, no we don't believe that stigma in dementia, we don't think so. According to our religious teaching when somebody suffered from dementia in his or her old ages... that means whatever sins we did in this world, you will be forgiven. This is better. If Allah gave us any punishment after death, it will be really big and cruel, we could not fight that. So for dementia in old ages that means you are forgiven. That means it will better for her (the vignette character) next life when somebody suffered from dementia in this world. (Man, 56 years)

I don't worry too much if I have dementia! Allah will help! Whatever Allah does, does for good. Allah has brought us into this country now Allah will help. Don't worry much! (Woman, 46 years)

4.7.3 Main theme three: Perceptions of caring for people with dementia

Two major sub-themes emerged in relation to this primary theme, such as the role of gender in care burden, and the perceived stigma in caregiving.

4.7.3.1 Sub-theme one: The role of gender in care burden

When the participants were directly asked to explain who should provide care for the people with dementia, they overwhelmingly expressed that caring for people with dementia ought to be a family duty. There were no clear differences between the male and female participants'

responses in the focus group discussions. Although most participants viewed caring for the person with dementia as mandatory, the female participants perceived higher subjective levels of burden and personal stress. The male participants explained that culturally, Bangladeshi women are expected to be hushed, obedient, and subservient to the senior members of the family, including husbands, parents, and parents-in-laws; they should also be caring to the children. Perhaps surprisingly to some, there was a clear consensus among the participants about who in the family was responsible for caring for a person with dementia. The majority of participants, men and women alike, stated that the women's roles involved not only caring for the person with dementia, but also taking care of others in the family. In addition, household chores and other duties in the family are traditionally determined by women's gender roles (e.g., these are typically performed by the daughters-in-law). The following excerpt from a male participant echoes the perceptions and attitudes toward women's gender roles in caring duties.

If we're married or before married parents look after the children. Then son's wife normally looks after the family. Depends father, mother, father's mother, wife, or grandmother it (caring) comes while systematically within the Bengali family looks after the younger as well as the older. If my wife is frail, then if I am able to do something I would do that. But at the same time, we rely on most of the moms or ladies of the houses in the Bengali communities. This is my view. My wife looks after my son, my wife looks after me, and she would look after my parents as well as (look after) her parents plus my pets. (Man, 76 years)

On the other hand, not only did the men think that women ought to look after their husbands and children, but all of the female participants seemed to take caring duties for granted. In addition, female participants wanted to continue their perceived caring journeys for the person with dementia, while also completing other domestic tasks, as long as they were physically capable. After listening to the vignettes, the following participant talked about what she would do as a family carer if her husband was suffering from dementia:

For women, it is our duty to look after our husbands, my responsibility to look after my husband. No matter how my physical or psychological condition is but it is my duty to look after my husband. Maybe it will be difficult to do the physical hard job while lifting him or giving him bath but if my children or other young people available I would ask them to help me with lifting. I will do my best to look after my husband. (Woman, 43 years)

The above statement suggests that women do not have any choice regarding their caring duties, which are culturally assigned behaviours and expectations based on their gender.

When the participant quoted above was asked to clarify his statement, as it seemed women hold many roles within the household, the participant stressed that this was normal and that most people who are born and brought up in the Bangladeshi community have this expectation that women will take on the caregiving role:

Yes, for women too many things to do... Yes, we expect this from women. This is how we have been brought up in the Bangladeshi community. (Man, 76 years)

The following participant had about a 40-year age difference from the participant quoted above, but they both shared an identical traditional ideology toward women's caring duties:

Its (women's caring roles) our custom, its Bangladeshi cultural things. (Man, 37 years)

The female participants expressed that their caring duties were culturally shaped.

Wife looks after husband, this is right in our culture. This is traditional that wife looks after husbands. This is our duty to look after our husbands. (Woman, 47 years)

The above quotation is indicative of how women's attitudes toward their husbands and caring duties may be shaped by expectations of cultural rules and norms. Despite their wives' physical weakening, they placed a higher priority on their husbands' health and well-being. Even though the female participants did not complain and were rather stoical about their deleterious caring experiences in the family, many of the women participants acknowledged the strains of coping with household chores and caring duties while recognizing that they were powerless as well, as their workload was much heavier and imposed by their husbands. The female participants critically reflect on their experiences that their husbands were uncooperative, negligent, and unhelpful. The impact of husbands had manifested in the women's portrayals of the meaning of 'good husbands', and the women stated they would cope well with their caring duties if they had good husbands. The women believed that good husbands would listen to them, share in their domestic caring duties, and appreciate their hard work and worries. The majority of the women expected that their husbands would be empathetic, understanding, appreciative, and caring toward their wives.

Very few husbands in our community do understand wives' illness, wives' well-being, wives' happiness. Majority of men in our culture do not look after their wives... If wife becomes ill, cannot do any work such as, wife had a brain stroke, dementia, paralysed and could not move from one place to another. In that circumstances, if husband helps wife that difficult time then he is a good husband. (Woman, 43 years)

As mentioned above, five out of nine female participants also perceived that their husbands appeared to hold steady and negative attitudes toward caring roles. They said that the majority

of the male members of the Bangladeshi community in the UK do not hold the same caregiving ideologies like female participants do; none of the female participants seemed to have these expectations from the male members of the Bangladeshi community.

No problem for wife is looking after her husband with dementia. But husband looking after his wife with dementia will be very difficult. (Woman, 55 years)

Some females explained that their current physical and emotional strains were considerably associated with old age, gender issues, their greater carer burden, being busy, and fatigue. In addition, many female participants reported that they were suffering from functional decline, which profoundly affected their current ability to perform caring duties for their family members. The participants also expressed frustration as they continued their caring duties despite their physical strains.

We women are going through many physical problems, yet we have to do all caring duties in the house. But if men have any kind of illness they always moan 'Ya Allah' (Oh God) I have got this disease, no one is taking care of me. (Woman, 46 years)

Explanations of burden differed from person to person in the focus group discussions. However, the burden of caregiving within the family was only expressed in the female focus group and not within the male focus group discussions, who did not express caring as a burden on them. The participants in the female focus group generally described their day-to-day caring experiences as annoying and burdensome. Furthermore, they spontaneously raised the concept of caring as a burden, as they expressed being silent sufferers with long-term caregiving experience. The female participants found that caring for their loved ones was profoundly disruptive within their day-to-day lives. They described that they have too many roles to play in the household, and they were exhausted after doing all the hard work on their own. I explored the degree of burden that the family carers experienced in their daily lives, which may have resulted in physical and mental burnout.

Oh yes, of course, we are annoyed after doing all the hard work. Looking after older people, husband, children, cooking, cleaning etc. are very difficult for a single person. It is not possible keep everybody happy. If we can get some help then it will be helpful. (Woman, 46 years)

Moreover, the female participants expressed that the family carers in the Bangladeshi community often became invisible persons in the family. The nature of the caregiving role is a complex everyday task for family carers, as they have to tend to other priorities in the family as well. The participants further explained that they have to play different roles in the family, based on time and relationship demands. For instance, daughters-in-law sometimes identified

themselves as serving daughters-in-law in their husbands' houses, where most of the time they act as family carers for their husbands or parents-in-law; at the same time, they also take care of their young children. Despite the burdens and strains of caring, many participants described how they were performing this hard work around the clock, and that sometimes they did not even receive any appreciation from their husbands or from others in the family. As a consequence, the perception of caring for a person with dementia regrettably seems to add to women's subjective burden of caring-related strain, which is already being experienced by family carers of people without dementia and their families. Nevertheless, the female participants also perceived a higher level of caregiving burden among family carers for people with dementia, and they also expressed how the relationships between family carers and the persons with dementia as the care recipients may change over time.

It was understood that the use of vignettes in the focus groups prompted further discussions among the participants based on their personal experiences in real life. The use of dementia vignettes ignited a focus group discussion, and the participants provided an expansive clarification within the framework of the vignette's character. After listening to the vignettes, one female participant explained her perceived concerns about the person with dementia from the vignettes, and she further stated how she would react in the given circumstances. She added, that moving forward from her current caregiving role, she would have to develop a new and effective caring strategy to cope with the heavy unforeseen caring burden that may be experienced while looking after someone with dementia.

I have to look after her (the vignette character) as a baby, because in her old age she's become a baby again. I have to take care her 24 hours, need to check now and then has she fallen anywhere, has she eaten properly, need to give her bath etc. (Woman, 46 years)

In contrast, another female participant described what perceptions and attitudes her husband might hold toward his wife if she suffers from dementia.

If the wife is suffering from dementia and keeps forgetting then husband will not understand wife's condition. If wife forgets, the husband will never tell her in details. Maybe husband will tell once or twice but the third time he will be furious as wife forgot. (Woman, 43 years)

Reflecting on the character in the vignette, another participant explained how caring for everyone in the family is very important and unavoidable. Caring is often a 24-hour job that can be very demanding, stressful, and annoying. On top of that, dealing with a dementia patient's repetitive behaviour might be very challenging. Repetitive behaviours, as well as other dementia symptoms, were perceived as distressing and a constant annoyance for

families and family carers. Obviously, the family carers' lack of knowledge about dementia and their perpetual 24-hour caring duties indicate that their lives are a constant struggle for resources and support.

It is annoying when older people keep repeating things. Carers are busy 24 hours doing household chores and caring for everyone. How long possibly one could look after someone like this suffering from memory problems? This is very difficult. (Woman, 55 years)

This quotation referred to a feeling of loss, helplessness, and resentment, as the participant feared about the longevity for caring for someone with dementia. Therefore, numerous ambiguities can arise as the participants try to determine whether they might be able to meet the increased demand for long-term dementia care within the family. On the other hand, they might be increasingly worried about their own health or worried about where to get help and support, particularly after experiencing all of the traditional and stereotypical attitudes about female caregiving roles in the family held by most Bangladeshi community members.

4.7.3.2 Sub-theme two: Perceived stigma in caregiving

This current sub-theme sought to provide a detailed description how they perceive stigma as a family carer, particularly of someone living with dementia, as well as how any stigma related to caregiving might affect the family carers' lives in the wider community.

The female participants described how, in Bangladesh, domestic workers or servants hold the lowest status in society, and they are the most vulnerable group for exploitation. Due to a lack of economic opportunity and poverty, domestic maidservants predominantly come from the most disadvantaged groups, with minimal or no access to education; furthermore, they are the most vulnerable group in Bangladesh. Domestic workers or maidservants have fewer legal rights, and they typically do not have any established working hours; in fact, many of them must work long hours. Being a paid carer was seen as challenging, and there were overwhelming feelings of shame or embarrassment among the family carer, family members, and within the wider community. There are apparent resemblances between paid servants and paid carers, and identical moral principles underlie these two service positions. Negative attitudes and perceptions toward servants in the Bangladeshi society are widespread. Similar fear-mongering attitudes toward being a paid carer among Bangladeshi community members prevent these individuals from taking up caring jobs in the UK. Moreover, the participants

described that the wider community viewed paid carers with suspicion, which would have a broad, negative impact not only on family carers, but on their families as well:

In Bangladesh, caring job is done by a servant or nurse who has less respect and rights in the society and we have this same mentality in this country. There is a lot of stigmas in the community to work as a paid carer. People will start talking when carers will go over other people houses and do the caring job. That is why nobody want to be a paid carer for a normal patient or for any dementia patient. This attitude is damaging our community. (Woman, 46 years)

Moreover, the participants explained that irrespective of whether they engaged in paid or unpaid caring duties, they would be embarrassed to take up caring as employment. Members of the Bangladeshi community would monitor dementia family carers with suspicion; scepticism would arise regarding the carers' motives, and families would investigate the family carers' affection for, or mistrust their obligation toward, the people with dementia, particularly if the carer was not an immediate family member. Furthermore, the participants were concerned that community members would compare their occupations as carers for people with dementia with the services offered by a stigmatised servant.

Obviously, Bangladeshi carer is hard to find. Because they're ashamed of doing this job, caring for someone other than the family members. Someone will see her and say look 'she is doing this caring job for other people and she is working there like a servant'. (Woman, 39 years)

The participants generally expressed that in the Bangladeshi community, looking after one's older parents in their own homes, regardless of the parent's physical or mental illness, was a strong cultural and religious duty. As discussed earlier, female members primarily take on the role of family carers, so they would look after older people in the family. However, there is still a sense of stigma attached to those carers who provide care for older people who are not their own family members. The female participants' general perception was that caring for someone with dementia, who was not their own family member, would carry a similar stigma as that described earlier. In addition, keeping the persons with dementia at home with the family was described by family members as an important matter in the Bangladeshi community. The participants said that the moral duty of caring for someone other than a family member with dementia would be judged negatively by the wider community. Moreover, the participants defined the community's perceptions of taking on a career in caring is not only a source of stigma for the family carers, but it would also bring shame upon the families. The assumption in the wider community is that the female is not looking after her own loved one with dementia; rather, she is visiting other people's houses to provide care for money. The participants

blamed Bangladeshi culture, stating that it deters them from becoming professional carers. The research findings suggest that cultural differences are indeed an influential determinant for becoming a waged carer.

This is all about culture; this is our Bangladeshi culture. This is our mentality. We cannot deal with caring jobs for other people like English carers do. (Woman, 60 years)

In the Bangladeshi community, the family is viewed as a major source of honour, and everyone in the family takes an active part in protecting and maintaining that honour within the community. There are many social factors that help to preserve family members' honour. For example, women are either constrained to the boundaries of their households, or they have circumscribed individual freedom of movement; visiting places recurrently are controlled for women. If women do not follow these constraints, this can easily damage the family's honour and that woman can be labelled as a bad woman. The female focus group participants expressed a high degree of anxiety, and mentioned how these stereotypes and traditional gender ideologies discouraged women from taking up caring as a profession. It was clear from the findings that feelings of shame and the stigma related to caring for someone with dementia were perceived by the community members and not by the family carers themselves.

Notwithstanding, the participants said that unlike in English culture, overarching Bangladeshi society values discouraged women from applying to caring occupations. The participants reported that to date, the perceptions and collective community-based stigma toward caregiving outside the family was damaging the image of the Bangladeshi communities. The participants very anxiously acknowledged that there were many older people without children living in the community, and that there were even numerous instances where adult children had abandoned their older parents. The participants' main concern was as follows: if the community held persistently negative attitudes toward caring professions, who would look after those older Bangladeshi adults who are ageing without children?

Older people who do not have children will need carer. Even if you have children and after marriage they will have their own family and children. We will have to live on our own in an empty house. This is our tension now who will look after us when we will more older and unable to look after ourselves. We will need Bangladeshi carers that time. (Woman, 60 years)

However, it is important to note that some participants were hopeful that the attitudes toward providing care for someone outside the family may change in the future. Stigmatizing attitudes and perceptions related to working as a paid or unpaid family carer can be significantly reduced by learning and training initiatives. However, the carers explained their caregiving

perceptions as cumbersome given the gender roles as well as community attitudes toward caregiving profession to achieve.

You would be able to do that if you had enough training for dementia caring. But as we're saying to go look after someone with dementia from other community is not doable, possible. Because we don't look after someone with dementia in our community who is not our family members or relatives. (Woman, 50 years)

The findings represent the current lack of knowledge and understanding about the nature of dementia; moreover, they highlight that there is a need to increase dementia literacy and training among the participants, as well as to the wider community. Perhaps the scarcity of knowledge about dementia indicated that the wider community was not aware of what was involved when caring for someone with dementia. All of the participants believed that in order to provide care for people with dementia, they would need dementia education and training. The findings also suggest that the participants only possessed perceptions about dementia and caregiving in dementia. If they acquire experiential knowledge of dementia, then they will, in a sense, have more opportunities to learn new skills and meet other family carers. The female participants mentioned how direct learning and learning through experience are the best ways to combat caregiving stigma, and it would help them influence others to avoid stigma. Adequate public awareness and understanding is very important to eliminating the stigmas associated with dementia and caregiving.

4.8 Discussion

As a qualitative research project, this focus group study provides an understanding of the perceptions held by Bangladeshi community members concerning ageing and dementia. The purpose of this study was to add to the ever-increasing volume of health care literature, where Bangladeshi community members are inclined to be partially represented within mainstream ageing and dementia health care services in Britain. Specifically, this study aimed to explore the Bangladeshi community members' knowledge and perceptions about dementia. It also explicitly aimed to determine Bangladeshi community members' perceptions toward carers of people with dementia. This discussion section was steered by the research question and enlightened by the findings of the thematic analysis, as described earlier in this study. The primary research question was the following:

- What are the participants' knowledge and attitudes toward dementia?

4.8.1 Discussion of the key findings

The following key findings emerged from the focus group study and the thematic analysis:

- Overall, ageing is a negative experience for the majority of the participants;
- The majority of the female participants feel older than their actual age;
- There was a widespread lack of knowledge and awareness of dementia in participants of both the male and female focus group;
- There was no stigma toward having dementia;
- Stigma surrounding paid caregiving is a major theme among female focus group participants.

The present study also explored the participants' gender-based perceptions of their self-perceived ages, and it also uncovered the significant differences between them. Notably, compared to male participants, it seemed that the women felt 20 years older than their actual ages. For instance, three women in their forties described themselves as old (the youngest in that group was 43 years of age). On the other hand, the men stated that old age began between the ages of 60 to 70 years. However, one interesting fact found among the early settlers was that there were significant differences between elderly Bangladeshi spouses, where married men were up to 20 years older than their wives (Qureshi, 1997). Even more, the current average life expectancy in the UK for all women, regardless of ethnicity, is 82.8 years (ONS, 2015), whereas the average life expectancy for Bangladeshi ethnic women in the UK is 79.8 years (Lievesley, 2010). In addition, the average life expectancy for all males in the UK, regardless of ethnicity, was 3.7 years lower than that for all females in the UK, whereas the average life expectancy of ethnic Bangladeshi men was approximately five years lower than that for Bangladeshi women (Lievesley, 2010; ONS, 2015). Traditionally, age-related stereotypes have focused on women, instead of men, in the Bangladeshi society, which was reflected in this research. Importantly, stereotypical attitudes toward women do not always come from the men or from society; however, a woman begins to perceive her own ageing process at an earlier time than men, which is reflected in the women's perceptions of their own physical and mental health, as well as of their own well-being in this research.

For the first time, a number of prominent findings emerged from the current study, particularly with respect to the Bangladeshi community members' perceived lack of knowledge and understanding of dementia within the family. To the best of my knowledge, this is first study to explore the knowledge and perceptions of dementia among the Bangladeshi community. All the participants regarded dementia as memory loss, and the various symptoms of dementia were mostly perceived as reflective of the normal ageing process and other physical illnesses rather than cognitive decline. Overall, the findings of this study corroborate with those of two qualitative research studies that were conducted by Fontaine et al. (2007) and Uppal et al. (2013), who focused on dementia awareness among other South Asian (Indian Punjabi and

Sikh) communities in the UK. These two studies also used hypothetical dementia-related vignettes to better understand the participants' knowledge of dementia. While the participants of Uppal et al.'s (2013) study had little prior knowledge of dementia, the female participants in this current study had never heard of dementia before, which is in line with the study findings of Fontaine et al. (2007).

In addition, to date, the stigma attached to dementia is a consistent theme that has emerged in all of the other published literature about South Asian communities' perceptions, attitudes, and knowledge of dementia (Adamson, 2001; Bowes & Wilkinson, 2003; Brijnath & Manderson, 2011; Fontaine et al., 2007; Godfrey & Townsend, 2001; Lawrence et al., 2010; Mackenzie, 2006; Uppal et al., 2013). One significant result of this current study is that the findings on this matter contrasted with those of previous studies (Adamson, 2001; Bowes & Wilkinson, 2003; Brijnath & Manderson, 2011; Fontaine et al., 2007; Godfrey & Townsend, 2001; Lawrence et al., 2010; Mackenzie, 2006; Uppal et al., 2013). Specifically, during the focus group discussions, once the vignettes had been presented, I asked direct questions related to stigma, so that the participants could answer the questions in a detailed manner. As a point of reference for the groups, I presented some results from Mackenzie's (2006) study about the stigma associated with dementia, which was conducted among 16 South Asian (Indian and Pakistani) community members. Like other studies, Mackenzie's (2006) study found that stigma severely affected the South Asian peoples' family and community lives, as well relentlessly impacted the participants' decision to access health care. However, unlike previous studies, no evidence of stigma arose from the conversations with the participants from the Bangladeshi community that participated in this current study. The participants' understanding of stigma also differed vastly from that of other studies conducted within other South Asian communities. For instance, the other studies found that participants perceived dementia as 'madness', which was damaging to their family lives and affected their participation in the broader community (Adamson, 2001; Bowes & Wilkinson, 2003; Brijnath & Manderson, 2011; Godfrey & Townsend, 2001; Lawrence et al., 2010; Mackenzie, 2006). Conversely, the participants in the present study stated that 'dementia' and 'madness' were not related, as dementia was regarded positively while madness was perceived in a negative light. The participants from this study understood madness in a significantly different way from other South Asian participants. Here, the participants regarded madness as related to a person who is haunted by bad spirits; they phrased it as '*bhuta dhorse*' (haunted by a ghost). In addition, their understanding of dementia was typically related to the normal ageing process, where memory loss was unavoidable.

The current study also uncovered a new finding that has not yet been exposed in other studies: the stigma associated with paid caregiving, which prevented members of the Bangladeshi

community from taking up caregiving employment in the UK. While Bangladeshis are three times more likely to care for dependent family members than White British (Carers UK, 2011), there is a fear of stigma attached to provide care for someone outside the family boundaries. There is no research whatsoever within the Bangladeshi community on the experiences and concerns of Bangladeshi individuals providing care for their non-relatives with dementia. Female participants alleged that the Bangladeshi community's narrow perceptions of paid carers restrained them from becoming a formal carer.

Decision-making power is a significant feature of Bangladeshi families. Decision-making related to health care and other matters is an extremely important male-dominated activity in the Bangladeshi community. However, no studies to date specifically focused on this issue in the Bangladeshi community in the UK. The Bangladeshi community is largely a male-dominated patriarchal society. In this patriarchal family structure, the eldest man in the house is the head of the family; next in line is the eldest male son. Patriarchy is based on power relations within the family, as the adult male breadwinner controls everything. The current study found that instead of accessing the health care services available in the UK, the primary male breadwinners sometimes place more pressure on family carers (typically women) to look after the elderly and others in the family. Therefore, additional research should focus on examining alternative decision makers in the Bangladeshi communities, particularly as they access various health care services. The Bangladeshi community members sometimes obediently comply with the instructions given to them by their doctors, mosque's imams, or other religious leaders; therefore, it is possible that the real decision makers may actually be someone from outside the family.

Older Bangladeshi adults primarily turn to family members to receive support and care. These individuals among the participants were unable to think of any governmental services or programmes that provided care for the elderly in their country of origin. Thus, there is a need to broaden the discussion within the Bangladeshi community to inform them of what additional supports are available, as this may prevent them from seeking and rejecting help from the currently available professional services. Elder people have high expectations that their children should provide family care, which might not be possible given their busy lives and the demands of living in a modern society like Britain. There is also a need to discuss the reality that children who were born and raised in Britain cannot avoid being influenced by British values. Although the culture, religious beliefs, and values of individual Bangladeshi communities should be respected and promoted, these are dynamic constructs that change across time. There is a need to hold sensitive discussions and debates about these factors under circumstances where they can be addressed in such a way that does not undermine

Bangladeshi culture; rather, these discussions should highlight the importance and changing nature of these constructs to better inform care practices.

4.9 Summary

The purpose of this chapter has been to explore knowledge and perceptions about ageing, dementia and caregiving among the Bangladeshi people (who were not affected by dementia) living in England. Personal perceptions of the ageing process were mostly related to physical decline. Across the genders, a lack of knowledge and understanding of dementia awareness was evident, but stigma about dementia was non-existent. In contrast, there was a strong sense of stigma attached to being a paid carer. Respondents felt that current healthcare services failed to meet the religious needs of Bangladeshi Muslim older people, and subsequently could hinder or deter Bangladeshi people living with dementia and their family carers' willingness to seek and use appropriate health and support services. This study provides current research findings where no other qualitative research has examined the knowledge and attitude about dementia among a Bangladeshi community in England. In this context, it is vital for future studies to highlight the importance of raising dementia awareness and provide more information to Bangladeshi community members about dementia, dementia caregiving as well as religiously sensitive healthcare services.

The next chapter sets out the analysis and discusses the findings following the interviews with the six family carers of their relatives with dementia. The data will be analysed by pulling out concepts that were identified and grouping them into codes and themes about the family carers' experience. The chapter goes on to explore the experiences of caring and the coping strategies that family carer adopted. It also sets out the family carers' involvement with health and social care services.

Chapter 5: The journey with dementia from the perspective of Bangladeshi family carers in England

5.1 Background

This chapter presents the third phase of the findings to address the research question in the primary study: 'what range of knowledge, views, perceptions, beliefs, and range of experiences do Bangladeshi family carers have about dementia?' There is a paucity of research, on the experiences and concerns of individuals within the Bangladeshi community providing care for their relatives with dementia. This qualitative study explores Bangladeshi family carers' knowledge and day-to-day experiences living in England. The final data collection of this three-phase research study aimed to conduct semi-structured audio-taped qualitative interviews with Bangladeshi family carers who play an important role in supporting their older relatives living with dementia.

5.2 The research settings

Given the lack of research among the Bangladeshi community in England, choosing the right research locations was an essential part of this research. Initially, I intended to conduct this research among the Bangladeshi community in Portsmouth only. However, evidence from qualitative studies shows that it is essential to conduct research in multiple social locations in order to get a broad knowledge of the phenomenon under exploration (Holloway, 1997; Yin, 2012). Therefore, phase three of this study was conducted in two settings of England where a majority of Bangladeshi immigrants have settled permanently: Portsmouth and London. The principal reasons for choosing these two regions is that they represent heavy concentrations of Bangladeshi people. More than 55 per cent of the UK's Bangladeshi population lives in London and about 2 per cent of total Portsmouth population are Bangladeshi (ONS, 2013a). The 2011 census showed that there were well over 250,078 Bangladeshi people living in London and the South East of England, and between them about 3,649 Bangladeshi were living in Portsmouth, a number that has increased by 44.69% from the 2001 census (Census 2011). As the last decades have shown Bangladeshis to be the largest ethnic minority group in Portsmouth and that its population has increased rapidly, it is most likely that the current Bangladeshi population in Portsmouth has increased since the time of the 2011 census as well. Moreover, research communities, government as well as voluntary and charity organisations have overwhelmingly focused on London and very little on Bangladeshi

communities outside London. Therefore, along with London, Portsmouth has been selected for the settings of this study as well.

Table 7 - Interview location

Family carers	Home	University
Portsmouth	1	3
London	2	0
Total	3	3
	3 + 3 = 6 Family Carers	

5.2.1 Gaining access

In order to gain access to the potential participants, I established relationships with the local gatekeepers trusted by the Bangladeshi community members. Gatekeeping is an essential part of conducting a research project as well as a process of permitting or denying access to a particular research site (Lee, 2005; Willems, 2001). Previous research showed that recruiting potential participants from ethnic minority communities was enhanced by following a more direct and culturally specific approach through their allied community associations rather than using old-style, secondary methods, such as finding participants through advertising and mail (MacEntee et al., 2002). Other studies also emphasise that researchers from the same ethnic background may be more likely to reach and access community members who share their ethnicity (Nazroo, 1998; Smaje & Field, 1997). Since I belong to the Bangladeshi Muslim community, I could communicate the expectations and requirements for the interviews to be conducted whilst understanding the customs and conventions. This ensured both maximum access to the community and minimised misunderstandings and expectations.

In Portsmouth, potential participants were recruited through local community leaders such as community development workers and the mosque's imams. They were selected because they have established contact with the local Bangladeshi community, and they are often trusted and known through their leadership or otherwise have a significant role in that community. They acted as a liaison between myself and the potential participants to facilitate effective

communication. They also facilitated effective communication between myself and prospective participants by distributing research packs, which included an invitation letter (Appendix J) with a photograph of myself, the participant information sheet (Appendix K), the participant consent form (Appendix L), and a reply slip (Appendix M). All of these recruitment materials were produced both in English and Bengali to reach the wider linguistic groups in Portsmouth and London. After receiving and reviewing the research information pack, potential participants could indicate whether they wished to take part in the interviews. I ensured that the participants met the eligibility criteria. If prospective participants wished to take part in the interviews, they were encouraged to ask questions to seek clarification. On the day of the interview, each participant was asked to sign a consent form to confirm that they agreed to take part in the study. However, it was made clear that they were free to withdraw at any time without giving a reason.

In London, prospective participants were approached through a UK-based care and research charity for people with dementia and their family carers. That charity runs a social club for BME people with dementia and their family carers in a local mosque. The charity manager was contacted via telephone calls as well as emails explaining the study and criteria for inclusion. The manager gave permission in principle for the family carers to be approached. As a result, I had the opportunity to distribute research information packs to the family carers.

5.2.2 Choice of Venue

Each participant was given an opportunity to choose for the interview to take place in their home or at the University of Portsmouth premises. Three semi-structured interviews were conducted at my University, either within the School of Health Sciences and Social Work and University Library, for which we sought permission to use secure and private interview rooms. The remaining three interviews were conducted at the participants' own homes.

5.2.3 Building a rapport with participants

Evidence shows that building a rapport with participants is often stated as an essential part of the qualitative research interview method (Bogdan & Biklen, 1998; Clarke, 2006). Establishing a culture of trust and building a good rapport between myself and the research participants was crucial for collecting culturally sensitive data as well as for facilitating an accurate assessment of the data (Papadopoulos, Tilki, & Lees, 2004; Spring et al., 2003). Keeping this in mind, from the beginning of this study I developed strategies for doing this. Traditionally, when visiting a Bangladeshi family, it is customary to bring at least a box of sweets and fruits. Therefore, whenever I visited a family carer's house to conduct an interview, I brought

chocolates and fruits for the carer's family. It is also a custom within the Bangladeshi culture to offer a rice meal to anyone who visits a Bangladeshi family or at least tea and snacks (Jennings, Thompson, Merrell, Bogin, & Heinrich, 2014). Hence, I was also served tea and snacks during the interview and offered a rice meal later. My cultural knowledge, sensitivity, and ability to exhibit culturally appropriate behaviour helped build a bridge of trust between me and the participants (Liamputtong, 2010). In addition, interviewing participants in their homes provided me with many advantages; specifically, I could gain implicit knowledge and understanding of the family carer's living context. I was also introduced to other family members. During one of the interviews, I was introduced to a family carer's mother who had dementia and sat next to the family carer quietly for half of the interview. The openness between myself and the participants helped to develop an environment of trust which was an invaluable experience for me.

5.3 Inclusion criteria for semi-structured interviews

Following the research ethics committee's approval, participants were selected according to the following inclusion criteria:

- Being of Bangladeshi origin or British-born Bangladeshi adult family carers (minimum 18 years, with no upper age limit) who were caring for, or had cared for, Bangladeshi people with dementia.
- Having been a family carer for at least six months for a family member or a relative who was diagnosed with dementia.
- Having previously been a family carer for someone with dementia no longer than two years ago.
- Being able to provide written informed consent.
- Being able to take part in a semi-structured interview conducted either in Bengali, English, or a combination of both.

5.3.1 Exclusion criteria

- Not having been a regular family carer for at least six months.
- Having cared for someone longer than two years ago.
- Being unable to provide written informed consent.
- Being unable to take part in a semi-structured interview conducted in either Bengali, English, or a combination of both.

5.4 Data collection

Chapter Three provided an overview of the methodology and methods used for this study. That chapter outlined the general procedures that followed in one-to-one semi-structured interviews for this phase of the study.

5.4.1 Interview schedule

Informed by current literature, an interview schedule (Appendix I) was produced to incorporate findings from the qualitative research synthesis in phase one as well as from the outcome of phase two. The interview schedule was extensively peer reviewed five months prior to data collection. The interview schedule consisted of a series of topics that guided the interview process, but the sequence of topics, as well as areas where the participant was encouraged to introduce new topics, deviate, and provide context relevant to the purpose of the research study were not set. According to Robson (2002), closed questions, such as demographic and background questions, were asked first followed by factual or sensitive questions. Although a series of topics as well as a few prompts were provided, I was able to expand the topic questions with prompts to provide contextual information during the interviews, which allowed the participants to succinctly express their views (Mitchell & Jolley, 2007).

5.5 Data analysis

5.5.1 Thematic analysis procedure

To provide consistency, a thematic analysis was again chosen as the preferred method to analyse the findings from the one-to-one semi-structured interviews. The thematic analysis delivered an efficient component to the data analysis that extensively allowed me to understand the phenomenon under investigation.

Braun and Clarke's (2006) detailed step-by-step thematic analysis process has been discussed extensively in the previous chapter (see Chapter 4), but a once-over, from the Bangladeshi dementia family carers' viewpoint, is justified here. Braun & Clarke's thematic analysis follows six clear and detailed key stages. Figure 9 provides a detailed description of the specific steps taken during the data analysis. The thematic analysis process was recursive, rather than linear, and therefore, I regularly revisited to check and clarify the key stages. The thematic analysis allowed me to realise what phenomena prevailed in situation where Bangladeshi family carers provided care for people with dementia and a close examination of why this was the case.

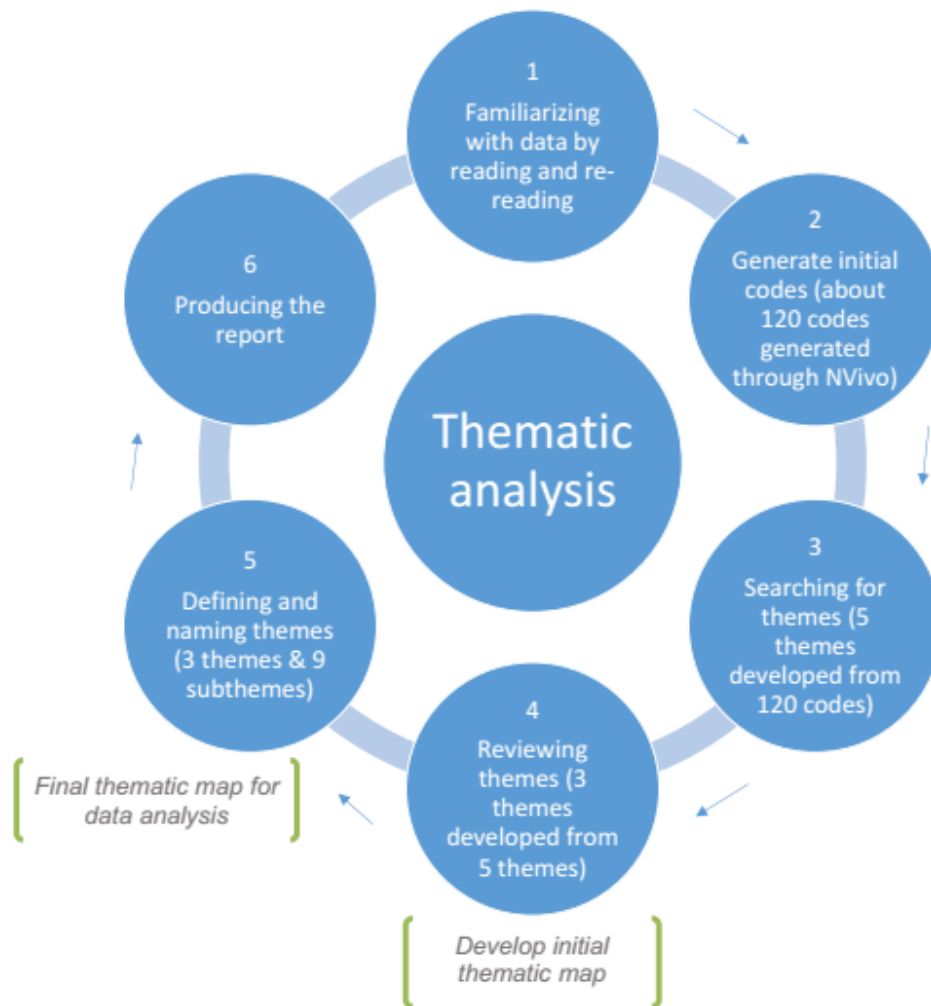


Figure 9 - Identifying themes via thematic analysis

Phase one: Familiarising yourself with the data

I collected verbal data by digitally recording individual interviews with two Dictaphones and subsequently produced transcripts using the NVivo 10 software. This was a key stage and it enabled me to become familiarised with the initial data collection process as well as become immersed in the entire data set (Bird, 2005; Braun & Clarke, 2006). As soon as the transcription and data familiarisation was accomplished, I commenced the thematic analysis process. At this stage, I actively read and re-read the transcripts, searching for interesting issues, values, concepts, repeated phrases, or patterns and making notes of any phenomena of interest that might inform the data analysis.

Phase two: Generating initial code

This phase involved going through the data line by line while noting all interesting words and phrases, through quotations and excerpts, to provide tentative meaning, or initial codes, which represented some brief summary of a fundamental element or elements in the data (Appendices N and O). NVivo software, I coded methodically through the whole data set, which confirmed accuracy, enhanced credibility, thoroughness, a full attention to detail in the data analysis process and, therefore, I produced a more broad representation of data for analysis than I would have by coding manually (Bazeley, 2007). After scrutiny, I identified an extended large number of codes: some 120 codes were generated along with their associated data excerpts. These codes succinctly conveyed the key messages in the data not only to me, but also to the readers without reading the full transcripts themselves (Braun & Clarke, 2014).

Phase three: Searching for themes

After the preliminary coding in the data stage and the subsequent examination of codes, I assembled all the relevant codes into potential themes, but only the preliminary themes that effectively described distinct aspects of the data. The NVivo software effortlessly assisted the reshuffle of codes into numerous groups based on likenesses which were pooled and provided a model of the themes and their corresponding codes and data. Also, as Braun and Clarke (2006) suggest, I did not abandon any irrelevant codes at this stage. Instead, I created a folder theme in NVivo called 'Miscellaneous' to store these codes, which were later discarded. At the completion of this phase, I established five main themes and 20 sub-themes altogether and organised them into an initial thematic map presented below in Figure 10.

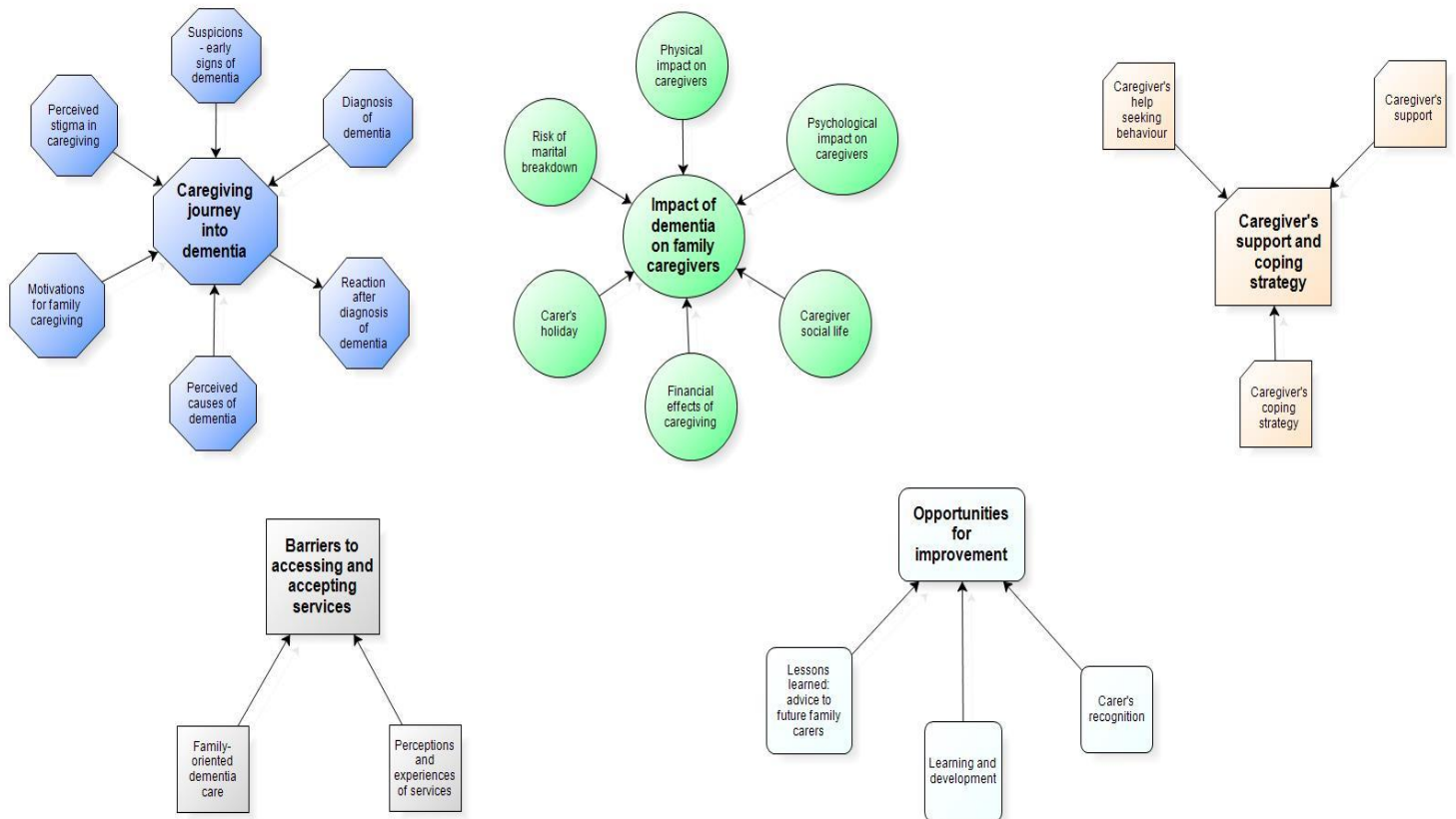


Figure 10 - Initial thematic map

Phase four: Reviewing themes

During this phase, I narrowed the set of initial themes to 'candidate themes': individually diverse themes which were noticeably distinct from each other. I began to review and refine themes through re-reading the whole data set, which included starting from the phase one data segment as well as re-examining the miscellaneous code folders in NVivo. According to Braun and Clarke (2006), reviewing themes ends after the thorough examination of themes and coded extracts, which results in generating a satisfactory 'candidate thematic map' of the data set. As a result, five themes were reduced to three themes and nine sub-themes were developed presented below in Figure 11.

Phase five: Defining and naming themes

This phase entailed developing the overall analysis process through defining and refining the themes. At this point, I assigned final names for each theme that were concise and easily understandable. Robust theme names succinctly apprehended the essence of each theme, and explicitly described the stories in each theme with compelling data quotations. Subsequently, three themes and subthemes were defined and refined to design a complete

narrative for analysis. A final thematic map with the main themes and several sub-themes was developed and represented in Figure 11. The main themes defined were: (1) the journey into dementia family caregiving (2) the impact of dementia on family carers; and (3) dementia family carers help and support.

Phase six: Producing the report

Finally, in the last phase, the absolute set of themes and thematic map were written up in a report in a coherent, convincing, interesting, logical, and argumentative way. Writing up the report was not only a simply descriptive process, but it delivered a thorough analysis of the significant features of the unique theme exemplified by selected, or illustrative, quotations as well as linking findings with existing works.

5.6 Findings

5.6.1 Demographic profiles of the family carers

This section provides a brief outline of the family carers who were interviewed as part of this research study. Table 8 provides an overview of each participant's biographical details including their gender, age, education, occupation, marital status, and last but not least their relationship to the person with dementia. The family carers were given unique study code numbers to protect their anonymity.

Table 8 - Demographic profile of the family carers

Family carer code number	Age	Gender	Relationship to the PWD	Length of time family caregiving	Birthplace	Education	Occupation	Marital status	Location
Family Carer #1	55	Male	Son – Mother	2	Bangladesh	Intermediate Equivalent to A Level	Business (Retired)	Married	Portsmouth
Family Carer #2	34	Female	Daughter – Mother	20	Bangladesh	NVQ in Business Studies	Not Working	Separated	London
Family Carer #3	64	Female	Spouse – Husband	10	Bangladesh	Primary Level	Not Working	Married	London
Family Carer #4	23	Female	Daughter – Father	6	England	University Undergrad	Student + Part time Shop Assistant	Single	Portsmouth
Family Carer #5	37	Male	Son - Father	6	England	HND Business	Part Time, Indian Restaurant	Married	Portsmouth
Bereaved Family Carer	52	Male	Son – Mother	7	Bangladesh	Honours Degree	Taxi Driver	Married	Portsmouth

A total of six Bangladeshi family carers participated in the study and they lived either in Portsmouth or London and were caring for a family member with dementia. Half of the participants were female and half were male. Their age range was from 23 to 64 years, with a mean age of 44.16 years. All family carers lived with and reported providing care to a family member with dementia. Between them, two female family carers, a daughter and wife, lived in London and provided care for their mother and husband, respectively. Of the Portsmouth family carers, three were male and one was female. The latter was the youngest family carer in our sample, caring for her father with dementia. All males were non-spouse family carers, looking after their elderly parents with dementia. Out of six family carers, four were born in Bangladesh and two were born in England. The number of people with dementia in this research was six, three females and three males. The mean age of the people diagnosed with dementia was 75.33 years old. The youngest person with dementia in our sample was a 64 year old woman who was diagnosed with dementia at the age of 63.

5.7 Emergent themes

The family carers frankly discussed their caregiving experiences for their family members with dementia. Their caregiving experiences consisted of day-to-day caring responsibilities. In many respects, these seemed to be dominated by a daily round of caring responsibilities and related household tasks.

Figure 11 displays the three major themes identified relating to the family carers' experiences of dementia. These were:

- The journey into dementia family caregiving
- The impact of dementia on family carers
- Dementia family carers help and support

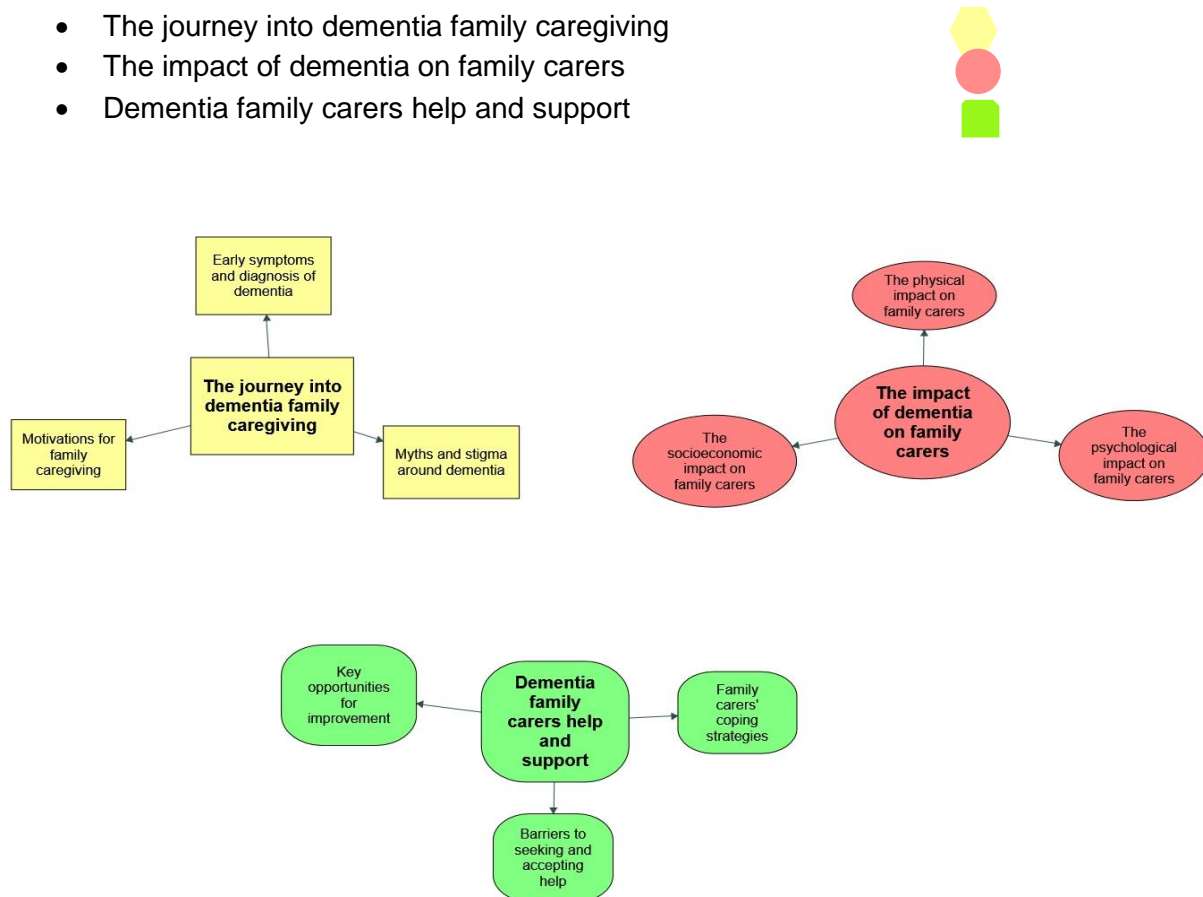


Figure 11 - Final thematic map: major themes and sub-themes

In the context of the above thematic map, each main theme has a number of distinct sub themes, and they will now be discussed below in more detail.

5.7.1 Main theme one: The journey into dementia family caregiving

The diagnosis of dementia made the participants learn a new way of providing care, which was continuous with their early family caring role. The first main theme, the journey into dementia caregiving, comprises of three sub-themes: (1) early symptoms and diagnosis of

dementia, (2) myths and stigma around dementia, and (3) motivations for family caregiving. These themes revealed the Bangladeshi family caregiving experience in the journey through the development of knowledge and understanding of potential dementia symptoms, getting the diagnosis, and providing appropriate care.

5.7.1.1 Sub-theme one: Early symptoms and diagnosis of dementia

The early recognition of symptoms and diagnosis of dementia was vital for gaining knowledge as well as seeking help and support. However, the majority of family carers reported that it had taken a long period of time to familiarise themselves with the early symptoms of dementia. Eventually, all the family carers appeared to have recognised the premature symptoms of dementia that were initially perceived as unusual or inexplicable personality changes. However, not every family carer immediately sought help for their family member during this early stage of developing dementia. Two of the six family carers waited up to 10 years to seek help and learn about dementia as their family members' displayed potential dementia symptoms. The minimum time spent to detect potential changes and symptoms of dementia is up to three months (see Table 9).

Table 9 – Family carers' time to recognise the symptoms of dementia

Family Carer	Time to detect dementia
Carer #1	Up to 8 years
Carer #2	Up to 10 years
Carer #3	Up to 2 years
Carer #4	Up to 1 year
Carer #5	Up to 2 years
Bereaved Carer	Up to 3 months

Between the two-family carers who took almost 10 years to detect the signs of dementia, the first family carer was previously looking after her father, and now currently her mother, with dementia. Her father died from dementia, but he was never diagnosed. She acknowledged it was hard to pinpoint when her father first showed potential dementia symptoms as it was continuing for a long time until he died. In many occasions, she contacted her GP, however, her Bangladeshi doctor repeatedly dismissed her concern for her father and suggested that it was nothing serious but only signs of getting old. The second family carer mentioned that back in 2006, there was no awareness of dementia like we have today.

With my dad, I didn't realise. Because he had never been diagnosed with dementia. So, when we went to [our] GP, he said it was because of my father's old age. He didn't say anything about dementia. We didn't know what to do with him. We thought you know he's gone and became like a child. I became his mother. (Family Carer #2, 34 years)

However, she had a positive experience with her new GP for her mother's diagnosis of dementia in 2012.

It's the little things it started off [with], like she used to muddle up with her medication. My mum took insulin. Instead of 15 minutes she took 45 minutes quite a few times and ended up in [the] A&E to save her life. I still didn't know why she was muddling up with her medicine in such a dangerous way. She also got her prayers muddled up. Those things I told my GP and [the] GP gave me the referral for my mom. In the hospital, we had her dementia assessment done and since then she was diagnosed and living with dementia. (Family Carer #2, 34 years)

She expressed her resentment, as she did not know the cause of her father's death, however, she was relieved when her mother was diagnosed with dementia with the same symptoms her father had gone through without receiving any help. As her mother was diagnosed for dementia with the same symptoms, although at that time it was unknown, now she believes that her father died from dementia.

In a similar manner to Family Carer #2 above, Family Carer #3's husband's dementia symptoms were dismissed by GP and they were unable to get a diagnosis.

[During the] first two years we didn't know it was dementia. He used to cry all the time. [The] doctor asked: did he have anyone back in Bangladesh? He had his brother in Bangladesh, and [the] doctor said he might [be] cry[ing] for his brother. [The] doctor could not find out what was the reason for his problem. [The] doctor asked me many questions, e.g., did he have any quarrels with me or any other family members? (Family Carer #3, 64 years)

Family Carer #3 went on to say that her husband's symptoms were increasing day by day and after a few months he developed uncontrollable urinary incontinence. However, again, the doctor was reluctant to refer him for a dementia diagnosis. Instead, the doctor suggested that his symptoms were due to the natural causes of ageing.

After living with potential dementia symptoms for one year, he was having difficulties with urinating. Suddenly he began to urinate unexpectedly and unconsciously. [The] doctor said [that] men normally suffered from urinating in old age. (Family Carer #3, 64 years).

She did not discover that those symptoms could be possible signs of dementia until she met a dementia adviser from the Alzheimer Society at an event.

I attended a dementia event and met Mrs X, [a] dementia support worker from [the] Alzheimer's Society. She introduced me [to] a nurse and said they would come to visit my husband. Then Mrs X, [the] nurse, a social worker, and a doctor came to see my husband. [The] doctor said they would need to take him to the hospital for [a] brain CT scanning. So, they took him to the hospital for [a] CT scan. After reading [the] CT scan result, [the] doctor said [that] he was suffering from dementia. (Family Carer #3, 64 years)

However, the remaining four family carers had a positive experience with dementia diagnosis and referrals, although not without similar difficulties in recognizing the potential symptoms of dementia. The other male family carer had to wait for eight years, the second longest time, to get a diagnosis of his mother's dementia. Her admission to the hospital was not due to her early signs of dementia, but because of severe eczema in her legs. Her diagnosis of dementia occurred only after her hospital admission for an acute medical problem. During her treatment for severe eczema, the doctor confirmed that she had dementia.

She had another physical problem, a bad case of eczema all over her legs. I took her to the QA hospital and the doctors said she had dementia. (Family Carer #1, 55 years)

Another family carer described his early suspicion that his father may have had dementia when he began to show speech or language impairment.

I first realised his speech was not correct. When I asked him [a] question about anything he [would] tell me [a] different thing. He was not like this before and that's when I thought something was not right. Sometimes I saw [that] he [was] acting like he [was] drinking tea but there [would be] no cup of tea. He [did] that for quite a long time, about two years. Obviously, I [went] to the doctor and we told him all the problems. They said he [had] dementia. (Family Carer #5, 37 years)

The early signs of dementia noticed were not solely restricted to memory problems, but physical or other kinds of cognitive and communicative problems, such as confusion or personality changes. The family carers' observations of unusual factors that could be potential early clues of dementia in their family members varied significantly. The family carers' statements confirmed their lack of knowledge of dementia and that their family member's admission to the hospital was not due to memory loss, but for other major physical issues, and that the doctor subsequently ascertained that the underlying cause was dementia. Another participant explained that his mother was suffering from hallucinations and delusions, which led him to speak to his colleague for help. The family carer then immediately booked an appointment with a specialist, which resulted in the shortest possible period for a diagnosis of dementia identified in this research.

I noticed she talk[ed] to [the] television even [when the] TV [was] switched off. My sister was in Bangladesh, but she said that her daughter [was] calling to go to her house. So, I thought 'what's wrong?' After a chat with my colleague, I went to [the] doctor. [The]

doctor did [a] CT scan and said [that] she was suffering from dementia. (Bereaved Family Carer, 52 years)

Each family carer experienced critical points with their caring journey for people with dementia, but their involvements were different in each case. Particularly, identifying the potential dementia symptoms and the process of diagnosis were crucial for a good beginning of their caring journey, rather than living with uncertainty. However, the process of diagnosis did not always begin speedily for each of these family carers after a visit to the GP or by consultation with a colleague or another immediate family member. The majority of the family carers acknowledged that they had no prior knowledge of dementia, with four out of six of them stating that they had never heard of dementia before their loved ones' diagnoses.

It is clear from the findings that even after the diagnosis, the family carers did not automatically believe the doctors. Four family carers had no prior knowledge of dementia before their relatives' diagnosis and initially two of them did not accept it. Prior to the diagnosis, the family carers often experienced changes in their relatives' behaviour, including fluctuations in their ability to perform everyday activities, where symptoms became less steady and severe with time.

First, we did not believe the doctor when they said he [had] dementia. First, we thought, what is this disease dementia and why would he get dementia? But later we asked the doctor a lot of questions. Then the doctor explained to us what dementia is. (Family Carer #3, 64 years)

When the doctors confirmed the diagnosis of dementia, the family carers stated that they learned more about dementia themselves with the aid of the internet, as well as by reading books about dementia.

I wanted to find out more about dementia and I did the research myself. I looked into [the] internet, [the] NHS website, to know how dementia affects somebody, what is [the] cure, and how to care for [a] dementia patient. (Family Carer #5, 37 years)

One family carer explained how believing the doctor came as a relief. She was apprehensive and upset about her mother's strange behaviour and new symptoms, but she outlined how gaining more knowledge about the factors associated with dementia alleviated her turmoil and distress.

I did believe the doctor. I was very upset; I didn't know what to do. But it was a relief for me. Because my father died with confusion and now my mom is going through this. At least then I knew what was wrong with my mom as well as my dad. (Family Carer #2, 34 years)

In two out of six cases, a diagnosis of dementia came as a shock to the family carer's immediate family as well as to the extended family members. This involved the family carer

explaining the process of diagnosis and the term 'dementia' to other family members, which created additional pressure for them. One family carer became very anxious after learning that her husband had dementia. She and her children thought that dementia was a life-threatening contagious disease, and all the children suggested that she should go back to Bangladesh and stay there for the remainder of his life.

My children asked me whether I wanted to go back to Bangladesh as a result of his dementia disease. First, we thought we would go back to Bangladesh because dementia might be a dangerous disease and we could not cope with it. Then [the] doctors told us not to worry, they gave us knowledge about dementia. (Family Carer #3, 64 years)

5.7.1.2 Sub-theme two: Myths and stigma around dementia

In this current study, I explored the myths of ageing and the misconceptions about the causes of dementia that accompanied the Bangladeshi family carers' understanding of dementia. Numerous physical and mental illnesses have been attributed by the family carers as possible causes of dementia, e.g., diabetes, depression, and stress.

She has been suffering from diabetes [for the] last 24 years, and [for the] last 3/4 years [she has been] suffering from dementia. So, mom has got dementia [due to] her diabetes. You know she got depressed after my father died and [the] depression caused her to suffer from dementia as well. (Family Carer #2, 34 years)

When asked, one of the family carers interviewed was reluctant to answer the question about the perceived causes of his mother's dementia.

Now it's a very difficult question. But [the] doctor said some parts of her brain cells have been damaged. [The] doctor also said that dementia ... develops slowly. This is what happened to my mother. (Family Carer #1, 55 years)

Nonetheless, agreeing with the doctor's above explanation about his mother's dementia condition, Family Carer #1 went on to say that the symptoms of dementia are perceived differently in the Bangladeshi community and rejected the myths that dementia was a common part of ageing and loneliness.

I think it is wrong when people say 'loneliness is the cause of dementia'. She is used to live with a large family and there is no space for loneliness. (Family Carer #1, 55 years)

When asked, all the participants also strongly denied the myths and misconceptions that dementia was caused by *karma* (bad deeds) or because of a person's previous sins. Instead, one participant believed that her husband's dementia was caused and given by Allah (God)

as a mercy. According to her religious faith, her husband's dementia, as well as any other health and illnesses, and every success in life, was because of Allah.

Researcher: *Do you think that someone is suffering from dementia because he or she has done some sins in his or her past life and that is why he or she is now suffering from dementia in his or her old ages?*

Text box 5 - Interview question

No, I don't think so. Allah gives disease, everything happens if Allah wishes. Every disease, every suffering comes from Allah. Allah gives disease, Allah cures, we cannot say anything baba (son). (Family Carer #3, 64 years)

The findings of this current research have provided some evidence to suggest that Bangladeshi family carers plus the wider Bangladeshi community harboured no stigmas and resentments for dementia as well as for the people with dementia. Family carers did not experience any noticeable stigma after the diagnosis of dementia or along their caring journey, although family carers were merely incapable of providing religiously appropriate care for their loved ones, such as same-sex care.

No stigma, there is no stigma. Why should I feel embarrassed? My mother is suffering from dementia and I am looking after her. I don't know is there any stigma related to our relationship. (Family Carer #1, 55 years)

Family carers also emphasised that dementia could happen to anyone. Extended family members as well as the Bangladeshi community members were compassionate toward the family carers and the care recipients.

Oh, I see what you mean. No, no one says a bad thing about his dementia. I never heard of it. Because everyone knows that it can happen to anyone. Instead they are sympathetic toward my dad. (Family Carer #5, 37 years)

Most of the family carers (five out of six) used the word 'sympathise', when asked about the community members' attitude toward the family carers as well as toward the persons with dementia. This following family carer mentioned that her neighbour sometimes cooked food for the person with dementia.

Our neighbours (Bangladeshi) are very kind. Sometime they send food for him, for all of us. They always ask about him, always sympathise toward us. Although some people do not know what dementia is but still they don't see this disease with stigma. Because they know anybody can suffer from any disease. (Family Carer #3, 64 years)

Although the above family carer assumed there was no stigma within the Bangladeshi community, in the end they also stressed uncertainty about the future generation's perception of the stigma of dementia.

As far as I can think, I don't think there is any stigma within our community. I don't know what will happen in the future with this current generation. (Family Carer #1, 55 years)

Two out of six family carers interviewed described that the lack of knowledge about dementia among the Bangladeshi community members led them to suspect that the person with dementia was merely suffering from an unknown disease. Hence, they were sympathetic toward the person with dementia. The family carer below stated that there was no stigma before or after the diagnosis of both her parents' dementia, but she experienced persistent fear before her mother's diagnosis of dementia. She did not have any prior knowledge about dementia. However, she was not frightened anymore after the doctor confirmed her mother's dementia condition.

I don't feel ashamed. I have never spoken to anyone who showed any kind of stigma toward me or my mom. The thing is people don't know what it is. They only know that my mom is ill. So, they just give my mom sympathy, that's it. (Family Carer #2, 34 years)

The other family carer said that some individuals were unable to notice any changes to her father with dementia by his exterior behaviour and appearance. Hence, they presumed that there was nothing wrong with him and doubted about the diagnosis of his dementia.

Some do not believe he has dementia. Some people came to see my father after he was diagnosed with dementia. They said "Oh but he looks perfectly fine, he's dressed up fine, and he's eating fine" so what's the problem? (Family Carer #4, 23 years)

This research explores an important finding for the first time among the Bangladeshi community from the perspective of myths and stigma around dementia and arranged marriage. It is worth mentioning again that the only family carer in our sample who was 64 years old was a woman, a mother of eight children, three sons and five daughters. I was particularly interested to find out if there were any arranged marriage issues regarding their father's dementia problems in the family. She explained that her husband's diagnosis of dementia took place in the middle of her daughters' marriage ceremonies. Two daughters were married before his dementia diagnosis and the other three daughters' weddings happened after his dementia diagnosis. However, there were no stigmas associated with their father's condition of dementia among the newlyweds' families.

His two daughters got married before he [was] diagnosed with dementia and three daughters got married after he [was] diagnosed with dementia. No stigma, there was no such problem for arranging their marriages. (Family Carer #3, 64 years)

5.7.1.3 Sub-theme three: Motivations for family caregiving

Family carers have supplied care to their older loved ones before and after developing dementia, although not without experiencing physical and emotional burdens and strains. This theme investigates what motivated Bangladeshi family carers to provide long-term dementia care for their relatives. The motivation behind the dementia caring journey had been influenced by many factors. The findings reveal a number of distinct motivations behind providing dementia care for their relatives (Figure 12). Caregiving motives which place more emphasis on the family carers' emotional state regarding their interpersonal connections with the care recipients were more widespread than motives stemming from feelings of filial piety, or cultural and religious obligations. The data confirmed two distinct but overlapping categories that notably articulated the family carers' motives to care for their relatives with dementia. One category was of family carers with interpersonal motives and the other was of family carers with motives that reflect filial, cultural and religious obligations. The latter category consisted of familial carers, such as a son or daughter looking after their father or mother with dementia, the former category consisted of a strong bond and an enduring close attachment between the family carers and care recipients.

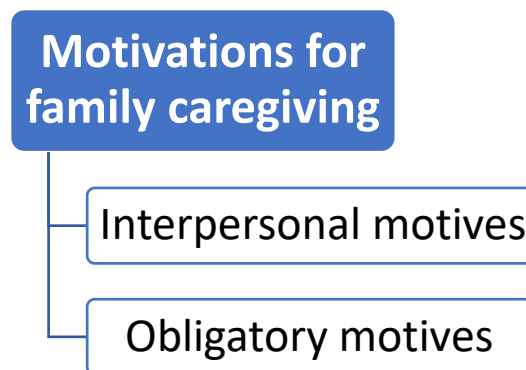


Figure 12 - Key motivators in family caregiving

Interpersonal motives

The findings suggested that the family carer's personal commitment and their interpersonal motives primarily influenced them to provide care for their relatives with dementia. Interpersonal motives are constructed on a strong and close relationship between family carers and their care recipients with dementia. The findings examined the aspects of relationship quality among the family carers, such as intimacy and attachment, in father-son or mother-daughter relationships. Family carers describe that providing care for their relatives with dementia was an automatic visceral response and it was a purely discretionary decision. No significant differences in the closeness of the relationship were found between son and

daughter carers. However, family carers also stated that their caring responsibilities were enhanced by the positive relationship they had with the persons with dementia before their diagnosis. The family carers' motives focused on the unique characteristics of their care recipient. Thus, their parent or spouse came first as a person rather than because of their religion and culture.

It depends on how close their relationships [are] with the person with dementia. Because I was very close to my father, maybe another person would not be that close or feel for him to look after him. (Family Carer #5, 37 years)

Family carers also ruled out the cultural and religious connotations behind giving care toward their relatives with dementia. The majority of the family carers (five out of six) described that their caregiving commitment was generated voluntarily from their personal attachment with their relatives with dementia. Two family carers expressed that their personal interests toward caregiving helped them to become a better person as well as to attain their personal fulfilment.

Culture and religion can't help if I don't want to do it. I think it is something [to do with] who I am. This is something I did for my father. This is something I would love to do for my mom. This is [the] kind of person I am. It's made me a better person actually. I don't know anything else. (Family Carer #2, 34 years)

Family carers rejected the traditional religious and cultural values and instead believed in their moral values and interpersonal relationships with the person with dementia. The moral obligation that derived from empathy, kindness, showing compassion, and endurance was perceived to be enough to provide care for their relatives with dementia outside their religious values. Three family carers expressed that their caregiving motives were deeply concerned with their relatives' well-being without giving more importance to their religion alone.

I am not worried about getting [a] reward from Allah at the moment. Religion, culture, and anything else come at later stages. I was worried about my mom as my first priority. I had to leave my good job for my mother and everything else comes second, third, and fourth. (Bereaved Family Carer, 52 years)

Obligatory motives

Followed by interpersonal motives, the findings also revealed obligatory motives. Despite the fact that caregiving is hard and demanding work, the tradition of showing respect and caring for the elderly is deeply rooted in Bangladeshi families. Some family carers believe that care is a filial obligation because their parents gave them life, and provided them help and support when they were very young and helpless. It was their time now to repay them and they did not have any other option other than providing care to them.

The thing is when I was young my mother and father looked after me. They [brought] me into this world and they looked after [everything] for me. Now this is our time to do something for them in return by providing them enough support when they need us. (Family Carer #5, 37 years)

Another family carer, a wife, described that her role as a carer would be sustained until the day she had died, which was a result of the pledge and vow she and her husband agreed to when they were first married. Even as a 64-year-old carer, her health was deteriorating day by day, she further emphasised that her caregiving motives were not only restricted to her immediate family members, but were also felt toward her neighbours. On the other hand, a few mixed motives also emerged from her interview, including personal relationship, moral obligations, and cultural and religious obligations. Her cultural and religious beliefs also significantly supported her caring role as a lifelong reward and she believed that a reward would be given hereafter.

Now the relationship we have created for many years, the knot we tied so many years ago, we cannot break that [with] whatever suffering we are going through. As long as Allah gives me [the] ability, I will look after my husband. If we have [the] teaching of our Allah and Prophet, then we will protect our relationship knot despite this dementia suffering. I will receive [a] reward from Allah if I do this. I have to look after my family, if I can, then I will look after my neighbours. I am helping others because Allah told us to help others. (Family Carer #3, 64 years)

However, some family carers (2 out of 6) found this sense of ‘cultural and religious obligation’ difficult to deal with. One family carer suggested that cultural and religious obligations have a profound negative impact on the Bangladeshi society, hence, he was morally obligated to provide care for his mother.

This is a major problem in our culture. This is one kind of major obligation to look after older people with dementia in our culture. I could send her back to Bangladesh but I [would] not have peace in mind. (Family Carer #1, 55 years)

It is undeniable that family carers from traditional Bangladeshi families held strong religious and cultural values in regard to providing care for people with dementia. The above two-family carers’ statements, however, seem to reflect the influence of Westernisation and acculturation in England. The younger generation of Bangladeshi communities may tend to reject their cultural and religious obligations to care. Nevertheless, in contrast to the above caring motives, five of the six family carers interviewed showed lower motivations to provide personal care for older people of the opposite sex with dementia. Family carers explained that providing intimate opposite sex care was inappropriate for both men and women. However, in this research, one wife providing intimate and personal caring tasks for her husband with dementia was uncomplicated and positively motivated.

5.7.2 Main theme two: The impact of dementia on family carers

This major theme emerged from the data examining family carers' physical, psychological, social, and financial impacts of delivering care for their family members with dementia. All six family carers were living and providing care for the people with dementia in their own homes. This theme covers the Bangladeshi family carers' indescribably difficult and unpleasant experiences concerning the overwhelming preponderance of physical, emotional, and socio-economic burdens in their caring journeys. It is worthy to note that the manifestation and implication of burden and stress varied according to the family carer's age, gender, and marital status in this research.

5.7.2.1 Sub-theme one: The physical impact on family carers

This theme explores the finding that providing care for a person with dementia had a powerful impact on the family carer's physical health. Family carers described that as the person's condition deteriorated, they required constant care that was both physically demanding and challenging. Interestingly, five out of six family carers stated that caring for people with dementia took more effort than looking after a new born baby.

Sometime she thinks she is in pain, you know, I don't know. So those days would be really miserable. It's like having a baby, looking after a baby. That you have to change her nappies, feed her, you know you need to do everything for her. That is what physically becomes very difficult. (Family Carer #2, 34 years)

The family carers described that they constantly needed to be with their relatives with dementia, and that their lives became a lot more restrictive as a result. The participants described their typical days of caring as tremendously busy, involving difficult and simultaneous tasks, full of fatigue and worry. During the interview, one female family carer emphasised the difficulties of dealing with her husband's incontinence and managing his personal hygiene on a daily basis.

Every day three times at least I have to clean him. He cannot say when he needs to go for toilet. [From] time to time I check on him if he needs to go [to the] toilet. So, in 24 hours I have to clean him two or three times. I have to clean everything, including his clothes, bedsit, carpet, etc. He is heavy; I cannot move him alone sometimes. This is the main problem. (Family Carer #3, 64 years)

Three of the six family carers interviewed, with an average age of 57.33 (range 52–64), were suffering from various health issues themselves and lacked the physical strength to continue their caring duties. Family carers stated that their relatives with dementia required heavy care that involved lifting and physical care, which resulted in strain and physical injury for two female family carers. The 64-year-old wife, as quoted above, genuinely wanted to provide care

for the person with whom she shared her entire life. Although she was not suffering from dementia, she was ageing at the same time as well as lacking the physical strength to provide care. In addition, a male family carer described that his physical condition was deteriorating by providing care for his mother with dementia.

I have many health problems. I have diabetes, cholesterol, and high blood pressure, This increased for my heavy caring duties for my mother. (Family Carer #1, 55 years)

The family carers reported that because they were carers, they did not get enough sleep during nights. Night time disturbances were common among the persons with dementia and the family carers had to stay awake with them. One male family carer said that his mother's sleeping bed was next to his bed where he slept with his wife, so that he could keep his eye on her. Sleep deprivation left family carers feeling exhausted and one family carer was given sleeping pills by her doctors. However, she did not want to take sleeping pills in case anything happened to her husband while she was asleep.

Doctors always give me sleeping pills because I cannot sleep. But I do not take sleeping pills. If I take sleeping pills that will not help my husband's problem. If I fall asleep at night [and] he falls or has another problem, who will look after him? (Family Carer #3, 64 years)

5.7.2.2 Sub-theme two: The psychological impact on family carers

This sub-theme describes the Bangladeshi family carers' psychological impact of caring for their family members with dementia. This sub-theme also highlights how the family carers maintained their lives and continued their caring journey despite the emotional strain. The family carers' emotional effects of caring for their family members with dementia were discovered in the findings, which also underlined the family carers' substantial need for support to deal with the psychological impacts. At times, people with dementia suffer from forgetfulness, confusion, agitation, loss of personality, and the inability to recognise members of the family. The family carers described that as their family members' dementia progressed from mild to moderate to severe, they slowly experienced losing the persons they cared for, which had a devastating psychological impact and placed an enormous strain on the family carers.

Two family carers described how they lost their relatives through dementia. The parent in past times was the head of the family; they once provided the proper family protection and were the principal sources of emotional support for family carers. Now their roles have been reversed. One family carer explained that by providing physical and psychological support, she became the mother of her mother with dementia.

Which really upsets me, you know, as a daughter, because this is the person I used to seek for my comfort. And that person is not there anymore, I lost that person. When you [have a] problem, you go and tell your mom, but we can't do it anymore. Because our mom doesn't understand, our real mom, the person herself is not there anymore. She is a very different person now. (Family Carer #2, 34 years)

However, one of the six family carers reported adopting a more practical, rather than emotional, approach in their role as a carer. Specifically, this individual was more likely to deny or cover up any emotional or psychological issues; however, this approach did not necessarily imply that she lacked interest in caring for her father, who had dementia. Rather, she seemed manage her emotions, which reportedly helped her cope with her father's condition.

Umm... (long silence) I don't know, I'm OK with it. I had to deal with it, I am not an emotional person. I am not sure about my other family members. I know some people find it kind of heart breaking to see him like that. But I mean, I don't know, I don't get anything like that. (Family Carer #4, 23 years)

Family carers who delivered long hours of care continuously over a prolonged period of time had higher levels of stress. A spouse carer described her frustration because she was under tension and stress 24/7 due to looking after her husband.

Everyday it's a very difficult job 'baba re' (son)... morning to night. Tension, always tension day and night. (Family Carer #3, 64 years)

Moreover, the family carers were particularly concerned about the possibility of the persons with dementia getting lost or leaving the gas fire on in the kitchen. Of the six family carers interviewed, three family carers experienced that on multiple occasions: the person with dementia disappeared from the house when they found that the doors were open. As a result, the family carers were frustrated, and they had to be vigilant 24/7 in case the people with dementia got lost or ignited a fire in the kitchen.

We were worried for my mom because when we left the keys she [could] grab the keys easily. Then she would go out and [get] lost. And she leaves the gas cooker switch on pretending she is cooking. We're always worried, something [very bad] could happen. (Bereaved Family Carer, 52 years)

Although the agency carers used to come and do the cleaning tasks, five out of the six family carers interviewed stated that they had to stay with the person while the agency carer cleaned them. The family carers feared that due to lack of cultural knowledge, the agency worker would not clean the person in an appropriate way in line with the family carers' standards. This put greater pressure on the family carers. One family carer described that her father with dementia lost the ability to speak English after he was diagnosed with dementia and this caused her extra stress.

He used to speak English but after his dementia he can't speak English anymore. That's the main reason one of us has to be present with the carers. Because he gets really confused. I constantly explain to him that he is going to get turned or they're going to move him off the bed. I always have to translate to him whatever doctors or nurses said to him. (Family Carer #4, 23 years)

Another family carer described that the final stages of caregiving for his mother with dementia created a unique psychological challenge for him. His caring duties came to an end when his mother died. Losing a parent to dementia is always an excruciating experience for children. The death of the family carer's mother had a profound impact on his personal life. Following his mother's death, he underwent months of loneliness, depression, despair, grief, and mostly loss.

I was very much devastated by my mother's dementia condition. I thought [there was] no way I could cope with my mother's condition. I could not [watch] my mom go through dementia. When she was suffering from severe dementia and when she died, I was very depressed for 3 months. I could not do anything. (Bereaved Family Carer, 52 years)

The risks of marital breakdown

Three family carers were married with children, one of whom recently got married. All of the male family carers and their families lived in the same household as the care recipients with dementia.

We're newly married, I don't want to give her the burden of my father. Because she would think "What is going on? I have come to your house and now I have got all the burden from your family already." (Family Carer #5, 37 years)

My wife, she was working as well. That is the main reason I left the job, to care for my mom. (Bereaved Family Carer, 52 years)

Two of the three married male family carers of people with dementia had complex relationships with their wives. The male family carers felt uncertain about their future marital statuses and this led them to experience distress while they were performing their caring duties. The male family carers dreaded that excessive caring duties for the people with dementia would result in frustration and the inability to maintain their marital relationships with their wives. In addition, the lack of time the family carers had for themselves and their wives had severely affected their married lives. The family carers described their overwhelming caring duties and because of the lack of intimacy, their wives found it difficult to stay together with them. Consequently, two male family carers' marital relationships deteriorated over a period of time and they feared their marital breakdown.

Another thing I should tell you, my marriage was almost going to break. Because my wife was not happy, if you know what I mean. My wife was complaining that we're newly married but I don't spend any time with her. She wanted to go ...shopping with me and wanted to go [on] holidays. But I told her 'he is my dad I have to do this for him. When [the] carer comes I will take you ...shopping'. I explained to her and later she understood. I told her 'look my dad is not going to be with me forever but this time I have to do this for him'. (Family Carer #5, 37 years)

I sacrificed [a] lot of things for my mom, nobody else [is going to] do that. If [this] happened in English/European families, their marriages would break down. My marriage was almost going to break down. But because of our culture and [religious] background, my wife ...understood what was going on. But I don't know what will happen in the future in our community. (Bereaved Family Carer, 52 years)

The quotations above articulate that there was not only a lack of caring attitudes from the male carers' wives, but two wives felt threatened by their husbands' potential caring relationship with the person with dementia. Although the male family carers' enormous caring duties decreased, the scope for maintaining intimate husband-wife relationships did not limit the male family carers' from continuing their caring responsibilities for their relatives with dementia.

Stereotyping attitudes from service providers

The family carers experienced frustration and conflict with the staff from the local authority social services, which placed greater psychological strain on them. The stereotyping of particular ethnic minorities was perhaps the most significant factor that impacted the ability of Bangladeshi family carers to fully access health and social care services. Two family carers from London explained that the local authority's intentional discrimination and racism against them as Bangladeshis was the key reason for their negative attitude toward the healthcare services. One family carer expressed her frustration, anger, and fear as she had to contend with discriminatory and stereotyping attitudes from the benefit office staff members on a regular basis. The family carer felt that being a Bangladeshi ethnic minority who was in receipt of unemployment benefits, as well as living in supportive housing, contributed to the perspective that harsh judgements about her caring role were being made by the staff members at the local benefits agency office. At times, the family carer felt unsupported and unappreciated as the staff from the benefit office undermined her caregiving role for her mother with dementia.

Most benefit office staff don't know what dementia is. I told them I'm a 24 hour carer for my mother with dementia. You know the lady in the benefit office was so rude to me, she said "I don't care if you're a dementia carer". They also said "your mother got dementia, so what then?" They asked me what I am going to do when my mother has died. I'm so embarrassed, so upset. (Family Carer #2, 34 years)

Another family carer, who had been caring for her husband for an extended period of time, experienced similar stereotyping situations. She mentioned that she was dissatisfied and angry with how hospitals and councils reacted. This was not a one-off experience, but rather a record of several experiences.

[The] council gives pads to my husband. They asked me, everyday how many pads I used for my husband? I said four, then they said I used too many pads. I went mad after listening to that. What would I do with [the] pads if I [didn't] need them? If he is OK then I don't use more pads. Similarly, [the] hospital upsets me many times this way. Their behaviour I don't like, they are not treating us well. (Family Carer #3, 64 years)

However, half of the family carers interviewed in Portsmouth spoke highly of the service providers and the majority of family carers also appreciated the support delivered by hospital doctors and the reassurance they offered to family carers and to their relatives with dementia.

[The] doctors and [the] hospital, they are very good. They helped me so much. Because every time I took him to the hospital they helped me lot. Sometime we had to take him to [the] A&E and they sort of give him some saline, they keep [him for] one or two days and [then he] comes back home again. (Family Carer #5, 37 years)

5.7.2.3 Sub-theme three: The socioeconomic impact on family carers

There are substantial social and financial effects associated with providing care to a person with dementia. Many of the family carers interviewed described that their caring responsibilities restricted their social lives. Above all, perhaps predictably given the evidence that the Bangladeshi community has the highest rate of poverty among all other ethnic minorities in the UK, the findings from this research reveal that the majority of the family carers were worse off due to the strain of their financial circumstances. These effects are interrelated, such as economic adversity, which circumscribed the family carers' social activities.

It has totally gone. I had a very good life. I have [a] lot of good friends, we used to go out, get together, have [a] laugh. But since my mother got dementia, it has totally disappeared. I had to leave my decent job, good friends, and social networking, everything. Because you cannot replace your mother, my mother was very important to me, [more] than anything else. (Bereaved Family Carer, 52 years)

Family carer's financial implication

Five out of six family carers interviewed stressed that they were more apprehensive due to their financial difficulties and social disadvantages. All but one of the family carers experienced unique employment challenges while trying to maintain a balance between their employment and full-time caregiving responsibilities. Two of the family carers had worked full-time up to two months before their relatives were diagnosed with dementia. One female family carer had

never had paid work. A male family carer left his well-paid job and became a taxi driver. Driving a taxi fitted around his caring role for his mother with dementia.

Money was [a] big problem for me. Because I had to leave my well-paid job. I used to earn over thirty-two thousand a year. I left my job for my mother's dementia and jumped into a taxi job. (Bereaved Family Carer, 52 years)

Two other family carers (one male and one female) reduced their hours of work because of their heavy caring responsibilities. For one female family carer, after leaving her job entirely, the family carer's benefit was her only source of independent income. However, the weekly benefit she received was not enough for her average household expenses and the extra costs her three children incurred. Therefore, she had to cut back on some expenditures as she was unable to meet her children's basic needs.

It's a struggle; I have to say. I only get [a] £60 weekly carer's benefit, which is not much. I have got three children, the bills and the expenses for the children. They need more things, they want to do more activities. Sometime I have to say no to them. I cannot afford that. So financially this not only affects me, [it] affects them too. (Family Carer #2, 34 years)

Although five family carers acknowledged the major financial strain that accompanied their caregiving responsibilities, one female family carer did not express any financial pressures due to her parents' financially solvent situation. Instead, financial stability gave them the freedom to purchase their own commodities.

We have no financial problems because my father suffers from dementia. If he needs incontinence pads and stuff like that we buy it because he uses different types. It has never been a problem. (Family Carer #4, 23 years)

5.7.3 Main theme three: Dementia family carers help and support

The previous themes explored the greatest challenges the family carers faced when caring for a family member with dementia. The current theme uncovers the state of the Bangladeshi family carers' caregiving support and help in relation to their service needs and barriers. This theme addresses the challenges Bangladeshi family carers face when accessing support and help. This section also explores in more detail the subjective and peripheral healthcare access barriers for family carers of people with dementia. The majority of the family carers interviewed in this research discussed their excruciating experiences with the people with dementia and the practical challenges in dealing with psychological, physical, and financial factors which had a profound impact on their personal lives. However, among those family carers interviewed, most of them were hesitant to seek help and support for their caregiving roles. In light of the data that emerged from the six family carers' interviews focusing on their support

needs and barriers, three sub-themes developed from this broad theme. Although all of the sub-themes are interrelated under this broad theme, they are presented as three unique and consistent categories below.

5.7.3.1 Sub-theme one: Family carers' coping strategies

The findings reveal that the family carers used a variety of strategies to cope with their day-to-day crises while caring for people with dementia. According to Lazarus & Folkman (1984), the coping mechanisms adopted by the family carers can be conceptualised into two major categories: problem-focused coping strategies and emotion-focused coping strategies. Problem-focused coping strategies are defined as those approaches in which the family carers become involved to alter the relationship between themselves, the people with dementia, the care settings, and the stressors (Lazarus & Folkman, 1984). Emotion-focused coping strategies involve reducing and managing the level of emotional distress experienced by the family carers rather than solving the problematic situation or the source of stress (Carver, Scheier, & Weintraub, 1989). This theme explores the notion that male family carers more frequently used problem-focused coping strategies, such as acceptance and confronting the problem, while seeking information, family, and social support. Female family carers more frequently used emotion-focused strategies, such as grieving, worrying, wishful thinking, prayers, counselling, and talking therapy. However, the family carers used a variety of specific coping strategies by using both problem-focused and emotion-focused strategies, sometimes at the same time and to different degrees. Prayers and wishful thinking as coping strategies were used by both the male and female family carers. Furthermore, the coping strategies differed according to the family carers' age, gender, and locations. Therefore, there was no clear consensus between the most effective strategies for male and female family carers. Nonetheless, the family carers who used both the problem focused and emotion focused approaches seemed to effectively manage their stressors.

This sub-theme focuses on the family carers' resilience and coping strategies, as well as their access to help. The earlier data showed that the family carers and family members took up to 10 years to recognise the potential dementia symptoms in their family members. In addition, this theme found that once their family members were diagnosed with dementia, the family carers did not look for services straight away. They coped and cared for the persons with dementia by themselves. The most utilised coping strategies among the family carers were communicating and seeking help from immediate family members, respite services, attending family carer support groups, religion and spirituality, self-counselling, and talking therapy. This research also found that the family carers' coping strategies were strongly associated with

their self-motivation, family commitment, and self-determination for their loved ones, and that it was solely their perseverance that helped them continue their demanding caring roles.

Table 10 - Coping factors and strategies

Coping factors	Coping strategy
Problem focused coping	Managing caring struggles by carers themselves
	Informal help seeking, for example seeking help from close family members, extended family members, friends, and neighbours
	Formal help seeking, for example seeking help from GPs, hospital doctors, social support workers, care agencies, and Alzheimer's society
Emotion focused coping	Holiday for both carers, and the people with dementia
	Prayers and reading
	Counselling, talking therapy, and sharing problems, frustrations, and rewards with other carers in the carers' support groups

Problem-focused coping strategies

This research found that the family carers' coping strategies were associated with their self-motivation, family commitment for their loved ones, and their perseverance, which helped them continue their demanding caring roles. The findings also confirmed that the family carers' determination to cope and provide care for the people with dementia was highly influenced by their interpersonal motives and moral commitments as well as by their filial obligations. In addition, the family carers' first priority was for the persons with dementia and they ignored their own health. Nonetheless, knowing that people with dementia have shortened life expectancies was another form of coping strategy among the family carers. The family carers continued their practical caring roles as they knew that they would not have to care for the person with dementia for a prolonged period.

[There is] no one to help me. I have to do this caring job and [cope] with stresses alone. Every day I wake up with the determination that I have to do it. Something I always remember [is] that I have to keep going, I have to do this anyhow. Because I know he's not going to be here very [long]. That's how I do it. (Family Carer #5, 37 years)

The help seeking behaviour of Bangladeshi family carers for people with dementia was fundamental to their coping strategies. The family carers talked about a diversity of help seeking resources, such as family (informal) and formal (GP, carers agency, social services, Alzheimer's Society) help seeking. Although the help seeking behaviour among the family

carers varied, there were some consistent trends. First, the family carers were more likely to seek help from their family members rather than healthcare services. However, regrettably for a majority of the family carers, care provision from family members was not always accessible or was not enough. Moreover, some family carers had concerns that their family members had their own difficulties to deal with and wished not to bother their close or extended family members. Ultimately, five of the family carers found it difficult to get the practical and emotional support and involvement they needed from their family members. Hence, the family carers either sought support from health and social care services or coped with stress on their own.

My brother and sister live in London. They [have] their own families. Maybe my brother could help me [in] more ways. But [they have] no time for my father. I did everything for my father from the beginning. They could share my caring job. I expected support from my family but I did not get that. (Family Carer #5, 37 years)

I have relatives [who] live nearby but I never asked [for] any help from them. They cannot help, they have their own problems. I know, I have to do my own suffering. [My] daughters helped before their marriages; now [they are] living with their husbands. (Family Carer #3, 64 years)

However, one London-based family carer described that in order to cope with the pressures of dementia caregiving, she relied heavily on her family members who were more than happy to share her caring responsibilities. The other family carers described their personal coping strategies and the community support services they utilised to help them cope with their caring roles. Indeed, the findings from this research sample show that filial obligation increased some of the family carers' burden and distress. Turning to family members for help may reflect the family carers' greater intimacy and understanding toward other family members. The findings on help seeking behaviour identifies that the need for social support goes beyond the traditional coping strategies, as this current research shows that only one out of the six family carers brought their problems to and received support from family members rather than social and community services.

I am quite lucky though because I have got an extended family. My other sisters would be happy to do it. You know we actually fight over our mom who wants to look after her. They jump in whenever I need them for help. If I get ill, my sister will come over and she will stay here to look after my mom. Also, if I am not in for an hour my elder son or my nephew [are] at home to take care my mom. (Family Carer #2, 34 years)

After experiencing the devastating psychological, physical, and socioeconomic impacts of dementia caregiving, one Portsmouth based family carer made his own caring arrangements to cope with his caring burden by paying for a carer himself. The male family carer had to set up home-based care arrangements with a combination of his own caring role and a paid care

worker for his father with dementia. The family carer used his father's personal budget and had to ask for money from his extended family members.

How can I explain to you? It is extremely hard for me. I have to go to work at 5 o'clock in the morning. I asked [a] caring agency for a carer to look after my dad while I go to work. So from 5 am to 9 am, a carer cares for him only for 3 days. But it was not enough at all. I had to get a carer, paying by myself, from 9 am to 11 am. So, we have a carer from 5 am till 9 am and then from 9 am till 11 am [for] 3 days every week. (Family Carer #5, 37 years)

Emotional coping strategies

Emotion-focused coping strategies were particularly sundry among the family carers. The family carers reported that their physical and emotional health was greatly affected by providing day-to-day care for their loved ones with dementia. Emotional support and taking a break from caregiving was intensely vital for the family carers to maintain their emotional and physical wellbeing. Therefore, wishful thinking was an effective emotional coping strategy the family carers considered, such as, taking a holiday themselves or taking the person with dementia with them.

I wish I could go somewhere for [a] few days, then my tension would go away. If I could take him on holiday with me somewhere to a beautiful place would be nice. Not [to an] other country, [there are] even many beautiful places in the UK I could take him. If he could visit Bangladesh, he would love to see that. He has not been to Bangladesh in the last 12 years. If [only the] government would help us to take him on any holiday or [to] Bangladesh! (Family Carer #3, 64 years)

The above family carer indicated that she was unable to receive caring support from her adult children and she did not have enough money for a holiday. In addition, the formal resources, such as the option of a residential respite care for the persons with dementia, were not deemed a priority among the Bangladeshi family carers. The family carer mentioned that she desperately wanted a holiday, but she did not want to send her husband to a residential care home while she was on holiday even for a few days.

While it was not for everybody, several of the interviewees had attended a local carer support group, and two-family carers described that this had been emotionally invaluable. Learning from peers provided a combination of empathy and insight into their mutual problems and encouraged the exchange of effective strategies for coping with the stresses entailed in the transition to the role of a family carer.

Mom and I both go there. People with dementia do activities there. As a carer, you get a break. You meet other carers. You can discuss with other carers about what they do

and how they are coping. You can ask for their advice as well and they are helpful. (Family Carer #2, 34 years)

Furthermore, four family carers from Portsmouth never attended a carer support group. One family carer commented that, although his GP told him about their meeting with all local carers, he could not attend because he was busy with his caring responsibilities.

The doctor said every Friday they meet with all the carers to share their experience. They invited me to attend their meeting but I didn't have time to go there, you know I was [too] busy. (Family Carer #5, 37 years)

The family carers differed in their sensitivity and vulnerability to emotional- and problem-focused patterns of coping, as well as in their interpretations and reactions. One family carer neither sought emotional support from family members nor from governmental services, and others often tackled the stress on their own. The findings reveal that there was a difference between female spousal carers and male adult child carers, who differed in their use of coping strategies. The research also found that the use of wishful thinking as an emotional coping strategy differed by the carers' age and gender. Thus, both age and gender examined in this sub-theme are important factors to investigate the relationship between coping strategies and carer outcomes.

I took him to Bangladesh for two weeks because he wanted to see everybody. It was a dream for him. His mom was about 100 years old. He was so happy to see her and others. Although it was a hard journey through the airports and on the planes, I made that possible for him. I feel good, I'm glad I did that for him. But the doctor said don't take him. (Family Carer #5, 37 years)

Religious beliefs and practices, as well as counselling by talking to friends and family members about their challenging caring experiences, were the most frequently mentioned coping strategies for the family carers, followed by sports, exercise, reading, and walking by the sea. One family carer used prayers and sought assurance from Allah as a coping mechanism, whereas another family carer mentioned that counselling and talking therapy helped him to cope with his caregiving stress.

My religion helps me to cope with my stress. I wasn't very religious before but now I practise my religion [more]. It helps me. (Family Carer #2, 34 years)

I really appreciate the talking therapy, psychological therapy. They are very good for relieving stress. I did talking therapies mostly with my wife and with some of my friends. (Bereaved Family Carer, 52 years)

Two family carers reported that the sea view and walks on the beach helped them reduce stress and had positive impacts on their physical wellbeing while coping with their caregiving responsibilities.

Sometimes, he makes me happy because when we do activities together, [we] spend quality time together. Like we go to Southsea and he likes [the] birds and [the] beach. And I keep chairs and some chips in the car. I walk by the sea. Sometimes we sit by the sea and eat chips. These little things I enjoy with him. (Family Carer #5, 37 years)

5.7.3.2 Sub-theme two: Barriers to seeking and accepting help

This sub-theme brings together the results from the previous sub-theme to observe what coping strategies were associated with the family carers' barriers to seek and accept help. The analysis considered the issues that were most important for the Bangladeshi family carers to seek and accept support and what negatively impacted their caregiving situations. The results revealed that seeking help was one of the most complex decisions the family carers made.

Family care management

There are some underlying issues that play a part in the underuse of healthcare services. The first issue was self-management as an essential means of providing care, which was partly responsible for the family carers' delay in seeking help. The family carers sought help when they could no longer cope by themselves or when the hospital doctors recommended and referred them to social workers for help. They began seeking help after a lengthy period of 2 to 10 years after the experiences of first strain, during which the family carers heavily relied on coping strategies that involved managing stress on their own. One of the six family carers actively managed by herself for 10 continuous years without receiving any help.

Table 11 - Time to managing family care by themselves

Family Carer	Time to managing by themselves
Carer #1, Son-Mother	Up to 2 years
Carer #2, Daughter-Mother	Up to 10 years (continued)
Carer #3, Wife	Up to 2 years
Carer #4, Daughter-Father	Up to 4 years
Carer #5, Son-Father	Up to 2 years
Carer # 6, Son-Mother, Bereaved Carer	Up to 2 years

It is apparent that after a seemingly endless and persistent caregiving journey, to reach a point to seek help was a relatively complex process that was neither easy nor positive. The family carers waited until a critical crisis at an unexpected moment when their relative's condition was deteriorating and the carer's burden was unmanageable. Many of the family carers involved in this research did not seek help for themselves because they felt that the needs of their relatives with dementia were more important than their own needs. Receiving help for their relatives with dementia was the most useful and suitable way the family carers could get help.

I did not ask or receive any support from anyone. The support I was asking for was for my husband. If he gets better, then everything is better. He cannot say ... if he needs any help. That's why I ask [for] support for him only. (Family Carer #3, 64 years)

There were mixed findings about whether or not seeking help from close or extended family members or neighbours triggered an opportunity to ask for help from more formal sources, such as health and social care services. In terms of help seeking behaviour, initially, the Bangladeshi family carers were inclined to seek help from a close family member, which was the most preferred resource. However, five out of the six family carers expressed great concern about receiving help from their family members. The majority of the family carers said that they were unlikely to obtain practical and emotional caregiving support from their family members. Most of the family members did not live near the person who needed care and the family carers, and they had their own responsibilities as they had their own families.

Who would you ask for help except your own family? We cannot ask [for] our extended family's help. They would say they are busy with their lives and their own family. They have [more] responsibility for their own families than [for] my family. (Family Carer #3, 64 years)

However, contrary to the above examples, one family carer in this research sample, who had been looking after her mother with dementia, received her family's support.

We are lucky, in our community we are lucky. If I am unable to look after my mom. My other sisters would be happy to do it. You know we actually fight over our mom [and] who [gets] to look after her. (Family Carer #2, 34 years)

This research found that help from neighbours and community members was not readily available for the family carers or for the people with dementia. Family carers explained the common reasons for not seeking help from neighbours and community members. The family carers acknowledged that the vast majority of Bangladeshi community members have a lack of knowledge and understanding of dementia. The family carers felt that the lack of knowledge and services among the community members was a major barrier for family carers to seek help from them.

The Bangladeshi community, they all know that my father is ill, they know he is not well. But there is nothing, no help to be honest. There is nothing anyone could do for him. (Family Carer #5, 37 years)

Self-esteem and sensitivities of not understanding dementia caregiving problems were likely to hold the family carers back from seeking help from their neighbours. The family carers emphasised that seeking and accepting help from their neighbours would be a burden on them. There was a fear of embarrassment and feelings of inferiority as well as uncertainty among two family carers who thought that their neighbours would refuse to offer help. The family carers had negative perceptions about their neighbours; hence, they were reluctant to share their dementia caregiving problems with them.

Sometimes I left my house keys [at] my neighbour's house. I told the carers if they come to clean the house while I am away they can get the keys from my neighbour. Then I stopped doing that because it is my burden, I cannot leave my burden to others. In case they may refuse to help, that is why I don't ask anyone for help. (Family Carer #3, 64 years)

Unaware of services

There were various findings regarding the barriers to accessing services among the Bangladeshi family carers. This research reveals that these obstacles were present at many levels, not just from the perspective of the family carers, but also from that of the service providers toward the Bangladeshi ethnic minority. The findings suggest that the service providers could also bridge the gap by improving their engagement with the Bangladeshi ethnic minority. The family carers from Portsmouth indicated that the Alzheimer's Society of Portsmouth were unaware that dementia was a problem in the Bangladeshi community. Despite being the UK's leading dementia support and research charity organisation, the Alzheimer's Society has done little to break the service access barriers among the Bangladeshi ethnic minority population in Portsmouth. The family carers in Portsmouth, in receipt of home-based respite care, were asked if they had ever heard from the Alzheimer's Society of Portsmouth. Four out of the six Portsmouth based family carers replied that they had not heard from the Alzheimer's society of Portsmouth.

No, I did not contact [the] Alzheimer's Society of Portsmouth neither [did] they contact me. I knew a nurse who mentioned [the] Alzheimer's Society of Portsmouth, but I never heard of anything from [the] Alzheimer's Society of Portsmouth. (Family Carer #1, 55 years)

On the other hand, both of the family carers interviewed in London rated the Alzheimer's Society highly. They expressed their positive appreciation for the excellence of the service they provided and the helpful and friendly approach of the representatives from the

Alzheimer's Society. Both family carers agreed that the staff from the Alzheimer's Society were kind, reliable, and that they were monitored by the Alzheimer's society team who were willing to provide support. It was probably the case in London, unlike Portsmouth, a Bangladeshi minority ethnic staff was recruited to reach out to the community and build relationships with the family carers and the people with dementia. In this way, the staff acted as a bridge between the Alzheimer's Society and the Bangladeshi community.

Alzheimer's Society, they are brilliant. When we go there, they are really nice. They come to [make a] home visit. They talk to mom and I can have a good talk with them about any concern that I have. Sometime they pass you to [an]other department that can help you. (Family Carer #2, 34 years)

Negative perceptions of care homes

Although the family carers mentioned some uncertainties about seeking help from their close and extended family members, neighbours, and the wider Bangladeshi community, they were sceptical about sending their relatives with dementia to a residential care home. The family carers felt that according to their culture and religion, looking after people with dementia in their own homes would be the least restrictive option. All of the six interviewees strongly agreed that placing their relatives with dementia in a residential care home was a last resort option.

Social services offered me ... residential care services for my mother. But we didn't accept that offer because I did not think they would be able to keep her in a care home. It would be very difficult. Even when [the] carer comes in the house I need to be with her all the time, otherwise the carer cannot manage alone. (Family Carer #1, 55 years)

The findings also reveal that Islamic teachings and beliefs, cultural practices, customs, manners, etiquette, and the values of Bangladeshi Muslim family carers play a significant role in help seeking behaviour. The family carers described that their religious beliefs and cultural practices place a strong emphasis on caring for their relatives with dementia in the home, and that a residential care home was not a feasible solution. The family carers' religious and cultural background as Bangladeshi Muslims led them to follow Islamic teachings and discouraged them from sending their relatives to residential care homes.

As a Muslim, we have many things to follow which care homes will not follow. We like to look after our elder parents, family comes first. As a Muslim, we have many problems [in] sending our parents to a care home e.g. halal food, cleanliness, medicine time etc. Plus, they will give him food but he will not eat. Many problems, language problems, communication problems etc. (Family Carer #5, 37 years)

Although the majority of the family carers did not have any first-hand experience with care homes, they certainly held a wide range of negative perceptions toward them, suggesting

possibilities of abuse and neglect, which were strong reasons for why they did not send their relatives to care homes. Keeping the person with dementia in their own home and providing care for them would be beneficial for their children's education as well.

There are many problems with care homes in this country. I heard from the people who sent their relatives to a care home. Carers treat the patients very badly. At least, he can see his family members [in] the comfort of his own home. And [the] children can see [their] father as well as ...look after him whenever they can. This is good for my children's future as they are learning how to care for someone who needs care. Because when they are older like their father, then they can expect care from their children. (Family Carer #3, 64 years)

Negative experience of healthcare in the past

This research found that a previous involvement with healthcare services had intensified a female family carer's frustration, which might have negatively influenced her subsequent help seeking behaviour. The findings demonstrated that previous negative experiences can create misunderstanding and distrust among carers that can lead to unwillingness to engage with the residential care home services. An important point to note here is that the family carer's poor experience was related to hospital nurses and services, which negatively impacted the carer's perception of residential care home services. This research examined the potential effects of institutional racial discrimination on inhibiting the carers' help seeking behaviour. A female family carer reported that she experienced racism and witnessed discrimination against her father. As such, she believed that the same could happen to her mother. The family carer felt that her mother could get better services from home, which is a safer and more caring environment than the services she would receive in a care home. Exposure to institutionalised care and racial discrimination triggers feelings such as vulnerability, discouragement, and dejection.

You know, when my dad was in Mile End hospital, they did not change my dad's nappies. So, he had blisters on his bottom. Can you imagine [the] agony I was going through for my dad? It was 8 months [of] a nightmare for me. One night he was so cold; they didn't [even] give him a blanket. That kind of experience has taught me, I would never give my mom to give to anybody like that, I wouldn't trust them. It doesn't matter how much they said they can pay good care. They wouldn't be able to give the care that I give to my mom, the love that I give, the support that I give, the comfort that I give. (Family Carer #2, 34 years)

Trigger to help seeking

After becoming entangled in an extended and strenuous caregiving journey, help seeking pathways began at the onset of a crisis point. Help seeking behaviour was influenced by the

family carers' subjective experiences of the people with dementia regarding their intimate personal care, culture, and religion. The interviews identified key triggers that prompted the family carers to seek help. For five out of the six family carers, the circumstance at which the person with dementia became incontinent, particularly faecal incontinence, was an acutely difficult point after which they sought ample help and support. The family carers appeared more likely to seek help for personal care such as dealing with incontinence, toileting, bathing, and dressing, rather than physical types of care such as lifting, help with walking, feeding, and general vigilance. Five family carers mostly sought home-based respite services for personal and practical care and one of the five family carers also used a combination of both home-based respite and day care services. As mentioned earlier, one of the six family carers did not utilise any of the services except for attending the Alzheimer Society's monthly dementia café meeting.

I ... manag[ed] for two years [and] then I asked for help. I carried on until she could clean herself. She started to wet herself which I found really difficult to do by myself. Because as a son I cannot do my mom's personal cleaning. This is the main reason I asked for help. (Bereaved Family Carer, 52 years)

The family carers in this study found that dealing with their family member's incontinence was emotionally harrowing. As the above examples demonstrate, the issue of intimate personal care was the most common trigger for which the family carers sought help. Overwhelmingly, the person cared for was most commonly a parent – which was the case for five out the six family carers, while one woman cared for her husband. Notwithstanding, four out of the six participants cared for a relative of the opposite sex. Three of the family carers were sons or daughters who cared for a parent of the opposite sex. As a wife, opposite sex caring for her husband was appropriate; however, daughters felt it inappropriate to provide intimate care for their fathers. Cultural and religious beliefs view opposite-sex caring as a transgression of social taboos. The following family carer emphasised his views about same sex caring was not an issue for giving and receiving intimate care but it was for opposite sex caring:

If the person with dementia was my father then I could do everything. But she is my mother and for cultural and religious reasons I cannot do all the caring duties for her. I do everything except changing my mother nappies and giving her a bath. For cultural and religious reasons [she] needs a female carer. (Family Carer #1, 55 years)

The opposite-sex caring issues impacted the family carers negatively due to their gender-roles and their personal caring duties within the family, i.e., the belief that sons should not do their mother's personal caring, or that daughters should not care for their fathers. Notwithstanding, and perhaps unsurprisingly, not only is opposite-sex caregiving particularly challenging, same-sex intimate personal care is not culturally appropriate. In contrast to the above participant,

one male family carer found same-sex caregiving challenging because he was uncomfortable while performing personal caring tasks for his father with dementia.

Sometime he opens his bowel[s] on the floor and sometime on [the] bed. Then I have to clean up the mess because there is no carer at 3 am in the morning. Sometimes I have to clean his bottom, wipe him off by myself and it was very difficult for me. (Family Carer #5, 37 years)

In addition to intimate personal caring issues, one family carer needed help to move and handle the person with dementia.

As soon as he [was] bedridden, obviously it was hard to turn or pull him. Then he [was] admitted to hospital and I ... spoke to one of the nurses. They arranged for social workers to meet with us. (Family Carer #4, 23 years)

5.7.3.3 Sub-theme three: Key opportunities for improvement

As indicated in the previous theme, family carers were baffled over the suggestion of receiving some kind of formal support. Although reluctant at first, after the hospital doctors' recommendations and referrals, some types of formal services offered were eventually accepted by the Bangladeshi family carers. The research found that, whilst most of the family carers received some home-based respite care services, only one family carer was receiving a combination of both home-based respite and day care respite services. It is notable that among the family carers, there was a female family carer who did not accept any form of respite care services for her mother with dementia. The findings demonstrate that the family carers who used home-based respite care services had considerably higher levels of carer stress, anger, and frustration than the family carer who did not utilise such services. As a result of their experiences, once they engaged with the provision of the home-based respite care, the family carers reported that they identified a number of key dilemmas which posed a greater level of frustration and dissatisfaction among them.

Table 12 - Pattern of formal services utilised

Type of Support Services	Number of carers accepted (out of total 6 carers)
Home based respite care	5 carers
Day care respite service	1 carer
Privately paid services	1 carer
Residential care home services	0 carer
None of the above services accepted	1 carer

The problems articulated in this area are the following: issues with a culturally inappropriate assessment; a shortage of culturally appropriate support and services, which included the unavailability of Bangladeshi Muslim same-sex carers; a lack of cultural and religious knowledge among the agency respite carers; a lack of flexibility and choice in home-based respite care services; and the fact that family carers felt that the respite services were insufficient or inadequate in meeting their caregiving needs. As a result, Bangladeshi family carers faced a triple jeopardy due to the growing shortage of same sex Muslim carers, the scarcity of Bangladeshi same sex carers, and the overall scarcity of same sex carers in the UK.

Culturally appropriate care

The findings suggest that ethnic homogeneity was related to home-based respite care service satisfaction. There was an overwhelming consensus among the family carers that having a Bangladeshi respite carer option available would be the most preferable option. However, having respite carers from the same Bangladeshi ethnic background as their own was largely unavailable in Portsmouth. The family carers also expressed concern that in most cases the respite care service providers were not familiar with or failed to recognise the importance of the concept of ethnicity in the care of Bangladeshi people with dementia in Portsmouth. The findings suggest that the family carers confronted a complex situation in which they requested a home-based respite carer. The research also found that when requested, the family carers' gender was given priority over religion and ethnicity. The majority of the family carers emphasised that they would allow a respite carer from a non-Muslim background, but they must be a same sex carer, rather than a Bangladeshi or Muslim carer of the opposite sex. The research discovered that the family carers indicated a hierarchy of respite carers for their relatives with dementia. First priority was given to a Bangladeshi same sex Muslim carer,

followed by a non-Muslim Bangladeshi same sex carer, then any non-Bangladeshi Muslim same sex carer. The priority was for a carer of the same sex from any religion or ethnic backgrounds (Figure 13).

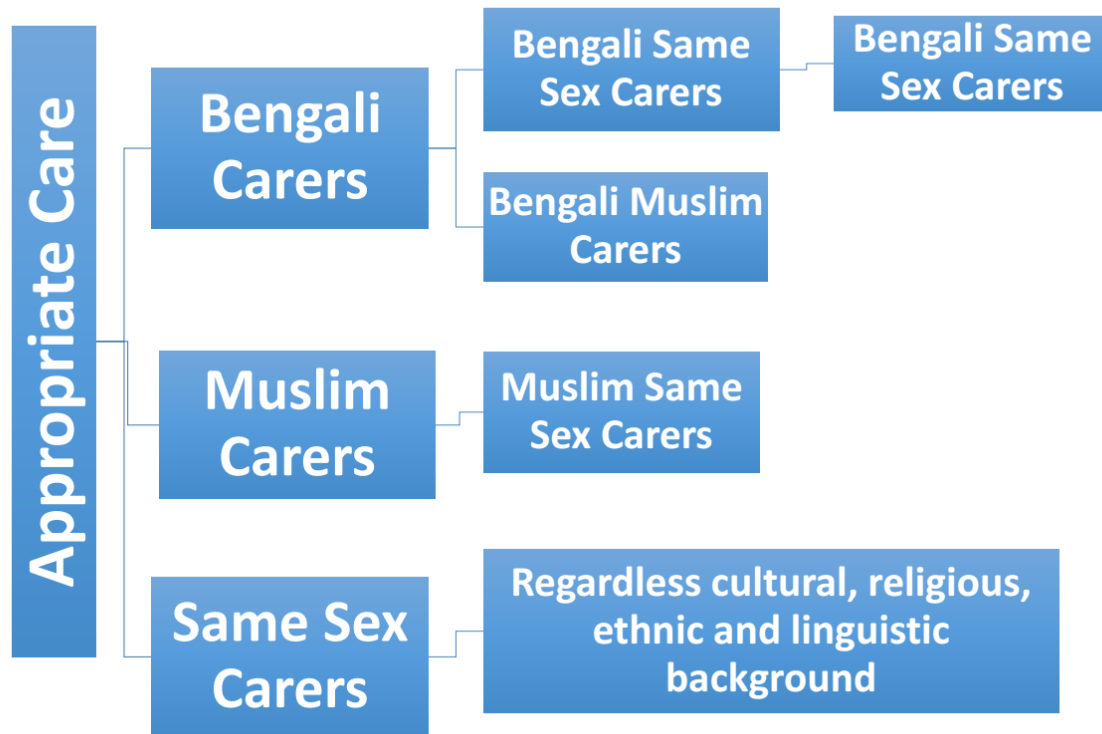


Figure 13 - Culturally appropriate care

[An] agency carer cared for my mother but there was a huge cultural gap. We did not allow them to send a male carer to our house, first of all. Second thing is, even the female carer [did] not know how to work between two cultures. The female care did not know how to work for a Bengali Muslim person with dementia. We could not find a Bengali carer who [could] come and look after my mom. (Bereaved Family Carer, 52 years)

As mentioned above, the only reason why the family carers requested and accepted home-based respite services was to deal with their relatives' incontinence, and to maintain their personal hygiene. Although they accepted respite services, they could not rely on them. They had to be vigilant and be present with the respite carers whenever they visited the person receiving care. Religious Bangladeshi Muslims are adamant about personal hygiene and the family carers explained that they had to follow strict hygienic rules. The respite workers had to also follow similar stringent requirements for cleanliness. However, the majority of the family

carers (4 out of 6) were dissatisfied with how their relatives with dementia were cleaned by the respite workers.

At the beginning, it was not appropriate at all. Then I had to ask how they should do it. And eventually they did it. Because they used to use only wipers to wipe. They didn't use water. But if you use water after [the] wipe; that cleans much better. They need to understand each culture. If you want to work with other people you need to know their culture. That's why I have been doing this for mom. (Bereaved Family Carer, 52 years)

The key issue that the majority of the family carers found with the home-based care service was that the care workers did not spend enough time with the people with dementia. Four family carers expressed their deepest concerns that the level of respite care received was inadequate to meet their needs. Four of the family carers interviewed in Portsmouth received six hours or less of home-based respite care each week. One family carer in London received seven hours or more combined home-based and day care respite services. In many cases, the services were limited to only 15 minutes in the morning and 15 minutes in the evening, which was clearly insufficient to meet their demands. The family carers were also unhappy about the inconvenient visiting times, the inconsistent quality of the respite workers, inflexibility, lack of continuity of care, and a poor caring attitude among some of the agency carers. The family carers felt that some of the respite workers were only concerned about earning money and not about the people they provided care for. Due to a lack of sleep during nights, some people with dementia woke up late in the morning and a respite worker coming early in the morning created problems for them. In addition, they did not want to schedule the respite care for late in the morning or in some cases early in the morning, as this would have disturbed religious activities, such as prayer, reciting holy books etc.

[The] carers service gave six hours [of] care every week, but we requested more hours. They [were] unable to give us more than 6 hours of care. Now where do we get more support, nobody will do that. Dementia caring is a 24 hour job, now they gave us only [a] six hour job. If they could give us more than that, [it] would be more helpful. Because we cannot maintain any social life, we cannot go anywhere together. (Family Carer #1, 55 years)

Four family carers described that they had no family support whatsoever and one family carer said that the help he received from the home-based respite services was not enough. Therefore, he had to pay privately for supplementary services not covered by his home-based respite care services. He employed a paid carer for his father's incontinence care and some housework, such as making tea so that he could go to work.

The caring agency was giving their maximum support but that was not enough for me. And I cannot ask for more as they can't give so I paid for a carer. (Family Carer #5, 37 years)

The family carers often expressed feelings of helplessness, frustration, and anger because the home-based respite services were not sufficient to care for the people with dementia. As such, they were asked whether they had been offered a carers assessment. Half of the family carers interviewed (3 out of 6) did not appear to have had a carer's assessment and one family carer was not familiar with the term 'carer's assessment'. In most areas, family carers' needs assessments were carried out by the local authority's social services department and in other areas by care agencies on behalf of the local authority. Most of these family carers described that their key concern was safeguarding their relatives with dementia and providing them with the support they required. The three family carers who had been involved in the carer's needs assessments complained that the carer's assessments did not benefit them to accommodate their needs. The family carers reported that the local authority's care assessment failed to recognise their unique day-to-day challenges and they were refused further assistance. As a result, as mentioned earlier, one family carer privately arranged for a respite carer to fulfil the caregiving needs of his father with dementia.

No, I didn't do an assessment. Even though I knew about it but I didn't go for it. My brother came down who lives in London. He said no we don't need that. (Bereaved Family Carer, 52 years)

Yes, they assessed my needs but they have provided only 6 hours of care per week which is nothing. Their assessment does not meet my needs. They cannot provide more what I need. That's why [the] carer's assessment does not make any sense to me. They said they would do everything, but in reality, they cannot do everything and they are in their limits. (Family Carer #1, 55 years)

There was another concern raised by the majority of the family carers (5 out of 6), about the relationship between the respite care workers and their care recipients with dementia, particularly when home-based respite service providers sent different respite care workers every time. The family carers expressed that knowing their respite workers would enhance the experiences of their relatives with dementia and would help to build a rapport between them. The family carers felt that it was very important to receive the same respite carer workers or familiar faces for the safety and wellbeing of the person receiving care. However, the family carers stressed how unsupportive or problematic it was to have numerous changes in the respite workers visiting their relatives every time. Changing the respite workers not only confused, upset, and frightened the person with dementia but also resulted in an instability of care, especially when receiving intimate care. The family carers had witnessed some examples in which the respite workers showed a lack of dignity and respect when they first provided care for the people with dementia. For this reason, some family carers had to explain to each new respite worker how they must clean their relatives with dementia in a culturally

and religiously appropriate way, and how they should maintain dignity and respect. However, the family carers and the care receiver's stress could be reduced by sending the same respite workers every time so that they did not have to guide them each time.

If [the] same carer [came] every day then he [would] become familiar with the carer's face and he [would] talk to them. But when [a] new carer comes, he does not know them, he does not want to communicate with new people. [The] problem is [that the] council sends new carers every day, they change carers every day, which is very difficult for people with dementia. Sending one carer today and another carer tomorrow is very problematic. (Family Carer #3, 64 years)

Because every time [the] caring agency sends different carers. So when the new carers come again I have to explain to them and show them how to clean my mom in a culturally appropriate way. That's the problem, otherwise they won't do it properly. (Bereaved Family Carer, 52 years)

The family carers reported that the lack of flexibility and lack of choices were the other key issues they had with home-based respite care. Two family carers described their unpleasant experiences, as there was no flexibility in respite care. For example, the respite carer came at a certain time, however, people with dementia cannot be expected to maintain a routine life. The respite care service provider followed their office routines by sending carers at certain times of the day rather than at the convenience of the people with dementia and their family carers. For example, some people with dementia were still asleep when respite workers came at 9 o'clock in the morning, or they would sometimes wake up very early in the morning when there was no overnight or early morning respite services available. The family carers felt that the respite service providers needed to find a way to build routines that were flexible and able to meet the needs of people with dementia.

Agency carers come between 9 am to 10 am and if dad is asleep during that time, I used to tell the carers 'no, he is asleep, please don't call him and let him sleep'. His sleep is important because most of the time he can't sleep. But the carer's time is fixed, they never come back. There is no flexibility with the carer's timing. (Family Carer #5, 37 years)

Learning and development

The family carers were overwhelmingly keen to stress that the cultural values and religious beliefs of people with dementia should be recognised and respected. A need for better staff training was identified, especially in how to treat older people with dignity and respect. The flipside of this point of view was a relentless fear. Without proper cultural education and training, non-Bangladeshi carers would not be able to deliver those services. To share their thoughts and advice, the majority of the participants raised a number of lessons they had learned from their relatives with dementia which could be applied to services for future

dementia family carers. The family carers suggested that the quality of care they received for their relatives with dementia was very much reliant on the cultural and religious background of the individual respite worker. They expressed the concern that most of the respite workers were not culturally and religiously experienced, skilled, or that they did not have any written care guidelines or care plans for Bangladesh people with dementia. Family carers generally agreed on the need to offer education and training opportunities to agency carers so that they would be able provide culturally appropriate care. The participants offered diverse views on the type of religious education and cultural training required for the Bangladeshi community. A few participants suggested that home-based respite carers need to go beyond general training to deal with multiple caregiving roles and offer specialised cultural training related to the Bangladeshi community.

Because every culture works differently. Maybe they need to do [a] bit of research about Bangladeshi culture. For example, for [a] male dementia patient, a male carer and for a female patient, a female carer, no, no discrimination. So, the learning and developments could be for them [to gain] knowledge and [understand] importance of halal food for Muslim patients, cleanliness to not only provide tissues after using the toilet but there should be proper management for using water afterwards. (Family Carer #5, 37 years)

Another family carer identified some key factors which could build positive relationships and a bridge between healthcare services and Bangladeshi people in the UK, such as engaging with better communication and the recruitment of care staff from the Bangladeshi community. Expressing and sharing information by speaking the same language was seen as a key issue for engaging with Bangladeshi family carers and people with dementia. A family carer suggested that the service providers should create opportunities for the care staff to learn Bengali in order to deal with Bangladeshi clients. Therefore, this would help the family carers convince themselves that their religious and cultural background was fully recognised and accepted into the mainstream health care services, rather than being overlooked.

Because of the language barrier, there is no good communication between the agency carers, patients, and family members. They need to learn the Bengali language. However, this problem can be solved if the carers' agencies recruit more Bengali carers for Bangladeshi families with dementia. (Family Carer #1, 55 years)

On the other hand, only one family carer realised that full knowledge cannot be expected from non-Bangladeshi healthcare providers. As a non-Bangladeshi cannot be expected to understand the core values of Bangladeshi culture and religion, it is crucial for a Bangladeshi family carer to explain these values to the English agency carers. For an English carer, there is no easy way or shortcut to learn about Bangladeshi culture and religion, as sensitive issues in religion and culture should be handled deftly. The participant pointed out that dealing with

a non-Bangladeshi respite carer might be disruptive, however, clarifying those issues with proper discussion and negotiation could minimise the problem.

The carers come to our house to clean my dad and we explain to them to cover my dad up with a towel for his dignity. You know if they are not aware about something just explain it. They understand, just to say them it is because of religion or culture. Obviously, they are not going to learn everything from our culture and religion. It is our job to explain to them. Just because they are White and it's not their fault as they don't know our culture or religion. We cannot blame them, just explain to them. (Family Carer #4, 23 years)

Develop a specialist provision

The findings indicate that the majority of the participants were concerned about the overall Bangladeshi population growth in the UK as well as the increasing number of older people with dementia which has put a strain on family carers. The participants pointed out that the UK health and social care services need to find a solution for the service needs of the older Bangladeshi people with dementia to minimise the increasing pressure. Therefore, the family carers, both in Portsmouth and London, suggested that there should be initiatives to create separate residential care homes for Bangladeshi Muslims. Most of the family carers (5 out of 6) demanded that the one way forward was to develop a specialist dementia service provision for the Bangladeshi ethnic minority community in the UK. Presumably, developing specialist service provisions for the Bangladeshi ethnic minority would circumvent their negative perceptions about care homes, such as same sex caring issues, halal foods, cleanliness, and language barriers. At the same time, the participants suggested that such facilities would build a greater trust and understanding about UK healthcare services and social care services across the Bangladeshi community.

Our Bangladeshi community is getting larger day-by-day in London and other parts of [the] UK. They need more separate services for Bangladeshi people. (Family Carer #3, 64 years)

I think, we should have a culturally appropriate service for [the] Bangladeshi community in Portsmouth. It would be ideal, if they [had a] caring service who [could] provide the language and religious background knowledge. We don't have this kind of service in Portsmouth but in London. (Bereaved Family Carer, 52 years)

Although there was a general desire among the family carers for specialist dementia services for the Bangladeshi ethnic minority people in the UK, the barriers to those specialist services remain inadequately understood. Having a specialist provision or recruiting Bangladeshi family carers for mainstream home care services that meet the Bangladeshi community members' needs was believed to be a positive development. However, the participants were concerned

about the sustainability of the specialist service provision. The participants felt rather uncertain about the availability of Bangladeshi family carers which would clearly challenge the service providers' credibility to manage the service for the Bangladeshi community. The participants further commented that creating a specialist service provision and the availability of Bangladeshi family carers would not completely convince them to send their relatives to a care home. The family carers' peace of mind was important and they were unsure what the future would hold for them.

If a care home was built by our Bangladeshi community with Bangladeshi carers then I might think ...to send [her to] that Bangladeshi care home. I cannot guarantee now but I [might] consider [it]. My ...satisfaction and peace of mind is important at the moment. How can I send my mother to a care home? It would not give me peace of mind. (Family Carer #1, 55 years)

5.11 Discussion

5.11.1 Lack of dementia awareness

This is the first study to explore knowledge and experiences of dementia among the Bangladeshi family carers of people with dementia in England. The main findings from the interviews reveal that the majority of family carers have a lack of knowledge and awareness of the symptoms of dementia. A lack of knowledge seems to be a common issue across the previous studies and symptoms of dementia are perceived differently within broader BAME communities. However, the research discovered a shift in the conceptualisation of dementia among the Bangladeshi family carers against the conventional concept of memory loss, with memory loss being consistently conceived as an outcome of the ageing processes in the previous studies conducted among BAME groups. Even though the knowledge and understanding about dementia is very low and inconsistent in previous studies, the presentation of dementia is unique to Bangladeshi family carers. Previous studies reported that memory loss was the first symptom of dementia that the South Asian could identify easily. However, most Bangladeshi family carers identified behavioural changes in their relatives prior to their conceptualisation of dementia, which, of course, always occurred with the help of their doctors. On the other hand, memory loss was perceived as a normal ageing process among the overall South Asians. Unlike other published research on South Asian communities (McCleary 2012), no family carers in this study said that it was a normal ageing process; everyone believed dementia was a medical condition such as a brain disease and that anyone could suffer from it. Therefore, believing that dementia is a medical condition facilitated family carers to hand over their relatives with dementia to the control of health specialists.

Differences in beliefs about the causes of dementia among the South Asian family carers and family members were found in past studies. Religious affiliation was greater within the South Asian communities and the participants reported that dementia was potentially caused by evil spirits or punishment for their previous life's sins (Adamson 2001, McKenzie 2006, McCleary 2012). As a result, the family members placed the blame on the person with dementia for their strange and unforeseen circumstances (Adamson, 2001; Bowes & Wilkinson, 2003). However, this study did not find a link between dementia and the perception of being punished of past sins or being possessed by bad spirits. These findings contradict previous studies on the way in which South Asian family carers perceived the causes of dementia. One possible explanation for this variation in beliefs is that, generally, Bangladeshi people trust their GP and hospital doctors and value their advice. Bangladeshi people perceive professionals like GP and hospital doctors as experts on any health problem. They believe health professionals have the authority to make any decision concerning the patients' wellbeing (Khanom, 2009). This research led to the conclusion that religion and culture has less negative influence on Bangladeshi family carers' understanding of dementia. Therefore, Bangladeshi family carers cannot be represented homogeneously with other South Asians or BME communities.

5.11.2 No stigma attached to dementia

Previous research demonstrates variability in attitudes toward dementia and feelings of stigma and highlights the need for further research to understand the extent of stigma, among all stakeholders: people living with dementia, family carers and service providers for specific South Asian communities. This research must assess its causes and determine what might help to alleviate it. Mackenzie's (2006) study found that South Asian family carers believed that dementia was caused by bad spiritual influences, which led family carers to hide the person with dementia from anyone other than family members. Participants also perceived that having a family member with dementia would invite condemnation upon their family. As a result, family carers were isolated from the friends and other family members within the community. A similar concept of stigma was reported in the findings of Jutlla and Moreland (2009), Jolley et al. (2009), and Bowes and Wilkinson (2003), as family members and the community members blamed the persons with dementia for their own condition. Concealing the dementia frequently meant hiding the afflicted person due to possible consequences from family members as well as the community (Jutlla & Moreland, 2009).

However, taking into account cultural, religious or other beliefs, the fear of stigma was not present at all in the six Bangladeshi family carers interviewed for this current study. Moreover, in contrast with previous studies, participants described that they never hid the signs and symptoms of dementia before or after their relatives' developed dementia. One possible

explanation for this is the uniqueness of their religious and cultural identity. Bangladeshi family carers believe that their religion, Islam, is a complete way of life which is influenced by the concepts patterned in the Qur'an. It comprises of comprehensive and rational beliefs and rites, moral values and obligations. To have dementia is believed to be the will of Allah and anyone could suffer from it. This belief is congruent with (Rassool, 2000) and (Rozario, 2008), who found that an illness was perceived as a gift to test their purity. However, Muslim people are not homogeneous around the world; rather, there is a widespread diversity of different denominations within the religion of Islam. Some Muslim countries are less religious than others, some practices and strictly follow the Qur'an and Hadiths (the sayings of the Prophet Muhammad, pbuh) and some do not. Research found that British Bangladeshis are more religious than British Pakistanis, whereas Pakistanis are more Westernised than Bangladeshis in the UK (Parveen, Morrison, & Robinson, 2011). Therefore, this explanation for what family carers in the earlier studies perceived to be the cause of dementia should have been restricted to the experience of Pakistani, Hindu, or Sikh family carers rather than suggesting it has relevance for Bangladeshi family carers. This highlights the need for specificity when researching the various BME communities in the UK. The findings of the current research are consistent with Vanaleesin, Suttharangsee, and Hatthakit (2007), who conducted a qualitative study among the Thai Muslim community. Their study revealed that participants did not believe in mental health stigma while looking after patients with schizophrenia. This could suggest that the Bangladeshi communities' lack of stigma is not an isolated phenomenon but a characteristic of other Muslim communities as well. In practice, another possible explanation may be generational differences among Bangladeshi and among other BME immigrant communities, suggesting that up to date research into the issue of dementia stigma is warranted.

Furthermore, research conducted among Indian, Pakistani, Sri Lankan, and Sikh communities and revealed that mental illness and dementia were seen as obstacles to arranged marriages and families kept them secret (Bilkhu, 2016; Bowes & Wilkinson, 2003; Time to Change, 2010). Family members were being stigmatised by members of the wider community, which posed a serious threat to their marriage prospects. However, in the current study, dementia did not pose any problem when the participants' daughters' marriages were being arranged. One participant explained that prior to her daughters' marriages, the families of the grooms looked into her family background, and she did not hide her husband's dementia problem. However, in contrast to previous studies, there was no link between dementia and arranged marriage in this current study. The participant reported that her daughter's family members also believed that anyone could suffer from dementia and that it was the will of God.

5.11.3 Family caregiving obligations and consequences

Religious obligation to care has been found to be a strong influential element in the dementia caring role among South Asian communities. These religious values offered an internal personal support and peace of mind for the family carers through the difficult journey of caring for their loved ones with dementia (Adamson & Donovan, 2005; Bowes & Wilkinson, 2003; Godfrey & Townsend, 2001; Lawrence et al., 2008; Lawrence et al., 2010; Mackenzie, 2006). Those studies reported that family carers were fulfilling religious duties toward their elderly relatives with dementia as well as toward God by providing care, which was the normal and expected thing to do as a true religious person. Another study found that adult children were most likely to perceive caring as a cultural duty as well as an expected obligation toward their parents with dementia (Botsford et al., 2011). However, cultural and religious obligations seemed absent from the accounts of British-Bangladeshi children caring for their parents with dementia in this current study. Cultural and religious obligations were outweighed by interpersonal motivations to provide care. They reflected that caring for someone who was old or physically or mentally not capable of looking after themselves was a natural, inevitable duty. The current study explored that participants referred to cultural obligations when describing the negative consequences of caring arising from the absence of satisfactory support in the UK. There is a paucity of research about the challenges experienced by Bangladeshi family carers in their roles caring simultaneously for elderly relatives, husbands, and children. In an earlier study, such consequences were presented chiefly as a result of the family carer burden. However, current research findings recommended that Bangladeshi family carers diverge from other South Asian family carers in the UK in their expressions of caregiving. This study's findings are consistent with previous research conducted by Parveen et al. (2011), who found that British-Bangladeshi family carers were more willing to provide family care than British Indian and Pakistani family carers. Although family carers acknowledged some difficulties along their caregiving journeys, this did not discourage them from providing care.

5.11.4 Gender roles in family caregiving

The current study provide some very noteworthy findings with regard to the impact of gender on a family carer's role. There is a plethora of research on South Asian daughters-in-law who are the main family carers and obliged to look after their husbands' relatives. Previous studies have found that in South Asian communities, there was a strong expectation for daughters-in-law to provide care and there were high numbers of daughters-in-law doing this on a daily basis (Adamson & Donovan, 2005; Botsford et al., 2011; Bowes & Wilkinson, 2003; Godfrey & Townsend, 2001; Jutlla, 2011; Jutlla & Moreland, 2009; Mukadam et al., 2011; Qadir et al., 2013; Turner et al., 2005). Even outside South Asian communities, recent trends showed that overall caring duties from daughters-in-law increased (Hirst, 2002). Furthermore, analyses of

the British General Household Survey data revealed that caring was a major part of women's gender roles and any justifications were considered inappropriate when they failed to provide care (Henz, 2009). However, for the first time, findings from the current study sample revealed an uncommon concept: that none of the daughters-in-law of the main family carers were directly involved in providing care for their parents-in-law, disregarding the traditional gender differences as well as the division of power and labour between men and women.

Much past research focused mainly on the effects of caregiving on women, however, few studies examined the consequences for male fulltime family carers. The current study found that providing care for parents with dementia harshly penalised their employment, as they had to leave their well-paid jobs. However, employment status appeared as an excuse for the daughters-in-law not to become family carers of their parents-in-law. It seemed that husband carers appreciated that their wives were deemed unable to provide care for their parents-in-law as they were in the labour force. On the other hand, sons as male family carers' caregiving responsibilities toward their parents justified them leaving their jobs. Although financial strain was harder as a result, there was a satisfaction among the family carers about their roles.

5.11.5 Barriers in accessing and accepting services

There is a scarcity of research about help seeking behaviours among Bangladeshi family carers of their relatives with dementia. Bangladeshi family carers may be among the most neglected and underserved BME communities with respect to dementia and other health services in Britain (Merrell, Kinsella, Murphy, Philpin, & Ali, 2005). Although data from the current study suggest that it is vital for service providers and home carers to be of the same religion and cultural identity as the persons with dementia, there were conflicting results concerning the advantages of having ethnically similar healthcare professionals and family carers. Consistent with previous research involving South Asian family carers, the current study found that having healthcare staff from the same community who speak the same language did not necessarily improve family carers' satisfaction (Katbamna, Bhakta, Ahmad, Baker, & Parker, 2002). In London, family carers were receiving support services from BME service providers and they identified that some factors, e.g., carers arriving late, rushing the patients, shouting and other hostile attitudes affected their service satisfaction. Since most health professionals have more authority than family carers, regardless of their ethnicity, power differentials as well conflict between service providers and service users are inevitable (Rose, Fleischmann, Tonkiss, Campbell, & Wykes, 2002). In addition, family carers were unable to override the decisions of local authorities about how they wanted care for their relatives with dementia to be delivered.

Another study found that there was a fear of the consequences of seeking help. Such stigma is related to the issue of seeking help. Perceived religious causes of dementia ('*karma*', or bad deeds earlier in life) have been documented as a source of stigma in the previous studies conducted amongst South Asian communities. It was thought that dementia was God's punishment for previous sins. The stigma and shame of dementia within communities generates a barrier to seeking support within the community and healthcare providers (Bowes & Wilkinson, 2003; Fontaine et al., 2007). Negative religious perceptions of dementia as karmic retribution or punishment presented a barrier to help seeking, as it was believed that seeking support from service providers would bring shame upon the families and would threatened families' position in the community (Bowes & Wilkinson, 2003; Fontaine et al., 2007; Lawrence, Samsi, Banerjee, Morgan, & Murray, 2011). Despite efforts to develop healthcare access in the South Asian community, this often led to families hiding the person with dementia (Mackenzie, 2006). Therefore, management of the caregiving task was described as hiding the person with dementia due to possible consequences from family members as well as the wider community (Juttla & Moreland, 2009). In contrast to the majority of previous studies, where researchers identified stigma as one of the most salient barriers to seeking healthcare support for their relatives with dementia, the current study found no trace of the stigmatisation of dementia.

There were consistent overarching themes that applied to all barriers identified, and a range of additional justifications was specified. Some barriers could be overcome simple solutions, such as providing same sex carers or a carer from the same religious group. However, due to the lack of same sex carers from the same religious group, this issue is quite complex: healthcare services are less equipped to support the Bangladeshi community. Despite this, high expectations of receiving culturally and religiously appropriate services were quite common among the participants. The current study discovered that there were good intentions to supply Bangladeshi family carers' religious needs by healthcare providers in Portsmouth, but in the end the facility and the resources available were inadequate to accomplish this. The Bangladeshi community in Portsmouth has been represented disproportionately in dementia services, given its comparative presence in the general population (Turner et al., 2004). Historically, healthcare services are less equipped to support the religious needs of South Asian ethnic minorities and so deliver care of a lower standard to those groups than they can to White groups (Keynejad, 2008). In other words, service providers working with ethnic minority family carers may make inappropriate assumptions about them because of their cultural and religious identities, leading to covert discriminatory practices. It is often, in fact, stated that ethnic minorities looked after themselves and do not need outside help and resources, which undermines the support provided.

The current study challenged the general claim that Bangladeshi families looked after their own. This research has not discovered a sweeping decline in the sense of accessing and accepting government services. Rather, family carers sought help from service providers and tried hard to shield their relatives with dementia from the difficulties they faced in managing caring arrangements with services providers. Specifically, they wanted to ensure that their relatives with dementia were given culturally appropriate services. Family carers also informally educated and trained the agency carers that they believed would help to increase agency carers' knowledge about culturally appropriate services and promote a better understanding of needs of the Bangladeshi people. Current research results are consistent with the outcome of Katbamna et al.'s (2004) study, which found that British-Indian and British-Pakistani family carers had scant aid and support within the family and were unwilling to look for support from extended family members. Katbamna et al.'s (2004) study also reported that South Asian family carers had a very negative attitude toward service providers and family carers were reluctant to seek support. However, family carers in this current study sought and received formal support from service providers. Themes that emerged in the present study identify significant cultural and religious dissimilarities in the usage of healthcare services. For most of the South Asian family carers, access to support services (health or social care) occurred as an outcome of an acute hospital admission (Godfrey 2001). However, in this study, for opposite sex caring issues, family carers accessed caring services. In addition, previous studies reported that the lack of knowledge was the main reason not to access healthcare services among South Asian family members with dementia (Meltzer et al., 2000 and Jutlla & Moreland 2009). However, this was not the case for the Bangladeshi participants in this study and the lack of appropriate cultural and religious services was the main reason for withdrawing from the services.

5.11.6 Specialist dementia care provision

Cultural and religious matching of people with dementia with professional staff could act as a solution for effective service delivery. Participants demand a specialist dementia service provision where cultural and religious matching will be guaranteed. By providing a specialist service provision, cultural and religious matching may prove an advantage where people with dementia and their family carers feel assured by promises of confidentiality. In addition, those facilities could guarantee the observance of cultural and religious sensitivities and same sex care. One previous study showed that service providers who had direct involvement of delivering services to South Asian people with dementia and their family carers called for an end to segregated services, which they assumed only strengthened and worsened prevailing attitudes (Bowes and Wilkinson, 2004). Participants recommended a specialist provision, as an alternative, a more cohesive approach to health and social care services. Furthermore, the

findings supported a general claim made by Nicholls' (2006) study that mainstream care services might be accepted by ethnic minority communities if they were culturally sensitive. However, incongruent with previous studies' findings, the current study's participants argued and rejected the notion of a single, integrated services provision. Most participants emphasised the importance of their individual choice and called for the provision of more specialist dementia care services for Bangladeshis.

5.12 Summary

The purpose of this chapter has been to examine in detail family carers' experiences of caring for their relatives with dementia. The current study reveals that most family carers have a lack of knowledge and awareness of the symptoms of dementia. Family carers exhibited a strong sense of family obligation, religious beliefs, and interpersonal motives to provide care for their relatives with dementia at home. Family carers appeared to accept and take for granted, expectations to fulfil considerable caregiving roles. A scarcity of cultural and religious sensitive resources for the needs of Muslim patients meant that Bangladeshi family carers were more likely to provide direct care themselves rather than receiving care from service providers. Sending a relative with dementia to a residential care home was seen as unacceptable.

The next chapter will reflect on the overall study. It will summarise the research, including what the key findings from all three phases have revealed and provide further discussion. It will examine the original contributions of this study to existing knowledge, as well as highlighting specific implications for clinical practitioners and policy makers. Finally, recommendations for future research are made before drawing some final conclusions.

Chapter 6: Overall discussion and conclusions

6.1 Background

This chapter offers a general discussion of the study, its conclusions, and the implications of the research. Moreover, it will discuss the limitations, recommendations and suggestions for future research. To organise the evidence discussed and presented, this chapter has been divided into the following subsections: (i) summary of the research phases, (ii) original empirical contribution, (iii) researcher's reflections of the research process, (iv) limitations, (v) recommendations for future research, (vi) implications for policy and practice, and (vii) conclusions.

6.2 Summary of the research phases

The purpose of this research was to study Bangladeshi communities' understanding of dementia. It was completed in three distinct phases. The first phase examined the knowledge and awareness of dementia and the provision of dementia care tasks among the wider South Asian communities as reflected in the academic literature. The first phase drew together the current evidence base, which informed the development of the focus groups and the interview schedules for phases two and three. Following the synthesis in the first phase, the second and third phases of the study included focus group discussions with adults of Bangladeshi origin, people without dementia across all socio-economic backgrounds, and semi-structured qualitative interviews with the family carers of Bangladeshi elderly people living with dementia. As a result of using interviews and focus groups, combined with a qualitative synthesis, current research has revealed a new understanding of the knowledge, beliefs, attitudes and awareness regarding dementia and caregiving among the Bangladeshi community in the UK.

By linking the results of the three phases of the current study, it appears that there are some clear similarities and differences. The most similarities are found between the second and third phases of the study. However, the most fundamental distinction between the qualitative synthesis and the focus group interviews, which contrasts previous studies on dementia, is the cultural basis of norms and values upon which perceptions are formed by the complementary South Asian health beliefs, religious-cultural norms and values. Perhaps unsurprisingly, inconsistencies in the findings are to be expected. On the other hand, the qualitative synthesis in phase one was conducted among the rest of the South Asian communities and the qualitative synthesis sample population was much larger than that of the current study. Participants in the qualitative synthesis were both people with dementia and the family carers of those living with dementia; whereas in the current study, the participants were

adults without dementia (in phase two), and the family carers of the people with dementia (in phase three). Primary data and contrasting findings were examined to produce new knowledge that was often quite different from what had previously been empirically observed. The following section, ‘original empirical contribution’, explores many of the similarities and differences exhibited between South Asian and Bangladeshi communities, captured in the three phases.

6.3 Original empirical contribution

Phase One	Phase Two	Phase Three
<ul style="list-style-type: none"> • Poor knowledge and understanding of dementia • Understanding of dementia mostly perceived as normal ageing process, memory loss and God's punishment for sins committed in the past • Stigma about dementia was widespread • Daughters-in-law were the main family carers 	<ul style="list-style-type: none"> • Poor knowledge and understanding of dementia • Understanding of dementia was also mostly perceived as memory loss • No stigma related to understanding of dementia • The stigma associated with paid caregiving • Respondents perceived that daughters-in-law should provide the care for the family members with dementia • Separate specialist dementia service provision for UK Bangladeshi community 	<ul style="list-style-type: none"> • Poor knowledge and understanding of dementia • Family carers viewed dementia as a medical condition • No stigma experienced by the family caregivers of the people with dementia • No daughters-in-law were providing care for the family members with dementia • Separate specialist dementia service provision for UK Bangladeshi community was desired

Figure 14 - Original empirical contribution

The current research provides an empirical contribution since there has been no other qualitative research examining the knowledge and understanding of dementia among the Bangladeshi community in England or elsewhere. In addition, there has been no research exploring the views of the family carers of Bangladeshi people with dementia or their practices in the management of dementia caregiving. A lack of knowledge, understanding, and awareness of dementia amongst Bangladeshi adults without dementia and the Bangladeshi dementia family carers was observed throughout the two phases and is also seen amongst other South Asian immigrants in the UK. Analysis of the phase two (focus group discussions) data implies that Bangladeshi people with dementia were not only underrepresented in the wider community but also in their own communities. For example, at the end of the focus group discussions, no participants were able to mention whether they had known any Bangladeshi

older people who lived with dementia or any Bangladeshi family carers who cared for their relatives with dementia.

Previous research conducted in the UK stated that there is no corresponding word for the term 'dementia' in South Asian languages; rather, it is explained with derogatory words, such as 'madness', or thought to be an act of God, forgetfulness or natural memory loss associated with old age (Adamson, 2001; Bowes & Wilkinson, 2003; Lawrence et al., 2010; Milne & Chryssanthopoulou, 2005; Uppal & Bonas, 2014). Studies conducted in India and Pakistan revealed that participants used similar Hindi and Urdu terms to describe dementia, such as *sathiyana* or 'above sixtyish/getting old' and *sathiana* or 'senility', (Brijanth & Manderson, 2011; Qadir et al. 2013). Another Indian study revealed that participants described dementia as a 'brain problem' (V. Patel & Prince, 2001). Aligning with earlier work, dementia was also mostly perceived as natural memory loss across male and female focus group discussions in phase two of this current research. However, the participants in phase two of the current study were more inclined to focus on the positive aspects of memory loss associated with normal ageing and dementia. Participants used two affirmative, equivalent Bengali words to describe dementia: '*mon vula*', meaning forgetful mind, and '*oron sokti harano*', memory loss. On the other hand, memory problems were not viewed as a main feature of dementia by the family carers of people with dementia, but other physical problems were described, which is congruent with some previous studies (Mukadam et al., 2011; Fontaine et al., 2007; McCleary et al., 2012).

However, the findings of the current study revealed contradictory perceptions among participants in the second and third phases. Unlike the findings of phases one and two of the current study and other previous studies, in phase three, the family carers of Bangladeshi people with dementia viewed dementia as a medical condition, rather than merely considering it as part of the normal ageing process. It may be that family carers tried to encourage people with dementia to seek help and to receive healthcare and social support, or tried to preserve hope with respect to their relatives with dementia. Given the lack of previous knowledge, dementia-related issues arouse a sense of urgency within the family. Believing dementia was a medical condition, perhaps, helped family carers to cope with the uncertainty and gave hope for subsequent remedy. The new insight offered here is that dependence on the medical description of dementia contradicts the previous research which found that perceptions largely aligned with cultural- and religious- based conceptions of the causes of dementia. Generally, ethnic minorities have been traditionally neglected in areas such as health in the UK (Barnard & Turner, 2011; Myers, 2009; Nazroo, 2014; Rassool, 2006). In the current study, family carers benefitted from accepting dementia as a medical situation and effective interactions with service providers helped them to prepare themselves for dementia care.

Interestingly, both phases two and three of the current study showed that, in some ways, perception and experience regarding dementia-related issues were parallel but also varied on some points. Although the current study is not designed to investigate the extent to which the perceptions of Bangladeshi adults without dementia validate the reality of those who live with and provide care for people with dementia, a further analysis here might be fruitful for gaining deeper insight. The findings support the theory that perception is not fixed, but is flexible, and may not reflect reality (Witt & Proffitt, 2007). The current research shows that the perception of dementia caregiving among Bangladeshi adults without dementia does not necessarily reflect the actual experience of dementia caregiving among Bangladeshi family carers of people with dementia. There are reasons for thinking about why the perception and the reality of dementia and caregiving were largely dissimilar among Bangladeshi community members. However, one must not overlook the dementia family carers' 'hands-on' experience in the ascribing of dementia knowledge and caregiving skills. Issues related to dementia are merely perceptions for non-dementia family carers. Exceptionally, through experience, Bangladeshi family members who are socialised into dementia family carer roles learn to confront reality and encounter caregiving strain, while other South Asians seem to manage dementia problems by 'hiding dementia under the table' due to perceived harsh consequences from family and community members (Jutlla & Moreland, 2009).

Unlike previous studies conducted among South Asian communities, another striking theme emerged from both phase two and three of this current study regarding stigma among the Bangladeshi community in the UK. In both phases, there was no evidence for stigma, which was consistent with a US study on attitudes in the Black African-American community, which revealed no stigma related with dementia (Dilworth-Anderson & Gibson, 2002). The signs and symptoms linked to dementia that escalated stigma among other South Asian community members were perceived as expected among the Black African-Americans in the USA, and hence, were non-stigmatised. The current study's findings revealed that dementia was not considered a stigma at all among the participants, which aligns with other previous work on Muslim patients with schizophrenia in Thailand that showed that schizophrenia was perceived to be due to the will of Allah (Vanaleesin et al., 2007). What made the Bangladeshi community different from other South Asian communities in the UK and elsewhere regarding the stigma associated with dementia? It might be inferred from evidence from the current study that Bangladeshi Muslims' beliefs about dementia and other relevant health issues are heavily influenced by the Qur'an (Muslim holy book) and sayings (Hadith) of the Prophet Muhammad (peace be upon him). Despite the increasing number of Muslim communities in Europe and elsewhere, little is known about Muslim beliefs regarding physical, psychological, and social health and healthcare, particularly those of the Bangladeshi Muslim community. The Islamic

religion plays a significant role among Muslim families with anyone suffering from physical, psychological or social problems (Ciftci, Jones, & Corrigan, 2013; Peek, 2005; Rassool, 2000). Similarly, the Islamic belief that dementia is derived from Allah as a test, blessing, or forgiveness is common among the participants in this current study.

Resonating with earlier studies, Bangladeshi community members professed a strong belief in Allah and seemed to conform to Kibria's (2008, 2011a) explanation of 'revivalist Islam'. Revivalist Islam is multifaceted, with a combination of 'Bengali Islam' (represents Bangladeshi traditional society and social stratification); 'fundamentalist Islam' (strictly followed by the Qur'an and Sunnah, the Prophet Muhammad's teachings); and the 'new Islam' or 'European Islam' (a modern Islam based on the Qur'an and Sunnah, as well as rooted in personal choice and reflection). In my study sample, it appeared that phase two respondents mostly abided by Bengali and fundamentalist Islam, whereas, phase three respondents were influenced by the new Islam of the revivalist Islam. Under these broad terms, from an implicit sense, revivalist Islam has given the Bangladeshi community a distinct Muslim identity, which can articulate a sense of difference from other South-Asian Muslim communities in the UK. The revivalist Islam also offers Bangladeshi Muslim communities a way of coping with the challenges associated with living in the UK, as posed in all spheres of life, such as health and social care, illness and treatment.

The growing knowledge of this revivalist Islam gives the Bangladeshi Muslims in my sample the power to contest dementia stigma in two ways. First, the belief that dementia is caused by Allah conceivably alleviates the stigma associated with the development of this disease. Second, by shifting the accountability for their relatives' dementia issues to medical conditions, it may be that the stigma associated with dementia is eliminated. This evidence is partly supported by a previous study conducted among British Bangladeshi Muslims in relation to genetic disorders, which found that participants believed that their children's illnesses were caused by Allah's will and they were not stigmatised in any of Allah's affairs (Rozario, 2008). Nonetheless, while earlier studies commonly mentioned that, among South Asians, Muslims believed that dementia was due to bad spirits, it was found that the studies conducted among the Pakistani community revealed how dementia is viewed as being related to stigma, or the 'evil eye'. However, Ibn Sina (980–1037), a Muslim scholar and the founder of modern medicine, dismissed such a concept thousands of years ago and gave psychological explanations for any mental issues or other somatic illnesses (Haque, 2004). Furthermore, recently, leading imams and Islamic scholars from the UK acknowledged the fact that Muslim communities are not protected from any mental health issues, which are on the rise worldwide (Asim, 2016). They also argued that there may still be some stigma attached to mental health issues in some Muslim communities, but that they were pointless. Therefore, the current

findings argue that there are no historic reasons in the Bangladeshi community for feeling stigma towards dementia. The current research also argues that a lack of stigma associated with dementia and mental health is not a phenomenon confined to the Bangladeshi Muslim community, but it is present in other Muslim communities as well.

My findings highlighted contradictory attitudes and a lack of caregiving preferences between phase one, two and three participants by drawing a clear line between the perceptions and reality of dementia caregiving. Evidence from the studies of phase one showed that majority of family members in South-Asian communities caring for older adults with dementia were primarily daughters-in-law, followed by wives and unmarried daughters, reflecting the traditional division of power and labour between men and women. In fact, most practical activities and household chores performed for elderly people with dementia were done so by female family members in the house, especially by the daughters-in-law. The evidence also shows that daughters-in-law in South-Asian communities have to play different roles based on time and relationship demands; for example, daughters-in-law were carers for persons with dementia (husbands or parents-in-law), and they were also carers of their young children (Godfrey & Townsend, 2001; Lawrence et al., 2008; Qadir et al., 2013). In addition, considering the status of women in the household, the distribution of power amongst women themselves is very complex in South-Asian communities. The relationship between daughters-in-law and mothers-in-law in the South-Asian communities is not always perceived as a positive and pleasant one to discuss.

Findings in phase two expanded on the findings of phase one, as it was highlighted that daughters-in-law were considered as default carers in the family. Culturally and religiously, Bangladeshi daughters-in-law are the primary carers and the pillars of family caregiving. The findings of phase two suggest that religious beliefs had an impact on Bangladeshi adults' perceptions and attitude towards dementia and caregiving. There was a striking resemblance between male and female focus group respondents' views on gender roles in the family and the increasing pressure of caregiving on women. Although males and females were highly analogous in their views of gender roles in the family, most women reported feeling isolated, withdrawn and dependent on their husbands. The findings indicate that women are being confined by pervasive traditional gender role expectations in the Bangladeshi community. The findings also indicate that since Bangladeshi daughters-in-law are the default family caregivers, seeking and accessing healthcare services is impractical.

Consistent with previous studies (Adamson & Donovan, 2005; Botsford et al., 2011; Emmatty, Bhatti, & Mukalel, 2006; Hirst, 2002; Milne & Chryssanthopoulou, 2005), the phase two participants' perceptions about daughters-in-law providing dementia care did not align with

phase three findings, where no daughters-in-law were the caregivers of their parents-in-law with dementia. The question may arise as to why other South-Asian daughters-in-law expressed the desire, and hence provided care, for their parents-in-law with dementia when the daughters-in-law in the current study adamantly rejected the caregiving responsibility. Certainly, in alignment with other South-Asian communities, the traditional Bangladeshi community also has a pervasive preference for daughters-in-law in providing family care; however, due to modernisation, it is essential not to dismiss the influence of education and financial aspects in determining the caregiving process in Bangladeshi families in the UK. Earlier studies found that in modern Britain, South-Asian women are rapidly increasing their participation in higher education and the labour market (Bagguley & Hussain, 2007; Dale, Fieldhouse, Shaheen, & Kalra, 2002; Wigfield & Turner, 2012). The current study in phase three found that daughters-in-law were engaged in employment while their parents-in-law were living with dementia, hence their inability to provide care was justified by their husbands and others in the family. Moreover, perhaps the British-born Bangladeshi daughters-in-law in phase three had better education and better language skills than the Indian-born or Bangladeshi-born daughters-in-law in phase one and two. Even though it is not uncommon, British-born Bangladeshi daughters-in-law have better education and language skills than their Bangladeshi-born husbands. It might be possible that British-born daughters-in-law declined their caregiving roles for their parents-in-law, but they extended their roles as spouses or mothers of their children or for their job responsibilities. Therefore, the assumption should not be made that the experience of other South Asian daughters-in-law is applicable to Bangladeshi daughters-in-law in the UK. More empirical research is needed to understand the complex relationships among Bangladeshi daughters-in-law, their husbands, parents-in-law, and their perceived gender roles and burden related to family caregiving.

On the other hand, similar to studies on Chinese and other BME communities (Chiu & Yu, 2001; Milne & Chryssanthopoulou, 2005), the current findings showed that sons or daughters as main family carers for their parents with dementia were highly motivated and felt an obligation to provide care. Unlike for other South Asian Muslim communities (Adamson, 2001; Mackenzie, 2006; Qadir et al., 2013), within the sample for this research, there was no evidence of negligence, abuse, annoyance, or blame toward the people with dementia while family carers were providing care. Perhaps their strong religious identities made them unique among other South Asian Muslim communities, as evidence found that Bangladeshi Muslims are more religious than other South Asian Muslim communities in the UK (Haque, 2000; Parveen et al., 2011). Indeed, Muslim communities are diverse (Rassool, 2000); perhaps Bangladeshi Muslim immigrants focus more on their religious identity than their South Asian ethnic identities. As a new immigrant group, by turning to religion, maybe Bangladeshi Muslim

communities benefitted from feeling isolated, which helped to ease psychosocial factors such as tension, racism, hostility, depression, hopelessness, and dementia and other mental health problems (Peek, 2005).

In addition, evidence from the current research challenges a previous study (Lawrence et al., 2008) which concluded that adult children as family carers who were born in the UK expressed less desire toward caregiving than family carers who were born in their countries of origin. The current study highlighted that regardless of their age gaps and countries of birth, the concept of caring is rooted in the filial obligation and religious framework of Islam. The findings also suggest that Bangladeshi adult children as family carers in my study sample influenced by filial obligation and the Islamic concepts contained in the Holy Qur'an. For example, in the Qur'an it is written *'And do good to parents. If any one of them or both reach old age, do not say to them: uff (a word or expression of anger or contempt) and do not scold them, and address them with respectful words' (17:23)*. As a result of this verse, first of all, to have dementia was believed to be the will of Allah and caring is believed to be an opportunity to seek forgiveness from Allah. In other words, perhaps adult children as family carers believed that if people with dementia were left without any help from their adult children, the children would be found wanting on the day of judgement. According to Islam, whoever suffers from any illnesses including dementia cannot be blamed. One who blamed or held a person with dementia in contempt would be committing a sin because health and illnesses and everything regarding a person are decided by Allah (Rassool, 2000). The current research shows that there is a good evidence that adult children caring for their parents with dementia in the Bangladeshi community. Again, this differs from previous studies which conclude that South Asian communities perceived that lack of family support was a major cause of dementia (Fontaine et al., 2007; Turner et al., 2005). Differences in South Asian participants' views and judgemental attitudes toward people with dementia and their family carers may be due to the fact that those studies were conducted among South Asian people without dementia and there were no family carers of people with dementia included in the study, hence, dementia was wrongly attributed to the lack of family support.

Previous research reported that, in the UK, despite the availability of public services and the growing number of South Asian people with dementia, few people with dementia and their family carers seek help from health and social care service providers (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Lawrence et al., 2008; McCleary et al., 2012; Mukadam et al., 2011; 2015). The reason is probably the lack of trust in healthcare services and service providers on the part of South Asian and other BME communities that has been highlighted in previous studies in the UK and elsewhere (Bowes & Wilkinson, 2003; Brown, Avis, & Hubbard, 2007; Fontaine et al., 2007; Jutlla, 2011; Kurtz & Street, 2006; LaVeist, Nickerson, & Bowie,

2000; Lawrence et al., 2008; Moriarty, 2008; Mukadam et al., 2011; Neale, Worrell, & Randhawa, 2009; Smith, Moreno-Leguizamon, & Grohmann, 2015; Whetten et al., 2006; Wilson & Deane, 2001). The study conducted by Whetten et al. (2006) found that mistrust toward healthcare services not only existed among BME healthcare service users, but also among the majority of White service users in the US. Whilst phase two of this current research supports existing evidence about seeking help and support from family members only, the results from phase three of the current study differ from the results of previous studies. The current study reported that family carers preferred to discuss any challenges associated with dementia with providers of healthcare services rather than contacting their friends and extended family members. The findings also highlighted that family carers' preferences to hold individual discussions with their White colleagues, GP, hospital doctors, nurses, and agency carers, as well as their involvement in the care, were instinctive and determined by their family situations. This was probably because the family carers were unsure that their next of kin would be of any help and some believed that asking for support would be impractical because they have their own families and problems. Notwithstanding this, feelings of hopelessness about illnesses, isolation from larger support groups and communities, and suffering in silence are contrary to the teachings of Islam. This argument is also supported by the Prophet Muhammad (pbuh) who said *'tie up your camel and then trust in God that it will not run away'*. Therefore, in contrast to some of the evidence regarding other South Asians, Bangladeshi family carers in this current research not only sought help and information from GP, hospitals, and social services but also learned details about dementia from the internet.

In fact, each ethnic community has its own set of norms, values, principles, ideas, religion and culture which may influence each generation in how they deal with their health and social care needs (Cohen, 2009; Gopal, 2014). Furthermore, immigrants' age and education, including generational differences, may determine their pattern of acculturation and acceptance of formal services in their countries of settlement. As first-generation immigrants, particularly, have a link to their country of origin and a lack of acculturation, as well as a lack of adaptation to the norms and values of the country of origin, they are probably more likely to maintain their traditional caring roles rather than seek support (Bhui & Bhugra, 2010; Bui, 2003; Emery, 2013). When Bangladeshi family carers seek help from service providers, it seems unfamiliar and sometimes unacceptable to the previous generation. The current generation of Bangladeshis, who were born and brought up in the UK, clearly have grown up in a modern world where they have been exposed to mainstream service providers from their early years of life. For instance, young family carers in this study have approached and integrated with mainstream services, thereby making it possible for the mainstream services to provide help and support. On the other hand, older generations often find it difficult to keep up with the

service availability and the challenge of service providers to understand the service needs of older generations becomes even greater.

Phase three's findings are congruent with McCleary et al.'s (2012) study of ethnically diverse communities' pathways to dementia diagnoses, which found that a diagnosis generally takes place after a critical medical condition or a hospital admission. In addition, the findings of this study argue that, while personal care for people with dementia was managed by family carers, help and support from care agencies, including the Alzheimer's Society, hospital nurses, and social services, was also greatly appreciated. However, this is not similar to the findings of previous studies: that people from South Asian communities prefer their own family members to provide personal care over health and social services (Katbamna, Ahmad, Bhakta, Baker, & Parker, 2004; Merrell et al., 2005). Several possible reasons for this are the greatness of carer load, preference for family carers from same ethnic and religious backgrounds, and the need for incontinence care, especially from same sex carers. On the other hand, these circumstances sometimes reflect the fact that South Asians and other ethnic minorities are oblivious of the existence of any support available for people with dementia and their family carers; thus, looking after their own or depending on extended family support at critical stages seems to be their only option.

Findings from this research show how Bangladeshi participants' hearty desires to care for their relatives with dementia fall within the family and how the meaning of care, the impact of care, and the interpersonal and religious contexts of caregiving create negative perceptions of residential home care. The interpersonal motives of the current generation of family carers seem far from fading away; maybe the caregiving attitude is inherent within the UK Bangladeshi families but is also strongly influenced by religious factors. Young Bangladeshi Muslims in the UK are influenced by the revivalist Islam, which is the new, purist Islamic commitment towards family caregiving, friends, religious communities and neighbours. These types of Islamic norms and values contrast with the comparatively composed forms of Islam that were traditionally found back in Bangladesh or among Bangladeshi Muslims in the USA (Kibria, 2008; Rozario, 2005). Islamic values are strong permanent forces within the Bangladeshi community and shape various aspects of caregiving, such as family carers' interpersonal motives, traditional values and culture. If family carers want to remain good Muslims, they must fear retribution from Allah for not providing care for their relatives with dementia. Therefore, family carers' religious beliefs as universal norms and values will consistently appear to increase their interpersonal motives and obligations to provide care from their family home. In other words, it may be possible that their caregiving attitudes were taken for granted, as they believed they would be better off in this world, as well as in the hereafter, by providing care for people with dementia. It could be argued that providing care

is more valuable for family carers than receiving care for people with dementia, as it is the only way to fulfil family carers' religious duties and secure their entry into heaven. In a similar vein, the idea of sending their relatives with dementia to a residential care home is deemed not only as a last resort but deeply unacceptable.

Finally, the findings show no guarantee that Bangladeshi people would utilise the provided health services, but a consistent theme emerged from both phases two and three of this study about a desire for the development of a separate, specialised dementia service provision for the UK Bangladeshi community. Separate specialist services for specific ethnic minority communities have thrived in the USA, but the development of separate services for BME communities is frustratingly slow in the UK (Bhui & Sashidharan, 2003). However, since the beginning of the National Health Services (NHS), specialism has become the dominant paradigm in the British healthcare system. For example, there are currently 146 specialised services, such as chemotherapy, renal and mental health problems, rare cancers and other areas, costing the NHS more than £14 billion a year (Kemsley, 2016). In a similar vein, potentially, it is difficult, if not impossible, to separate the residential care services for ethnic minorities from mainstream home care services. Separate specialist dementia service provisions for Bangladeshi people would mean the service would have to be run and managed by the Bangladeshi Muslim community. As such, implementation remains a distant prospect. There are a number of obstacles to this: as the current study found, Bangladeshi people do not want to be formal carers when the demands of receiving care from Bangladeshi Muslim family carers are too high. Instead, as it stands from this study, the preference of home-based respite is the one way to best serve this community. Service providers need to target more religious resources in supporting Bangladeshi people with dementia and their family carers to continue their ability to live with dementia at home. To conclude, unlike other South Asian attitudes toward mainstream care homes in the UK (Bowes & Wilkinson, 2003; Godfrey & Townsend, 2001), Bangladeshi family carers are very reluctant to send their relatives with dementia to mainstream care homes and merely accept the home-based respite care services.

6.4 Researcher's reflections of the research process

Prior to beginning my PhD research training, I had assumed that recruiting participants would perhaps be the most challenging part of this investigation. Having previously completed a Master's research project, utilising a qualitative approach conducted among the Bangladeshi community in London, I was reminded of the difficulties encountered when recruiting research participants, exacerbated by a short time frame. Soon, it became apparent that recruiting

participants for this research study would be the biggest challenge of this investigation and thus, I set out to develop a completely new, comprehensive recruitment strategy among the Bangladeshi community in London and Portsmouth.

One aspect of my approach to recruitment was to contact the Bangladesh Welfare Association (BWA), which deserves much merit, as it was one of the first charitable organisations in the UK and was established in 1954. The BWA has its own dedicated community services that are available all over the UK. The BWA also has branches in every big town and city in the UK, and it is dedicated to serving the Bangladeshi community. I used their generous services to locate potential participants for my Master's project in London. Likewise, at the beginning of recruitment for this PhD research study, I made early contact with the BWA services. Beginning with the BWA, I started to establish contacts among local Bangladeshi community leaders, imams, and social workers of Bangladeshi origin. Regular meetings with various community leaders followed, a number of which my first and second supervisors attended.

Another challenge was that, despite being a Bengali-speaking Bangladeshi and, as such, considering myself as an insider within the Bangladeshi community, I was considered an outsider in regional terms. Specifically, the majority of Bangladeshi people in the UK are from one region, Sylhet, which is located in the eastern region of Bangladesh; however, I originate from a different region, the Dhaka division, which is located in the south-central region of Bangladesh. Thus, the mainstream Bangladeshi community in the UK actually refer to themselves as being part of the Sylheti community, rather than the Bangladeshi community (GSC UK, 2012). Stated differently, the regional identity of the Bangladeshi community is closely connected to the Sylhet, whereas their national identity is a complex issue. Both my regional and national identities differ from those of the British Bangladeshi community, as my regional and national identities are Dhaka (Dhakaiya or non-Sylheti) and Bangladeshi, respectively, whereas those in the Bangladeshi community primarily identify as Sylheti and British. However, my closeness in proximity to the culture of my target group made me at least a partial insider for the purposes of this study.

I was aware that as an insider, I both had advantages and would face challenges. Evidence shows that being an insider increases validity through an understanding and closeness with participants in the research (Kanuha, 2000). However, one could argue that my insider perspective and shared experiences could promote cultural bias during the analysis process. Although it is almost impossible for any researcher to remain fully objective in their research, all researchers should try to overcome bias. Whilst I recognise that as an 'insider' from the Bangladeshi community, this may have influenced the interpretation of the collected data, I tried to stay 'open to the data' and manage bias. Research suggests that bias and subjectivity

can be minimised by remaining open when difficulties arise through diligent self-examination. There was no conflict of interest between myself, the interviewees or the various gatekeepers of this study. However, I always carried a reflective diary where I could record concise, reflective field notes and memos during and after each interview. The reflective diary included reflections on my own subjectivity, self-criticism and judgement, which helped to develop reflexivity in the research. Reflexivity helped me reflect upon my actions and values during the study. Particularly, reflexivity helped me to prepare and write up the data and to assess the opinions and views of others (Seale, 2012).

Lastly, various problems were encountered in the third phase of this study. Mutual trust became more important among the community members after the reported death of several Bangladeshi young men from Portsmouth who went to fight in Syria. Pressure was escalating inside and outside the Bangladeshi community in Portsmouth and community members became suspicious about the authorities. As a result, it was sometimes difficult to get through to potential participants in the mosques. Secondly, the recruitment of female participants was another challenging task for me. During the follow up phone calls, due to the gender differences between me and the family carers, it was sometimes problematic to get through to the appropriate person in the family. The male family members often answered the telephone and were unwilling to pass the phone to the female family members who were the main carers. On the other hand, in London, the Bangladeshi representative from the local Alzheimer's Society was contacted over the phone to find out if the Bangladeshi family carers would be interested to participate in the study. In addition, I became aware that there were a few more Bangladeshi-managed charity organisations that were running some support groups for Bangladeshi people with dementia and their family carers. However, in all cases, representatives were very difficult to get a hold of. I had to send multiple emails and make multiple phone calls before the representatives agreed to approach the family carers to discuss participating in the research.

6.5 Limitations

This is the first study that explored the perspectives of Bangladeshi adults without dementia as well as the experiences of the family carers of relatives with dementia. As a first study, this research covered the areas that it intended to in a systematic way. However, there were a few limitations in this study and future research in the Bangladeshi community may look to expand on these areas.

This study did not include the views and experiences of dementia from Bangladeshi persons with dementia. Due to strict ethical reasons, I was unable to include people with dementia in

this research although interviews involving people with dementia would have strengthened the research. Sampling issues are a key problem in research involving South-Asian people with dementia and their family carers. Historically, South-Asian immigrants have been a closed group in the UK (Bowes & Wilkinson, 2002). Samples are limited by the relatively low response rates involved in this research. Unfortunately, due to my gender and other suspicious issues (perhaps I am a government secret agent), Bangladeshi people are the most difficult to reach and recruit for research participation.

Due to the small quantity of participants obtained for this study, the sample may not be representative of all Bangladeshi carers of people with dementia. Although it was a small sample, it was a purposive sample, where participants were selected according to the study needs; the participation of these individuals enabled me to answer my research questions (Bogdan & Biklen, 1998; Glaser & Strauss, 1967). In both phase two and three of this current study, adoption of the maximum variation sampling method ensured that a wide range of viewpoints were included in the data collection and analysis. Apart from gender, which was represented across the two phases, multiple variations were used with the aim of capturing information from a diverse population of men and women from the Bangladeshi community. Participants were sought by choosing, where possible, men and women of different age groups and in a broad range of social classes (in terms of employment status and occupation), and marital status.

There were limitations in the representativeness and significance of the findings. The participants' age and gender between phases two and three of the study were different, meaning that the participants were not truly representative of each other. The male focus group was attended by a much older age group than those recruited in both the female focus group and the dementia family carers' group; moreover, all the focus group attendees had a lack of knowledge of dementia. Therefore, the findings from the focus groups may not be fully transferable across the entire population, nor among dementia family carers. Nevertheless, this study also had a minimum age criterion of 18 years of age; as such, the results are not readily transferable to younger populations.

Additionally, the sample (Portsmouth and London-based family carers) was geographically restricted in such a way that outcomes could not be generalised to the population of family carers as a whole. Research was not carried out all over the UK and therefore, lacked the views of Bangladeshi community members outside of Portsmouth and London. The findings of this research would have been more generalisable if data had been collected from various parts of the UK, such as Luton, Birmingham, Manchester, Cardiff, and Glasgow. This might give a better suggestion of how and when Bangladeshi family carers access dementia services

and explore their experiences to be able to compare between locations. However, due to its limited time frame, this study aimed to collect data from Portsmouth and London Bangladeshi communities and did achieve that.

When addressing the limitations and evaluating the quality of qualitative data collection and analysis, one must consider the trustworthiness, generalisability, reliability and reflexivity of the findings. These limitations were minimised in the following ways. First, I involved key gatekeepers and potential participants in the research design and evaluation processes. On several occasions I, along with my supervisors, met with community members and key gatekeepers at the Portsmouth mosque. As suggested by community members and gatekeepers, I conducted two separate focus group discussions, one each for males and females only, to attract more respondents. Then, I leveraged two critical techniques to evaluate my study: triangulation and member checking. I collected primary data using two methods (focus group discussions and individual semi-structured interviews). I used source or setting triangulation (i.e., I interviewed Bangladeshi community members from diverse backgrounds; these included males and females holding different professions, of different ages, and in two different settings – London and Portsmouth). Finally, I employed analysis triangulation using NVivo, a qualitative software, as well as pen-and-paper data analysis. I used NVivo as an audit trail; as a result, my qualitative analysis became very transparent and trustworthy. Lastly, I extensively utilized member checking. Once I completed data collection and transcribed the focus group and semi-structured interview data, I sent the results back to the participants for their review.

Another limitation of this study is that perhaps the sample of participants was biased by self-selection. All of the participants who took part in the study, including the 21 male and female participants in phase two and the six family carers from both gender groups in phase three, strongly denied stigma attached to their perceptions and understanding of dementia. It is possible that family carers who were particularly stigmatised may not have taken part in the study; however, the family carers who had been in the caring role for a long period of time and who were regular attendees of the Bangladeshi family carer group meetings suggested that community members' attitudes toward them were non-stigmatised.

Moreover, perhaps my gender was the reason for the small sample size in this study. The findings may be tentative because of the small sample size, but many of our findings are consistent with existing research, which provides direction for improving dementia services and further research. As a final point, this qualitative study of understanding dementia and caregiving experiences amongst the Bangladeshi community, a marginalised South Asian ethnic minority group in the UK, has constructed a novel experiential, empirical and theoretical

aid to current knowledge. Empirically, the study has focused on older Bangladeshi people suffering from dementia, which is also prevalent within BAME communities on a wider scale, as well as among the white population. However, the current study has discovered the breadth of healthcare provisions and family carers' experiences of living with dementia patients, where both sides have gender specific aspects. Evidently, there are some attributes of the results that are explicit to the Bangladeshi context only. Notwithstanding this, the findings, both empirically and theoretically, are of relevance to other service providers and people with dementia, as well as to their family carers both in general and to those from other immigrant Muslim or South Asian communities.

6.6 Implications and recommendations for research, policy, and practice

6.6.1 Recommendations for future research

To the best of my knowledge, there is no research regarding Bangladeshi people living with dementia, in the UK or elsewhere apart from the current study. As a first study among the Bangladeshis, it is believed that involving people with dementia in the research is as important as involving family carers of people with dementia. It is unlikely that the insights or new knowledge gained from the current research will be sufficient to fully understand the perspectives of older Bangladeshi people who live with dementia. As the current study has pointed out, research and practice need to align to build a cumulative knowledge base that focuses on the interests of both Bangladeshi people with dementia and their family carers. Furthermore, in the context of the current study, it is essential to recognise that research can impact action and produce new knowledge that can be applicable outside of the context of the research. The research also has implications for other UK BAME and White populations living with dementia, their family carers, significant others and healthcare professionals. Therefore, future research needs to contextualise its findings within the larger body of research so that its results can have implications for policy.

Although, traditionally, major challenges need to be considered when involving people with dementia in research, currently there is increasing recognition among researchers that people with dementia should be included in research as active participants (Beuscher & Grando, 2009; Dewing, 2002, 2007; Hubbard, Downs, & Tester, 2003; McKeown, Clarke, Ingleton, & Repper, 2010; Nygård, 2006). To the best of my knowledge, the views and experiences of people with dementia is not only an under-researched area among Bangladeshis, but also among other BAME communities. Therefore, it is believed that researchers, practitioners and policy makers need to know about experiences with dementia and hear the voices of people with dementia. Conversely, a failure to include people with dementia in the Bangladeshi

community in England will place future researchers at risk of bias by imposing their own ideas, perceptions and interpretations onto the accounts of the people with dementia in this community. In order to include people with dementia, researchers will need to seek further techniques and advice from the current literature on people with dementia around the world. As well, they will need to consider the impact of the Mental Capacity Act (MCA) 2005 on people with dementia. The MCA and other research shows that a diagnosis of dementia does not necessarily mean that the person diagnosed has no capacity to give or refuse consent (Department for Constitutional Affairs, 2007; Dewing, 2007; Nygård, 2006). More research suggests that building a good relationship with the participants with dementia may help the researcher obtain consent more easily (Nygård, 2006). Therefore, it is believed that having a researcher and gatekeepers from the same community who speak the same language and share the same culture may help to create some good relationships between the research community, the participants with dementia and their family carers, and the Bangladeshi community in general. Nonetheless, there may be some benefits for the people with dementia if the researcher can include them in the research by building good relationships with them. As a result, for example, older Bangladeshi people with dementia may view themselves as valued persons in the wider community if researchers show interest in them (Hellström, Nolan, Nordenfelt, & Lundh, 2007).

Similarly, the MCA (2005) supports the appointment of a proxy or 'consultee' in cases where the research participant lacks the capacity to give informed consent (Alonzi & Pringle, 2007). This is reasonable because the persons with dementia are well known by family carers for a long time prior to and after the dementia diagnosis; hence, the family carers will be able to understand the attitudes of the persons with dementia and will be able to give or refuse consent (Black, Rabins, Sugarman, & Karlawish, 2010; Higgins, 2012). Responsibility, however, will remain with the researcher to ensure that involvement in the research will be in the participants' best interests and will be in accordance with their wishes. Furthermore, Dewing (2007) proposes a model of the consent process comprising five elements: preparation and background, establishing the basis for consent, initial consent, ongoing consent monitoring, and feedback and support. Researchers may choose to consider this as a pathway for undertaking research with people with dementia, in addition to more traditional approaches. Lastly, whilst future research on people with dementia may not directly benefit the participants, it will have a good chance of benefitting society as a whole and people with dementia in the future. The best way to understand the views about dementia and the perceptions, beliefs, and experiences of older Bangladeshi people with dementia will be to include them in the research. Therefore, specific ethical issues must be considered for participants who lack the necessary mental capacity to make a free and informed choice.

Since this is the first qualitative study among the Bangladeshi community in the UK, there is no doubt that policy makers, practitioners, and the wider community should expect to see many further studies within this community to examine their various caregiving needs based on their religious needs. Future research can build on this current research, which identifies a clear path to make things better by promoting a religiously appropriate, dementia-friendly atmosphere for Bangladeshi people in the UK and elsewhere. Caregiving accountability among Bangladeshi families does not necessarily replicate the reality of White British or European families, as discussed earlier; instead, there is an assumption that 'they look after their own'. Certainly, Bangladeshi family carers are the backbone of the management of dementia caregiving; however, family carers' sensitivities toward their gender roles require further investigation. Based on the findings of the current study, there is also a possibility for a research plan which can explore how a carer's gender role ideology is associated with the carer's burden and strain. Are same-sex carers keener to accept the roles of family carers and are opposite sex carers more reluctant to be family carers of their relatives with dementia? Whilst in this current study, dealing with incontinence and performing personal caring tasks influenced help-seeking for some opposite sex carers, one same sex carer continued her caregiving tasks regardless. For Bangladeshi family carers, caregiving is a physically burdensome task, but struggling to maintain their religious beliefs and gender role ideologies is more stressful. Therefore, a more thorough examination of the notion of gender role ideologies in dementia caregiving and family carer's gender differences as major triggers for help-seeking among Bangladeshi communities is needed. Nevertheless, because gender-based caregiving interferes with their religious ideologies, further research will benefit from investigating how Bangladeshi Muslims' religious values influence experiences of caring for a person with dementia and how their religious beliefs affect their access to and experience of dementia care services.

6.6.2 Implications for policy and practice

Despite the Department of Health's declaration (DoH, 2002) that South Asians, such as Bangladeshis, were at a higher risk of developing dementia due to having an advanced prevalence of diabetes compared to the overall UK population, prior to the current research, there was no study investigating the Bangladeshi community's understanding and awareness of dementia. Even with the UK government's National Dementia Strategy (2009) for increasing the rate of early diagnosis of dementia, there is little direct evidence within the growing body of research about the barriers to dementia diagnoses among the Bangladeshi community. There is a general consensus that dementia among the South Asian ethnic minority population remains under-disclosed, under-diagnosed and under-treated in the UK. Regardless of ethnic

or racial groups, the number of people who are suffering from dementia in the UK is rapidly increasing and, by the ex-Prime Minister David Cameron's own admission, dementia has become a national crisis (Kmietowicz, 2012). The establishment of 'culturally competent' care for people with dementia is emphasised in the Prime Minister's Challenge on Dementia 2020. In addition, the 2008 carers' strategy designed both a short-term outline and long-term innovations for the future provision of carers. The project was supported by extra funding and proposed to reinforce carers in their caring role and empower them in their communications with service providers (DoH, 2008).

In 1997, the concept of 'personhood' fully emerged after its introduction by Tom Kitwood. Kitwood defined 'personhood' as the 'status or standing bestowed upon one human being, by others, in the context of social relationships and social being. It implies recognition, respect and trust' (Kitwood, 1997, p. 8). The National Dementia Strategy (DoH, 2009) outlined a five-year strategic plan which prioritised Kitwood's person-centred care as one of the top objectives to empower people with dementia and those who care for them. The current study revealed that person-centred care is the centre of all discourses about the experiences of dementia caregiving among the Bangladeshi family carers. Developing strategies to build positive relationships with Bangladeshi people with dementia and their family carers will not be possible without bringing a person-centred care approach to the centre of policy makers' and practitioners' attention. Bangladeshis may have some common beliefs, norms and values with other South Asians and other Muslim communities. As discussed earlier, however, Bangladeshi and other South Asian and Muslim communities are not homogeneous groups. Therefore, policy makers and service providers need to have a deep understanding of Bangladeshi community members' religious and cultural backgrounds. Bangladeshi people with dementia should be considered as a separate group, with individual care receiving requests, such as the family carers having a Bangladeshi cultural background, complete with high regard for family and elders, and personal modesty. Their Islamic values and religious beliefs need to be appreciated and incorporated into their caregiving plans.

In addition, the All Party Parliamentary Group for dementia (APPG) issued a report in 2013, entitled 'Dementia does not discriminate', which was focused on BAME communities' knowledge and experiences of dementia and care and support services. In summary, the APPG provided some illustrations of BAME communities receiving reduced care and support that did not meet cultural needs. Echoing with the Social Services Inspectorate investigation (Murray & Brown, 1998), the report also mentioned the common assumption, or possibly the stereotypical expectation, in British society that BAME families 'look after their own'. This view exists among staff from voluntary services, social services, and even the minority ethnic groups themselves (Willis, 2010). These preconceived judgements about the Bangladeshi and

other UK BAME communities not only damage their help seeking behaviours but also contribute to the failure of service providers. The results from the current study notably contradict the assumption that they 'look after their own', as Bangladeshi family carers often desperately need help from outside the family. The assumption that they 'look after their own' failed to take into consideration the complex nature of dementia caregiving for relatives with dementia such as opposite sex caregiving issues, employment related issues, and changes in perceived caregiving obligations among the daughters-in-law. Therefore, service providers need to be more sensitive when making assumptions about Bangladeshis and other South Asian immigrants.

Notwithstanding, the guidelines of the joint National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) recommend culturally competent care among service providers and that care should be culturally, religiously and spiritually sensitive (NICE/SCIE, 2006). In addition to this, in June 2016, for the first time, a strategic partnership of organisations published their Dementia Equity and Rights report, which highlighted the main issues arising for people with dementia and carers from socially diverse groups, including older people with dementia, young onset dementia, dementia within BAME communities, lesbian, gay, bisexual, and transgender (LGBT), and different socio-economic populations (REF, 2016). The report emphasised the significance of services that should be able to support people with dementia from diverse backgrounds and cultures. Dementia has, historically, been unrelated to equity and rights, where ethnic minority groups have been left out or misrepresented by the mainstream service providers. Although the report focused on inequalities and provided recommendations for how to provide better care among ethnic minorities, the provision of services did not consider the needs of particular groups, such as the Bangladeshi immigrant community.

The results of the current research have important implications for health and social care service providers working with Bangladeshi families of people with dementia and their family carers. The overall findings revealed that there is a lack of appropriate care for Bangladeshi people with dementia and their family carers living in England. The following recommendations refer to the Bangladeshi community in England but could be relevant to healthcare professionals working with Bangladeshi communities in other countries. Health and social care providers should have professional development regarding the Bangladeshi Muslim culture, beliefs and lifestyles when they work with the Bangladeshi immigrant community and they should consider how this affects their consultations and advice to family carers. Relevant healthcare staff should be given colloquial Bengali language training or have interpreters through clinic-based link workers.

It is apparent from this investigation that participants have diverse opinions on how they select healthcare services. As exhibited by the above discussion, gaps remain in each of the service providers (e.g. respite care, day care, and care home services), and the participants expressed that it would be beneficial for service providers to be trained in religious, cultural, and language skills. The views of Bangladeshi dementia family carers and their relatives with dementia were hardly considered in policy making, but the findings of this research can have a marked effect on developing services or creating them to tackle the distinct caregiving demands of the Bangladeshi community. Thus, the following recommendations are highlighted as the researcher's response to the study's findings. Challenges described by the research participants were identified and initiatives worthy of consideration by practitioners, policy makers, researchers were shown.

The Department of Health should consider funding a pilot campaign that would aim to raise the awareness of dementia among the Bangladeshi community in Portsmouth or other areas, rather than a campaign that is concentrated on London BAME communities only. Over the last few years, the Department of Health has funded a three-year 'Connecting Communities Project', focusing on eight London boroughs, namely, Croydon, Enfield, Hillingdon, Hounslow, Lambeth, Merton, Newham and Redbridge. That project provided the opportunity to report known issues related to dementia awareness, as well as immigrant communities' engagement with dementia care services. However, any future project should consider concentrating on one unique community at a time rather than representing many different communities under the so-called umbrella term 'BAME community', because ethnic minorities are not a homogeneous group.

Previous research reported that Bangladeshis are a somewhat closed group and early researchers struggled to identify and involve Bangladeshi participants in their research. Therefore, Portsmouth, London and other local authorities should ensure that the Joint Strategic Needs Assessment (JSNA) includes information on the numbers of people from Bangladeshi communities, their gender and age profiles, and their estimated numbers of people with dementia and family carers.

As the current study revealed that participants in Portsmouth never heard anything from the Alzheimer's Society of Portsmouth, the Society should consider raising awareness among the Bangladeshi community. The Alzheimer's Society should boost their Dementia Friends Programme among the Bangladeshi ethnic minority in Portsmouth so that the number of Dementia Champions in the programme will increase within this community. This opportunity will provide better knowledge and awareness about dementia and may reduce the caregiving burden.

As recommended by most participants in this study, service providers should improve their knowledge and skills by learning about the Bengali language, Islamic values and Bangladeshi culturally-sensitive care. Alternatively, service providers may recruit more staff from the Bangladeshi community who will be involved in the care and support for their own community members. However, family carers should be encouraged to take dementia training courses to deliver the best service to their relatives with dementia. As well, the courses will help them learn more about the dementia disease and subsequent daily caregiving consequences.

Another approach would be to partner with religious leaders such as imams, community leaders, community development workers, policy makers, practitioners and researchers to raise an awareness of dementia and to develop services for Bangladeshi community members. Imams should receive special training on dementia and caregiving perspectives so that they can deliver that knowledge during their weekly Friday sermons. Mosques can be used as very important venues for dementia awareness events, where more community members would be encouraged to attend. A strategic plan can be developed that will target and benefit not only Bangladeshi Muslim community members, but also other Muslims who use mosques as places of worship as a setting for dementia awareness. Within that strategic plan, imams should take advantage of their leadership roles to help spread messages about raising dementia awareness and the challenges faced by family carers. Individual studies previously conducted in Bangladesh, Afghanistan, the UK and Austria showed that partnerships with imams, and thereby mosques, can serve to improve community members' health beliefs, while reducing their healthcare inequalities. For example, imams in Bangladesh and Afghanistan helped increase community members' awareness of tuberculosis, and imams in Afghanistan used the Qur'an to promote birth-control planning (Mason, 2010; Rifat et al., 2008). Moreover, imams in the UK and Austria raised awareness about heart disease through their mosque-based lecture series (Bader, Musshauer, Sahin, Bezirkan, & Hochleitner, 2006; Zaidi, 2006). Therefore, a similar approach can be adopted in the UK, where imams can play key roles in framing concepts of dementia and family caregiving, as well as to increase dementia awareness. Although imams are men, both male and female mosque attendees can be guided and supported by imams. An event for female Bangladeshi family carers could be organised by imams to help the former learn and share their experiences related to caregiving and help-seeking behaviours.

Last but not least, sadly, diagnosis rates for dementia have been low, meaning that not only Bangladeshi and other BAME communities have experienced missed diagnoses of dementia, but also the wider population. Only 48 per cent of people with dementia obtained a diagnosis in England (Baker & Parkin, 2016). Findings from this current study recommend that there is a need for GP to develop better ways to detect dementia and give referrals in the initial phases

of the disease. Failure to make a timely diagnosis and referral may lead to years of delay in getting the required services. Early communication with GP and subsequently, timely recognition of dementia symptoms, as well as family carers' knowledge about dementia, may help the family carer to better understand their relatives' day to day activities. This would go a long way toward raising dementia awareness among the wider Bangladeshi community and would be followed by improvements in the quality of life both for people with dementia and their family carers.

6.7 Conclusion

To conclude, for the first time, this study has presented some valuable insights into the perspectives of Bangladeshi community members and family carers of the Bangladeshi people with dementia living in Portsmouth and London. Bangladeshi family carers living in the UK seek to maintain their values of providing family care for their relatives with dementia by constantly adhering to their interpersonal motives and Islamic principles. The findings of this research add new knowledge to the body of existing research on South Asian immigrants' dementia knowledge and awareness, but further research is required to fully understand person-centred care for Bangladeshi people with dementia based on their religious values and principles. However, the main purpose of this current research, which was to identify the level of knowledge and awareness of dementia among Bangladeshi community members, has been achieved. The results will provide an understanding to the service providers, policy makers and researchers of how dementia and family caregiving is experienced in the Bangladeshi community and why it has remained unreported and labelled within the broader BAME communities. Previous research on the experiences of family carers of people with dementia in BAME communities delivered practical understandings of the position of women in households, such as daughters-in-law. However, it also provided insight on the role of males as family carers and their experiences maintaining their marriages while still shouldering the burdens of full-time complex caregiving roles. A thorough analysis of this current research postulated not just new knowledge about Bangladeshi daughters-in-law who shifted their roles, but also for the first time, the results revealed Bangladeshi women's autonomy in caregiving decision-making, which is positively accepted by their husbands. The shifting role of women, from being traditional daughters-in-law to decision-makers, has allowed them to choose not to be dementia family carers for their Bangladeshi parents-in-law, which has consequences, significance and validity within the Bangladeshi as well as in the South Asian or other BAME immigrant communities.

Another important, distinctive aspect of this current research that was inconsistent with previous research was that it explored myths and misconceptions about the stigma attached to dementia, which was not something Bangladeshi adults without dementia or dementia family carers had experienced along their caring journey. This research revealed that the Bangladeshi Muslim community showed a very pragmatic attitude toward dementia, which was widely accepted as a medical condition and for which family carers openly sought health and social care support. Nevertheless, the data analysis captured underlying principles of their religious beliefs in the acceptance of dementia as a disease and in help-seeking, which was influenced by the Qu'ranic verses and Prophetic traditions. The Prophet Muhammad (pbuh) said, *'no misfortune or disease befalls a Muslim, no worry or grief or harm or distress – not even a thorn that pricks him – but God will expiate for some of his sins because of that.'* Even the Prophet Muhammad (pbuh) sought healthcare support for any illness and encouraged his family, companions, and Muslims at large, to seek appropriate healthcare support. Moreover, Islam considers all diseases, including mental illnesses, as trials or tests from God and those types of suffering expiate sins. In a similar vein, not only will people with dementia be rewarded in the hereafter, but also their family carers and family members who bear with them throughout the ordeal. Even the visitors of dementia patients will get their reward from Allah. The wider BAME communities may interpret dementia differently and may have preferred approaches of help seeking, but in the Bangladeshi community, Islam plays a pivotal role in their understanding of dementia and access to services. In order to engage Bangladeshi immigrants with dementia services, their explicit religious identities cannot be ignored. The experience of dementia can be seen as one of the examples of the ability of their religious identity to overcome any stigma-related issues with illness, as well as to deal with caregiving consequences.

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Appendices

Appendix A University of Portsmouth Science Faculty Ethics Committee Application Form for Phase Two of the study and Favourable Ethical Opinion Letter

Science Faculty Ethics Committee (SFEC)

ETHICAL REVIEW APPLICATION FORM¹

i. **Proposal Title:** Understanding knowledge and attitudes towards older people and dementia among the Bangladeshi community in England – Part two: A focus group study on adults of Bangladeshi origin

ii. **Principal Investigator (PI):** Mr Muhammad Zakir Hossain (PhD Student)

iii. **Co-investigator(s):** N/A

iv. **Supervisor(s)²:** First supervisor: Dr Ann Dewey, University of Portsmouth;
Second supervisor: Dr Yohai Hakak, University of Portsmouth;
Third & external supervisor: Dr Karan Jutla, University of Worcester

v. **School / Department:** School of Health Sciences and Social Work

vi. **Date of Submission:** 25.04.2014

vii. **Proposed study start date³:** May 2014

viii. **Is the research**

a. Staff b. Doctoral Student c. ~~Masters Student~~

ix. **Review Type**

a. ~~Full committee~~ b. Light-touch review

Rationale for review type choice (no more than 50 words):

The research participants will be adults' (minimum 18 years to no upper age limit) and therefore, minimal risks have been identified in this focus groups interviews study. Moreover, comments from two SHSSW reviewers did not identify any relevant ethical risks by carrying out this study, hence light touch review.

x. **Funding details**

a. ~~Fully funded by the University of Portsmouth.~~
b. ~~Jointly funded between UoP (X %) and (Y %)~~
c. Fully funded by: Mr Muhammad Zakir Hossain (PhD Student)

xi. **Peer Review** - Please confirm that the proposed research has been peer reviewed and provide a copy of the reviewers' response and the updated protocol / proposal. Your proposal will not be reviewed again but is for information to support ethical review.

¹ Please read the notes if you have not submitted an application to the SFEC previously

² If the PI is a student.

³ The exact date of starting may not be known, but please indicate the likely start date, mindful of the timescales for ethical review.



Faculty of Science
University of Portsmouth
St Michael's Building
White Swan Road
PORTSMOUTH
PO1 2DT

Mr M. Hossain
SHSSW
19th May 2014

FAVOURABLE OPINION

Protocol Title: Understanding knowledge and attitudes towards older people and dementia among the Bangladeshi community in England-Part two: A focus group study on adults of Bangladeshi origin
Date Reviewed: 1st-19th May 2014

Dear Mr Hossain,

Thank you for submitting your protocol for ethical review. Your application has been reviewed and I am pleased to inform you that it has been given a favourable opinion by the Science Faculty Ethics Committee. The following comments were made for you to consider:

Reviewer 1: My only comment would be to ensure that the applicant realises that the third phase of the study, which is not included in this application, will almost certainly raise different ethical issues and will need to be reviewed separately.

Reviewer 2: Just to comment that this is almost a model application. The manner in which the docs have been presented and the exceptional quality of the peer review make ethical review a straightforward process.

Reviewer 3: This application was very thorough and I do not see any substantial ethical issues with the study. I have 3 minor comments.

1. I assume that the University's insurance will cover this study off site
2. In appendix 2 please include the fact that the study has been reviewed by SFEC and been given a favourable opinion
3. In appendix 4, if a student wishes to volunteer - will they be classed as not working or should you have a separate category for them?

Reviewer 4: I have looked at the research proposal and I do not see any ethical issues with it; the students has clearly thought the project through thoroughly.

Please notify us in the future of any substantial amendments that may be required and send us a final study report. Good luck with the study.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'John Crossland'.

Dr John Crossland (SHSSW)
Science Faculty Ethics Committee

CC -
Dr Chris Markham – Chair of SFEC
Dr Jim House – Vice Chair of SFEC
Holly Shawyer – Faculty Administrator

**Appendix B University of Portsmouth Science Faculty Ethics Committee
Application Form for Phase Three of the study and Favourable Ethical Opinion
Letter**

Science Faculty Ethics Committee (SFEC)

ETHICAL REVIEW APPLICATION FORM¹

- i. **Proposal Title:** Views and Experiences of Bangladeshi Informal Carers of People with Dementia in England: A Qualitative Study
- ii. **Principal Investigator (PI):** Mr Muhammad Zakir Hossain (PhD Student)
- iii. **Co-investigator(s):** N/A
- iv. **Supervisor(s)²:** First supervisor: Dr Ann Dewey, University of Portsmouth;
Second supervisor: Dr Yohai Hakak, Brunel University;
Third supervisor: Dr Karan Jutlla, University of Worcester
- v. **School / Department:** School of Health Sciences and Social Work
- vi. **Date of Submission:** 19 Dec, 2014
- vii. **Proposed study start date³:** Jan 2015
- viii. **Is the research**
- a. ~~Staff~~ b. Doctoral Student c. ~~Masters Student~~
- ix. **Review Type**
- a. ~~Full committee~~ b. Light-touch review

Rationale for review type choice (no more than 50 words):

The research participants will be adult Bangladeshi informal carers of people with dementia (minimum 18 years to no upper age limit) and therefore, minimal risks have been identified in this semi-structure qualitative interviews study. We will recruit Bangladeshi Informal Carers from community sources only. Moreover, advice has been sought from Mr

¹ Please read the notes if you have not submitted an application to the SFEC previously

² If the PI is a student.

³ The exact date of starting may not be known, but please indicate the likely start date, mindful of the timescales for ethical review.



Faculty of Science
University of Portsmouth
St Michael's Building
White Swan Road
PORTSMOUTH
PO1 2DT

muhammad.hossain@port.ac.uk
19/01/15

Science Faculty Ethics Committee

Protocol Title: SFEC 2014-102, Views and experiences of Bangladeshi informal carers of people with Dementia in England: A Qualitative Study

Date application received: 05/01/15

Date Reviewed: 19/01/15

FAVOURABLE OPINION WITH MINOR CONDITIONS – SFEC 2014-102

Dear Mr Hossain,

Thank you for your submission for ethical review. Having completed their review, members of the Science Faculty Ethics Committee have reached a Favourable opinion, with minor conditions, of your proposed research. Please note that you are *not* required to resubmit your documents confirming that these conditions have been actioned.

- 1) On the participant information sheet please make it clear that recordings will be erased.
- 2) One reviewer noted that on the participant consent form the PI, by omission, commits to not sharing the data with other researchers. and suggested that with a small change to the consent letter the PI could share the data and make this clear to participants.
- 3) Recruitment letters need to be carefully proofread, there are a number of errors, e.g. in the participant information sheet on page 31, final sentence, paragraph one, the PI states that "Your family member can present if you wish during the interview." We suspect that "be" has been omitted between the "can" and the "present".
- 4) The complaints procedure should refer to the PI as first point of contact, the HoS as the second point of contact and the University Complaints Officer as the final point of contact.
- 5) The PI should follow the appropriate rules regarding the storage of digitised material.

Please notify the committee of any substantial amendments to the proposed procedures, send an annual report to the committee regarding study progress and a final study report once the study has concluded. Please send these to sci.fac@port.ac.uk.

Thank you for your submission and the Committee wishes you well with your study.

Dr Chris Markham – Chair of SFEC

A handwritten signature in black ink, appearing to read 'Chris Markham'.

offer any feedback on the Science Faculty Ethics Committee process please email sci.fac@port.ac.uk, to be forwarded to the Chair

Appendix C Invitation Letter (Focus Group Study, Phase Two)



PhD Research Title (গবেষণার বিষয়):	Understanding knowledge and attitude towards older people and dementia among the Bangladeshi community in England – Part two: A focus group study on adults of Bangladeshi origin (ইংল্যান্ডে বাংলাদেশি কমিউনিটির মধ্যে বয়স্কদের সম্পর্কে এবং ডিমেনশিয়া সম্পর্কে জালুন, বুঝুন- পর্ব ২: প্রাপ্তবয়স্ক বাংলাদেশীদের মধ্যে একটি গুণগত গবেষণা)
PhD Student (গবেষক)	Muhammad Zakir Hossain (জনাব মুহাম্মদ জাকির হোসাইন), University of Portsmouth (পোর্টসমাউথ বিশ্ববিদ্যালয়)
PhD Supervisors (সুপারভাইজারগণ)	Dr Ann Dewey, University of Portsmouth; ডঃ এনন ডুয়ে, (পোর্টসমাউথ বিশ্ববিদ্যালয়) Dr Yohai Hakak, University of Portsmouth; ডঃ ইয়োহাই হাকাক (পোর্টসমাউথ বিশ্ববিদ্যালয়) Dr Karan Jutla, University of Worcester; ডঃ কারান জটলা (অরস্টার বিশ্ববিদ্যালয়)

Dear Potential Participant,

My name is Muhammad Zakir Hossain. I am a PhD research student in the School of Health Sciences and Social Work Department at the University of Portsmouth. I am conducting a research study as part of the requirements of my PhD degree, and I would like to invite you to participate in either a female only (female facilitator) or male only focus group (male facilitator) discussion with others from the Bangladeshi community. A focus group is a discussion with a group of people concentrating on a particular topic e.g. dementia. The aim of a focus group is to gain a deeper understanding of your knowledge and attitudes; to hear your views, told in your own words. There is no right or wrong answer.

The purpose of this study is to produce new knowledge and understanding of the attitudes, perceptions and beliefs of the Bangladeshi community about ageing and dementia as well as increase awareness and understanding of dementia among Bangladeshi communities in England. It is up to you to decide whether or not you wish to take part. If you decide to participate, you will be asked to attend a focus group interview with others. We think this is likely to take about an hour, or little longer depending on what everybody wants to share. We will try to arrange the focus group meeting at a convenient time and place. If you would like to find out more information, please open the research packet to read the full written information sheet, which gives more detailed information.

Thank you for your consideration. Do please contact me if you want to discuss further. I can be contacted by telephone 023 9284 4461 (mobile 07583 373890 if you are happy) or email.

আসসালামু আলাইকুম,

আমার নাম মুহাম্মদ জাকির হোসাইন। আমি পরটসমাউথ উনিভার্সিটিতে পিএইচডি করছি। আমার গবেষণার বিষয় হলো “ইংল্যান্ডে বসবাসরত বাংলাদেশীদের মধ্যে ডিমেনশিয়া রোগ বিষয়ে জানা, বুঝা, এবং বাংলাদেশীদের মধ্যে ডিমেনশিয়া বিষয়ে সচেতনতা বৃদ্ধি করা”। আপনি মহিলা হলে আমি আপনাকে শুধুমাত্র মহিলা ফোকাস গ্রুপ আলোচনায় অংশগ্রহণের জন্য আমন্ত্রণ জানাতে চাই। আর আপনি পুরুষ হলে আমি আপনাকে শুধুমাত্র পুরুষদের ফোকাস গ্রুপ আলোচনায় অংশগ্রহণের জন্য আমন্ত্রণ জানাতে চাই। ফোকাস গ্রুপ হচ্ছে একটি বৈঠক, যেখানে গুণী জনেরা একটি গুরুত্বপূর্ণ বিষয় নিয়ে আলোচনা করেন।

এই গবেষণায় উদ্দেশ্য হচ্ছে ইংল্যান্ডে বসবাসরত বাংলাদেশি সম্প্রদায়ের মধ্যে ডিমেনশিয়া রোগ এবং ডিমেনশিয়া রোগ বৃদ্ধি সচেতনতার বিষয়ে বাংলাদেশি সম্প্রদায়ের মনোভাব, অনুভূতি ও বিশ্বাসের নতুন গুণাবলি এবং বোঝার উত্পাদন জানা। পরে আমি ডিমেনশিয়া রোগী এবং তাদের পরিবারের কেয়ারাটেকারদের সঙ্গে বয়স্ক ব্যক্তিদের সাথে সাক্ষাতকার নিবে। আপনি অংশ নিতে ইচ্ছুক হলে আপনাকে আট জনের একটি ফোকাস গ্রুপ সাক্ষাতকারে অংশ নিতে বলা হবে। আমরা আশা করছি এটি এক ঘণ্টার জন্য স্থায়ী হবে, তবে নির্ভর করবে সবাই কি কি আলোচনা করতে চান। আপনার উপর নির্ভর করবে আপনি অংশগ্রহণ করবেন কি না। যদি আপনি ফোকাস গ্রুপ আলোচনায় অংশগ্রহণের সিদ্ধান্ত নেন, ফোকাস গ্রুপ উপস্থিতির সময় এবং তারিখ নির্বাচন করার অনুরোধ জানিয়ে একটি গবেষণার তথ্য ফর্ম আপনার কাছে পাঠানো হবে। সর্বোচ্চ উপস্থিতির ভেটের মাধ্যমে ফোকাস গ্রুপ বৈঠক এর সময় ও তারিখ নির্ধারণ করা হবে। ফোকাস গ্রুপ আলোচনা আপনার সুবিধামত সময় ও স্থানে আয়োজন করা হবে, খুব সম্ভবত পোর্টসমাউথ জামে মসজিদে ফোকাস গ্রুপ বৈঠকটি অনুষ্ঠিত হবে। সূত্ররং আপনি যদি অংশগ্রহণ করতে চান তাহলে আপনাকে দেয়া প্যাকেটটি খুলুন এবং পূরণ করুন।

আপনার বিবেচনার জন্য আপনাকে ধন্যবাদ। আপনি যদি আরও আলোচনা করতে চান তাহলে আমার সাথে যোগাযোগ করুন অথবা ইমেইল (যদি আপনি চান তবে মোবাইলে কথা বলতে পারবেন ০৭৫৮৩ ৩৭৩ ৮৯০) অথবা আমার অফিস টেলিফোন নাম্বারে ০২৩ ৯২৮৪ ৪৪৬১ যোগাযোগ করা যেতে পারে। ধন্যবাদ।

With kind regards,

Muhammad Zakir Hossain

School of Health Sciences and Social Work

James Watson West, University of Portsmouth

2 King Richard 1st Road, Portsmouth, PO1 2FR. Tel: 023 9284 4461. Email: Muhammad.Hossain@port.ac.uk

Appendix D Participant Information Sheet (Focus Group Study, Phase Two)



School of Health Sciences and Social Work
University of Portsmouth
James Watson West
2 King Richard 1st Road
Portsmouth PO1 2FR
Tel: 023 9284 4461
Email: Muhammad.Hossain@port.ac.uk

Participant Information Sheet

অংশগ্রহণকারী তথ্য পত্র

Title of study: Understanding knowledge and attitude toward older people and dementia among the Bangladeshi community in England – Part two: A focus group study on adults of Bangladeshi origin

গবেষণার শিরোনাম: ইংল্যান্ডে বাংলাদেশি কমিউনিটির মধ্যে বয়স্কদের সম্পর্কে এবং ডিমেনশিয়া সম্পর্কে জানুন, বুঝুন- পর্ব ২: প্রাপ্তবয়স্ক বাংলাদেশীদের মধ্যে একটি গুণগত গবেষণা

Invitation

I would like to invite you to take part in our research study which involves taking part in a focus group discussion. A focus group is a discussion with a group of people concentrating on a particular topic e.g. dementia. The aim of a focus group is to gain a deeper understanding of your knowledge and attitudes; to hear your views, told in your own words. There is no right or wrong answer. Before you decide whether to take part or not, I want you to understand why the research is being done and what it involves. Please take time to read the following information carefully. Talk to others about the study if you wish. I will go through this information sheet with you if you would like me to. I suggest this should take about 15 minutes, but we can take longer, if you want to. Please ask me if anything is unclear – I am here to answer any questions, you may have. Nonetheless, for your convenience, after each section of English version, you will find the same information in Bengali.

আমন্ত্রণ

আমি আমাদের গবেষণা সমীক্ষার ফোকাস গ্রুপ আলবনাতে অংশ নিতে আপনাকে আমন্ত্রণ জানাতে চাই। ফোকাস গ্রুপ হচ্ছে একটি বৈঠক, যেখানে গুণী জনেরা একটি গুরুত্বপূর্ণ বিষয় নিয়ে আলোচনা করেন। উদারণ সরুপ এই ফোকাস গ্রুপ এ আপনারা ডিমেনশিয়া রোগ কি, ডিমেনশিয়া রোগ বিষয়ে আপনারা কি জানেন, বুঝেন সেটা নিয়ে আলোচনা করবেন। আপনি অংশ নিতে বা না করার সিদ্ধান্ত নেওয়ার আগে, আমি এই গবেষণা সম্পর্কে আপনাদের বিস্তারিত বলবো। ধৈর্য দরে নিম্নলিখিত তথ্যগুলি পড়ুন। যদি আপনি চান গবেষণা সম্পর্কে অন্যদের সঙ্গে কথা বলুন। আমি আপনার সাথে এই তথ্য পত্রটি রেখে যাবো। আমি এই প্রায় ১৫ মিনিট সময় লাগতে উচিত, কিন্তু আপনি আরও বেশি সময় নিতে পারেন, সেটি আপনার উপর নির্ভর করবো। কিছু বিষয় যদি স্পষ্ট মনে না হয় তাহলে আমাকে জিজ্ঞাসা করুন - আমি আপনাদের যে কোন প্রশ্নের উত্তর দিতে প্রস্তুত। ইংরেজি না পরতে চাইলে বাংলা সংস্করণে এই অংশগ্রহণ তথ্য পত্রটি পড়তে পারবেন। ধন্যবাদ।

What is the purpose of this study?

The purpose of this study is to produce new knowledge and understanding of the attitudes, perceptions and beliefs of the Bangladeshi community about ageing and dementia as well as increase awareness and understanding of dementia among Bangladeshi communities in England.

এই গবেষণায় উদ্দেশ্য কি?

এই গবেষণায় উদ্দেশ্যে হচ্ছে ইংল্যান্ডে বসবাসরত বাংলাদেশি সম্প্রদায়ের মধ্যে বার্ষিক্যজনিত সমস্যা, ডিমেনশিয়া রোগ এবং ডিমেনশিয়া রোগ বৃদ্ধি সচেতনতার বিষয়ে বাংলাদেশি সম্প্রদায়ের মনোভাব, অনুভূতি ও বিশ্বাসের নতুন জ্ঞান এবং বোঝার উৎস জ্ঞান। পাশাপাশি বাংলাদেশিদের মধ্যে ডিমেনশিয়া বিষয়ে সচেতনতা বৃদ্ধি করা।

What is a focus group?

A focus group is a discussion with a group of people concentrating on a particular topic e.g. ageing and dementia. The aim of a focus group is to gain a deeper understanding of your knowledge and attitudes; to hear your views, told in your own words. There is no right or wrong answer. I am inviting you to take part in Focus Group Discussions with adults of Bangladeshi origin living in Portsmouth. I am looking for males and females from all age groups (18+ years, no upper age limit) and from a range of occupations/employment status. We will be conducting two separate focus group discussion, one with females (by female facilitator) and another with males (by male facilitator). For each group discussion, so that everybody has an opportunity to contribute, I am looking for a maximum of 8 females and 8 males. We think this is likely to

take about an hour, or little longer depending on what everybody wants to share. Nonetheless, the focus group discussion which will most likely be conducted in Bengali, but can be conducted in English if preferred, or combination as appropriate and expressed wish by the majority of participants.

Although you may show interest in taking part of the focus group, you may not be selected to take part. This is because I am looking to ensure the focus groups represent different age groups, marital status and socio-economic groups. If you are not selected, I do thank you for your interest and if you wish to hear more about the findings from the study I can provide a summary report if you let me know you want to receive a copy.

ফোকাস গ্রুপ কি?

ফোকাস গ্রুপ হচ্ছে একটি বৈঠক, যেখানে গুণী জনেরা একটি গুরুত্বপূর্ণ বিষয় নিয়ে আলোচনা করেন। উদারণ সক্রপ এই ফোকাস গ্রুপ এ আপনারা বয়স বাড়া এবং ডিমেনশিয়া রোগ কি, ডিমেনশিয়া রোগ বিষয়ে আপনারা কি জানেন, বুঝেন সেটা নিয়ে আলোচনা করবেন। আমি পোর্টসমাউথে বসবাসকারী (ডিমেনশিয়া রোগী ছাড়া) বাংলাদেশী বংশোদ্ভূত মানুষের মধ্য থেকে প্রাপ্তবয়স্কদের সঙ্গে ফোকাস গ্রুপ সাক্ষাতকার অংশ নিতে আপনাকে আমন্ত্রণ জানাচ্ছি। আমি সব বয়সের (১৮-৭০ + বছর) থেকে ও দখলদারিত্ব / কর্মসংস্থানের অবস্থানের একটি পরিসীমা থেকে নারী ও পুরুষের সংখ্যা খুঁজছি। আমি দুটি পৃথক ফোকাস গ্রুপ আলোচনার ব্যবস্থা করবো। নারী এবং পুরুষদের জন্য আলাদা আলোচনা হবে। জার ফলে সবারই একটি অবদান রাখার সুযোগ থাকবে। প্রতিটি গ্রুপ আলোচনার জন্য, আমি সর্বাধিক ৮ জন নারী ও ৮ জন পুরুষ খুঁজছি।

আপনি ফোকাস দলের অংশ গ্রহণের আগ্রহ দেখাতে পারেন, কিন্তু এমনও হতে পারে আপনাকে অংশ নিতে নির্বাচন করা সম্ভব হবে না। কারণ আমি ফোকাস গ্রুপ বিভিন্ন বয়সের, বৈবাহিক অবস্থা এবং সামাজিক, অর্থনৈতিক দলের প্রতিনিধিত্ব নিশ্চিত করার জন্য খুঁজছি। আপনি যদি নির্বাচিত না হন, তাহলে আমি আপনার আগ্রহের জন্য আপনাকে আন্তরিক ধন্যবাদ জানাতে চাই। যদি আপনি সমীক্ষা থেকে ফলাফল সম্পর্কে আরো শুনতে চান, আপনি একটি কপি পেতে চান তাহলে আমি আপনাকে একটি সংক্ষিপ্ত রিপোর্ট প্রদান করতে পারবো গবেষণা যখন শেষ হবে।

Why have I been invited?

You are being invited to take part in this project because you are of Bangladeshi origin or British born Bangladeshi adult age groups minimum 18 years to 70 + years old living in Portsmouth, England. Moreover, apart from gender represented across the two groups, we will choose men and women of different age groups, upper and lower age range together with those representing different jobs/employment status, marital status, where possible, will be

sought to ensure maximum variation of experience, with the aim of capturing information from a diverse population of men and women from Bangladeshi community. For that reason, despite your interest in this research you might not be selected, but a copy of the report can be offered to you at the end of the study.

Notwithstanding, you have been invited from the diverse background and we would like to invite you to tell us your knowledge, views, perceptions, beliefs, and experiences about dementia and your attitude to healthcare service provision in England. There are no right or wrong answers to this – we are keen to hear a wide variety of opinions.

কেন আমাকে আমন্ত্রণ জানানো হয়েছে?

আপনাকে আমন্ত্রণ জানানো হচ্ছে কারন আপনি পোর্টসমাউথ, ইংল্যান্ডে বসবাসরত একজন বাংলাদেশী বংশোদ্ভূত বা ব্রিটিশ জন্মগ্রহণকারী বাংলাদেশী প্রাপ্তবয়স্ক (বয়স সর্বনিম্ন ১৮ বছর থেকে সর্বচ্চো ৭০ + বছর বয়সী)। তাছাড়া, ফোকাস গ্রুপ এ প্রতিনিধিত্ব করার জন্য উভয় লিঙ্গ থেকে, আমরা বিভিন্ন বয়সের, বিভিন্ন সামাজিক ক্লাস, বৈবাহিক অবস্থা, যেখানে সম্ভব এর ব্যাপক পরিসরের সঙ্গে উচ্চ এবং নিম্ন বয়স সীমার মধ্যে পুরুষ এবং মহিলাদের নির্বাচন করবো। সকল বয়সের অভিজ্ঞতা সর্বাধিক প্রকরণ নিশ্চিত করতে চাওয়া হবে, বাংলাদেশ সম্প্রদায় থেকে পুরুষ এবং মহিলাদের বিভিন্ন জনসংখ্যা থেকে তথ্য ধরে রাখার উদ্দেশ্য নিয়ে আমরা প্রতিনিদিত্ত মনোনয়ন করবো। অতএব, আপনাকে বিভিন্ন ব্যাকগ্রাউন্ড থেকে আমন্ত্রণ জানানো হয়েছে। আমাদেরকে আপনার ডিমেনশিয়া রোগ জ্ঞান সম্পর্কে বলতে আমরা আপনাকে আমন্ত্রণ জানাতে চাই। ডিমেনশিয়া রোগ এবং বাংলাদেশীদের মধ্যে কার ডিমেনশিয়া রোগ থাকলে তার চিকিৎসার জন্য ইংল্যান্ডে কিরকম স্বাস্থ্য সেবা ব্যবস্থাপনা রয়েছে সেটার বিষয়ে আপনার মতামত, অনুভূতি, বিশ্বাস, আমাদেরকে আপনি বলবেন। আপনার মতামত, মনোভাব উত্তরে কোনপ্রকার ভুলত্রুটি ধরা হবেনা কারন আমরা আপনার যেকোনো মতামত বিভিন্ন শুনতে আগ্রহী। আপনার উত্তর ভুল না সঠিক সেটি যাচাই করা হবেনা।

Do I have to take part?

No. It is up to you to decide to join this study. I will describe the study and go through this information sheet which I will then give you to keep. Please take your time to think about whether you want to take part or not. Share the information with your friends and family. If you decide to take part in the study, you will be asked to discuss your views and experiences, for example, ageing in the Bangladeshi community, caring for older persons, dementia diagnosis and treatment, barriers to accessing dementia health services, ways to overcome those barriers etc. Before that, firstly indicate on the 'reply slip' some details about you, for example, age, gender, employment status, marital status, availability etc. I will also ask you to sign a

consent form, on the day of the focus group discussion to confirm that you are still happy to take part. You are free to withdraw at any time without giving a reason.

আমাকে কি অংশ নিতে হবে?

না। এটা আপনার সিদ্ধান্ত আপনি অংশগ্রহণ করবেন কি না। আমি আপনার কাছে এই গবেষণা সম্পর্কে আলোচনা করবো এবং তথ্যপত্রটি দিব রাখার জন্য। আপনি এই তথ্যপত্রটি ভালভাবে পড়বেন, দরকার হলে পরিবার ও প্রতিবেশী বন্ধুদের নিয়ে আলোচনা করবেন। তারপর যদি আপনার অংশগ্রহণ করতে আগ্রহ জাগে তখন আমি আপনাকে এই খামের ভিতড়ে রাখা একটি সম্মতি ফর্মে স্বাক্ষর করতে বলব যে আপনি এই গবেষণাতে অংশগ্রহণ করতে রাজি। আপনি গবেষণাতে অংশগ্রহণ করার পর যদি মনে করেন আপনার বিরক্ত লাগছে তাহলে আপনি গবেষণা তৎখানাত ত্যাগ করতে পারবেন। আপনাকে কোন কয়ফিয়ত দিতে হবেনা আর আপনার কোন দিক দিয়ে প্রভাবান্বিত করা হবেনা।

What will happen to me if I take part?

If you decide to participate in the focus group discussion, a 'reply slip' will be sent to you with the research information pack asking you perhaps not to choose but indicate the best day of the week, and time (morning/afternoons/evenings) for focus group attendance. Decision about when the focus group will take place will be dependent on maximum attendance via preferences expressed, and availability of suitable venue. Once a group of potential participants has been selected, the researcher will call each person to confirm interest and availability. The researcher will give them time and location of the focus group and secure verbal confirmation. An email or text reminder will be sent two days before the scheduled focus group discussion, if preferred. If you decide to take part you will be asked to sign the consent form at the meeting. As mentioned above, we think focus group discussions is likely to take about an hour, or little longer depending on what everybody wants to share. However, we will be conducting two separate focus group discussion, one with females (by female facilitator) and another with males (by male facilitator) to ensure that a range of topics are discussed and those that wish to speak have an opportunity to contribute.

Other participants in the group will hear what you say, and it is possible that they could tell someone else. The focus group discussion will be audio recorded on a small portable device securely kept by the researcher and then transcribed in full for analysis. Names will not be used and removed from all interview transcripts and subsequent publications. However, direct quotations might be used in the report. Participants will be given a unique study code number which only researcher will know and participants will be informed that. Moreover, if you need a separate journey to travel to take part in the interview, we will be able to reimburse

reasonable travel cost. Nonetheless, if you want to you will be free to withdraw from the focus group discussion at any time without giving any explanation.

আমি অংশ নিতে চাইলে কি হবে?

যদি আপনি ফোকাস গ্রুপ আলোচনায় অংশগ্রহণের সিদ্ধান্ত নেন, ফোকাস গ্রুপ উপস্থিতির সময় এবং তারিখ নির্বাচন করার অনুরোধ জানিয়ে একটি গবেষণার তথ্য ফর্ম আপনার কাছে পাঠানো হবে। সর্বোচ্চ উপস্থিতির ভোটার মাধ্যমে ফোকাস গ্রুপ বৈঠক এর সময় ও তারিখ নির্ধারণ করা হবে। গবেষক তাদের সময় এবং ফোকাস গ্রুপ অবস্থান দিতে এবং মৌখিক নিশ্চয়তা প্রদান করবেন। গবেষক এছাড়াও তিনি মেইল (অথবা ইমেইল) তাদের একটি লিখিত নিশ্চয়তা এবং নির্ধারিত গ্রুপ বৈঠকের দুই দিন আগে তাদের মনে করিয়ে দিতে ফোন দিবেন। তাছাড়া, ফোকাস গ্রুপ সাক্ষাত্কারটি উভয় ভাষা ইংরেজি, বাংলা, বা মিশ্রণ হতে পারে। ফোকাস গ্রুপ আলোচনার আগে আপনি রাখা এবং একটি সম্মতি ফর্ম এ স্বাক্ষর দিতে বলা হবে এবং সেটি তাদেরকে দিয়ে দেয়া হবে।

আপনি অংশ নিতে সিদ্ধান্ত নেন তাহলে আপনি এখনও একটি কারণ প্রদান ছাড়াই আপনি বৈঠক ত্যাগ করতে পারবেন। আপনি অংশ নিতে ইচ্ছুক হলে আপনাকে আট জনের একটি ফোকাস গ্রুপ সাক্ষাত্কারে অংশ নিতে বলা হবে এবং সেটি এক ঘন্টার জন্য স্থায়ী হবে। আপনি সাক্ষাত্কারে অংশ নিতে ভ্রমণ করতে একটি পৃথক যাত্রা প্রয়োজন হলে, আমরা যুক্তিসঙ্গত ভ্রমণের খরচ পরিশোধ করতে পারবো। এই সাক্ষাত্কারটি একটি ছোট অডিও রেকর্ডারে রেকর্ড করা এবং তারপর বিশ্লেষণের জন্য পুরো প্রতিলিপি করা হবে।

What are the benefits of taking part?

There are no immediate benefits to you. Although, it is an opportunity for you to share your experiences. I hope that this study will lead to a better understanding of ageing and dementia among Bangladeshi community, where currently there is little research information. Nonetheless, as a small gesture of thanks we would like to offer you a £10 pound gift voucher for taking the time to participate in the focus group discussion.

অংশগ্রহণ করার কি কি সুবিধা?

অংশগ্রহণ করার কোনও সরাসরি সুবিধা নেই। কিন্তু আপনার অভিজ্ঞতা ভাগাভাগি করার এটা একটি সুযোগ। আমরা আশা করছি এই গবেষণা ভবিষ্যতে বাংলাদেশিদের জন্য অনেক সুযোগ সুবিধা বয়ে নিয়ে আসবে। কারণ এই মুহুর্তে বাংলাদেশিদের উপর কোনও গবেষণা পুরুপরিভাবে সম্পন্ন হয়নি। তাছাড়া, আপনার মূল্যবান সময়ের জন্য ধান্যবাদ হিসেবে আমরা আপনাকে ১০ পাউন্ড এর একটি গিফট ভাউচার উপহার হিসেবে দিবা।

What are the possible disadvantages and risks of taking part?

We do not anticipate any risks from your participation in this study and from you telling us about your experiences. Although, there are no known disadvantages or risks to you in taking part of this study, however it will require giving up approximately 1 hour of your time to complete the focus group discussion, depending on what you want to share in the group. However, distress due to reliving personal memories may be felt during the discussions. If in the unlikely circumstance, you experience distress as a result of the focus group, then please inform the researcher immediately. Moreover, you will be free to withdraw from the focus groups interviews at any time without giving any explanation.

অংশগ্রহণ করার অসুবিধা ও ঝুঁকিগুলো কি কি?

আমরা আপনার অভিজ্ঞতা বলার জন্য এই গবেষণাতে তেমন কোনও ঝুঁকি বা অসুবিধা দেখছি না। যদিও কোনও ফোকাস গ্রুপ সাক্ষাতকারী সমাপ্ত করার জন্য তাছাড়া অতীত স্মৃতি মনে করতে গিয়ে দুঃখ লাগতে পারে, মন-মানসিকতা খারাপ হতে পারে। বেশি দুঃখ ভারাক্রান্ত হয়ে পরলে আপনি বৈঠক ত্যাগ করতে পারবেন যে কোনও সময়।

Will my taking part in the study be kept confidential?

Yes. All the information collected during the course of research will be kept strictly confidential. You will be assigned an anonymous study number and not be identified by name in any reports or publications resulting from this study. If you take part in the study, it is possible that some of the data collected will be looked at by my supervisors from the University of Portsmouth. All completed interviews data will be stored in a locked cabinet and any electronic files will be password protected.

However, others in the group will hear what you say, and it is possible that they could tell someone else. Because we will be talking in a group, we cannot promise that what you say will remain completely private, but we will ask that you and all other group members respect the privacy of everyone in the group and what is said in the room, stays in the room. Moreover, although quotations will be used without names, but others may recognise the person by the distinct patterns of speech, words used.

গবেষণায় আমার অংশগ্রহণ কি গোপনীয় রাখা হবে?

হ্যাঁ। অবশ্যই গবেষণার সময় সংগৃহীত সব তথ্য কঠোরভাবে গোপনীয় রাখা হবে। আপনাকে একটি বেনামী গবেষণা নম্বর দেয়া হবে এবং রিপোর্ট বা এই গবেষণায় ফলে প্রকাশনা কোনো নাম দ্বারা চিহ্নিত করা যাবে না। সংগৃহীত

তথ্য আমি এবং আমার পোর্টসমাউথ বিশ্ববিদ্যালয় এর সুপারভাইজার দেখবে। সমস্ত সম্পন্ন সাক্ষাতকার তথ্য একটি তালাবন্দ সিন্দুকে সংরক্ষণ করা হবে এবং যে কোনো ইলেকট্রনিক ফাইল পাসওয়ার্ড সুরক্ষিত করা হবে।

তবে, দলের অন্যরা আপনাকে শুনতে পাবে এবং আপনি ও তাদের আলোচনা শুনতে পাবেন। তারা বাইরের অন্য কাউকে বলতে পারে এটা সম্ভব। আমরা শুরুতেই সবাইকে বলে রাখবো যে, আমরা বৈঠকে জা আলোচনা করবো তা সম্পূর্ণরূপে প্রাইভেট থাকবে। অঙ্গীকার করতে হবে আমরা অন্য সব দলের সদস্যরা দলের সবাই গোপনীয়তা সম্মান বজাই রাখবো।

Who is organizing and funding the research?

This is a self-funded PhD project; however, £1000.00 has been awarded by a University of Portsmouth grant to help with the expenses incurred.

কে এই গবেষণা সংগঠিত এবং অর্থায়ন করছে?

এটি একটি নিজ খরচে পিএইচডি প্রকল্প; এই গবেষণা পোর্টসমাউথ বিশ্ববিদ্যালয় দ্বারা সমর্থিত।

Who has reviewed the study?

This research study has been peer reviewed by two members of academic staff within the School of Health Sciences and Social Work. In addition, throughout the course of this study it will be monitored by a research study group which is likely to include my supervisors, representative from the University Ageing Network, dementia health care professional, community mental health development workers and patient representatives.

কে গবেষণা সমীক্ষা পর্যালোচনা করেছে?

এই গবেষণা গবেষণা স্বাস্থ্য বিজ্ঞান ও সামাজিক কাজকর্ম বিভাগের মধ্যে একাডেমিক কর্মীর দুজন সদস্যদের দ্বারা পর্যালোচনা করা হয়েছে। উপরন্তু, এই গবেষণা জুড়ে এটি বিশ্ববিদ্যালয় পুডো নেটওয়ার্ক, পেশাদারী ডিমেনশিয়া স্বাস্থ্য সেবা, কমিউনিটি মানসিক স্বাস্থ্য উন্নয়ন কর্মী এবং রোগীর প্রতিনিধি থেকে আমার সুপারভাইজার, প্রতিনিধি অন্তর্ভুক্ত থাকবেন, যা একটি গবেষণা গ্রুপ দ্বারা পরীক্ষা করা হবে।

Will I be recorded, and how will the recorded media be used?

The researchers will be using audio recording equipment during the sessions. The audio recording of your activities made during this research will only be used for analysis. In

addition, anonymised direct quotations from your interview audio recordings may be used in the reports or publications from the study, where your name will not be attached to them. No other use will be made of them without your written permission, and no one outside the research study group will be allowed access to the original recordings.

আমার কথা কি রেকর্ড করা হবে, এবং কিভাবে রেকর্ড ব্যবহার করা হবে?

গবেষক অডিও রেকর্ডিং যন্ত্র ব্যবহার করা হবে। এই গবেষণার সময় আপনার কার্যক্রম অডিও রেকর্ডিং শুধুমাত্র বিশ্লেষণের জন্য ব্যবহার করা হবে। উপরন্তু, আপনার ইন্টারভিউ অডিও রেকর্ডিং থেকে বেনামি সরাসরি উদ্ধৃতি গবেষণা থেকে রিপোর্ট বা প্রকাশনা ব্যবহার করা হতে পারে। অন্য কোনো ব্যবহার আপনার লিখিত অনুমতি ছাড়া করা হবে না, এবং গবেষণা দলের বাইরে কেউ আসল রেকর্ডিং এ প্রবেশ করতে অনুমতি দেওয়া হবে না।

What will happen at the end of the study?

We will seek to disseminate the findings at local community events, for example, mosques, Dementia Society, local Age UK groups, local Mental Health charities/ services etc. In addition, suitable conference presentations and relevant peer reviewed journals. For example, Alzheimer's & Dementia: The Journal of the Alzheimer's Association; Dementia, The international peer reviewed journal of social research and practice; The Journal of Dementia Care; International Journal of Older People Nursing; Ageing and Mental Health etc.

গবেষণা শেষে কি ঘটবে?

সমীক্ষা শেষে, ফলাফল সম্প্রদায় এবং সম্মেলনে উপস্থাপন করা হবে। সেইসাথে পিয়ার রিভিউ জার্নালেড মাধ্যমে সমস্ত পৃথিবীতে বিতরণ করা হবে। উদাহরণস্বরূপ, আলজেজইমের & ডিমেনশা: আলজেজইমের অ্যাসোসিয়েশনের জার্নাল; ডিমেনশা, সামাজিক গবেষণা ও অনুশীলন আন্তর্জাতিক পিয়ার রিভিউ জার্নাল; ডিমেনশা কেয়ার জার্নাল; পুরাতন মানুষ নার্সিং ইন্টারন্যাশনাল জার্নাল; পক্ষতা এবং মানসিক স্বাস্থ্য ইত্যাদি। আমরা আরো প্রস্তাব করেছি।

Further information and contact details:

For any further information about the research, please feel free to contact me:

আরো তথ্য এবং যোগাযোগের বিবরণ:

গবেষণা সম্পর্কে কোনও তথ্যের জন্য, বিনা দ্বিধায় দয়া করে আমার সাথে নিম্ন ঠিকানায় যোগাযোগ করুন:

Muhammad Hossain
PhD Doctoral Research Student
School of Health Sciences and Social Work
University of Portsmouth
James Watson (West)
2 King Richard 1st Road
Portsmouth
PO1 2FR
Telephone: 023 9284 4461 (24 hour answer phone)
Email: Muhammad.Hossain@port.ac.uk

Additional contact details (অতিরিক্ত যোগাযোগের বিবরণ):

Dr. Ann Dewey
Senior Lecturer
School of Health Sciences & Social Work
University of Portsmouth
James Watson Hall (West)
2 King Richard 1st Road
PORTSMOUTH
P01 2FR
Tel: 02392 844426
email ann.dewey@port.ac.uk

University Complaints by writing to (ইউনিভার্সিটি অভিযোগ চিঠির মাধ্যমে):

Dr Jeannette Bartholomew
Head of School
School of Health Sciences & Social Work
University of Portsmouth
James Watson Hall (West)
2 King Richard 1st Road
PORTSMOUTH
P01 2FR

NHS Complaints (এনএইচএস অভিযোগ):

Solent NHS Trust
Patient Experience and Engagement Service.
Telephone: 0800 013 2319

Appendix E Participant Consent Form (Focus Group Study, Phase Two)



CONSENT FORM

সম্মতি ফর্ম

Title of study: Understanding knowledge and attitude towards older people and dementia among the Bangladeshi community in England – Part two: A focus group study on adults of Bangladeshi origin

গবেষণার শিরোনাম: ইংল্যান্ডে বাংলাদেশি কমিউনিটির মধ্যে বয়স্কদের সম্পর্কে এবং ডিমেনশিয়া সম্পর্কে জানুন, বুঝুন- পর্ব ২: প্রাপ্তবয়স্ক বাংলাদেশীদের মধ্যে একটি গুণগত গবেষণা

Participant identification number (অংশগ্রহণকারী সনাক্তকারী নম্বর): _____

Name of researcher (গবেষকের নাম): Mr Muhammad Zakir Hossain (জনাব মুহাম্মদ জাকির হোসাইন)

Please put your initials in each box if you agree and then sign on the second page

যদি আপনি সম্মত হন তাহলে প্রতিটি বাক্সে আপনার আদাক্ষর করুন এবং নিচের বাক্সে স্বাক্ষর করুন

I confirm that I have read and understand the participant information sheet (version dated --/--/--) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily (আমি নিশ্চিত করছি যে, উপরের গবেষণার জন্য অংশগ্রহণকারী তথ্য শীটটি আমি ভালভাবে পড়েছি (সংস্করণের তারিখ --/--/--) এবং বুঝতে পেরেছি। আমার প্রশ্ন জিজ্ঞাসা করার সুযোগ রয়েছে, তথ্য বিবেচনা করার সুযোগ আছে এবং আমার সন্তোষজনকভাবে উত্তর গ্রহণ করার সুযোগ রয়েছে।

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason (আমি বুঝতে পেরেছি যে, আমার অংশগ্রহণ স্বেচ্ছাসেবী এবং আমি কোন কারণ প্রদান ছাড়াই যে কোনো সময়ে আমার অংশগ্রহণ প্রত্যাহার করতে পারবো)

I agree to audio recordings of my interview sessions (আমি আমার সাক্ষাৎকারের অডিও রেকর্ডিং এ রাজি আছি)

I agree to the publication of anonymised direct quotations from session notes or audio recordings (আমি আমার সাক্ষাৎকারের অডিও রেকর্ডিং থেকে সরাসরি বেনামী উদ্ধৃতি প্রকাশের সম্মতি দিচ্ছি)

I agree to records of my involvement being stored securely for the duration of the study (পুরো গবেষণা সময়কাল পর্যন্ত এই গবেষণাতে আমার সম্পৃক্ততা নিরাপদভাবে সংরক্ষণ করার জন্য অনুমতি দিলাম)

I agree to take part in the above study (আমি এই গবেষণাতে অংশগ্রহণ করতে রাজি আছি)

Participants name (অংশগ্রহণকারীর নাম)	Signature (স্বাক্ষর)	Date (তারিখ)
Name of person taking consent (সম্মতি গ্রহণকারীর নাম)	Signature (স্বাক্ষর)	Date (তারিখ)

1 copy will be kept secure by the researcher. 1 copy will be given to the participant.
১ কপি গবেষক দ্বারা নিরাপদে রাখা হবে। আর ১ কপি অংশগ্রহণকারীকে দেয়া হবে।

Date:

Version No.

Appendix F Reply Slip (Focus Group Study, Phase Two)



Dear Potential Participant, PLEASE COMPLETE THE FOLLOWING REPLY SLIP USING THE ATTACHED ENVELOPES (প্রিয় অংশগ্রহণকারী, অনুগ্রহ করে নিচের টেবিলের তথ্যগুলো পূরণ করুন)

Please indicate your preferred day and time for the focus group interviews by putting a tick mark [✓] (ফোকাস গ্রুপ সাক্ষাতকার জন্য আপনার পছন্দসই দিন ও সময় নির্ধারণ করুন, টিক (✓) চিহ্ন দিন).

I am interested in taking part in the focus group discussion (আমি ফোকাস গ্রুপ আলোচনায় অংশ গ্রহণ করতে আগ্রহী)		Yes (হ্যাঁ) (✓) <input type="checkbox"/>	No (না) (x) <input type="checkbox"/>
Date (তারিখ):	Time (সময়):	Place (স্থান):	
Your name (আপনার নাম):	Length of Residency (ইংল্যান্ডে থাকার সময়কাল):	Self-reported diagnosis of dementia? আপনি কি মনে করেন আপনার দিমেন্সিয়া আছে? <input type="radio"/> Yes (হ্যাঁ) <input type="radio"/> No (না)	My preference for dates (আপনার পছন্দমত দিন): <input type="radio"/> Monday (সোম) <input type="radio"/> Tuesday (মঙ্গল) <input type="radio"/> Wednesday (বুধ) <input type="radio"/> Thursday (বৃহস্পতি) <input type="radio"/> Friday (শুক্র)
Your gender (লিঙ্গ): <input type="radio"/> Male (পুরুষ) <input type="radio"/> Female (মহিলা)	If born outside England, how many years in England? (যদি আপনি বাংলাদেশে জন্মগ্রহণ করে থাকেন তবে ইংল্যান্ডে আপনার থাকার সময়কাল): <input type="radio"/>		
Marital status (বৈবাহিক অবস্থা): <input type="radio"/> Single (অবিবাহিত) <input type="radio"/> Married (বিবাহিত) <input type="radio"/> Divorced (তাল্যাকপ্রাপ্ত/ তাল্যাকপ্রাপ্তা)	If born inside England, how long have your parents been living in England? (যদি আপনি ইংল্যান্ডে জন্মগ্রহণ করে থাকেন তবে ইংল্যান্ডে আপনার পিতামাতার থাকার সময়কাল): <input type="radio"/>		
Your age (বয়স): <input type="radio"/> 18 to 30 (১৮-৩০) <input type="radio"/> 31 to 40 (৩১-৪০) <input type="radio"/> 41 to 50 (৪১-৫০) <input type="radio"/> 51 to 60 (৫১-৬০) <input type="radio"/> 61 to 70 (৬১-৭০) <input type="radio"/> Over 70 (৭০ এর উর্ধ্ব)	Your work (আপনার কাজ): <input type="radio"/> Working (কাজ করি) • Full time (সম্পূর্ণ সময়) • Part time (অর্ধেক সময়) <input type="radio"/> Not working (কাজ করি না)	Family carers/ significant others of the people with dementia? আপনার পরিবারের কিংবা অন্য আত্মীয়ও স্বজনের মধ্যে কারো কি দিমেন্সিয়া আছে? <input type="radio"/> Yes (হ্যাঁ) <input type="radio"/> No (না)	My preferred time (আপনার পছন্দমত সময়): <input type="radio"/> Morning (সকাল) <input type="radio"/> Afternoon (বিকাল) <input type="radio"/> Evening (সন্ধ্যা)
Place of Birth (জন্মস্থান): <input type="radio"/> Bangladesh (বাংলাদেশ) <input type="radio"/> England (ইংল্যান্ড) <input type="radio"/> Other countries (অন্যান্য দেশ)	If working, what is your job (যদি কাজ করেন তবে কি কাজ করেন): <input type="radio"/> <input type="radio"/>		

Thank you for your interest in the study. You might not be selected, if you want a copy of the report at the end of the study, indicate here Yes/No by email or written copy will be sent to home address by post. Please now send this information in the stamped addressed envelope provided. If you prefer to receive a copy of this letter by email, please include your contact details here. If you would prefer, telephone me on 023 9284 4461 (day time) or mobile 07583 373890 (evenings/weekend) and we can discuss further.

এই গবেষণায় আগ্রহ দেখানোর জন্য আপনাকে ধন্যবাদ। আপনি মনোনয়ন নাও হতে পারেন, আপনি যদি এই গবেষণার রিপোর্ট পেতে চান তবে এখানে হ্যাঁ/না উল্লেখ করুন। ইমেইল বা চিঠির মাধ্যমে পেতে চাইলে তাও উল্লেখ করুন। এখন অনুগ্রহ করে এই কাগজটি প্রি-পেইড খামে করে আমার ঠিকানায় পাঠাবেন। আপনি যদি এই চিঠিটি ই-মেইলে পেতে চান তবে আপনার ই-মেইল লিখুন। অথবা আপনি যদি আমার সঙ্গে টেলিফোনে কথা বলতে চান তাহলে আপনি আমাকে আমার অফিসের নাম্বার ০২৩ ৯২৮৪ ৪৪৬১ বা মোবাইলে ০৭৫৮৩ ৩৭৩৮৯০ ফোন করতে পারেন। ধন্যবাদ।

Signature (স্বাক্ষর):

Date (তারিখ):

Tel: Contact Number (আপনার টেলিফোন নাম্বার)

Appendix H Focus Group Topic Guides

Background information to be recorded by interviewer on hard copy

Name of interviewer _____

Date of interview _____

DRAFT

Focus Group Discussion Topic Guide

Good morning and welcome to our focus group discussion. First of all, we would like to thank you all for coming and we are looking forward to hearing your contribution. My name is Muhammad and I am a PhD student at the University of Portsmouth.

You were asked to take part in this project because you are a Bangladeshi origin or British born Bangladeshi adult age groups minimum 18 years to 70 + years old living in Portsmouth, England. We would like you to tell us your knowledge, views, perceptions, beliefs, and experiences about dementia and your attitude to healthcare service provision in England. There are no right or wrong answers to this – we are keen to hear a wide variety of opinions.

Before we begin, can we establish some ground rules please?

1. Mobile phones switch off please
2. Please feel free to speak up; there are no right or wrong answers
3. One person should talk at a time; please allow others to talk and finish their talk
4. Please respect each other's opinions
5. Please do not refer anyone by names (colleague; doctor)
6. What is said in this room stays here; please do not share anything outside the group meeting
7. We will be tape recording the discussion

The duration of the focus group discussions should be approximately 1 hour. We would like you to consider the following questions...

Purpose:

Conduct focus group discussions with adults across all age groups (18+ years, no upper age limit) and socio-economic backgrounds of Bangladeshi origin people without dementia. The purpose of the focus group data collection is to seek to answer the following psycho-social research questions:

1. What are their perceptions and attitudes about ageing and older adults?
2. What are their knowledge, perceptions, and attitudes toward dementia?

3. What are their perceptions and attitudes toward health services and what are their perceived barriers in uptake of health services?

The main purpose of interviewing those adults persons from all age groups without dementia by focus group discussions is to explore issues of knowledge, perception and attitudes toward dementia in order to compare and contrast these views with those who have dementia or caring for somebody with dementia. Focus groups will allow interaction between participants, argue, and challenge each other, like break ice.

We are going to discuss about these following topics in this meeting...

Topic Guides:

1. Perceptions and experiences of ageing
 - a. Household living arrangements
 - b. Family members
 - c. Decision maker
2. Knowledge and perception about dementia
 - a. Awareness and understanding of dementia
 - b. Causations of dementia
 - c. Stigma about dementia
3. Family Caregiving
 - a. Gender and caregiving
 - b. Caregiver strain
4. Perceptions of healthcare services
 - a. Knowledge and attitude toward current services
 - b. Barriers to services

DRAFT Focus Group Discussion questions

1. Section A: Perception and experience of ageing
 - a. Do you live with family and are there any older people in your family?
 - b. How would you define ageing or getting old?
 - c. Has anything changed as you have got older or your parents or grandparents are getting older?
 - d. What sorts of problem do older people suffer from?
2. Section B: Knowledge and perceptions about dementia
 - a. What is dementia?
 - b. What causes dementia? What are the symptoms of dementia?
 - c. Does dementia affect older people or younger people?
 - d. Now after listening to this vignette... What do you think about Mrs Parul in this vignette is? Why she was behaving this way? What were her problems?
 - e. Is there any stigma attached to Mrs Parul behaviour? Would you feel embarrass by looking after her?

3. Section C: Family caregiving
 - a. Who provides care for older people, children, or others get sick in the family?

4. Section D: Perceptions of healthcare services
 - a. Would you know how to get more information about dementia and where to get help if needed in the future?
 - b. Will there be any fears or concerns you might have about receiving health and social care services?
 - c. What kinds of services would be helpful if you or a loved one is experiencing dementia difficulties in future?

Finally, is there anything else importance/relevance you would like to add what has not been discussed in this group so far?

Once again, thank you very much for your time and your input. This will be very helpful for our research. Lastly, please bear in mind as we mentioned at the beginning about what was said in this room stayed here; please respect others privacy and do not share anything when you go outside. Thank you!

Semi-structured Interview Schedule

Family Carers of people with dementia

Interview length: Interview will last from some 60 to 90 minutes (approximately, depending on what participant wants to share)

Thank you very much for being willing to take part in an interview for this research project. My name is Muhammad Hossain, and I am a PhD student at the University of Portsmouth.

You have been invited to take part because you are, or have been, a carer for someone with dementia no longer than two years ago. We would like to hear your experiences of living with a person with dementia, or how you are coping with your caring role; and your experiences of accessing dementia healthcare services and other support. There is no right or wrong answer, we want to hear your experience and views, told in your own words – I'm really interested in hearing what you have to say.

Before we begin,

- Mobile phones switch off please
- We will be audio tape recording the discussion because this will record what you say accurately

Prompts: Can you tell me more>> need to get the people tell their story>> for the depth>> can you tell me more>> do not nod, sometime nodding stop people talking>> what do you mean by yes>> less about the answer >> more about the words>> tell me about a difficult>> what it is like to care>> how are you managing>> what about the services>> let them speak. Let them tell you a rich story?

Semi-structured interview questions:

1. What is your relationship to the cared for person? How long have you been a carer for the cared for person?
2. At the beginning – when/ how did you realise that something was wrong?

3. How long was it before you sought help?
4. How did you get a diagnosis? Did you believe about the diagnosis result?
5. Did you have any previous experience/ knowledge of dementia? Were you reluctant admitting the diagnosis result or any family members? Did you believe the doctor? Tell me what happened then?
6. How did you feel when the cared for person diagnosed? Has the diagnosis affected you and the cared for person's plans for the future?
7. Can you describe what it is like being a carer?
 - Supplementary questions:
 - Describe your typical day caring?
 - What are the practical implications in terms of daily living e.g. household tasks, financial implications, work and social life?
 - What is the emotional impact on you, on family and the person you care for?
8. What enables you to continue to care?
 - Prompt: Do you consider it to be part of your family duty, culture or religion?
9. How does caring impact on you? What coping strategies do you use?
 - Supplementary questions:
 - How do you cope with stress?
 - Are there practical things you do such as talk it through with someone within the extended family, ask for help from the community, or accessing external resources?
 - Can you describe some approaches that you use when things are difficult for you?
10. What support do you receive as a carer?
11. What would be considered the tipping points for residential care?
 - Supplementary questions:
 - Is it important to have other support, namely friends and family, community support other than yourself? Why?
 - What help did you get and from whom, was it what you wanted, was it helpful?
 - Prompt 1:
 - Where did you get help from? What sort of help did they offer you? Was it useful, whereas have you sought help from? How about Alzheimer's Society and Dementia Café, are they helpful? What else...
 - Prompt 2: (If not mentioned by the participants) Have you accessed healthcare services, which ones, what help did they give, was that helpful, if yes why, if not why not?
 - What services are the least useful? Apart from language what other problems are not useful for you? Tell me more?
 - Do you know that family carers are entitled to an assessment of their needs in order to access help and support services? Have you had an assessment yet?
 - Do you know what members of the local Bangladeshi community think about dementia? What do you think about their knowledge and attitudes? For example, how generally are you and the person you care are treated - with kindness, understanding, indifference, stigma, hostility, disrespect?
 - What factors do you feel would make your situation easier? Do you think that living in London is an advantage for receiving help?
12. What have you learned from your experiences as a carer?

13. What advice would you give to someone else? What would you say to someone who has just started this journey?
14. What are the learning and development needs of health and social care staff toward ethnic Bangladeshi family carers of people with dementia?
 - Supplementary questions:
 - Is your experience as a carer being recognised and valued?
 - Have you been provided with information, advice and support that meet the needs of the person with dementia, and you as a carer?
15. Finally, is there anything else that you would like to tell me that we have not discussed?

Once again, thank you very much for your time and your input. This will be very helpful for our research. Thank you!

Appendix J Invitation Letter for the carers of the people with dementia for an interview (Phase Three)



PhD Research Title (গবেষণার বিষয়):	Views and Experiences of Bangladeshi family Carers of People with Dementia in England: A Qualitative Study (ইংল্যান্ডে বাংলাদেশি কমিউনিটির মধ্যে ডিমেনশিয়া কেয়ারারদের মতামত এবং অভিজ্ঞতা সম্পর্কে জানা : একটি গুণগত গবেষণা)
PhD Student (গবেষক)	Muhammad Zakir Hossain মুহাম্মদ জাকির হুসাইন, University of Portsmouth পোর্টসমাউথ বিশ্ববিদ্যালয়
PhD Supervisors (সুপারভাইজারগণ)	Dr Ann Dewey, University of Portsmouth; ডঃ এনন ডুয়ে, (পোর্টসমাউথ বিশ্ববিদ্যালয়) Dr Yohai Hakak, Brunel University London; ডঃ ইয়োহাই হাঁকাক (ব্রুনেল বিশ্ববিদ্যালয়) Dr Karan Jutla, University of Worcester; ডঃ কারান জাটলা (অরস্টার বিশ্ববিদ্যালয়)

Dear Participant,

My name is Muhammad Zakir Hossain. I am a PhD research student in the School of Health Sciences and Social Work Department at the University of Portsmouth. I am conducting a research study as part of the requirements of my PhD degree, and I would like to invite you to participate in this research project.

The purpose of this study is to produce new knowledge and understanding of the attitudes, perceptions, beliefs and experiences of the Bangladeshi community about dementia caregiving and increase awareness and understanding of dementia among Bangladeshi communities in England. I will be conducting interviews with Bangladeshi family carers of people with dementia (now or within the last 2 years) to hear about their views, beliefs and experiences. I will also explore what are the current barriers and opportunities for Bangladeshi family carers for improving dementia care. I hope to interview 20 Bangladeshi adult family carers for this study.

If you decide to participate, you will be asked to meet with me for an interview about 60 to 90 minutes. The meeting will take place at a mutually upon time and place. If you would like to find out more information, please open the research packet to read the full written information sheet, which gives more detailed information. Thank you for your consideration. Do please contact me if you want to discuss further. I can be contacted by telephone 023 9284 4461 or email, address is provided below.



With kind regards,

Muhammad Zakir Hossain
School of Health Sciences and Social Work
James Watson West, University of Portsmouth
2 King Richard 1st Road, Portsmouth,
PO1 2FR. Tel: 023 9284 4461.
Email: Muhammad.Hossain@port.ac.uk

আসসালামু আলাইকুম,

আমার নাম মুহাম্মদ জাকির হুসাইন। আমি পরটস্মাউথ উনিভারসিটিতে পিএইচডি করছি। আমার গবেষণার বিষয় হলো “ইংল্যান্ডে বসবাসরত বাংলাদেশিদের মধে ডিমেনশিয়া রোগ বিষয়ে জানা, বুঝা, এবং বাংলাদেশিদের মধে ডিমেনশিয়া বিষয়ে সচেতনতা বৃদ্ধি করা”। আমি আপনাকে আলোচনায় অংশগ্রহণের জন্য আমন্ত্রণ জানাতে চাই।

এই গবেষণায় উদ্দেশ্যে হচ্ছে ইংল্যান্ডে বসবাসরত বাংলাদেশি সম্প্রদায়ের মধ্যে ডিমেনশিয়া রোগ এবং ডিমেনশিয়া রোগ বৃদ্ধি সচেতনতার বিষয়ে বাংলাদেশি সম্প্রদায়ের মনোভাব, অনুভূতি ও বিশ্বাসের নতুন জ্ঞান এবং বোঝার উত্পাদন জানা। পরে আমি ডিমেনশিয়া রোগী কেয়ারটেকারদের সাক্ষাত্কার নিবো। আপনি অংশ নিতে ইচ্ছুক হলে আপনাকে একটি সাক্ষাত্কারে অংশ নিতে বলা হবে। আমরা আশা করছি এটি এক ঘন্টার জন্য স্থায়ী হবে, তবে নির্ভর করবে আপনি কি কি আলোচনা করতে চান। আপনার উপর নির্ভর করবে আপনি অংশগ্রহণ করবেন কি না। যদি আপনি আলোচনায় অংশগ্রহণের সিদ্ধান্ত নেন, সাক্ষাতকারের দিন ও উপস্থিতির সময় এবং তারিখ নির্বাচন করার অনুরোধ জানিয়ে একটি গবেষণার তথ্য ফর্ম আপনার কাছে পাঠানো হবে। সর্বোচ্চ উপস্থিতির ভোটের মাধ্যমে সাক্ষাতকারের সময় ও তারিখ নির্ধারণ করা হবে। আলোচনা আপনাদের সুবিধামত সময় ও স্থানে আয়োজন করা হবে। সুতরাং আপনি যদি অংশগ্রহণ করতে চান তাহলে আপনাকে দেয়া প্যাকেটটি খুলুন এবং পূরণ করুন।

আপনার বিবেচনার জন্য আপনাকে ধন্যবাদ। আপনি যদি আরও আলোচনা করতে চান তাহলে আমার সাথে যোগাযোগ করুন অথবা ইমেইল অথবা আমার অফিস টেলিফোন নাম্বারে ০২৩ ৯২৮৪ ৪৪৬১ যোগাযোগ করা যেতে পারে। ধন্যবাদ।

[Date: 24, Nov 2014 Version No. 4 (final)]

Appendix K Participant Information Sheet for family carers (Phase Three)



School of Health Sciences and Social Work
University of Portsmouth
James Watson West
2 King Richard 1st Road
Portsmouth PO1 2FR
Tel: 02392844461
Email: Muhammad.Hossain@port.ac.uk

Participant Information Sheet for Family Carers (অংশগ্রহণকারী তথ্য পত্র)

Title of study: Views and Experiences of Bangladeshi family Carers of People with Dementia in England: A Qualitative Study

গবেষণার শিরোনাম: ইংল্যান্ডে বাংলাদেশি কমিউনিটির মধ্যে ডিমেনশিয়া কেয়ারারদের মতামত এবং অভিজ্ঞতা সম্পর্কে জানা : একটি গুণগত গবেষণা

Invitation

We would like to invite you to take part in our research study. Before you decide whether to take part or not, I want you to understand, why the research is being done and what it involves. Please take time to read the following information carefully. Talk to others about the study if you wish. I will go through this information sheet with you. I suggest this should take about 15 minutes, but we can take longer, if you want to. Please ask me if anything is unclear – I am here to answer any questions, you may have.

আমন্ত্রণ

আমি আমাদের গবেষণা সমীক্ষার আলোচনাতে অংশ নিতে আপনাকে আমন্ত্রণ জানাতে চাই .আপনি অংশ নিতে বা না করার সিদ্ধান্ত নেওয়ার আগে, আমি এই গবেষণা সম্পর্কে আপনাদের বিস্তারিত বলবো। ধৈর্য্য সহকারে নিম্নলিখিত তথ্যগুলি পড়ুন .যদি আপনি চান গবেষণা সম্পর্কে অন্যদের সঙ্গে কথা বলুন। আমি আপনার সাথে এই তথ্য পত্রটি রেখে যাবো। আমি এই প্রায় ১৫ মিনিট সময় লাগতে উচিত, কিন্তু আপনি আরও বেশি সময় নিতে পারেন ,সেটি আপনার উপর নির্ভর করবে। কিছু বিষয় যদি স্পষ্ট মনে না হয় তাহলে আমাকে জিজ্ঞাসা করুন -

আমি আপনাদের যে কোন প্রশ্নের উত্তর দিতে প্রস্তুত .ইংরেজি না পরতে চাইলে বাংলা সংস্করণে এই অংশগ্রহণ তথ্য প্ৰটি পড়তে পারবেন। ধন্যবাদ।

What is the purpose of this study?

The purpose of this study is to seek to answer the following research question:

- What are the range of knowledge, views about dementia, perceptions, beliefs, and experiences of Bangladeshi family carers, day to day caregiving experiences of managing and obtaining support?
- What are the perceived barriers and opportunities for Bangladeshi family carers for improving dementia care?

Therefore, the main objective of this study is to produce new knowledge and understanding of the attitudes, perceptions and beliefs of the Bangladeshi community about dementia caregiving and increase awareness and understanding of dementia among Bangladeshi communities in the UK. I will be conducting one-to-one audio taped interviews with the family carers of Bangladeshi people with dementia. I wish to hear your views and experience of supporting either a family member, friend or neighbour who is living with dementia. If you agree to take part, you would be one of the twenty carers I am looking to interview.

এই গবেষণায় উদ্দেশ্য কি?

এই গবেষণায় উদ্দেশ্যে হচ্ছে ইংল্যান্ডে বসবাসরত বাংলাদেশি সম্প্রদায়ের মধ্যে বার্ধক্যজনিত সমস্যা , ডিমেনশিয়া রোগ এবং ডিমেনশিয়া রোগ বৃদ্ধি সচেতনতার বিষয়ে বাংলাদেশি সম্প্রদায়ের কেয়ারদের মনোভাব, অনুভূতি ও বিশ্বাসের নতুন জ্ঞান এবং বোঝার উৎস্য জানা। পাশাপাশি বাংলাদেশিদের মধ্যে ডিমেনশিয়া বিষয়ে সচেতনতা বৃদ্ধি করা। আমি বাংলাদেশি বৃদ্ধ যারা স্মৃতিশক্তির সমস্যায় ভুগছেন ,কেয়ার হিসেবে যারা সেসব বৃদ্ধদের দেখাশুনা করছেন তাদের সাক্ষাৎকার নিবো। স্মৃতিশক্তি সমস্যায় আক্রান্ত বৃদ্ধদের যারা দেখাশুনা করছেন এমন ২০ জন কেয়ারটেকারদের সাক্ষাৎকার নিবো।

Why have I been invited?

You have been invited to take part because you are, or have been, a family carer for someone with dementia no longer than two years ago. Caring for someone with dementia can be daunting and challenging at times. We would like to hear your experiences of living with a dementia patient or how you are coping with your caring role; and your experiences of accessing dementia healthcare services and other support. There is no right or wrong answer,

we want to hear your experience and views, told in your own words – we are keen to hear a wide variety of opinions.

কেন আমাকে আমন্ত্রণ জানানো হয়েছে?

আপনাকে আমন্ত্রণ জানানো হচ্ছে কারণ আপনি ইংল্যান্ডে বসবাসরত একজন বাংলাদেশী বংশোদ্ভূত বা ব্রিটিশ জন্মগ্রহণকারী বাংলাদেশী প্রাপ্তবয়স্ক এবং আপনি একজন ডিমেনশিয়া আক্রান্ত ব্যক্তিকে দেখাশুনা করছেন ৬ মাসের বেশি সময় ধরে এবং সেটি ২ বছরের মধ্যে। অতএব, আপনাকে বিভিন্ন ব্যাকগ্রাউন্ড থেকে আমন্ত্রণ জানানো হয়েছে আপনার কেয়ারিং অভিজ্ঞতা বর্ণনা করার জন্য। ডিমেনশিয়া রোগ এবং বাংলাদেশীদের মধ্যে কারও ডিমেনশিয়া রোগ থাকলে তার চিকিৎসার জন্য ইংল্যান্ডে কিরকম স্বাস্থ্য সেবা ব্যবস্থাপনা রয়েছে সেটার বিষয়ে আপনার মতামত, অনুভূতি, বিশ্বাস, আমাদেরকে আপনি বলবেন। আপনার মতামত, মনোভাব উত্তরে কোনপ্রকার ভুলত্রুটি ধরা হবেনা কারণ আমরা আপনার যেকোনো মতামত বিভিন্ন শুনতে আগ্রহী। আপনার উত্তর ভুল না সঠিক সেটি যাচাই করা হবেনা।

Do I have to take part?

No. It is entirely up to you to decide to join this study. I will describe the study and go through this information sheet which I will then give you to keep. Please take your time to think about whether you want to take part or not. Share the information with your friends and family.

আমাকে কি অংশ নিতে হবে?

না। এটা আপনার সিদ্ধান্ত আপনি অংশগ্রহণ করবেন কি না। আমি আপনার কাছে এই গবেষণা সম্পর্কে আলোচনা করবো এবং তথ্যপত্রটি দিব রাখার জন্য। আপনি এই তথ্যপত্রটি ভালভাবে পড়বেন, দরকার হলে পরিবার ও প্রতিবেশী বন্ধুদের নিয়ে আলোচনা করবেন। তারপর যদি আপনার অংশগ্রহণ করতে আগ্রহ জাগে তখন আমি আপনাকে এই খামের ভিতড়ে রাখা একটি সম্মতি ফর্মে স্বাক্ষর করতে বলব যে আপনি এই গবেষণাতে অংশগ্রহণ করতে রাজি। আপনি গবেষণাতে অংশগ্রহণ করার পর যদি মনে করেন আপনার বিরক্ত লাগছে তাহলে আপনি গবেষণা তৎখনাত ত্যাগ করতে পারবেন। আপনাকে কোন কয়ফিয়ত দিতে হবেনা আর আপনার কোন দিক দিয়ে প্রভাবান্বিত করা হবেনা।

What will happen to me if I take part?

If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. An interview will be arranged at a time and location of your convenience. If the interview is taking place in a private location both you and the researcher will be asked to tell a third party where you will be, at what time and for how long. You may prefer to have

your family member or other with you during the interview. Although I want to hear your views, it is OK for them to be present during the interview.

Before the interview takes place I will ask you to sign a consent form to confirm that you are still happy to take part. Subsequently, I will ask you few questions about your demographic background, for example, your age, employment status, marital status, and relationship with the person you cared for. Finally, you will be asked to share your stories and experiences (both good and bad, we would like to hear your views) of caring for someone with dementia. You are free to withdraw at any time without giving a reason. Your decision whether or not to participate or withdraw from this study will not affect any current services available to you or any future services you may receive. This interview will be audio recorded on a small portable device kept by the researcher because this recording will help to set the accurate of data – your responses and opinions and then transcribed in full for analysis. You may still participate in the interview if you do not want the interview to be recorded. Please tell us in advance if you do not want to be recorded.

আমি অংশ নিতে চাইলে কি হবে?

যদি আপনি ইন্টারভিউ এ অংশগ্রহণের সিদ্ধান্ত নেন, উপস্থিতির সময় এবং তারিখ নির্বাচন করার অনুরোধ জানিয়ে একটি গবেষণার তথ্য ফর্ম আপনার কাছে পাঠানো হবে। সর্বোচ্চ উপস্থিতির ভোটার মাধ্যমে ইন্টারভিউ এর সময় ও তারিখ নির্ধারণ করা হবে। গবেষক তাদের সময় এবং অবস্থান সম্পর্কে মৌখিক নিশ্চয়তা প্রদান করবেন .গবেষক এছাড়াও তিনি মেইল) অথবা ইমেইল (তাদের একটি লিখিত নিশ্চয়তা এবং নির্ধারিত দুই দিন আগে তাদের মনে করিয়ে দিতে ফোন দিবেন .তাছাড়া, সাক্ষাত্কারটি উভয় ভাষা ইংরেজি, বাংলা, বা মিশ্রণ হতে পারে। ইন্টারভিউ এর আগে আপনি রাখা এবং একটি সম্মতি ফর্ম এ স্বাক্ষর দিতে বলা হবে এবং সেটি তাদেরকে দিয়ে দেয়া হবে।

আপনি অংশ নিতে সিদ্ধান্ত নেন তাহলে আপনি এখনও একটি কারণ প্রদান ছাড়াই আপনি ইন্টারভিউ ত্যাগ করতে পারবেন। আপনি অংশ নিতে ইচ্ছুক হলে আপনাকে একটি সাক্ষাত্কারে অংশ নিতে বলা হবে এবং সেটি এক ঘন্টার জন্য স্থায়ী হবে। আপনি সাক্ষাত্কারে অংশ নিতে ভ্রমণ করতে একটি পৃথক যাত্রা প্রয়োজন হলে, আমরা যুক্তিসঙ্গত ভ্রমণের খরচ পরিশোধ করতে পারবো .এই সাক্ষাত্কারটি একটি ছোট অডিও রেকর্ডারে রেকর্ড করা এবং তারপর বিশ্লেষণের জন্য পুরো প্রতিলিপি করা হবে। আপনি যদি আপনার ইন্টারভিউ রেকর্ড করতে না চান তবুও হয়তো আপনি এই রিসার্চ এ অংশগ্রহণ পারেন। দয়া করে আমাদেরকে আগেই জানাবেন যদি আপনি ইন্টারভিউ রেকর্ড করতে না চান। ধন্যবাদ।

What are the benefits of taking part?

There are no immediate benefits to you. Although, it is a great opportunity for you to share your experiences. We hope that this study will lead to a better understanding of dementia as

well as caring for someone with dementia among Bangladeshi community, where currently there is little research information. Although there were no direct benefits, a list of services (with full contact details) as a carer you could access has provided at the end of the PISs, we hope that would be more helpful for you.

অংশগ্রহণ করার কি কি সুবিধা?

অংশগ্রহণ করার কোনও সরাসরি সুবিধা নেই। কিন্তু আপনার অভিজ্ঞতা ভাগাভাগি করার এটা একটি সুযোগ। আমরা আশা করছি এই গবেষণা বিষয়ে বাংলাদেশিদের জন্য অনেক সুযোগ সুবিধা বয়ে নিয়ে আসবো। কারণ এই মুহুর্তে বাংলাদেশিদের উপর কোনও গবেষণা পুরুপুরিভাবে সম্পন্ন হয়নি। তাছাড়া, আপনার মূল্যবান সময়ের জন্য ধন্যবাদ হিসেবে আমরা আপনাকে ১০ পাউন্ড এর একটি গিফট ভাউচার উপহার হিসেবে দিবা।

What are the possible disadvantages and risks of taking part?

There are no known disadvantages or risks to you in taking part of this study, although it will require giving up approximately 60 minutes to 90 minutes of your time to complete the interview, depending on what you want to share with me. However, distress due to reliving personal memories may be felt during the interview. Should you feel unhappy at any time with the direction the conversation is taking, please let me know and I will stop the interview at once, restarting only if you want to go on. Your family member can be present if you wish during the interview.

Moreover, if you are feeling anxious or confused because as a carer of a dementia patient you may feel overwhelmed and frustrated sometime with your caring role, we can give you further information for support. For example, we have contacted the local Alzheimer's Society branch who will always be willing to talk to you and offer advice and information to support your needs. Portsmouth Dementia Adviser Service of Alzheimer's Society is particularly keen to offer support to the Bangladeshi community locally. Please see their detail addresses and other information including contact numbers at the bottom of this information sheet.

অংশগ্রহণ করার অসুবিধা ও ঝুঁকিগুলো কি কি?

আমরা আপনার অভিজ্ঞতা বলার জন্য এই গবেষণাতে তেমন কোনও ঝুঁকি বা অসুবিধা দেখাচ্ছি না। যদিও সাক্ষাতকারটি সমাপ্ত করার জন্য আপনাকে আপনার ১ থেকে ১.৩০ ঘন্টা সময় দিতে হবে। তাছাড়া অতীত স্মৃতি মনে করতে গিয়ে দুঃখ লাগতে পারে, মন-মানসিকতা খারাপ হতে পারে। বেশি দুঃখ ভারাক্রান্ত হয়ে পরলে আপনি বৈঠক ত্যাগ করতে পারবেন যে কোনও সময়। আপনি চাইলে আলজাইমার সোসাইটির সঙ্গে যোগাযোগ করতে পারেন। দয়া করে নিম্নে তাদের ঠিকানা দেখুন।

Will my taking part in the study be kept confidential?

Yes. All the information collected about you during the course of this research will be kept strictly confidential. All names will be removed and instead you will be a study number so you cannot be identified by name in any reports or publications resulting from this study. Although names will be removed, others may recognise pattern of speech or expressions so that anonymity cannot be guaranteed. In addition, it is possible that some of the data collected will be looked at by my supervisors from the University of Portsmouth. All completed interviews data will be stored in a locked cabinet and any electronic files will be password protected.

গবেষণায় আমার অংশগ্রহণ কি গোপনীয় রাখা হবে?

হ্যাঁ . অবশ্যই গবেষণার সময় সংগৃহীত সব তথ্য কঠোরভাবে গোপনীয় রাখা হবে . আপনাকে একটি বেনামী গবেষণা নম্বর দেয়া হবে এবং রিপোর্ট বা এই গবেষণায় ফলে প্রকাশনা কোনো নাম দ্বারা চিহ্নিত করা যাবে না . সংগৃহীত তথ্য আমি এবং আমার পোর্টসমাউথ বিশ্ববিদ্যালয় এর সুপারভাইজার দেখবে . সমস্ত সম্পন্ন সাক্ষাতকার তথ্য একটি তালাবন্দ সিন্দুকে সংরক্ষণ করা হবে এবং যে কোনো ইলেকট্রনিক ফাইল পাসওয়ার্ড সুরক্ষিত করা হবে। আমরা ইন্টারভিউ এ যা আলোচনা করবো তা সম্পূর্ণরূপে প্রাইভেট থাকবে। আপনার নাম আমরা ব্যবহার করবনা। আপনার নামের পরিবর্তে আমরা একটি নাম্বার ব্যবহার করবো। তারপরও আপনার কথা বলার ধরণ দেখে অনেকে হয়ত আপনাকে সনাক্ত করে ফেলতে পারে , সেজন্য অনেকসময় হয়তবা গুপনীয়তা গ্যারান্টি নাও দেওয়া যেতে পারে।

Who is organizing and funding the research?

This is a self-funded PhD project, but this research is supported by the University of Portsmouth.

কে এই গবেষণা সংগঠিত এবং অর্থায়ন করছে?

এটি একটি নিজ খরচে পিএইচডি প্রকল্প; এই গবেষণা পোর্টসমাউথ বিশ্ববিদ্যালয় দ্বারা সমর্থিত.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by the University of Portsmouth Research Ethics Committee (reference number: SFEC 2014-102) dated on: 19/01/2015. A Research Ethics Committee is a group of independent people who review research to protect the dignity, rights, safety and wellbeing of participants and researchers. In addition, throughout the course of this study it will be monitored by a research study group which is likely to include my supervisors, representative from the University Ageing Network, dementia health care professional, community mental health development workers and carer representatives.

কে গবেষণা সমীক্ষা পর্যালোচনা করেছে?

এই গবেষণা ইউনিভারসিটি অব পোর্টস্মাউথ এথিক্স কমিটি দ্বারা অনুমোদনকৃত, অনুমোদন নম্বর SFEC 2014-102 তারিখ 19/01/2015। তাছাড়া গবেষণা স্বাস্থ্য বিজ্ঞান ও সামাজিক কাজকর্ম বিভাগের মধ্যে একাডেমিক কর্মীর দুজন সদস্যদের দ্বারা পর্যালোচনা করা হয়েছে। উপরন্তু, এই গবেষণা জুড়ে এটি বিশ্ববিদ্যালয় পুডো নেটওয়ার্ক, পেশাদারী ডিমেনশিয়া স্বাস্থ্য সেবা, কমিউনিটি মানসিক স্বাস্থ্য উন্নয়ন কর্মী এবং রোগীর প্রতিনিধি থেকে আমার সুপারভাইজার, প্রতিনিধি অন্তর্ভুক্ত থাকবেন, যা একটি গবেষণা গ্রুপ দ্বারা পরীক্ষা করা হবে।

Will I be recorded, and how will the recorded media be used?

We will be using audio recording equipment during the sessions. Your response to the interview questions will be recorded for accuracy. The audio recording of your activities made during this research will only be used for analysis. No other use will be made of your audio recording without your written permission, and no one outside the research study group (myself and supervisors) will be allowed access to the original recordings. However, you may still participate in the interview if you do not want the interview to be recorded. Please tell us in advance if you do not want to be recorded. Nonetheless, all audio recordings will be erased at the end of the study.

আমার কথা কি রেকর্ড করা হবে, এবং কিভাবে রেকর্ড ব্যবহার করা হবে?

গবেষক অডিও রেকর্ডিং যন্ত্র ব্যবহার করা হবে। এই গবেষণার সময় আপনার কার্যক্রম অডিও রেকর্ডিং শুধুমাত্র বিশ্লেষণের জন্য ব্যবহার করা হবে। উপরন্তু, আপনার ইন্টারভিউ অডিও রেকর্ডিং থেকে বেনামি সরাসরি উদ্ধৃতি গবেষণা থেকে রিপোর্ট বা প্রকাশনা ব্যবহার করা হতে পারে। অন্য কোনো ব্যবহার আপনার লিখিত অনুমতি ছাড়া করা হবে না, এবং গবেষণা দলের বাইরে কেউ আসল রেকর্ডিং এ প্রবেশ করতে অনুমতি দেওয়া হবে না। সকল রেকর্ডিং গবেষণা শেষে মুছে ফেলা হবে।

What will happen at the end of the study?

We will seek to disseminate the findings at local community events, for example, mosques, Alzheimer's Society, Carers UK, local Age UK groups, local Mental Health charities/ services etc. In addition, suitable conference presentations and relevant peer reviewed journals. For example, Alzheimer's & Dementia: The Journal of the Alzheimer's Association; Dementia, The international peer reviewed journal of social research and practice; The Journal of Dementia Care; International Journal of Older People Nursing; Ageing and Mental Health etc.

গবেষণা শেষে কি ঘটবে?

সমীক্ষা শেষে, ফলাফল সম্প্রদায় এবং সম্মেলনে উপস্থাপন করা হবে। সেইসাথে পিয়ার রিভিউ জার্নালেড মাধ্যমে সমস্ত পৃথিবীতে বিতরণ করা হবে। উদাহরণস্বরূপ, আলেকজহইমের & ডিমনেশা :আলেজহইমের অ্যাসোসিয়েশনের জার্নাল; ডিমনেশা, সামাজিক গবেষণা ও অনুশীলন আন্তর্জাতিক পিয়ার রিভিউ জার্নাল; ডিমনেশা কেয়ার জার্নাল; পুরাতন মানুষ নার্সিং ইন্টারন্যাশনাল জার্নাল; পক্ষতা এবং মানসিক স্বাস্থ্য ইত্যাদি। আমরা আরো প্রস্তাব করেছি।

Further information and contact details:

For any further information about the research, please feel free to contact me:

আরো তথ্য এবং যোগাযোগের বিবরণ :

গবেষণা সম্পর্কে কোনও তথ্যের জন্য, বিনা দ্বিধায় দয়া করে আমার সাথে নিম্ন ঠিকানায় যোগাযোগ করুন:

Principal Investigator:
Muhammad Hossain
PhD Research Student
School of Health Sciences and Social Work
University of Portsmouth
James Watson (West)
2 King Richard 1st Road
Portsmouth
PO1 2FR
Telephone: 023 9284 4461 (24 hour answer phone)
Email: Muhammad.Hossain@port.ac.uk



Additional contact details (অতিরিক্ত যোগাযোগের বিবরণ)

PhD Supervisor:
Dr. Ann Dewey
Senior Lecturer, Department Research Degrees Co-ordinator
School of Health Sciences & Social Work
University of Portsmouth
James Watson Hall (West)
2 King Richard 1st Road
PORTSMOUTH
P01 2FR
Tel: 02392 844426
email ann.dewey@port.ac.uk

Local Dementia and other Carers support Contact Details for Bangladeshi Community
(ডিমনেশিয়া সাহায্যের জন্য যোগাযোগের বিবরণ)

Portsmouth Dementia Adviser Service

Alzheimer's Society

The Dementia Adviser service is primarily for people who are pre-diagnosed or recently diagnosed with Dementia, as well as their supporters and carers. It provides them with a named contact at the start of their journey and which can sign post them to other relevant services if the person requires additional support. Referral to the service may come from GP, CMHTs or other health and social care professionals, or self-referral.

ডিমেনশিয়া উপদেষ্টা সেবা ডিমেনশিয়া সঙ্গে ডায়াগনসিস হওয়ার পূর্বে বা সম্প্রতি নির্ণয় করা হয় যারা, সেইসাথে তাদের সমর্থক এবং কেয়ারারদের জন্য প্রাথমিকভাবে হয়। এটা ব্যক্তির অতিরিক্ত সমর্থন প্রয়োজন অন্যান্য প্রাসঙ্গিক সেবা তাদের পোস্ট সাইন ইন করতে পারেন, যা তাদের যাত্রা এবং শুরু করার একটি নামে পরিচিতি সঙ্গে তাদের প্রদান করে। সেবা রেফারেল জিপি, **CMHTs** বা অন্যান্য স্বাস্থ্য ও সামাজিক সেবা পেশাদার, বা স্ব-রেফারেল থেকে আসতে পারে।

Address:

John Pounds Centre

23 Queen Street

Portsmouth PO1 3HN

Telephone: 023 9282 1777

Email: portsmouthDA@alzheimers.org.uk

Carers Centre

The Carers Centre is a community resource dedicated to the support of all carers in the city of Portsmouth. Carers Centre is a one stop shop for carers in the city of Portsmouth, offering a variety of support, including financial, training, young carers, adult mental health, emotional support, and also a carers supported self-assessment.

কেয়ারারদের সেন্টার পোর্টসমাউথ শহরের সব দেখাশোনা সমর্থন নিবেদিত একটি সম্প্রদায় সম্পদ। যারা দেখাশোনা সেন্টার আর্থিক, প্রশিক্ষণ, তরুণ দেখাশোনা, প্রাপ্তবয়স্ক মানসিক স্বাস্থ্য, মানসিক সমর্থন, এবং একটি দেখাশোনা সমর্থিত স্ব-মূল্যায়ন সহ বিভিন্ন সমর্থন, প্রস্তাব, পোর্টসমাউথ বিভাগ কেয়ারারদের জন্য একটি এক স্টপ দোকান।

Address:

Carers Centre

117 Orchard Road

Southsea

Hampshire

PO4 0AD

Telephone: 023 9275 6780 or 023 9285 1864

Email: carerscentre@portsmouthcc.gov.uk

Carers UK

Carers UK making life better for carers.

এক কথায় কেয়ারার ইউকে সব কেয়ারদের জীবনকে সহজ করার একমাত্র জায়গা। আপনি যোগাযোগ করুন আজই। নিচের ফ্রি নাম্বারে ফোন করে খোঁজ নিন।

<http://www.carersuk.org/>

Tel: 0808 808 7777 (calls free from landline and mobile networks)

[The Princess Royal Trust for Carers in Hampshire](#)

A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. If you are a carer, your local Carers' Centre may be able to help make things easier for you. Each centre delivers a wide range of local support services to meet the needs of carers in its community. These range from support services catered to the carer, the needs of the person you care for and the services your council may provide.

কেয়ারার এই সাহায্য ছাড়াই পরিচালনা করতে পারে এমন পরিবার বা বন্ধুদের অবৈতনিক সমর্থন উপলব্ধ করা হয় যে কোন বয়সের যে কেউ। এই অসুস্থ ভঙ্গুর, প্রতিবন্ধী বা মানসিক স্বাস্থ্য বা অপব্যবহারের সমস্যা আছে একটি আপেক্ষিক, অংশীদার বা বন্ধু জন্য পরিচর্যা হতে পারে। আপনি কেয়ারার হন, তাহলে আপনার স্থানীয় কেয়ারারদের 'সেন্টার আপনার জন্য জিনিষ সহজ করতে সাহায্য করতে সক্ষম হতে পারে। প্রতিটি কেন্দ্রে তার সম্প্রদায়ের মধ্যে যারা দেখাশোনা চাহিদা পূরণের স্থানীয় সহায়তা পরিষেবার বিস্তৃত বিতরণ করে। কেয়ারার যাও কেয়ারদের সহায়তা পরিষেবা থেকে এই পরিসীমা, আপনার জন্য যত্ন ব্যক্তি চাহিদা ও সেবা আপনার কাউন্সিল প্রদান করতে পারে।

Address:

Winchester Carers Centre

Tel: 01264 835246

info@carercentre.com

www.carercentre.com

University Complaints by writing to ইউনিভারসিটি অভিযোগ চিঠির মাধ্যম:

First point of contact:

Muhammad Hossain

PhD Research Student

School of Health Sciences and Social Work

University of Portsmouth

James Watson (West)

2 King Richard 1st Road

Portsmouth

PO1 2FR

Telephone: 023 9284 4461 (24 hour answer phone)

Email: Muhammad.Hossain@port.ac.uk

Second point of contact:

Dr Jeannette Bartholomew

Head of School

School of Health Sciences & Social Work

University of Portsmouth

James Watson Hall (West)

2 King Richard 1st Road

PORTSMOUTH, PO1 2FR

Third point of contact: University complaints officer

Samantha Hill

Title: Information Disclosure and Complaints Manager

Tel: +44 (0)23 9284 3642

Email: Samantha.hill@port.ac.uk

NHS Complaints) এনএইচএস অভিযোগ(:

Solent NHS Trust

Patient Experience and Engagement Service.

Telephone: 0800 013 2319

Appendix L Participant Consent Form (Phase Three)



CONSENT FORM

সম্মতি ফর্ম

Title of study: Views and Experiences of Bangladeshi Informal Carers of People with Dementia in England: A Qualitative Study গবেষণার শিরোনাম: ইংল্যান্ডে বাংলাদেশি কমিউনিটির মধ্যে ডিমেনশিয়া কেয়ারারদের মতামত এবং অভিজ্ঞতা সম্পর্কে জানা : একটি গুণগত গবেষণা

Participant identification number (অংশগ্রহণকারী সনাক্তকারী নম্বর): _____

Name of researcher (গবেষকের নাম): Mr Muhammad Zakir Hossain (জনাব মুহাম্মদ জাকির হোসাইন)

Please put your initials in each box which applies below and then sign in the box at the bottom of the page

খদি আপনি সম্মত হন তাহলে প্রতিটি বাক্সে আপনার আদ্যক্ষর করুন এবং নিচের বাক্সে স্বাক্ষর করুন

I confirm that I have read and understand the participant information sheet (version dated -/--/--) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily (আমি নিশ্চিত করছি যে, উপরের গবেষণার জন্য অংশগ্রহণকারী তথ্য শীটটি আমি ভালভাবে পড়েছি (সংস্করণের তারিখ --/--/--) এবং বুঝতে পেরেছি। আমার প্রশ্ন জিজ্ঞাসা করার সুযোগ রয়েছে, তথ্য বিবেচনা করার সুযোগ আছে এবং আমার সন্তোষজনকভাবে উত্তর গ্রহণ করার সুযোগ রয়েছে।

YES	NO
-----	----

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason (আমি বুঝতে পেরেছি যে, আমার অংশগ্রহণ স্বৈচ্ছাসেবী এবং আমি কোন কারণ প্রদান ছাড়াই যে কোনো সময়ে আমার অংশগ্রহণ প্রত্যাহার করতে পারবো)

YES	NO
-----	----

I agree to audio recordings of my interview sessions. (আমি আমার সাক্ষাৎকারের অডিও রেকর্ডিং এ রাজি আছি)

YES	NO
-----	----

I agree to the publication of anonymised direct quotations from session notes or audio recordings (আমি আমার সাক্ষাৎকারের অডিও রেকর্ডিং থেকে সরাসরি বেনামী উদ্ধৃতি প্রকাশের সম্মতি দিচ্ছি)

YES	NO
-----	----

I agree to records of my involvement being stored securely for the duration of the study (পুরো গবেষণা সময়কাল পর্যন্ত এই গবেষণাতে আমার সম্পৃক্ততা নিরাপদভাবে সংরক্ষণ করার জন্য অনুমতি দিলাম)

YES	NO
-----	----

I agree to take part in the above study (আমি এই গবেষণাতে অংশগ্রহণ করতে রাজি আছি)

YES	NO
-----	----

Participants name (অংশগ্রহণকারীর নাম)	Signature (স্বাক্ষর)	Date (তারিখ)
Name of person taking consent (সম্মতি গ্রহণকারীর নাম)	Signature (স্বাক্ষর)	Date (তারিখ)

1 copy will be kept secure by the researcher. 1 copy will be given to the participant.

১ কপি গবেষক দ্বারা নিরাপদে রাখা হবে। আর ১ কপি অংশগ্রহণকারীকে দেয়া হবে।

Date: 21, Oct 2014

Version No. 5 (final)

Appendix M Reply Slip (Phase Three)



Dear Potential Participant, PLEASE COMPLETE THE FOLLOWING REPLY SLIP USING THE ATTACHED ENVELOPES (প্রিয় অংশগ্রহণকারী, অনুগ্রহ করে নিচের টেবিলের তথ্যগুলো পূরণ করুন)

Please indicate your preferred day and time for the semi-structure interviews by putting a tick mark [✓] (সম্মতকার এর জন্য আপনার পছন্দসই দিন ও সময় নির্ধারণ করুন, টিক (✓) চিহ্ন দিন) .

I am interested in taking part in the study (আমি গবেষণায় অংশ গ্রহণ করতে আগ্রহী)		Yes (হ্যাঁ) (✓)	<input type="checkbox"/>	No (না) (x)	<input type="checkbox"/>
Date (তারিখ):		Time (সময়):		Place (স্থান):	
Your name (আপনার নাম):	Your age (বয়স): ○ 18 to 30 (১৮-৩০) ○ 31 to 40 (৩১-৪০) ○ 41 to 50 (৪১-৫০) ○ 51 to 60 (৫১-৬০) ○ 61 to 70 (৬১-৭০) ○ Over 70 (৭০ এর উর্ধ্বে)	What is your relationship with the person you have been cared for? ○ ○ ○	If working, what is your job (যদি কাজ করেন তবে কি কাজ করেন): ○ ○ ○ Full time (সম্পূর্ণ সময়) ○ Part time (অর্ধেক সময়)		
Your gender (লিঙ্গ): ○ Male (পুরুষ) ○ Female (মহিলা)	Marital status (বৈবাহিক অবস্থা): ○ Single (অবিবাহিত) ○ Married (বিবাহিত) ○ Divorced (তালাকপ্রাপ্ত/ তালাকপ্রাপ্তা) ○ Widower (স্বামী/স্ত্রী বেঁচে নেই)	My preference for dates (আপনার পছন্দমত দিন): ○ Monday (সোম) ○ Tuesday (মঙ্গল) ○ Wednesday (বুধ) ○ Thursday (বৃহস্পতি) ○ Friday (শুক্র)	How long have you been a carer? ○ 6 months + ○ 1-5 years ○ 6-10 years ○ 11-15 years ○ 16-20 years ○ 20 years + ○ Ex-carers (not more than 2 years ago)	Place of Birth (জন্মস্থান): ○ Bangladesh (বাংলাদেশ) ○ England (ইংল্যান্ড) ○ Other countries (অন্যান্য দেশ)	Years of Residency (ইংল্যান্ডে থাকার সময়কাল): If born outside England, how many years in England? (যদি আপনি বাংলাদেশে জন্মগ্রহণ করে থাকেন তবে ইংল্যান্ডে আপনার থাকার সময়কাল): ○
My preferred time (আপনার পছন্দমত সময়): ○ Morning (সকাল) ○ Afternoon (বিকাল) ○ Evening (সন্ধ্যা)	Your work (আপনার কাজ): ○ Working (কাজ করি) ○ Not working (কাজ করি না)	If born in England, how long has the person you cared for been living in England? (যদি আপনি ইংল্যান্ডে জন্মগ্রহণ করে থাকেন তবে ইংল্যান্ডে আপনি যাকে দেখাশুনা করতেন তার থাকার সময়কাল): ○			

As I want to ensure I have a mix of age range, years of caring, males/females, you may not be selected to take part in this study. I would like to thank you for your interest in the study. If you would like a summary of the report at the end of the study, indicate here (delete as appropriate) Yes/No by Email/ written copy will be sent to home address by post if you send details. If you would prefer, telephone me on 023 9284 4461 and we can discuss further.

এই গবেষণায় আগ্রহ দেখানোর জন্য আপনাকে ধন্যবাদ। আপনি মনোনয়ন নাও হতে পারেন, আপনি যদি এই গবেষণার রিপোর্ট পেতে চান তবে এখানে হ্যাঁ/না উল্লেখ করুন। ইমেইল বা চিঠির মাধ্যমে পেতে চাইলে তাও উল্লেখ করুন। এখন অনুগ্রহ করে এই কাগজটি প্রিন্ট-সেইড খামে করে আমার ঠিকানায় পাঠাবেন। আপনি যদি এই চিঠিটি ই-মেইলে পেতে চান তবে আপনার ই-মেইল লিখুন। অথবা আপনি যদি আমার সঙ্গে টেলিফোনে কথা বলতে চান তাহলে আপনি আমাকে আমার অফিসের নাম্বার ০২৩ ৯২৮৪ ৪৪৬১ ফোন করতে পারেন। ধন্যবাদ।

Signature (স্বাক্ষর):
Tel: Contact Number (আপনার টেলিফোন নাম্বার)

Date (তারিখ):

Date: 21, Oct 2014

Version No. 5 (final)

Appendix N NVivo coding procedures

01 FEB 2016 - Copy (NVivo 11).nvp - NVivo Pro

FILE HOME CREATE DATA ANALYZE QUERY EXPLORE LAYOUT VIEW

Navigation View Find Quick Coding Dock All Undock All Close All Close Window List View List View Coding Highlight Annotations See Also Links Relationships Links Framework Matrix Classification Report Previous Next Color Scheme Visualization

Nodes

- Nodes
 - Focus Group Nodes
 - Focus Group Themes
 - Interview Nodes
 - Cases
 - Focus Group Nodes
 - FGD Participants Case
 - Interview Nodes
 - Interview Participant
 - Relationships
 - Node Matrices

Interview Themes

Name	Sources	Referen
1 Caregiving journey into dementia	4	8
1 Early symptoms and diagnosis of	0	0
1 Suspicions - early signs of de	7	21
Help seeking behaviour for	6	14
2 Diagnosis of dementia	6	15
Family carers' reaction after	6	16
2 Myths and stigma around dement	0	0
1 Perceived causes of dementia	3	14
2 Perceived stigma in caregivers	4	6
Arranged marriage	1	2
Bangladeshi community's at	6	18
3 Motivations for family caregiving	2	2
Cultural and religious obligation	3	5
Interpersonal responsibility and	6	15
Providing intimate care	1	3
2 Impact of dementia on family caregiv	0	0
1 Physical impact on caregivers	5	31
Carers' experiences of living wit	4	8
Looking after dementia patient	5	12
Practical implications	1	3

1 Suspicions - early signs of de

didn't know what dementia was. Then it was hmm... when she started forgetting me. So that's when it became a concern for me you know.

Reference 3 - 0.42% Coverage

Hmm... I doubt something was wrong with my mom when I saw my mom took her all medication wrong and I had to take her to the A&E. It was not one day incident which happened many times before I sought help.

Reference 4 - 1.19% Coverage

My mom sometime forgets who I am, sometime she forgets where she is. You know its the little things it started with off. There wasn't a major thing, it was just umm little things. That you know she was normally she would do her prayer. You know she is Muslim, so therefore, she has been saying her prayer for such a long time. But recently she has got her prayers muddled up. Those things I told to my GPs and that's why GP gave me the referral for my mom. In the hospital we had her dementia assessment done and since then she was diagnosed with dementia and living with dementia.

Reference 5 - 0.73% Coverage

I would say that took me so long. Because if I add my dad's experience then it would start from 2002. My dad showing dementia symptoms since 2002 till he died in 2006. We have been taking my dad to GPs, hospital nobody told me it was dementia. No help was available. Then my mom was showing her dementia symptoms since 2010 and she got diagnosed in 2012.

Internals\Phase 2\Interview Transcripts\Amirun #3> - 5 2 references coded [2.22% Coverage]

Reference 1 - 1.65% Coverage

The time was in early 2005 and two years had passed already before we knew that my

Coding Density

Summary Reference Tag Audio

1 Caregiving journey into dementia

Looking after dementia patient harder than looking after a baby

2 Suspicions of dementia

Help seeking behaviour for potential dementia symptoms

Appendix O Pen and paper coding

Necessity knows no law

If no one can do it, no one should do it

Getting support from family or community is not an option

		on time and scope. Chinese community they can we cannot do that.	
108	50:49.4 - 50:58.1	Is it important to have other support, namely friends and family, community support other than yourself? Why? What help did you get and from whom, was it what you wanted, was it helpful?	Main Theme: Carer's Support
109	50:58.1 - 54:55.4	Yes it is important to receive support from others but how much you get and how do you get that? Carers service give 6 hours care every week but we requested more hours. They are unable to give us more than 6 hours of care. Now where do we get more support, nobody will do that? Dementia caring is a 24 hours job, now they gave us for only 6 hours job. If they could give us more then that would be more helpful. Because we cannot maintain any social life, we cannot go anywhere together.	6 hours not enough Home based respite care services
110	54:55.3 - 55:27.2	Do you know that informal carers are entitled to an assessment of their needs in order to access help and support services? Have you had an assessment yet?	Sub-theme: Carer's Assessment
111	55:27.2 - 56:50.5	Yes they assessed my needs but they have provided only 6 hours of care per week which is nothing. Their assessment does not meet my need and they are in their limits. They cannot provide more what I need. That's why carers assessment does not make any sense to me. They said they would do everything but in reality they cannot do everything and they are in their limits.	Carer's assessment is useless Service providers failed to be enough support
112	56:50.5 - 58:24.0	Do you know what members of the local Bangladeshi community think about dementia? What do you think about their knowledge and attitudes? For example, how generally are you and the person you care are treated - with kindness, understanding, indifference, stigma, hostility, disrespect?	Stigma is irrelevant
113	57:28.6 - 59:54.7	No, nobody is there to help me. No stigma, there is no stigma, I don't think. Why should I feel embarrassed. My mother is suffering from dementia and I am looking after. I don't know is there any stigma related to our relationships. However, community people are sympathise towards my mother and the family. Because it is hard for everybody in our family. Bangladeshi community feel sorry for me. Instead Bangladeshi religious leaders, seniors in the community say I am doing a good job. I have peace of mind that I am looking for my mother. I think, culturally and religiously Bangladeshi community will always appreciate whoever looks after their older parents. As far as I can think, I don't think there is any stigma within our community. I don't know what will happen in the future with this current generation.	No stigma is being heard Community mental health is important No perceived dementia stigma in dementia caregiving

Carers and support and help

Nobody helps

Myth and stigma in dementia

No perceived stigma in caregivers

Reasons with dementia

Appendix P Male Focus Group Discussion at Portsmouth Jami Mosque



Appendix Q Advertisement for Semi-structured Interview with carers of people with dementia (Phase Three)



Appendix R Research Ethics Review Checklist - Form UPR16

FORM UPR16

Research Ethics Review Checklist



Please include this completed form as an appendix to your thesis (see the Postgraduate Research Student Handbook for more information)

Postgraduate Research Student (PGRS) Information		Student ID:	637785
PGRS Name:	Muhammad Zakir Hossain		
Department:	SHSSW	First Supervisor:	Dr John Crossland
Start Date: (or progression date for Prof Doc students)	Feb 2012		
Study Mode and Route:	Part-time <input checked="" type="checkbox"/>	MPhil <input type="checkbox"/>	MD <input type="checkbox"/>
	Full-time <input type="checkbox"/>	PhD <input checked="" type="checkbox"/>	Professional Doctorate <input type="checkbox"/>

Title of Thesis:	UNDERSTANDING DEMENTIA AMONG THE BANGLADESHI COMMUNITY IN ENGLAND
Thesis Word Count: (excluding ancillary data)	77, 940

If you are unsure about any of the following, please contact the local representative on your Faculty Ethics Committee for advice. Please note that it is your responsibility to follow the University's Ethics Policy and any relevant University, academic or professional guidelines in the conduct of your study

Although the Ethics Committee may have given your study a favourable opinion, the final responsibility for the ethical conduct of this work lies with the researcher(s).

UKRIO Finished Research Checklist:


(If you would like to know more about the checklist, please see your Faculty or Departmental Ethics Committee rep or see the online version of the full checklist at: <http://www.ukrio.org/what-we-do/code-of-practice-for-research/>)

a) Have all of your research and findings been reported accurately, honestly and within a reasonable time frame?	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
b) Have all contributions to knowledge been acknowledged?	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
c) Have you complied with all agreements relating to intellectual property, publication and authorship?	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
d) Has your research data been retained in a secure and accessible form and will it remain so for the required duration?	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>
e) Does your research comply with all legal, ethical, and contractual requirements?	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>

Candidate Statement:

I have considered the ethical dimensions of the above named research project, and have successfully obtained the necessary ethical approval(s)

Ethical review number(s) from Faculty Ethics Committee (or from NRES/SCREC):	Two separate ethical approvals were obtained successfully for the Two Primary Phases of this research study as follows:
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	<p>1. Phase Two: No ethical review number was given. Protocol Title: Understanding knowledge and attitudes towards older people and dementia among the Bangladeshi community in England-Part two: A focus group student on adults of Bangladeshi origin Date Reviewed: 1st - 19th May 2014</p>
	<p>2. Phase Three: Ethical Review Number: SFEC 2014-102 Protocol Title: Views and experiences of Bangladeshi informal carers of people with Dementia in England: A Qualitative Study Date application received: 05/01/15 Date Reviewed: 19/01/15</p>
<p>If you have <i>not</i> submitted your work for ethical review, and/or you have answered 'No' to one or more of questions a) to e), please explain below why this is so:</p>	
<p> </p>	
<p>Signed (PGRS): </p>	<p>Date: 16.08.2017</p>